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Arthritis Community Research & Evaluation Unit

**ARTHRITIS COMMUNITY RESEARCH &
EVALUATION UNIT (ACREU)**

University Health Network

**AN OVERVIEW OF DEVELOPMENTS
IN COMPREHENSIVE
INTERDISCIPLINARY MODELS OF
CARE FOR ARTHRITIS: PROVIDER
AND PATIENT PERSPECTIVES**

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TABLE OF CONTENTS

Executive Summary	5
1.0 THE NEED FOR MODELS OF CARE FOR ARTHRITIS	8
1.1 Introduction.....	8
1.2 Goals and Objectives	9
1.3 Structure of the Report	10
1.4 Key Definitions	10
1.5 Overall Methodology	11
1.5.1 Procedure	11
1.5.2 Recruitment of Participants.....	11
1.6 Analysis.....	13
2.0 KEY INFORMANT STUDY OF INTERNATIONAL MODELS OF CARE	14
2.1 Sample Characteristics	14
2.2 Emergent Models of Care.....	16
2.2.1 Specialized Arthritis Programs.....	16
2.2.2 Models of Care Utilizing Health Care Providers in Expanded Clinical Roles	19
2.2.3 Models to Promote Access in Rural and Remote Communities.....	23
2.2.4 Community-Based Care.....	27
2.3 Strategies for Overcoming Challenges of Successful Models of Care for Arthritis.....	29
2.4 Developing Models of Care	32
2.5 Summary of International Models of Care	33
3.0 KEY INFORMANT INTERVIEWS: INDIVIDUALS LIVING WITH ARTHRITIS ..	35
3.1 Introduction.....	35
3.2 Participant Description	35
3.3 Patient Perspectives on Arthritis Management.....	37
3.4 Patient Perspectives on Challenges Related to Access	42
3.5 Patient Perspectives on Specific Models of Care	48
3.6 Summary of Individuals with Arthritis.....	52
4.0 RECOMMENDATIONS AND CONCLUSIONS	53
4.1 Recommendations for Key Elements of Models of Care	53
4.2 Conclusions.....	57

TABLE OF FIGURES

Figure 1: Key Informants by Profession	15
Figure 2: Patient Journey in Specialized Arthritis Programs	16
Figure 3: Patient Journey in Assessment or Triage Teams	20
Figure 4: Patient Journey in Expanded Role Model	21
Figure 5: Patient Journey Using Telemedicine	24
Figure 6: Patient Journey with Visiting Health Care Providers	25
Figure 7: Patient Journey in Community-Based Care	27
Figure 8: Essential Elements of a Care System for Arthritis	53
Exhibit 1 Questions to consider when developing models of care	32

TABLES

Table 1: Key Informants by Country of Origin	14
Table 2: Key Informants by Setting	14
Table 3: Key Informants by Province	15
Table 4: Strategies for Overcoming Challenges	31
Table 5: Strengths and priorities of models	33
Table 6: Characteristics of Sample - Participants with Arthritis	36

APPENDICES

A Evidence and Best Practices	65
B Definitions of Arthritis	68
C Examples of Arthritis Programs and Services	69
D Key Informant Interview Guide for Health Care Providers, Academics, and Administrators	91
E Key Informant Interview Guide for People Living with Arthritis	93

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Executive Summary

Introduction

Arthritis is a leading cause of pain, physical disability and health care utilization. It is a serious, chronic, and disabling disease affecting 1.6 million Ontarians. There is no cure for most types of arthritis, but treatments exist that have been shown to prevent disability, maintain function and reduce pain associated with arthritis. Essential components of care in the health care system include access to informed primary care physicians and rehabilitation therapists, prompt referral to rheumatologists for people with inflammatory arthritis, and referral to orthopaedic surgeons for corrective surgery or total joint replacement to alleviate pain and disability. Yet, trends indicate a growing care gap between the number of people with arthritis and availability of and access to relevant and timely services. This gap is likely to continue to grow as the population ages and the number of people with arthritis increases.

Consequently, there is a critical need to explore alternative models of health care delivery in order to ensure that Ontarians have timely access to quality care.

Goal and Objectives

The purpose of the overall study is to explore care models for arthritis using existing research, knowledge of experts in the field, and perspectives of individuals living with arthritis. This report builds on previous work documented in the Arthritis Community Research and Evaluation Unit working report *An Exploration of Comprehensive Interdisciplinary Models for Arthritis* in which key informant interviews were conducted with health care providers, educators, and administrators in Ontario.

The specific objectives are:

1. To identify best practice models of care and alternative models of service delivery from the perspectives of key informants working in the arthritis field as well as current research,
2. To identify important components of arthritis management from the perspectives of individuals with arthritis,
3. To explore the acceptability of various models of care with individuals with arthritis, and
4. To make recommendations to the Ontario Ministry of Health and Long-Term Care that include processes required to implement and evaluate proposed models.

Methods

Semi-structured interviews were conducted with two groups a) health care providers, academics and administrators and b) individuals living with arthritis. Data were analyzed using a constant comparative approach.

Results

Key Informants (Health care providers, Academics and Administrators)

Innovative models of health service delivery have been developed within Canada and abroad to deliver care to people with arthritis in primary health care, secondary care and the community. Four main models of care emerged from the key informant interviews with health care providers, including:

- Specialized arthritis programs,
- Models using health care providers in expanded clinical roles,
- Models promoting access in remote and rural communities, and
- Community-based care.

These models evolved to meet at least one of two main purposes: 1) to deliver comprehensive interdisciplinary services for people with arthritis or 2) to promote access to quality services. While specialized arthritis programs focus on delivery of comprehensive, specialized, multidisciplinary team care for the arthritis population, community-based services tend to focus on a broader population and offer community support and resources. Models using health professionals in expanded roles and models promoting remote and rural access evolved, at least in part, to overcome gaps in care and address access issues such as waiting lists and shortages of health care providers, such as rheumatologists and orthopaedic surgeons. Clearly, there is no one model that will work in all populations and all circumstances. Although further evaluation of these models of care is warranted, the models are promising.

Individuals Living with Arthritis

In dealing with the associated daily challenges, individuals who were interviewed adopted strategies and utilized a range of health system and community resources to varying degrees. Some participants were primarily “self-managers” and were less likely to rely on formal supports. When discussing health care delivery, participants identified health care provider characteristics such as empathy, concern, trust and being a team player as being important. Emotional support, shared decision-making and education (for patients, health care providers and the public) were also important aspects of health care delivery. Access issues related to waiting, financial eligibility, coordination and continuity of care, location and accessibility, health care utilization, scheduling of services, follow-up care and referrals were important health care issues from the perspectives of people living with the disease. The models discussed, including team care, non-physician care and telemedicine, were generally favourably received by participants as long as health care providers were knowledgeable, skilled and trusted.

Conclusion

In this research, health care providers and people with arthritis identified common elements of quality health care delivery. These include health care provider knowledge and skills in arthritis, coordination of services and continuity of care. People with arthritis were generally accepting of proposed models of care delivery as long as they felt trust in the health care providers. Given the significant impact of arthritis on the lives of Ontarians and health care system pressures, innovations such as those demonstrated in this report are critical to ensuring that the population as a whole has equitable access to services when needed. Next steps should include further evaluation of models of care for arthritis, integration of arthritis into broader chronic disease prevention and management, and collaboration amongst key stakeholders in arthritis to further develop models of care for arthritis.

1.0 THE NEED FOR MODELS OF CARE FOR ARTHRITIS

1.1 Introduction

Arthritis is a leading cause of pain, physical disability and health care utilization¹⁻⁴. It is a serious, chronic, and disabling disease affecting 1.6 million Ontarians. These numbers are predicted to escalate, and by 2026, an estimated 2.8 million Ontarians aged 15 and over will have arthritis⁴. Arthritis comes in many forms, with more than a hundred different types⁵. Osteoarthritis is the most common type of arthritis affecting over 10% of the population, especially older people^{6,7}. Inflammatory arthritis, such as rheumatoid arthritis, is a serious disease, which requires appropriate medical management. Arthritis affects wide aspects of life such as labour force participation, leisure, travel and social activities^{3,8-10}. It is also costly from an economic standpoint with two-thirds of the costs due to short and long term disability¹¹⁻¹³.

There is no cure for most types of arthritis, but treatments exist that have been shown to prevent disability, maintain function and reduce pain associated with arthritis¹⁴⁻¹⁷. Best practices for arthritis management include interventions such as education, exercise, energy conservation and joint protection, and pharmacologic management (Refer to Appendix A for a summary of best practices or the Arthritis Community Research and Evaluation Unit [ACREU] Working Report *Care for People with Arthritis: Evidence and Best Practices*¹⁸). Essential components relating to the health care system include access to informed primary care physicians, prompt referral to rheumatologists for people with inflammatory arthritis, and referral to orthopaedic surgeons for corrective surgery or total joint replacement to alleviate pain and disability. Rehabilitation professionals such as physiotherapists and occupational therapists also have an important role to play at all stages of the disease.

Access to Care

Primary care physicians are often the first source of medical treatment and information for patients with arthritis. Yet, as a group, primary care physicians are poorly prepared for tasks such as the identification, treatment, and referral of patients to the appropriate specialists. Primary care physicians report they are less confident and have fewer skills to complete musculoskeletal examinations compared with other clinical encounters¹⁹⁻²¹. Early diagnosis and referral to specialists is critical for people with inflammatory arthritis, especially with the development of new medications that have potential to reduce the signs and symptoms of disease and decrease joint destruction from arthritis, particularly in the early stages of the disease²²⁻³³.

There is wide provincial variation in the availability of rheumatologists and orthopaedic surgeons in Ontario^{34,35}, with concomitant variations in waiting times³⁶. Waiting times are further exacerbated by shortages in the number of specialists.

For example, the proportion of rheumatologists per population in Canada is already below the suggested target, and if current trends in rheumatology recruitment continue, it is expected to fall even further³⁷. Waiting times for joint replacement surgery are the focus of a special initiative by the Ontario Ministry of Health Long-Term Care. Access to physiotherapists and occupational therapists is also a growing concern in Ontario, given the move to private sector funding and lengthy wait times for publicly funded services. This is especially true for people with chronic conditions such as arthritis³⁸. In arthritis care, trends already indicate an increasing care gap between the number of people with arthritis and availability of, and access to, relevant and timely services^{4:39}. This gap is likely to continue to grow as the population ages and the number of people with arthritis increases. Consequently, there is a critical need to explore alternative models of health care delivery. Only by understanding how to best organize and deliver health care services to Ontarians can we ensure all patients have timely access to the services when needed.

Canada is not alone in experiencing access to care issues for people with arthritis. A number of innovative models of care have been developed for people with arthritis within various health care systems and communities both nationally and internationally. This report builds on previous work documented in the Arthritis Community Research and Evaluation Unit working report *An Exploration of Comprehensive Interdisciplinary Models for Arthritis*, in which key informant interviews were conducted with health care providers, educators, and administrators in Ontario. The scope of these key informant interviews has been expanded to the rest of Canada and internationally. A series of interviews were also carried out to capture the perspectives of people with arthritis.

1.2 Goals and Objectives

The purpose of the overall study is to explore care models for arthritis using existing research, knowledge of experts in the field, and perspectives of individuals living with arthritis.

The specific objectives are:

1. To identify best practice models of care and alternative models of service delivery from the perspectives of key informants working in the arthritis field as well as current research,
2. To identify important components of arthritis management from the perspectives of individuals with arthritis,
3. To explore the acceptability of various models of care with individuals with arthritis, and
4. To make recommendations to the Ontario Ministry of Health and Long-Term Care that include processes required to implement and evaluate proposed models.

Arthritis is only one of many chronic diseases, and the challenge of providing care to an aging population in the face of shortage of resources is not unique to this condition. Many aspects of the models of care discussed in this report could well be adapted to or incorporated into more comprehensive models of care for chronic disabling diseases in general. The findings presented in this report, therefore, could provide the foundation to contribute more generally to debates in Ontario on chronic disease management.

1.3 Structure of the Report

This report presents research findings from key informant interviews with a) health care providers, researchers, and administrators in Canada and internationally, and b) individuals with arthritis in Ontario. The report will be divided into the following sections:

- Section 2.0 - Key Informant Study of International Models of Care
- Section 3.0 - Key Informant Interviews of Individuals Living with Arthritis
- Section 4.0 – Recommendations and Conclusion

1.4 Key Definitions

Definitions of the major types of arthritis can be found in Appendix B.

Models of Care

For the purposes of this report, a model of care is defined as an approach or method for managing the disease for individuals with arthritis. Models of care can encompass aspects of care delivered by health care providers within the health care system as well as services and programs delivered by non-health care providers within the community.

Expanded Clinical Role

In this report, the term ‘expanded role’ will be used broadly to describe any clinical role that is a) a broadening of knowledge and skills in a specific practice area within scope of practice (includes expanded practice in which some activities require delegation by a physician) or b) beyond the regulatory scope of practice for a given profession (such as extended practice - see extended scope practitioner definition). Extended scope practitioners, nurse practitioners, physiotherapy/occupational therapy practitioners, and primary therapists will all be referred to as expanded roles for the purposes of this report. Refer to Appendix C for more details on the physiotherapy/occupational therapy practitioner model and primary therapist model.

The following are common definitions of the roles of extended scope practitioner and nurse practitioner.

Extended Scope Practitioner

Extended scope practitioners include physiotherapists and occupational therapists. Extended scope physiotherapists, for example, are clinical physiotherapy specialists

in any recognized specialty with an extended scope of practice. This might include requesting or undertaking investigations (X-rays or blood tests), using the results of investigations to assist clinical diagnosis and management of patients, listing for surgery, and referral to other health care providers⁴⁰.

Nurse Practitioner

A nurse practitioner is a registered nurse with advanced academic and clinical experience, which enables him or her to diagnose and manage most common chronic diseases, either independently or as part of a health care team. A nurse practitioner provides some care previously offered only by physicians and in some geographic areas has the ability to prescribe medications^{41;42}.

1.5 Overall Methodology

1.5.1 Procedure

A qualitative methodology was used for data collection. Semi-structured interviews were conducted following guidelines set out by Krueger⁴³. Key informant interviews are an investigative technique for gathering data in a short time frame to gain a broad spectrum of views on a topic.

Interview guides were developed based on a literature review of best practices in arthritis management and models of care for arthritis, as well as consultation with colleagues. Separate interview guides were developed for a) health care providers, academics and administrators (Appendix D) and b) people with arthritis (Appendix E). Questions were open-ended and nondirective to encourage participants to identify issues of importance to them. As the discussion progressed, the questions became more specific to issues of arthritis care delivery, and probes were used to stimulate further discussion if necessary. Some questions were based on themes that arose in other interviews. Interviews were audio-taped and transcribed.

Interviews were conducted by two research associates with experience in qualitative research, one with a background in physiotherapy and the other in health promotion. At the beginning of the interview, the interviewer emphasized the confidential nature of the discussion. Consent forms were signed by participants prior to the interview.

1.5.2 Recruitment of Participants

Health care providers, academics and administrators

A purposive sample of individuals that represent various models of care delivery and/or were known as opinion leaders in arthritis care delivery were contacted to participate in the study. Key informants were selected for broad representation of professions, practice sectors and geographic variation. Prospective key informants

were primarily identified through existing contacts, Canadian partners of the Getting a Grip on Arthritis project, and through the Care III Conference, An International Forum on Arthritis Care (2005). Key informants were also identified using a snowball technique whereby the key informants who were interviewed were asked to recommend other individuals who could inform this study. Twenty-four individuals participated in the first phase of the study in 2004/2005, in which the study participants were limited to Ontario. A further 50 key informants participated in Phase II of the study in 2005/2006, which included individuals from across Canada and countries with primarily publicly-funded health care system (all of which are members of the Organisation for Economic Co-operation and Development [OECD]). Data from Phase I and Phase II of the study both contributed to the analysis and findings for this report. A further subset of key informants was asked to complete a summary of their programs to be included in the final report (Appendix B).

Potential participants were initially contacted by telephone or electronic mail to enquire about their interest in participating in the study. Individuals who expressed an interest were sent an information letter and consent form for the study. After the letter was sent, potential participants were contacted by a research associate to answer any questions they might have about the study and to arrange an interview time.

People Living with Arthritis

Potential participants were recruited through:

1. The Arthritis Society staff in Ontario,
2. Postings with consumer groups,
3. Postings at a rheumatology clinic at Toronto Western Hospital and various primary care physicians' clinics, and
4. Postings (events, flyers, and newsletters) through The Arthritis Society.

Potential participants contacted the research associates through a toll-free telephone number to express interest in participating in the study. A telephone script was used to describe the study and to determine eligibility for admission to the study based on the inclusion criteria. Participants were required to meet the following eligibility requirements:

- A diagnosis of arthritis from a physician,
- Aged 18 years or older,
- Able to participate in a 1 hour interview,
- A resident of Ontario, and
- Able to understand and converse in English.

1.6 Analysis

Data were analyzed using a constant comparative approach⁴⁴. A coding scheme was developed using an iterative, inductive approach. Two research associates performed initial open-coding of the interviews. Codes were compared and contrasted to develop a finalized coding scheme. Once a satisfactory level of agreement was reached, two research associates coded each transcript, using this coding scheme. They subsequently met to review the coding to ensure consistency in the definitions and interpretations of codes. The coded transcript data was entered into NUD*IST Version 6 (N6), a data software program designed to assist with management of qualitative data. The data were then examined for common themes within and among each interview.

2.0 KEY INFORMANT STUDY OF INTERNATIONAL MODELS OF CARE

A variety of initiatives for arthritis care delivery are underway throughout Canada and internationally. Many of these initiatives focus on delivering comprehensive quality services, improving access to services, and making the best use of current resources. This section describes the results of the key informant study of health care providers, academics and administrators.

2.1 Sample Characteristics

In total, 74 key informants were interviewed between 2004 and 2006. Most participants were from Canada (n=59). Fifteen participants were from other countries that have similar publicly funded health care systems to Canada (Table 1). Thirty-three participants worked in a community setting while 22 worked in hospitals. Seventeen participants worked in an academic setting, although they often held clinical and administrative appointments as well (Table 2).

Table 1: Key Informants by Country of Origin

Country	Number
Canada	59
Australia	1
Netherlands	2
Norway	2
Sweden	4
United Kingdom	6
Total	74

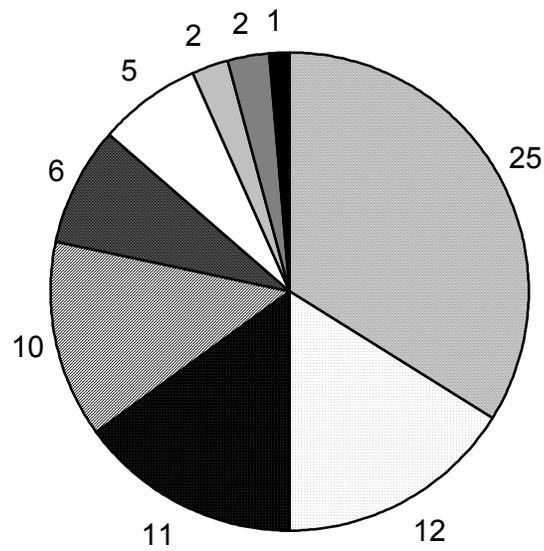
Table 2: Key Informants by Setting

Setting	Number
Community	33
Hospital	22
Both Community and Hospital	2
Academic	17
Total	74

Figure 1 illustrates the number of providers by professional designation. The largest numbers of key informants were physical therapists (25), nurses (12) or rheumatologists (11). On average, participants had 15.4 years experience working in the arthritis field, with a range of one to 40 years.

The majority of participants from Canada were from Ontario (33) (Table 3). Twenty-four of these participants were from Phase I of the study, which was limited to participants from Ontario. Participation from Quebec was limited despite recruitment efforts and availability of study information in French and an interviewer who could conduct interviews in French.

Figure 1: Key Informants by Profession



Physical therapist	Nurse	Rheumatologist
Other	Occupational therapist	Orthopaedic surgeon
Primary care physician	Social worker	Psychologist

Table 3: Key Informants by Province

Province	Number
Ontario	33
British Columbia	6
Alberta	5
Manitoba	4
Nova Scotia	4
Saskatchewan	2
Newfoundland	2
Quebec	1
New Brunswick	1
Prince Edward Island	1
Territories	0*
Total	59

*One key informant was from Manitoba but also represented a program in Nunavut

2.2 Emergent Models of Care

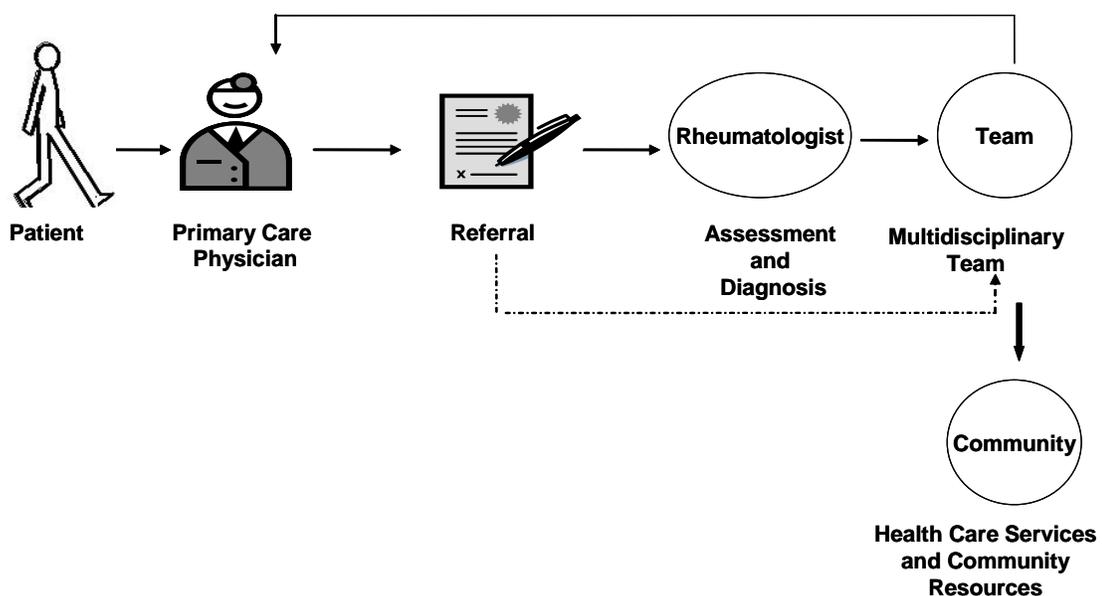
Four common models of care delivery emerged from the key informants' descriptions of their programs and services. Criteria were used to classify these programs and services into types of models of care based on key characteristics such as roles of health care providers in the model, processes for delivery of care and setting for care delivery. The types of models of care include:

- Specialized arthritis programs,
- Models using health care providers in expanded clinical roles,
- Models promoting access in remote and rural communities, and
- Community-based care.

Although programs and services have been classified into one of these four categories based on their primary features, these models are not mutually exclusive. For example, a model of service delivery that was classified as a model using expanded roles of health care providers may or may not also function as a specialized arthritis program. Some key informants described programs and services that did not fit criteria for classification into one of the four models of care described below (e.g. solo practitioners). Other key informants had extensive knowledge of arthritis care and the health care system. Results from these interviews were also used in the development of this report. Each type of model will be described with key features and coinciding strengths, weaknesses, opportunities, and threats.

2.2.1 Specialized Arthritis Programs

Figure 2: Patient Journey in Specialized Arthritis Programs



Programs and services that typify this model of care are characterized by four key factors:

- 1) Services are provided to individuals who have a diagnosis of arthritis.
- 2) A multidisciplinary team of health care providers delivers care.
- 3) A broad range of services and interventions are available.
- 4) Services are commonly provided in a hospital setting, including rheumatology departments and designated arthritis programs.

In this model, the patient journey typically begins with a visit to a primary care physician who then refers the patient to a rheumatologist for assessment and diagnosis. From the rheumatologist the patient may be referred to other members of the health care team. Less frequently, patients are referred directly to an arthritis program for a team assessment. This typically occurs with patients diagnosed with osteoarthritis (OA) or when a community rheumatologist has diagnosed the patient with inflammatory arthritis and refers the patient to an arthritis program for team care. Some programs have a case manager or coordinator of care.

The Patient

Key informants reported that patients with various types of arthritis utilized the services of arthritis programs. However, most commonly these programs focus on inflammatory arthritis patients, such as rheumatoid arthritis (RA), psoriatic arthritis and ankylosing spondylitis. Individuals with OA also participate in these programs. Often interventions are offered in a group format for this population.

The Team

Commonly, teams are defined as a small number of members with the appropriate mix of expertise to complete a task, who are committed to a purpose and have achievable performance goals for which they are collectively responsible⁴⁵. This definition of team is an appropriate one for this model of care. Key informants from arthritis programs most commonly reported the following professionals as members of the arthritis team:

- Rheumatologist
- Physiotherapist
- Occupational therapist
- Nurse (or nurse practitioner or clinical nurse specialist)
- Social worker

Dieticians, pharmacists, psychologists and orthopaedic surgeons were less frequently included as members of arthritis teams. The interaction and communication amongst team members was identified as a key component of this model. Key informants described communication mechanisms, including regular patient rounds or team meetings to discuss patient care and goal setting. Less commonly, key informants reported that the patient also attends team meetings to discuss goal setting.

Services

This model is characterized by the comprehensiveness of a range of services, including both individual and group interventions. Key informants reported medical management of the disease, physiotherapy and exercise, occupational therapy and joint protection, and social work to deal with issues of stress, coping and finances as methods to address arthritis. Patient education is a predominant feature of such programs in both group and individual formats.

Location

This model tends to be located in a hospital setting, either in a rheumatology department or specific arthritis outpatient or day patient program. Key informants reported that inpatient rheumatology is decreasing and available only for patients requiring short term monitoring of medications, for patients with systemic problems, and for surgical patients.

Strengths and opportunities of the model

Key informants from arthritis programs described the following strengths and opportunities of the model:

- Employs a multidisciplinary team approach to patient care, including effective team communication and joint decision-making
- Offers access to a number of service providers in one location (“one-stop shopping”)
- Has a depth of arthritis skills and knowledge of health care providers on the team
- Encourages mutual respect amongst team members
- Establishes clear understanding of the roles of each team member
- Adopts a client-centred approach to service delivery
- Ensures interventions are based on best available evidence
- Provides patient education as a key component of care

Weakness of and threats to the model

Key informants from arthritis programs described the following weaknesses of and threats to the model:

- Lack of sustainability of funding
- Geographic challenge of providing access to services
- Ability to re-enter the system once patients are discharged from a program (e.g. ensuring access to education programs when the patient is ready for education)
- Lack of health care resources in primary health care to refer patients for further services following discharge (e.g. reduction of publicly funded physiotherapy and lack of community or pool programs)
- Challenge of moving away from disease-specific silos and integrating arthritis programs into chronic disease model
- Challenge of coordinating multidisciplinary services

- Scarcity of health human resources to deliver services (e.g. rheumatologist shortages)
- Decreased inpatient care for arthritis patients has led to health care providers who have less specialized skills caring for this population during inpatient stay
- High use of health human resources within one setting perceived to be costly (e.g. multidisciplinary teams)
- Meeting the needs of all patients using the best approach for each patient (e.g. some patients do not want to participate in group programs)

Evaluation

Evaluation of multidisciplinary team care for individuals with arthritis has been evaluated with positive outcomes in the hospital setting. Findings have shown that team care is equally effective in inpatient or day care settings⁴⁶⁻⁴⁹. Several positive outcomes have been demonstrated with a team approach to care of patients with arthritis, including decreased pain, decreased disease activity, increased ability to perform activities of daily living, overall increased function, increased psychosocial adaptation, decreased disability and perceptions of disability, and increased overall health^{46;50-53}.

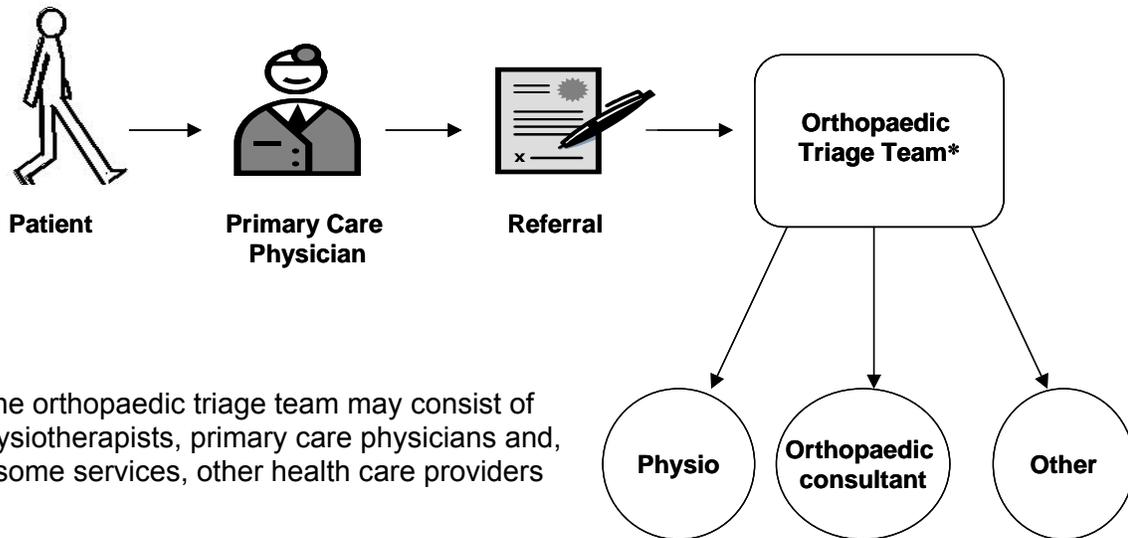
2.2.2 Models of Care Utilizing Health Care Providers in Expanded Clinical Roles

The emergence of models of care utilizing the skills of health care providers in expanded clinical roles has evolved partly as a result of access to care issues. Health care providers, such as nurse practitioners, physiotherapists and occupational therapists working in expanded roles (e.g. extended scope physiotherapists and physiotherapist practitioners) generally work in models of care with one of two primary purposes: 1) to assess patients with musculoskeletal conditions and refer to appropriate services (triage), and 2) to provide ongoing management of patients with arthritis working in collaboration with a consultant. Overall, models of care utilizing expanded roles of health care providers are based on a common desire to improve access to care for patients with arthritis.

These models will be described separately but the results of the analysis of strengths, weaknesses, opportunities and threats are presented jointly following the descriptions.

Use of health care providers in expanded clinical roles to improve access to orthopaedic services

Figure 3: Patient Journey in Assessment or Triage Teams



In the United Kingdom, utilization of health care providers in expanded clinical roles evolved to:

- Address long wait times for orthopaedic consultation,
- Increase efficiency in the system by ensuring more appropriate orthopaedic surgery referrals, and
- Improve the management of patients with musculoskeletal problems⁵⁴.

The key feature of this model is its 'middle door' option in which patients referred for orthopaedic consult are initially assessed and treated by other health care providers.

In this model, the patient's journey in the system typically begins with a primary care physician who refers to a triage team. The composition of the triage team varies with some teams led by extended scope physiotherapists and other teams consisting of physiotherapists and primary care physicians. In other services, there is a greater emphasis on a multidisciplinary approach in which other health care providers such as podiatrists and occupational therapists are also team members. The triage teams assess, advise and request appropriate investigations. Treatments such as joint injections are also available and can be provided by extended scope therapists. Patient education and self-management strategies are incorporated into service delivery. Primary health care providers often provide ongoing management.

In this orthopaedic model, arthritis patients who use this service most commonly have hip and knee OA. The model has typically been structured around joint specific clinics with services often located in community hospitals.

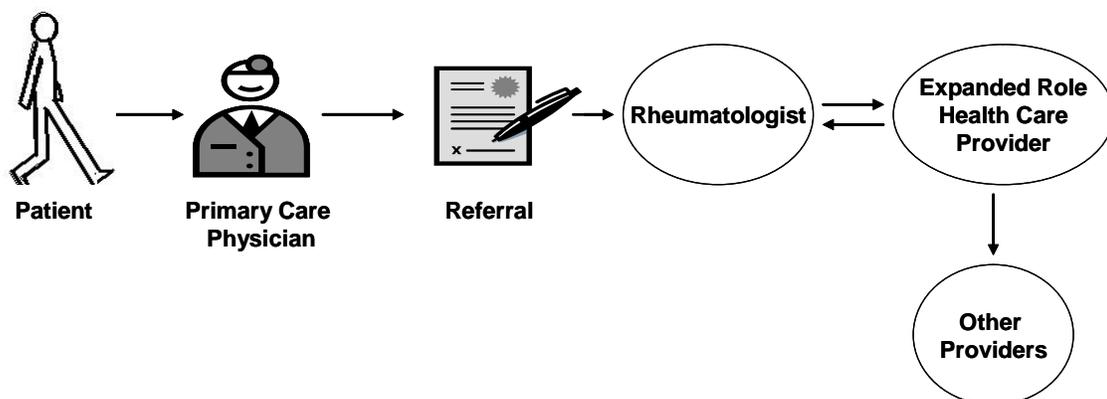
Evaluation

Evaluation of this model has demonstrated improved efficiency, in which between 16% and 20% of patients required onward referral to an orthopaedic surgeon. In one example, 70% of these referrals to the orthopaedic surgeon were then listed for surgery. Prior to implementation of the model as many as 70% of patients seeing an orthopaedic surgeon had not been listed for surgery. Consultant waiting times were also reduced. In one service, the wait time decreased from 18 months to 4.25 months with the implementation of this model of care. Patient and provider satisfaction of these services has also been high ⁵⁴.

Research has demonstrated the effectiveness of specially-trained physiotherapists in the assessment and management of referrals in hospital orthopaedic departments with positive clinical and patient satisfaction outcomes in comparison to junior orthopaedic surgeons⁵⁵.

Ongoing arthritis management using health care providers in expanded roles

Figure 4: Patient Journey in Expanded Role Model



In Canada, and in other countries, health care providers working in expanded clinical roles provide ongoing management to patients with arthritis while working alongside a consultant. Key informants often described the consultant as being a rheumatologist. In this model, the primary entry point to the health care system is the primary care physician. Patients are then referred to a rheumatologist who does the initial assessment of the patient. Appropriate patients are referred to a health care provider working in an expanded role, most often a nurse practitioner or clinical nurse specialist, and in some cases, a physiotherapist or occupational therapist, for ongoing monitoring and management over time.

In this expanded role, health care providers perform musculoskeletal examinations, do ongoing monitoring, and make recommendations regarding changes to medications, and make referrals to other health care providers. In complex cases patients may require medical intervention necessitating consult with a rheumatologist, but a health care provider working in an expanded role may still act as the primary contact for the patient and as a case manager. In more stable cases, patient care is managed by this health care provider, with less frequent follow-up by the rheumatologist. Patient education and self-management are often integral components of the model, including education about medications.

This model is often used in the outpatient hospital setting for patients with various types of arthritis, most commonly inflammatory arthritis (RA, psoriatic arthritis, spondyloarthropathy, scleroderma).

Evaluation

Evaluation of the nurse practitioner model in rheumatology has found that patients in the rheumatology nurse practitioner clinics had significantly lower levels of pain, increased knowledge, and greater satisfaction with their care than the physician-led clinics^{56;57}. The nurse practitioner managed 83% of care without referral to the rheumatologist⁵⁶.

Models of care utilizing physiotherapists in expanded roles in rheumatology management have had limited evaluation. One study found that waiting times for care were significantly less for therapist-run clinics, and the therapists spent a longer time consulting with their patients⁵⁸. The physiotherapist practitioner model (PTP) of care in Canada was evaluated for consumer satisfaction. The PTP clinic generated the same rating of overall satisfaction as the physician clinics. In the group of patients who saw either a PTP or physician, PTP patients gave higher ratings in the domains of access and communication but were lower for the domain of continuity compared to rheumatology clinics⁵⁹.

Strengths and opportunities of the expanded role model

Key informants identified a number of strengths and opportunities of this model including the following:

- Decreases wait times for consultant care
- Promotes early access to care by freeing up consultant time
- Promotes the utilization of the most appropriate providers to assess and manage patients
- Provides access to a range of health care providers
- Facilitates linkages between consultants and other health care providers
- Maximizes the utilization of the skills and competencies of all providers
- Focuses on patient education and self-management strategies
- Promotes a focus on psychosocial issues such as sexuality

- Facilitates continuity of care by accessing the same provider over time (Arthritis management using health care providers in expanded roles model)

Weakness of and threats to expanded role model

Key informants identified a number of weaknesses of and threats to this model including the following:

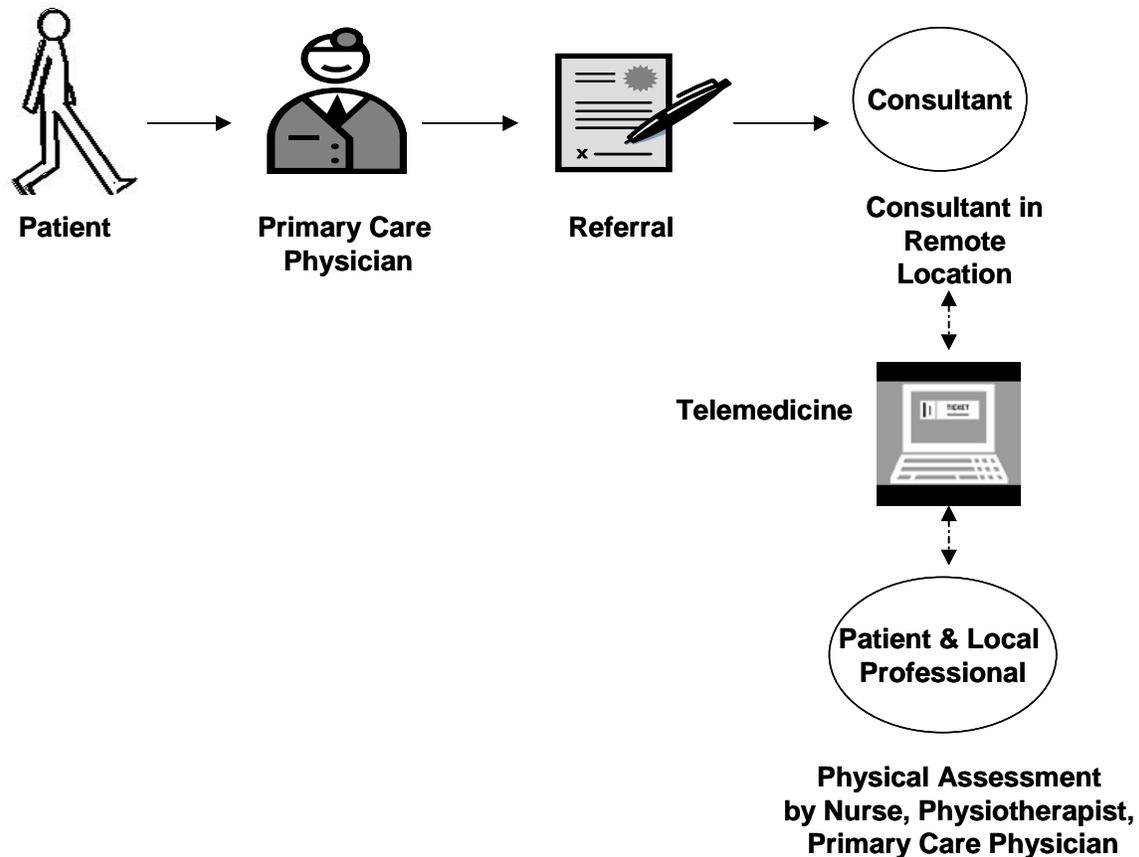
- Lack of transferability of expanded role of therapists to other settings in Canada
- Lack of recognition and awareness of roles by patients, health care providers, the public and administration
- Potential lack of acceptance of role by public
- Potential lack of acceptance by physicians (e.g. barriers in acceptance to performing joint injections in the United Kingdom)
- Lack of sustained funding for roles and administrative support for model
- Lack of structures for billing for consultation services in Canada
- Lack of communication between primary and secondary care
- Health human resource shortages of specialists
- Perception that all health care providers within a given profession have the same skills and expertise
- Perception that spending more time with expanded role health care providers is more resource intensive than shorter visits with consultants
- Challenge of introducing specializations such as arthritis in rehabilitation
- Follows the medical model with a focus on diagnosis

2.2.3 Models to Promote Access in Rural and Remote Communities

Two common modes of health service delivery reported by key informants as methods for working with rural and remote communities were telemedicine and traveling health care providers. These models are typified by the utilization of alternative modes of delivery in order to increase access to health care providers such as rheumatologists, orthopaedic surgeons and physiotherapists for individuals with arthritis living in remote locations. These two modes of delivery will be described separately.

Telemedicine

Figure 5: Patient Journey Using Telemedicine



Telemedicine is a means of sharing health information and providing health care services using telecommunications⁶⁰. This model has been used to promote access to consultant care. After the patient is referred from the primary care physician to a consultant, telemedicine is used to link the patient to the consultant in a remote location. A nurse, physiotherapist and/or primary care physician are often present with the patient locally in order to perform the musculoskeletal assessment while the consultant views the process. Key informants most commonly described using this technology for follow-up of stable patients with inflammatory arthritis, rather than the initial consultation.

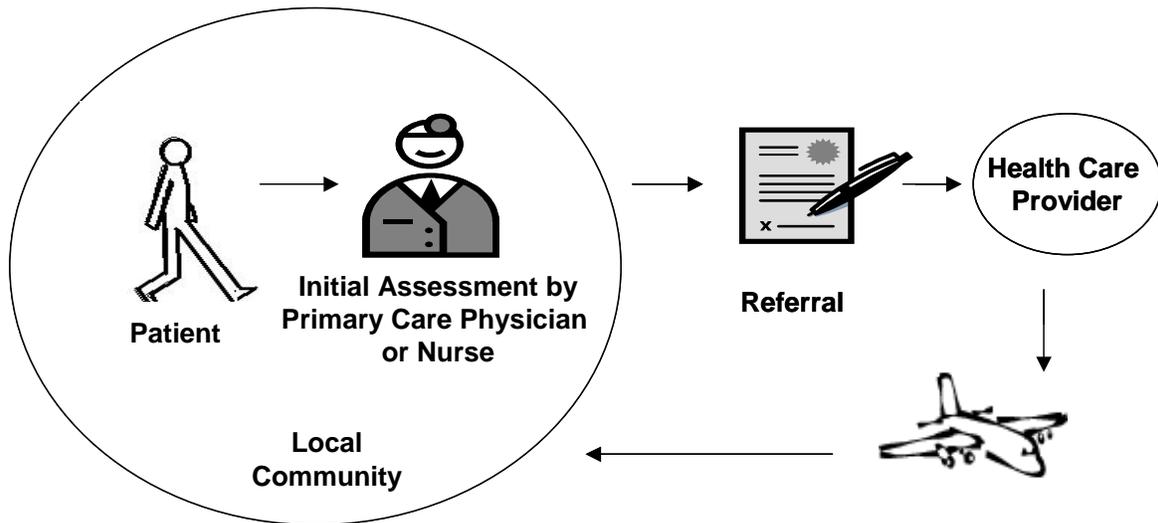
Evaluation

Evaluation of patient outcomes has shown there is relatively convincing evidence supporting the use of telemedicine in some areas of medicine. However, it has been suggested that further research is needed, particularly to examine the cost-effectiveness of this model of health care delivery⁶¹. Research has shown that telehealth rheumatology is a viable model to promote equitable access to care. Telehealth rheumatology consultations have been shown to be feasible, acceptable,

and cost- and time-effective in locations where services are not readily available⁶⁰. One study has also found that televisual consultations in rheumatology were highly accurate and acceptable to patients, primary care physicians, and specialists⁶².

Visiting Health Care Providers

Figure 6: Patient Journey with Visiting Health Care Providers



This model has been used to address health human resources shortages and promote timely access to care in rural and remote areas. The patient journey begins with an initial assessment by a primary care physician or, in some remote communities, a nurse. Referrals are made to the appropriate health care provider, often a consultant, who travels to local communities on a regular basis to provide assessment and management of patients in a local clinic. This mode of care delivery is also used to provide ongoing rehabilitation services and care by primary care physicians. A key feature of this model is central coordination of referrals for patients with arthritis by the health care provider in the local community. This model provides services for patients with different types of arthritis, frequently inflammatory arthritis, living in rural and remote locations, including Aboriginal communities.

In one Canadian example, the traveling consultant model incorporates the utilization of a physiotherapist working in an expanded role. The physiotherapist has a triage role of conducting initial assessments of patients prior to the consultation with the visiting rheumatologist. The physiotherapist also provides ongoing management and monitoring of patients between visits and informs the rheumatologist of any concerns. In another example, a nurse at a remote clinic plays a similar coordinating and monitoring role.

Strengths and opportunities of the models: Models to promote access in rural and remote communities

Key informants identified a number of strengths and opportunities of these models including the following:

- Facilitates timely access to care in remote areas, including consultant services
- Facilitates central coordination of health care delivery
- Promotes collaboration with other providers to deliver care
- Facilitates communication and coordination amongst health care providers on the team
- Promotes linkages and partnerships within communities

Weaknesses of and threats to the models: Models to promote access in rural and remote communities

Key informants identified weaknesses and threats to these models including the following:

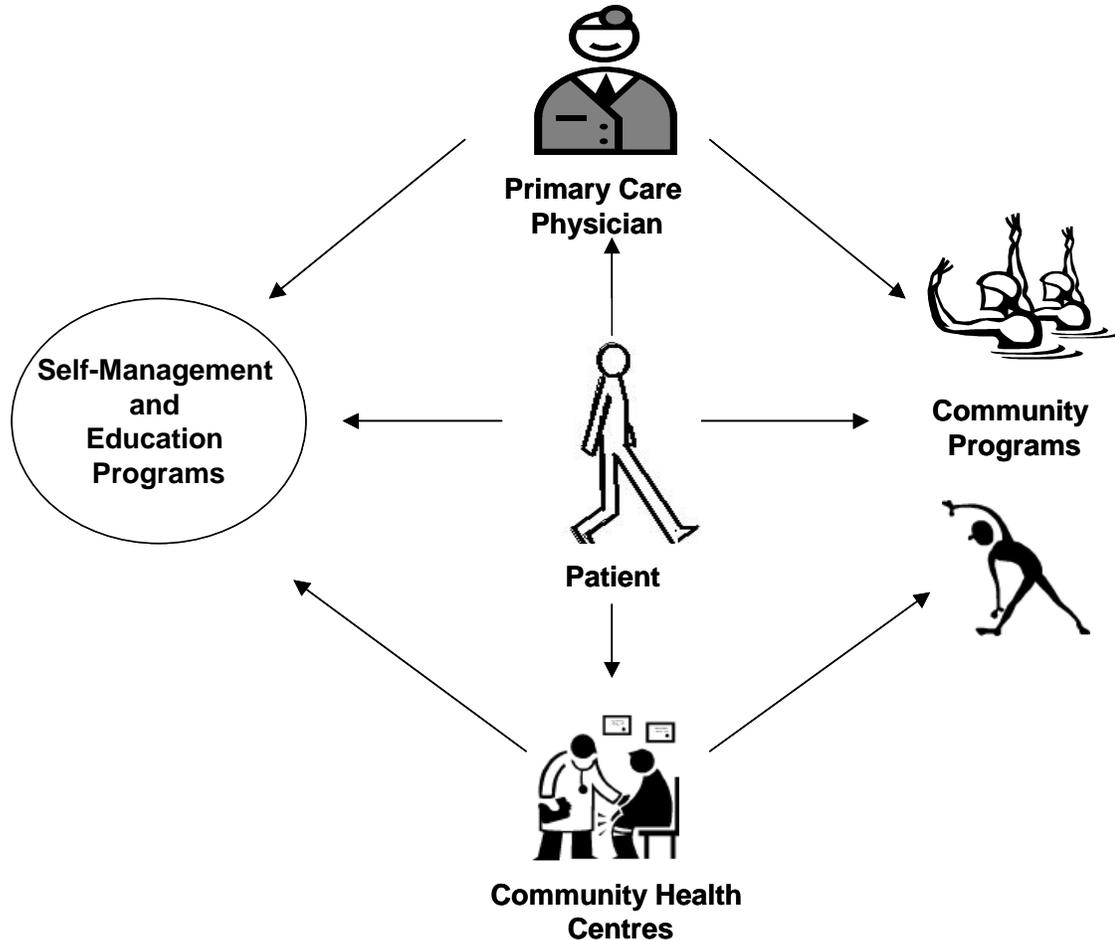
- Lack of sustainable funding for model
- Challenge of special needs of rural and remote communities including poverty and cultural differences
- Lack of specialists and health human resource shortages a challenge to provision of care to communities
- Lack of knowledge and awareness of arthritis in communities
- Lack of knowledge and awareness of arthritis by health care providers

Evaluation

No formal research was found evaluating this mode of delivery of services in arthritis care. However, specific programs do collect data for process evaluation, such as the number of specialist consults.

2.2.4 Community-Based Care

Figure 7: Patient Journey in Community-Based Care



The key features that typify a community-based model of care are: 1) services are available in the community outside of a hospital setting, and 2) in addition to health care providers, service providers may also be volunteers, exercise trainers or other providers. Patients may access programs and services directly through self-referral or via referral from a primary care physician or other health care provider in the community. Key informants described a range of interventions that are offered to people with arthritis including the following:

- Patient education
- Public education
- Arthritis (or chronic disease) self-management programs
- Pool programs
- Exercise programs
- Health promotion and healthy living initiatives

- Primary prevention initiatives targeting risk factors of chronic disease (e.g. obesity)
- Peer support groups
- Physiotherapy interventions, such as exercise and therapeutic modalities
- Occupational therapy interventions, including splinting
- Medical management

Programs and services are often not specific to arthritis patients, and include other types of chronic diseases. Key informants working in this model reported working with individuals with both inflammatory arthritis and OA. A broad range of providers were reported to work in community based settings including physicians, nurses, physiotherapists, occupational therapists, social workers, and dieticians. Other providers involved in this model are health promoters, as well as kinesiologists or exercise trainers working in community fitness programs. Volunteers with arthritis are often critical to the delivery of programs such as the Arthritis Self-Management Program and support groups.

Strengths and opportunities of Community-Based Model

Key informants described the following strengths and opportunities of the community based model:

- Focus on chronic disease management and lifestyle changes
- Strong community networks and partnerships amongst community organizations
- Focus on primary prevention initiatives that may reduce costs to the health care system
- Ease of communication and cross-referrals amongst providers in community
- Community involvement and engagement of people with arthritis as leaders of programs
- Access to community resources addresses gaps in the formal health care system

Weaknesses of and Threats to Community-Based Model

Key informants described the following weaknesses or and threats to the community-based model:

- Isolation and lack of access to services in rural areas
- Lack of personal transportation or public transit to access services
- Societal focus on physician care and services and lack of understanding of the role of other health care providers or community resources
- Wait lists for services such as publicly-funded physiotherapy
- Societal focus on a cure for disease rather than wellness and healthy living
- Lack of stable funding
- Maintaining and training staff and volunteers working in community-based organizations

Evaluation

Programs that are often delivered in community-based settings have been evaluated such as self-management programs. The *Arthritis Self-Management Program* (ASMP) by Lorig and colleagues has the most supporting evidence⁶³. The original ASMP was revised to emphasize efficacy-enhancing strategies, as baseline self-efficacy was found to predict future health status, changes in self-efficacy and were associated with changes in health status⁶⁴. The generic *Chronic Disease Self-Management Program* has also had positive results for people with arthritis⁶⁵.

The provision of non-clinical community-based exercise classes targeting older persons with specific chronic musculoskeletal disease such as RA and OA are limited⁶⁶. However, research demonstrates that supervised exercise classes appeared to be as effective as treatment provided on a one-to-one basis⁶⁷. Exercise in a group setting⁶⁸ is also advantageous because a social context with peers having similar disease-related symptoms may improve attendance⁶⁶. Attendance, or adherence, is important to ensure program effectiveness. One study on a community-based aquatic exercise program demonstrated the importance of consistent participation on achieving outcomes such as improved quality of well-being, physical function and change in arthritis quality of life⁶⁹.

2.3 Strategies for Overcoming Challenges of Successful Models of Care for Arthritis

The major issues commonly identified by key informants that impact the delivery of quality care to individuals with arthritis can be summarized into three main themes:

- *Health human resource shortages*
 - Shortages of orthopaedic surgeons, rheumatologists, primary care physicians, physiotherapists and occupational therapists
- *Lack of timely access to care*
 - Long wait times and distances to services
- *Lack of arthritis knowledge and awareness*
 - Primary care physicians' lack of skills in musculoskeletal assessment and diagnosis
 - Other health care providers' lack of knowledge of arthritis and associated diseases
 - Inadequate understanding by health care administrators
 - Public perceptions that 'arthritis is a disease of the aging'

Lack of sustainable predictable funding to support models was a threat to all models of care and affects all of these areas.

Key informants suggested a number of strategies to overcome health system challenges. Some of these strategies are described in Table 4 for each of the four types of models of care. Other overall suggestions for improving arthritis care were:

- Use health care providers in expanded roles in patient follow-up and patient education to ensure best use of resources and free up consultant time for other tasks such as consultation with new patients.
- Perform task engineering to examine how services are delivered, and use provider expertise to the maximum.
- Communicate research findings and evidence to policy makers and funding agencies to demonstrate the economic burden of illness, the benefits of a healthy population (both societal and economic) and the benefits of self-management programs.
- Build partnerships and improve communication processes amongst all members of a health care team (e.g. use of team rounds, use of technology such as electronic records).
- Build partnerships within communities and with academic institutions to share skills and knowledge of arthritis.
- Partner patients with peers who have arthritis to provide support and overcome issues of compliance with treatment.
- Increase time spent in the operating room and decrease clinic time to overcome barriers in access to orthopaedic surgery.
- Identify champions within communities to lead the development of models of care that meet local needs.
- Include patients in the development of models of health care (including patient and consumer groups), and use their experience to improve the health system.
- Empower patients to coordinate their own care when they are able to in order to address the challenge of coordination of services.
- Establish buy-in and support from administrators by engaging them in the planning process early on and sharing research and evidence about best practices.

Table 4: Strategies for Overcoming Challenges

Categories of Models of Care				
Strategies for Overcoming Challenges	Specialized Arthritis Programs	Expanded Role Models	Models Promoting Access in Rural or Remote Communities	Community-Based Models
<i>Lack of timely access</i>	<p>Link to community programs to ensure patients have ongoing access to community resources and support</p> <p>Use patient-initiated care to address issues related to wait lists</p> <p>Establish clear admission criteria to guide programs</p>	<p>Increase use of expanded role to rural and remote areas as well as specialized hospital-based programs</p>	<p>Provide home visits for people who are unable access services</p>	<p>Provide home visits for people who are unable to access services</p> <p>Have specialists visit community clinics</p>
<i>Health care provider resources</i>	<p>Maximize the skills and experience of all health care providers on the team</p> <p>Increase the number of consultants in training to address shortages of physicians</p>	<p>Ensure adequate resources for administrative support are available</p> <p>Calculate capacity and demand to develop service</p>	<p>Train local community members in skills to deliver care when health care workers are not present (i.e. rehabilitation community workers)</p>	<p>Train health care provider in the community on arthritis best practices</p>
<i>Lack of knowledge and awareness</i>	<p>Use Internet for provision of education to patients and providers to reach wider audience</p> <p>Develop mechanisms for follow-up or that allow patients to contact the program when they are ready for educational interventions</p>	<p>Collaborate with, unify and lobby professional colleges and to educate community regarding these roles</p> <p>To address resistance from physicians, provide evidence of the skills and cost savings of these roles; demonstrate the skills needed and get consultants on board early</p>	<p>Use media (i.e. radio and television) to promote arthritis awareness in communities</p> <p>Increase the knowledge and skills of home care workers in the local communities</p> <p>Translate arthritis education into appropriate languages and make tools culturally appropriate</p>	<p>Increase publicity of arthritis in the community using media and public awareness campaigns</p> <p>Emphasize upstream prevention messages to prevent development and progression of the disease, including weight control and exercise</p> <p>Utilize exercise trainers in the community to promote health</p> <p>Coordinate messages across chronic diseases</p>

2.4 Developing Models of Care

Locally and internationally, a number of alternative approaches have been developed to overcome issues in access to quality care for people with arthritis. Examples of the types of models of care described in this report can be found in Appendix C, which includes descriptions of specific programs and services that illustrate each type of model. Other variations of the service delivery models are currently being developed. For example, in Canada models of care that aim to decrease wait times for orthopaedic surgery are currently being evaluated. These models tend to focus on case management and seamless navigation of patients through the health care system. Clearly, various models may be utilized to address different needs across the continuum of care. When developing models of care for arthritis, careful consideration of population needs and service goals is critical to service planning. Suggestions of factors to consider when developing models of care are listed in Exhibit 1.

Exhibit 1. Questions to consider when developing models of care

When developing models of care, it is important to consider the following factors:

- What is the local burden of illness in the population that will be accessing the services (i.e. type of arthritis, stage of disease)?
- What is the geographic location and catchment area of the population served (i.e. rural, urban, remote)?
- What is the current capacity of health human resources (i.e. rheumatologists, orthopaedic surgeons, physiotherapists)?
- What variables in the system affect access to care (i.e. referral to specialist)? Where are the bottlenecks?
- In what setting is the service to be delivered (primary care and/or secondary care)?
- What is the overall goal of the program or service (i.e. triage of patients or comprehensive long-term management)?
- What other local resources are available for your patients to access?
- What are the current arthritis best practices?
- What is the evidence to support different models of health care delivery?

Based on the key informant interviews and research evidence, the key strengths and priorities of the various models of care are presented in Table 5. Although models of care may have several features, this table aims to summarize the main reasons to implement such a model of care.

Table 5: Strengths and priorities of models

Strengths and priorities of the model	Categories of Models			
	Specialized arthritis programs	Expanded role models	Rural and remote delivery models	Community-based care
Decrease wait times for services		•	•	
Rationalize specialist resources		•	•	
Access to a broad range of providers and services	•			•
Focus on a holistic, chronic disease approach to care				•
Provide one stop shopping for care	•			•
Ensure staff have a depth of knowledge and skills in arthritis care	•	•		
Maximize skills and competencies of all providers		•		
Evidence-based	•	•	•	•
Promote continuity of care	•	•	•	•
Promote community involvement and community partnerships			•	•

2.5 Summary of International Models of Care

The health care system is under pressure to provide the best care for patients with arthritis under the strain of shortages in health care providers and long waiting lists. In response to this crisis, innovative models of health service delivery have been developed within Canada and abroad. Four main models of care emerged from the key informant interviews with health care providers, including: specialized arthritis programs, models using health care providers in expanded clinical roles, community-based care, and models promoting remote and rural access. These models evolved to meet at least one of two main purposes:

- 1) To deliver comprehensive interdisciplinary services for people with arthritis, or
- 2) To promote access to quality services.

Models of care often varied in terms of the population served, the setting and local needs. The strengths and weaknesses of each model should be considered in the planning and development of models of care for specific communities and populations. Although further evaluation of these models of care is warranted, the evidence is promising for positive outcomes. Given the urgency to develop innovative models of care for arthritis, it is time to move forward with a research and implementation agenda in Ontario and Canada.

3.0 KEY INFORMANT INTERVIEWS: INDIVIDUALS LIVING WITH ARTHRITIS

3.1 Introduction

In addition to obtaining provider opinions on essential elements of arthritis models of care, it is also important to speak with people who have arthritis. This is critical in order to understand the perspectives of individuals living with the disease; they have their own expertise, experience, and knowledge of the disease. It was thought that such perspectives would facilitate a better understanding of current barriers in the health care system and community, and identify what is needed to help people manage their disease effectively.

3.2 Participant Description

In 2005-2006, 19 participants provided personal insight about the issues important to them to manage their arthritis and to improve arthritis care in Ontario. Table 6 summarizes patient characteristics and demographics. The majority of participants were female and had various types of arthritis, including rheumatoid arthritis (RA), osteoarthritis (OA), fibromyalgia and psoriatic arthritis. Half of participants had other chronic conditions. Participants had limited disability with a mean score of 0.7, as measured by the Degree of Difficulty Subscale of the Modified Health Assessment Questionnaire⁷⁰. The mean score is reported on eight items, (score 0-3), with a lower score representing less difficulty. These descriptive characteristics are consistent with community-based samples of other studies.

Table 6: Characteristics of Sample - Participants with Arthritis

	N
DEMOGRAPHIC VARIABLES (n=19)	
Age, mean \pm SD years	55.8 \pm 10.9
Gender	
Female	17
Male	2
Education	
Secondary School or less	7
Trades certificate/diploma	2
Post Secondary	10
Living Arrangements	
Alone	5
With spouse	5
With spouse & children	5
With children	2
With parents	2
ILLNESS RELATED VARIABLES	
Arthritis Type	
RA	4
RA + 1 or more other arthritis types	5
OA	5
OA + 1 or more other arthritis types	4
Psoriatic Arthritis	1
Duration, mean \pm SD years	10.5 (7.6)
Co-morbid chronic conditions	
Yes	9
No	10
MHAQ	
Degree of Difficulty Subscale, mean \pm SD	0.7 \pm 0.4

3.3 Patient Perspectives on Arthritis Management

Impact and Challenges

Arthritis can be a devastating disease with serious impacts on various life areas. Arthritis leads to loss of mobility, diminished grip strength, reduced range of motion and pain. Participants described a resulting impact on many areas including activities of daily living (e.g. household chores, driving, child care, sleeping), work status (e.g. reduced hours, modified work environment), leisure activities (e.g. hobbies, sports), social life, as well as family life. The emotional effect of arthritis was considered as serious as the physical damage, particularly for individuals with RA.

Participants were faced with many challenges related to the disease. Battling the perceptions of others was an ongoing struggle. As arthritis is not associated with dying, it has diminished status compared with diseases like cancer and heart disease. The lack of awareness and understanding in the general public and specific groups, such as insurance companies, workplaces (employers and employees), family and friends, as well as health care providers, was reported as a barrier.

“The general public that don't know about arthritis, don't understand. They don't understand why you look so well and you can't, you can hardly walk or you don't feel like doing what it is they want you to do...”

Participants reported loss and change related to their independence and sense of identity, particularly in reference to work. Most participants, especially those with RA, identified financial concerns such as reduced income and gaps in health coverage between government coverage and private insurance company reimbursement. As drugs consumed an increasing proportion of a family's income, participants sought out additional funding sources and were forced to make adjustments in their lifestyles.

Part of living with arthritis was to accept it as a chronic disease that “was not going away”.

“Such an overwhelming feeling of not knowing anything about this and not having any control over it. And it's not something that's going to be fixed, like a fracture or a disease that can be cured”.

Denial (after diagnosis and throughout the disease) was said to impede participants' effective management of their arthritis.

Patient Characteristics

Participants appeared to fall into two groupings. “Self managers” used few formal health system resources (these being mostly primary care physicians and rheumatologists/orthopedic surgeons) and few community resources. As one participant explained:

“I prefer to do what I need to do and as long as I go and check in once every so many months and everything is okay and, you know, that is how I make sure that I am doing it right.”

The second group was comprised of individuals who used a variety of resources, both health system (physicians and other health care providers) and community resources such as The Arthritis Society and exercise programs. Participants who had had arthritis for several years tended to fit into the self-managing grouping. Some “self-managers” reported using non-pharmaceutical or natural products.

Past/Future Concerns

The unpredictability of the disease meant planning to do things was difficult and limited participation in everyday living. Living in the moment was important as participants could not anticipate how they would be feeling at a given time point in the future. Participants were also concerned about what to expect for their future health.

“For years we did not make any long term plans as far as vacation or even leaving like where I live because we did not know how I was going to feel one day to the next.”

Strategies

Participants developed “self-management” strategies to live with this chronic condition.

“...your health is no longer in a doctor’s hand. This is how I look at it. Your health is really in your hands.”

Participants eliminated, limited or modified activities. They used education, pacing, assistive devices (e.g. orthotics), therapeutic modalities (e.g. heat), movement and exercise, dietary adjustments, help from family and friends and cognitive strategies (e.g. positive thinking). Some people tried to generally lead a healthy lifestyle. Others remained active in the community and modified work arrangements. Lastly, prescribed and non-prescribed medications were used by participants. Although medication does improve mobility and reduces the constant pain side effects were a concern. Medications were identified by some as a worthwhile “trade-off” to improve current well-being and present-day mobility. Others opted for complementary and alternative medicines, such as glucosamine.

Community Resources

Not all individuals interviewed used community resources. The resources mentioned were categorized as arthritis-specific resources or as general community programs/services not designed specifically for arthritis (e.g. YMCA pool programs, seniors programs). Community resources most frequently referred to and used by participants were exercise programs, especially pool programs. Other community-based resources were The Arthritis Society, organizations for equipment and assistive devices, support groups, tai chi, Pilates, Community Care Access Centre home care, yoga and Victorian Order of Nurses (VON) Seniors Maintaining Active Roles Together (SMART) program. Maintaining funding for community resources was considered an ongoing concern.

One participant spoke of transitioning from an arthritis-specific program to a general program:

"...it was over a year, I went twice a week for over a year and it was in a therapy pool and it was just, it did me so much good it was unbelievable. And once they closed down, so I did not want to discontinue it, so I thought well maybe I have gained enough strength that I could do the "Y" and just join a regular Aqua fit class and that is what I did and I was fine with it. So, I just go to the "Y" now."

Emotional Support

Participants identified both formal (e.g. support groups, social workers, mental health services) and informal (e.g. family, peers) sources of emotional support. Some formal support groups involved family members. Not everybody had a personal need for formal support. However, participants did identify the overall value of such groups. Primary care physicians and rheumatologists would not necessarily be sought out for emotional support.

Emotional support was noted as an additional benefit of participation in social or education groups and volunteer activities. Peer support was highly valuable.

"...it is such a relief to find somebody else that has gone through similar situations. So I think it, you know, even though the people in my life, they are very, very understanding and very, very helpful, it is just, you know, somebody who has been there and knows exactly how that feels, it is a completely different sort of situation, and it is very helpful."

Other sources of emotional support included supportive employers and coworkers, Internet chat rooms (peer support), pets and religion/church.

Decision-making

Awareness of one's personal limitations as well as a trusting relationship with one's physician or other health care providers were identified as being important to make appropriate decisions to be able to take charge of the disease.

Decisions were made by a physician alone (telling patients), by participants alone, or in a shared fashion between the participant and physician or other health care provider. Shared decision-making is facilitated by information - i.e. the patient having knowledge about strategy options and the health care provider knowing about the patient's disease process. In this model the patient has the ultimate decision as to the appropriate action.

"Dr. X told me last week, 'Do you want me to schedule you right now or do you want to wait awhile?' I said, 'You know what; it's under control. Let's see how it goes for a few months,'" and I said to him, "If I want to go ahead with the operation, do I need to come back through my own family doctor?" He said, "No, you come straight to me." In other words, once you are referred, then he and I can determine when and if I have the operation."

Many participants were proactive and "took charge" of their own care and wanted to be the leader in the team or in the relationship with their health care provider. These participants felt it was their responsibility to seek out treatment options and educate themselves.

"I think the patient should be well-informed whether they do it themselves by getting the information or asking enough questions of their doctors."

These participants also spoke of being their own advocate and finding and following up with health care providers. A couple of participants noted some people prefer their care to be directed by a health care provider as opposed to being self-directed.

Decisions about treatment were influenced by various factors. Participants wanted to use less invasive strategies first before trying treatment options such as surgery. One participant stated that he was delaying surgery as long as possible in hopes that there will be new options in the future due to advances in medicine.

"...I just keep delaying on the basis that maybe they might come up with a magic bullet of some sort or another..."

Two participants raised an issue of diminished decision-making power, in which decisions about medications are dictated by insurance companies.

“...because your insurance company doesn't reimburse. So there's a gap in the system between what the government allows for and what insurance pays for and what the client really needs.”

Patient Education

Education was highlighted as being necessary to make wise decisions. As people increased their knowledge they gained control. The purpose of education was two-fold: 1) to provide information about the disease and how to manage it, and 2) to share information about community and other resources and how to access these. Also, one participant identified the need to understand the language, often English, in order to enhance the uptake of educational initiatives and to make informed decisions.

Participants learned from the Internet, The Arthritis Society, health care providers, print resources, pharmacies, community information sessions, Arthritis Self-Management Program (ASMP) and other formal education programs, conferences and other people with arthritis. Participants identified that education should be ongoing throughout the disease, tailored to the individual, easy to understand and delivered in either an individual or group format. Information must be accurate and age-relevant.

Timing of education was also said to be an important consideration.

“So, they need to have the information, it is what gives you control, it is what empowers you, but it just has to be timed right. Otherwise, it is just, it is lost.”

One participant suggested screening people regarding their readiness for education.

Health Care Provider Characteristics and Education

Most of the discussion on provider characteristics focused on physicians, specifically primary care physicians and rheumatologists. Participants identified the following important health care provider characteristics:

- Knowledgeable (about disease, resources available – e.g. The Arthritis Society)
- Empathic
- Understanding
- Willing to listen
- Treating the person, not the disease (medications are only one part)
- Motivating
- Competent
- Trustworthy
- Dedicated

- Concerned
- Progressive
- Team player (with patient and other health care providers)
- Empowering

“If somebody is really concerned in looking after a person, that’s a major step, for the individual too, to want to say, “Hey, I’m being given proper care, I feel important.”

Participants preferred physicians to work with the patient in an equal partnership in which joint decision-making occurs and there is an ongoing dialogue, although one person identified that the physician is still the “expert”. Participants preferred primary care physicians who are willing to learn and find out if they do not know the answer and to be more proactive in diagnosing and treating. It was also suggested that health care providers need to communicate with patients in an unrushed environment to assess their readiness to implement strategies suggested.

Several participants identified that they would like physicians to provide more information.

“They need to be referring patients there [The Arthritis Society]. They need to be specific about it, and say okay this is how...these are the kinds of programs you’ll need to be going on, contact the Arthritis Society and find out what they can offer you, instead of just saying here’s your pills, come back and see me in two weeks...”

However, it was also recognized that due to physicians’ time constraints other health care providers may be more appropriate sources of information, including information on community resources.

To be effective at managing arthritis, including patient education, participants identified that health care providers need specific training on arthritis (diagnosis and management), its associated diseases and community resources. It was thought that physician education would facilitate more rapid diagnosis and appropriate management.

3.4 Patient Perspectives on Challenges Related to Access

Participants were asked to comment on access to the health care system. Access issues may be heightened depending on disease trajectory (e.g. qualifying for coverage only if problem is acute) and diagnosis (e.g. OA patients may have less access to rheumatology services).

Wait Times

Waiting for appointments and procedures leads to avoidable deterioration/ damage and possibly more invasive treatment.

“But by the time I got the referral from my GP and the x-rays and so on, it was at least six weeks or longer before I saw him, by then there was nothing he could do with my pinky finger as far as injecting it. That is when all the surgery started on my hand.”

Participants described various wait points with respect to health care, in particular waiting for specialist services (i.e. rheumatologists, orthopaedic surgeons) and related procedures (e.g. surgery). Some also mentioned waiting for publicly funded physiotherapy services and community resources, such as ASMP, assistive devices, and pool programs. Living in a rural location was said to increase wait times. Participants seemed to believe that waiting for services was to be expected.

“Yes and it took 3 months to get in to see him, which is quick.”

Participants identified strategies they used to gain more timely access to services, including being coordinators of their own care, becoming informed through other people with arthritis and accepting appointments at odd hours (e.g. 2 am appointment at a 24-hour MRI clinic). One woman spoke of calling around to find her own specialist who would take her as a patient.

Eligibility for Financial Assistance and Insurance Coverage

Many participants experienced financial strains related to being ineligible for assistance or insurance coverage or as a result of the reduced income of disability benefits. Lack of awareness of possible funding options and eligibility was brought up by some participants.

“...when your insurance company doesn't cover the majority of the more expensive drugs... What can we use to get some of this money back?”

Types of support participants received include medical/health benefits (government, private, work) and disability coverage.

Some participants had problems qualifying for support. Furthermore, even when assistance was received, participants identified other prohibitive issues, such as lack of coverage or partial coverage of medications by government or insurance companies.

“...because your insurance company doesn't reimburse so there's a gap in the system between what the government allows for and what insurance pays for and what the client really needs.”

An upfront investment of newer, more expensive, but more effective medications that enable people with arthritis to remain employed may be more economical in the long run. Several participants were concerned with the lengthy time it takes to be reimbursed from the Ontario Trillium Foundation, although it was not difficult to access. Delisting of previously funded public services (e.g. optometry, physiotherapy) also created problems.

Strategies to overcome these challenges included coordinating benefits by allocating expenses to more than one plan (e.g. work-related insurance benefits and Trillium; public and private) and advocating with insurance companies. Limiting one's access (e.g. booking shorter appointment times or fewer appointments for physiotherapy) to stretch benefits was an approach taken as well.

Coordination

Some participants expressed that coordination within the health care system and between the "hospital" and community was inadequate. Similarly there was a lack of coordination in the community between local physicians and specialized clinics. Although participants were often required to be coordinators of their own care, they did not believe they were always knowledgeable to do so.

"...just getting some help was a major ordeal...There's no coordination between the GPs, between the rheumatologist, between the physio. They never say well go here and they'll help you. You have to do it on your own. That I didn't know until this happened, I didn't know that the healthcare system had gotten to the point that if you don't coordinate it all it doesn't get coordinated."

Use of technology and communication was suggested as a way to improve coordination.

"I have found, certainly, the thing that makes it easier at [hospital name], is that things are sort of on-line, so certainly with my x-rays, everything gets uploaded onto the screen right away and I guess when you have different doctors in different areas it is sort of hard to get that information, you know, faxes do not always go through and that sort of thing."

Some participants thought that coordination would be a good role for a nurse. One participant suggested that someone could be specifically trained for the function of assessing patients' needs and matching providers to patients.

Continuity of Care

Continuity of care (seeing the same health care provider over time) was agreed to be essential by several participants. One participant shared:

“...I’ve gone to the walk-in clinic when I’ve needed to but I really want to find a proper GP.”

Having someone provide telephone follow-up, especially immediately after diagnosis was mentioned:

“...somebody that you could call with any questions, and that would call you too, make sure that she called you a week later to see how you’re coping.”

Another person talked about making a connection with a “back-up” rheumatologist in the event that her current specialist retires. Continuity of care was considered by one participant to be important with respect to a telemedicine consultation.

Location and Accessibility

Although many participants preferred resources to be in closer proximity, they did not want this at the expense of quality and were willing to travel for quality. People in less urban areas had come to expect that they had limited options. Due to lack of resources in rural areas, switching providers was difficult and an individual did not always have confidence in the quality of local services. Also, it was suggested that not all services needed to be hospital based; community-based resources were acceptable. There was a perception by some participants living outside Toronto, that “Toronto gets all the perks”, and there is a need to recognize growing centres outside the Greater Toronto Area.

“When you live north of the big Smoke, and people come from, there’s even some people from Sudbury have come down. Huntsville, Bracebridge, Collingwood, Owen Sound, Orangeville. They’ll come over to this hospital here for this program, because there’s nothing in their own outlying community... let’s face it we’re no longer just small towns out here. And it’s still Toronto gets all the perks. So until they really start to consider that there’s a ton of other people living outside, and that they’ve got to start putting some health care dollars into programs that help them.”

Preference for traveling out to services versus receiving in-home supports varied and was usually situational. Participants who were mobile (ambulatory) did not mind receiving services in another community, but they recognized that at some point in the future they may require in-home supports. Some had needed in-home care in the past, at times in the disease process when they were quite ill and unable to go out.

“Right now it does not matter because I am ambulatory and I am able to get where I have to go. Back in the 80’s or early 90’s it certainly would have mattered because it took me ages to go up the

stairs or go down the stairs, so definitely keeping in mind the disability end of it, as far as where they would locate a clinic or the hospital.”

One individual expressed that at times when a person is acutely ill, inpatient hospital care may be the preferred option. This same participant felt that going out to appointments helped reduce social isolation that often accompanies RA.

In terms of accessibility, when a person has limited mobility public transportation to appointments is exhausting, and not all areas are accessible.

“... if I had to do it by public transit with arthritis, if I didn't have a wife who's nine years younger than myself, if I didn't have a couple of grown up sons who can go...who both of whom have cars, ... if I lived out in the country and had to try and do it without, with a limited budget and can't afford to get a taxi and so on, I could see all kinds of problems.”

Two participants reported difficulties with stairs at the subway in the city and that elevators were not available or easy to find.

Proximity of location and issues of accessibility also had an impact on participation in community (e.g. attending programs, volunteering), especially in winter. One potential solution, having a team under one roof, was perceived to reduce barriers related to location and accessibility.

Health Care Utilization

Participants described contact with various specialist and non-specialist health care providers. All participants had a primary care physician. Nurses were identified by a few people. Most were currently seeing or had seen a physiotherapist in the past and half had seen an occupational therapist. Persons with OA were less likely to see a rheumatologist; one individual with a diagnosis of RA did not have a rheumatologist. Half of participants had seen an orthopaedic surgeon, while many participants consulted a pharmacist. Half of the participants identified contact with complementary medicine providers, including massage therapists, reflexologists, naturopaths, acupuncturists and chiropractors.

Rates of health care utilization varied from person to person and by provider type. Most participants currently seeing a rheumatologist had appointments three or four times per year. More frequent visits to primary care physicians were to obtain prescriptions, for specific complaints related to their arthritis or in leading up to a procedure (e.g. surgery). Some participants had standing appointments for follow-up and the next session, while others initiated appointments as needed. It was reported that once a person was maintained and the disease was

under control that utilization may decrease. There tended to be more frequent use early in the disease process.

One participant raised the importance of having services in the area as frequency of health care utilization increased. Cost was mentioned as a factor that determined frequency of health care utilization. Many participants expressed not wanting to use the system any more than absolutely necessary. As emphasized by one participant with OA,

"... it is chronic; it is not something that I have to go running to doctors for, and if I did run to doctors it wouldn't do me any good."

Scheduling

Overall, participants described situations in which there was little flexibility in scheduling appointments and that appointments were not always convenient. Most of the discussion focused on scheduling of physician appointments. To secure a rheumatology appointment, participants booked their appointment for the next visit at the current visit. Participants described primary care physicians and rheumatologists as being overbooked so scheduling was difficult.

In the city (Toronto) there are options for low demand appointments for some services (e.g. 24 hour MRI clinic) so appointments are more flexible. One participant raised the challenge of booking busy facilities for joint replacement and other surgeries due to limited operating room time for such procedures.

An additional issue raised was the lack of resources in rural communities, including community resources (e.g. pool programs, ASMP), which meant that participants would either not attend at all or would have to drive to other communities.

"There's only one arthritis support group, Rheumatoid Arthritis support group. It's in Ajax, and it's the last Thursday of the month, and it's at 7 o'clock in the evening, but that's it... when Thursday night came I didn't feel like going out. It was raining, it was dark, I was going to a strange area that I didn't know about and I didn't want to do it."

Follow-up care

Most participants preferred to initiate their own follow-up care with primary care physicians, other health care providers and community services as needed.

"...the Remicade I book myself, because I know if I don't book I could get left out of the system."

However, as mentioned earlier, most participants recognized that booking the follow-up appointment before leaving the current rheumatology appointment was

advisable due to long waits. Participants reported that they will self-initiate rheumatology appointments in crisis or urgent situations.

One participant raised the issue of having a single individual to coordinate follow-up care as the ideal. Another participant identified the issue of patients having higher needs immediately after receiving a diagnosis and that someone (e.g. nurse, therapist) should follow-up by telephone in one week. Follow-up care also included health care providers checking on test results.

Referral

Participants elaborated on a variety of providers for whom they sought referrals (e.g. specialists, rehabilitation services, complementary therapies, foot clinics and community resources). Physicians were considered an important source of referrals. As one participant recognized,

“If I have a family doctor, then I should be okay for the rest, because you need referrals to get in there.”

Access issues, including lack of resources in some communities, wait lists, and transportation/travel limitations affected referral effectiveness, and delayed referrals were said to lead to deterioration. For specialist referrals, some participants identified that once they were “in the system” they were able to arrange subsequent appointments without an additional referral from a primary care physician.

Participants implied that a primary reason for referral to other providers was a provider being unsure or unable to do anything further, or a treatment issue being beyond scope of practice.

“I think they have to do a better job at the initial, even when a G.P. suspects arthritis, that there be quicker access to the rheumatologist or internist like in our case.”

Participants sometimes chose referrals based on suggestions from family members. One woman found a specialist to be referred to on her own. Several participants described the need for a patient to initiate a referral and that an individual’s own advocacy efforts could lead to more timely and appropriate referrals.

3.5 Patient Perspectives on Specific Models of Care

Participants were asked to respond to the three following questions on specific models of care:

Team Delivery Model

Question: Arthritis can be managed by a team of health care providers working together with the client. For example, this might include a doctor, nurse and therapists working together in one location. Another way that help can be provided is by having one health care provider, for example your doctor, help manage the care of the person with arthritis. How would you prefer your arthritis care be delivered?

Most people identified a preference for a team approach, although several had not personally experienced team care. Only a few participants did not perceive a team to be a beneficial way to receive care.

Participants thought the team should be comprised of a mix of providers, such as physicians (primary care physicians, specialists), nurses, nurse practitioner, occupational therapists, physiotherapists, dietitians, and pharmacists. The patient was also considered to be an essential member of the team.

“I think the team work needs to come too between the doctor and the patient.”

One participant described herself as the one to direct the team, with team care being organized through the rheumatologist. A second person also saw herself as the leader.

A few people thought having the team in the same building was important.

“You don’t have to hike all over the city ...from one end of the city to another to get an appointment six months down the line.”

Others identified that coordination, regardless of whether the team was in one location, was an essential characteristic of a team.

It was discussed that team members needed mutual respect for each other and each member’s respective role, as well as good communication and sharing of information.

“I think the doctor, physiotherapist and surgeons all kind of have to work hand in hand.”

Participants were mixed in their opinions as to when in the disease process team care was most important. One participant viewed team care as a way to address waiting lists.

Non-Physician Provider Model

Question: How would you feel if more of your arthritis care was delivered by someone who is not a physician but has received special training in managing

arthritis? (For example, this might mean that a specially trained nurse, physiotherapist or occupational therapist help manage more of your care).

Having a non-physician provider who has specialized training in arthritis to deliver care was positively received by all participants, except one, who declined to comment because she is a self-manager and had limited experience with non-physician care. One individual felt rheumatology care would be best early on, but non-physician involvement would be acceptable later in the disease. A few participants felt non-physician care would be better, particularly for teaching specific non-pharmaceutical strategies, as physicians do not necessarily have the knowledge, skills or time. Professions identified for this role included nursing, nurse practitioner, occupational therapy and physiotherapy.

Participants identified several caveats:

- The non-physician provider must have the expertise (knowledge and skills) and proper training in musculoskeletal conditions.
- Physician involvement, especially a rheumatologist, is important to oversee care and to be responsible for medications.
- The non-physician provider's role would be to provide education, support and information on resources available, to do assessments (e.g. joint count) and to coordinate care.
- The individual would also be responsible to provide care in his/her area of expertise (e.g. dietitian for nutrition information and advice).

As two participants with RA stated:

"That's a fine idea as long as they have physician backup... rheumatologist backup... absolutely... but I'd want to know that there's a physician or a rheumatologist behind them." and

"It's more about the skills and knowledge than it is about who. But I'd have to be pretty confident that they know what they're talking about."

Telemedicine

Question: Telemedicine is another way care can be delivered. Telemedicine is the use of technology that allows a patient to be assessed by a health care provider that is located in an office in a different location. The health provider, often a specialist, can see and talk to the patient to help them with their health care needs by using telecommunications. How would you feel about having your health care delivered in this way?

Some people were not familiar with telemedicine. Participants were mixed in their perception of telemedicine. Generally participants thought this approach was acceptable but face-to-face was ideal. It was considered of particular benefit:

- To people in remote areas, to not have to travel long distances to specialists or wait for visiting specialists to come to their community,
- To people not well enough to travel,
- To prevent delayed intervention, and
- To increase consultation between specialists and primary care physicians.

A couple of participants preferred face-to-face encounters and were not open to telemedicine.

“I’d rather see my [rheumatologist] in person but if I was in Thunder Bay I’d be really thrilled to have access to people who were rheumatologists without having to get on a plane. So I would say that yes that would be very positive for people who didn’t have other ways of getting to a competent rheumatologist. Maybe somebody who was so poorly that getting downtown is very difficult for them.”

A few participants identified the importance of the hands-on joint manipulation and thought its effectiveness would be compromised unless the clinician with the patient was skilled and competent. In addition the patient needed to have established a level of trust with that provider. On the other hand, for certain procedures (e.g. to review x-ray results and demonstrate ROM activities) telemedicine would be beneficial.

“I think at certain points with arthritis you can do it, and I think for certain needs. For instance, if you are doing therapy and they're trying to show you something like that, whether you get it out of the book and try and do it or you go to a therapist and they show you or you could use a screen and they could see.”

One participant thought telemedicine would not be appropriate for people in a flare up. Another said telemedicine would not be favourable for older adults who may have difficulty understanding what is being communicated over a video screen.

“Because I think if you don't have some background information yourself it is very hard to understand, first of all it is hard to understand what they are telling you when they are face to face, I can't imagine you know an older person having you know someone on screen telling them...”

3.6 Summary of Individuals with Arthritis

Arthritis can be a devastating disease with many repercussions. In dealing with the associated daily challenges, individuals who were interviewed adopted strategies and utilized a range of health system and community resources to varying degrees. Some participants were primarily “self-managers” and were less likely to rely on formal supports. Regardless of patient characteristics, participants agreed that emotional support, shared decision-making and education (for patients, health care providers and public) were important. Access issues highlighted related to waiting, financial eligibility, coordination and continuity of care, location and accessibility, health care utilization, scheduling of services, follow-up care and referrals.

Health care provider characteristics such as empathy, concern, trust and being a team player were consistently important. The models discussed (team approach, non-physician provider care and telemedicine) were generally favourably received as long as health care providers were knowledgeable, skilled and trusted. Telemedicine was least preferred as many participants preferred face-to-face. However, it was viewed as a good alternative for rural areas lacking services, for individuals too ill to travel or for tasks not requiring hands-on contact.

This analysis did not specifically explore differences in arthritis management related to disease diagnosis or duration/disease trajectory. It is recommended that further research explore how specific diagnosis and duration affect an individual’s management of arthritis.

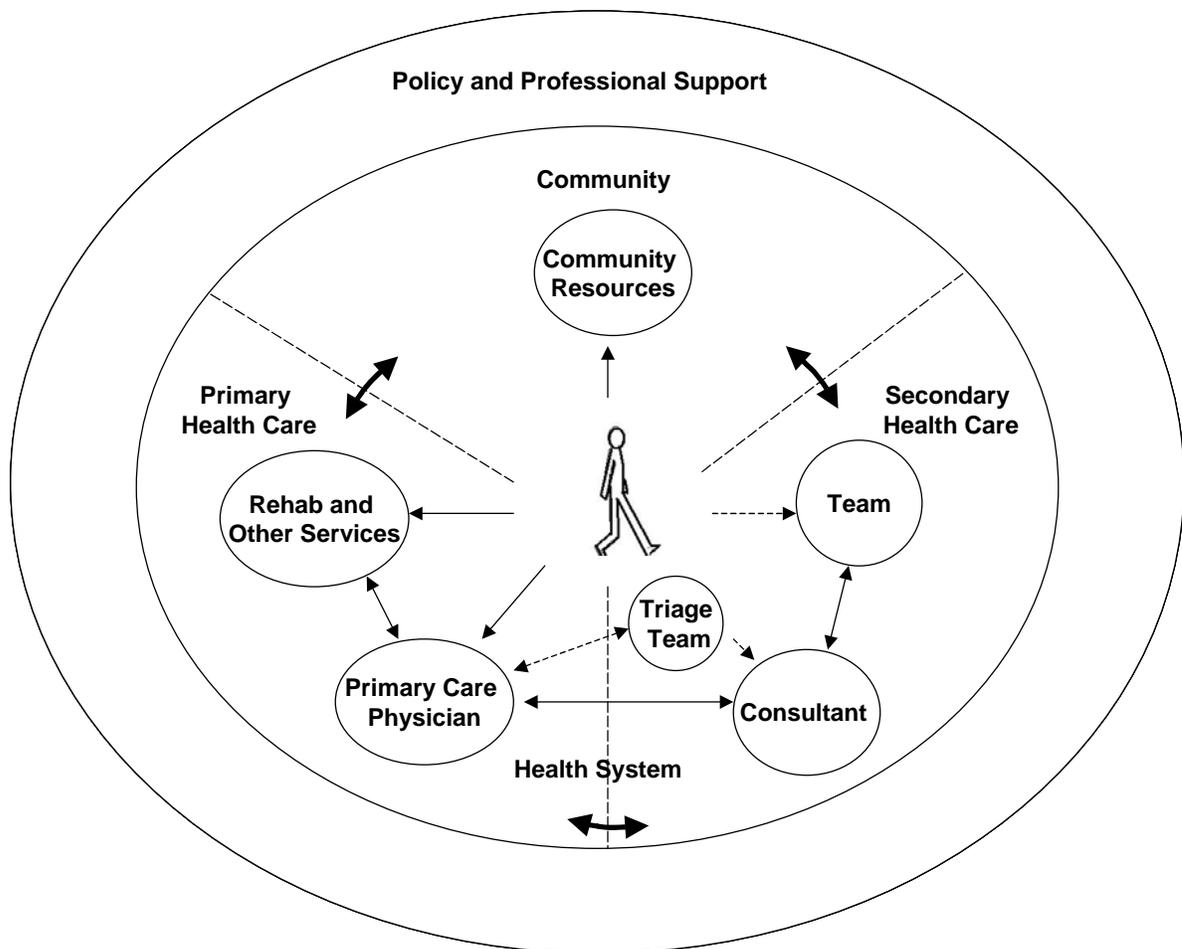
4.0 RECOMMENDATIONS AND CONCLUSIONS

4.1 Recommendations for Key Elements of Models of Care

The following are recommendations for comprehensive models of care for arthritis based on the findings from all of the interviews. These will be discussed within six components of a model of care: the patient, health care providers, the delivery system, health care system, the community, and policy and professional support.

Key informant health care providers and individuals with arthritis identified the essential elements that encourage high-quality arthritis care. Depending on the type of disease, stage of disease, and individual needs of the patient, a number of services across the continuum of care were identified to be important for patients to manage their arthritis effectively. Figure 8 displays the essential elements of a care system that encourages high-quality arthritis care.

Figure 8: Essential Elements of a Care System for Arthritis



The Patient

Empower patients through education and support for self-management.

- Focus education initiatives on the needs of individual patients. Patient education is key to promoting an informed active patient who is able to manage his/her disease. Education should include information about managing the disease as well as information on available community resources.
- Establish patient education initiatives that consider patient readiness for information. An optimal time for providing information after a diagnosis of arthritis is unclear. Since patients may be ready for educational interventions at different stages, it is important that education be ongoing. Patients must be able to re-access programs and services when they identify they are ready for information. Health care providers need to periodically assess patient readiness.
- Empower patients to manage their health and health care through support for self-management and education in individual and group formats. Research supports psycho-educational programs with a skills-building focus as opposed to being solely information-based.

The Health Care Provider

Develop collaborative knowledgeable networks of health care providers to help patients manage their arthritis.

- Identify processes to match health care providers and programs/services to patients. Multidisciplinary team care is most often recommended as the ideal in care delivery. However, patients may not need access to all members of a health care team at a given point in time. The provider support needed may vary depending on the type of arthritis and stage of disease.
- Develop mechanisms to facilitate communication within teams, including with the patient, and amongst health care providers across the continuum of care.
- Consider the utilization of allied health care providers working in expanded roles for triage and management of arthritis care.
- Ensure the team has a clear understanding of the roles of all members of the health care team.
- Develop processes for joint decision-making and goal setting with patients.

Ensure that health care providers working with people with arthritis have skills and knowledge about the condition and knowledge of best practices for treatment of arthritis.

- Implement continuing education initiatives aimed at improving the arthritis knowledge and skills of health care providers, including primary care physicians, and rehabilitation therapists. Getting a Grip on Arthritis is an

- example of an interdisciplinary initiative aimed at educating health care providers (Appendix C).
- Ensure adequate training in arthritis and related conditions for health care providers during their professional training. Patient Partners in Arthritis is an example of a national program utilizing the experience of patients with arthritis to teach musculoskeletal training to students.
 - Institute inter-professional education of health care providers at the university level to facilitate collaborative practice.
 - Establish standardized training programs for health care providers to develop expanded roles of practice.

Delivery System

Ensure people with arthritis have access to the right treatment by the right provider at the right time.

- Ensure patients have timely access to care. For patients with RA, access to disease modifying anti-rheumatic drugs (DMARDs) early has been shown to halt the progression of the disease and limit joint damage. Patients seen by a rheumatologist are more likely to be prescribed DMARDs.
- Ensure health care services are coordinated across the continuum of care. In many cases, it is the patient who assumes this role. A health care provider can also assume this role by acting as a case manager and helping the patient navigate through the system.
- Ensure comprehensive services are available for patients with arthritis including education, self-management, support and exercise.
- Promote continuity of care and ensure regular follow-up by a health care provider.
- Ensure health care interventions are based on the best available evidence.

Promote a client-centred approach to care delivery.

- Ensure patients are central to decision-making about their disease.
- Ensure emotional support is provided to patients. Patients with arthritis experience a variety of emotions and stress associated with the impact of living with the disease, as do their families. Formal supports, including guidance with financial and work-related issues, are important to holistic care.
- Include families in patient care and provide support as indicated.

The Health Care System

Ensure the appropriate structures and supports are in place in the health system to support arthritis care.

- Develop information systems to ensure access to patient data in a timely manner. This may include electronic referrals and electronic medical records.
- Allocate stable funding to sustain programs and services in the health system.
- Create monitoring systems and supports for health care providers and administrators to evaluate programs and services. Research and evaluation of programs and services is key to delivering care that results in positive patient outcomes and is cost-effective.

The Community

Provide support to communities to be able to adequately address arthritis and its associated issues to empower individuals with arthritis to take control of the disease.

- Develop public education strategies to promote awareness of arthritis in the community. Encourage community involvement in grassroots initiatives that promote arthritis awareness and education.
- Promote utilization of community programs such as pool programs and community exercise programs.
- Promote collaboration between the health care system and community programs. Communication and knowledge transfer between health care providers and exercise trainers and individuals working in the community can help patients to receive the support they need in the community.

Policy and Professional Support

Establish mechanisms to ensure supportive policies and structures are in place for stakeholders to appropriately manage arthritis as a chronic disease.

- Ensure adequate professional support from health care provider regulatory bodies for the development of health professions. This support is required to develop alternative models of care using health care providers in expanded roles that require care outside their traditional scope of practice.
- Develop policies to ensure effective patient care delivery. Set arthritis models of care into the context of chronic disease management strategies.
- Develop upstream approaches to health promotion for chronic diseases such as arthritis by addressing socioenvironmental risk conditions (e.g. poverty) to support individuals to make healthy choices.
- Establish partnerships with non-health sectors, including education, environment and employment to take a broad approach to developing healthy public policy related to arthritis.

4.2 Conclusions

How to best organize and deliver health care services to Ontarians is an ongoing challenge for policy makers and program planners. There is immediate need to address health care delivery to people with arthritis for several reasons. First, arthritis is one of the most prevalent chronic conditions in Ontario, and the burden of illness is expected to increase⁴. Second, the impact of arthritis on people living with this disease is not trivial. People with arthritis experience pain, disability and altered quality of life⁸. Finally, there are increasing pressures in the health care system that impede delivery of care to this population, including health care provider shortages and increasing wait times for care^{34-36;38}.

This research describes a number of types of models of care being used to deliver care to people with arthritis. Some of these models have been developed to ensure quality care while overcoming barriers in access to care including long waiting lists and shortages of health care providers. Given the significant impact of arthritis on the lives of Ontarians and health system pressures, innovations such as those demonstrated in this report are critical to ensure that the population as a whole has equitable access to services when needed.

In this research, health care providers and people with arthritis identified common elements of quality health care delivery. These include: health care provider knowledge and skills in arthritis, coordination of services, and continuity of care. People with arthritis were generally accepting of proposed models of care delivery as long as they felt trust in the health care providers.

The importance of a team approach was a common theme throughout the types of models of care. Although the composition, setting and function of the teams varied by type of model, key informants commonly described the importance of processes such as communication, coordination, goal setting and clear role definition. These findings echo other research on team care. In one study on effective teams, participants identified effective teams as having a clear purpose related to the organization, goals related to team tasks, strong leadership and structures to ensure decision-making, managing conflict and sharing ideas amongst the team, regular patterns of communication that are quick and easy, mutual respect of team players, and cohesion-building (building a sense of commitment and trust among team members)⁴⁵.

Timely access to care is critical when considering arthritis models of care. However, early access to facilitate diagnosis is only one aspect of timeliness. As arthritis typically lasts the duration of a person's life, care must also be available throughout the course of the disease to meet the needs of people at different stages of the disease trajectory when such care is required. This includes acute flares of the disease and changes in life situations that require professional guidance and support. Some patients will act as their own case managers and initiate care as they need it, thus necessitating a system that is flexible enough to

ensure rapid access to professional support for patients as they manage their disease.

The models in this report tend to focus on the health care system. While this is critical, it is also important that arthritis be set in the context of chronic disease prevention and management. Initiatives that target common risk factors for chronic diseases through promotion of healthy lifestyles and to address broad socioenvironmental risk conditions (e.g. poverty) are important. Patients with low socioeconomic status have worse disease activity, physical health, mental health, and quality of life than patients with high socioeconomic status⁷¹. An integrated approach to coordinating activities across various diseases, professions, the health care system and non-health sectors (e.g. education, employment, environment) is essential to address the broader determinants of health.

The current crisis of increasing demand in the face of resource shortages dictates new ways of delivering care in chronic disease. A number of models have been developed to meet this challenge. If new and innovative models of care utilizing other health care providers in expanded roles are to grow in Ontario, a collaborative approach to standardize training and provide professional support for these roles is critical. To move forward with arthritis care delivery, it is essential to both implement and evaluate service delivery models, including continued research into patient outcomes and cost-effectiveness of models of care. It is also important to understand the needs of individuals with arthritis at different stages of the disease trajectory and how the system can support these needs. A next step would be to bring stakeholders together to identify specific actions to move the models of care for arthritis agenda forward. It is time to make the health care system work for people living with chronic diseases such as arthritis.

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Appendix A. Evidence and Best Practices

Best Practices for Osteoarthritis (OA)	
Education	Patients receive education about self-management strategies and contacts for further information (e.g., Education and/or support groups, The Arthritis Society Help Line, Arthritis Self Management Program [ASMP])
Exercise & Physiotherapy	Patients receive a recommendation for exercise or referral to an exercise program or to a physiotherapist.
Joint Protection & Occupational Therapy	Patients receive instruction in joint protection and energy conservation techniques or a referral to an occupational therapist.
Assistive Devices	Patients with functional limitations in performing activities of daily living receive referral to rehabilitation specialist for assistive devices designed to improve function and independence.
Weight Management	Patients with a body mass index (BMI) greater than 25 receive a recommendation for weight loss or referral to a weight loss group or professional.
Social Support	Social support and coping strategies are discussed with patients. Counseling and referrals made as needed.
Analgesics	Patients requiring pharmacologic treatment for pain receive a recommendation for analgesics (e.g., acetaminophen, capsaicin cream). Glucosamine and/or acupuncture may be considered for mild to moderate OA of the knee.
Non-steroidal anti-inflammatory (NSAID) Risk	Patients with two or more of the following risk factors should avoid NSAID use: age > 75, history of peptic ulcer disease, history of GI bleeding, cardiovascular disease. If NSAIDs cannot be avoided, patients should receive misoprostol, a proton pump inhibitor, or a selective Cox-2 agent.
NSAIDs	Patients not responding to or not tolerating acetaminophen may progress to non-steroidal anti-inflammatory drugs (NSAIDs), advancing to higher doses as necessary. Topical NSAID may be considered.
Intra-articular	Intra-articular corticosteroids or hyaluronans are

Best Practices for Osteoarthritis (OA)	
Injections	considered for an OA painful knee. Oral corticosteroids (≤ 15 mg daily) or IM (80-120mg) or IA used as adjunctive therapy.
Surgery	Surgical referral is discussed with appropriate patients who continue to experience significant pain and functional disability despite optimal medical therapy.
Best Practices for Rheumatoid Arthritis (RA)	
Education	Patients receive education about self-management strategies and contacts for further information (e.g., Education and/or support groups, The Arthritis Society Help Line, Arthritis Self Management Program [ASMP])
Exercise & Physiotherapy	Patients receive a recommendation for exercise or referral to an exercise program or to a physiotherapist.
Joint Protection & Occupational Therapy	Patients receive instruction in joint protection and energy conservation techniques or a referral to an occupational therapist.
Assistive Devices	Patients with functional limitations in performing activities of daily living receive referral to rehabilitation specialist for assistive devices designed to improve function and independence.
Social Support	Social support and coping strategies are discussed with patients. Counseling and referrals made as needed.
Non-steroidal anti-inflammatory (NSAID) risk	Patients with two or more of the following risk factors should avoid NSAID use: age > 75, history of peptic ulcer disease, history of GI bleeding, cardiovascular disease. If NSAIDs cannot be avoided, patients should receive misoprostol, a proton pump inhibitor, or a selective Cox-2 agent.
NSAIDs	Patients should be started on a non-steroidal anti-inflammatory drugs (NSAIDs), advancing to higher doses as necessary. Topical NSAID may be considered.
Rheumatology Referral	Providers initiate an immediate rheumatology consultation re: treatment for patients with suspected

Best Practices for Rheumatoid Arthritis (RA)

inflammatory arthritis;

**Disease modifying
anti-rheumatic
drugs (DMARDs)**

Disease-modifying anti-rheumatic drugs (DMARDs) are considered for treatment of early RA.

Surgery

Surgical referral is discussed with appropriate patients who continue to experience significant pain and functional disability despite optimal medical therapy.

Appendix B. Definitions of Arthritis

	OSTEOARTHRITIS (OA)	RHEUMATOID ARTHRITIS (RA)	SYSTEMIC LUPUS ERYTHEMATOSUS (SLE)	ANKYLOSING SPONDYLITIS (AS)	GOUT
Background	OA results from the deterioration of the cartilage in one or more joints. Leads to joint damage, pain, and stiffness. Typically affects the hands, feet, knees, spine and hips.	RA is caused by the body's immune system attacking the body's joints (primarily hands and feet). This leads to pain, inflammation and joint damage. RA may also have involvement of other organ systems such as eyes, heart, and lungs.	SLE is a connective tissue disorder causing skin rashes and joint and muscle swelling and pain. There may also be organ involvement. This disease, as with RA, fluctuates over time, with flare-ups and periods of remission.	AS is inflammatory arthritis of the spine. Causes pain and stiffness in the back and bent posture. In most cases the disease is characterized by acute painful episodes and remissions. Disease severity varies widely among individuals.	Gout is a type of arthritis caused by too much uric acid in the body which is normally flushed out by the kidneys. Most often affects the big toe but can also affect the ankle, knee, foot, hand, wrist or elbow.
Prevalence	OA is the most common type of arthritis, affecting an estimated 10% of Canadian adults.	RA affects approximately 1% of Canadian adults, and at least twice as many women as men.	SLE affects 0.05% of Canadian adults. Women develop lupus up to 10 times more often than men.	AS affects as many as 1% of Canadian adults. Men develop AS 3 times more often than women.	Gout affects up to 3% of Canadian adults. Men are 4 times more likely than women to develop gout.
Possible Risk Factors	Old age, heredity, obesity, previous joint injury.	Sex hormones, heredity, race (high disease prevalence is seen among Aboriginal Peoples)	Heredity, hormones and a variety of environmental factors	Heredity and, possibly, gastro-intestinal or genitourinary infections	Heredity, certain medications (e.g. diuretics), alcohol and certain foods
Disease Management	<i>There is no cure for OA.</i> Treatments exist to decrease pain and improve joint mobility include medication (e.g. analgesics, anti-inflammatory drugs), exercise, physiotherapy and weight loss. In severe cases, the entire joint – particularly the hip or knee – may be replaced through surgery.	<i>There is no cure for RA.</i> Early, aggressive treatment by a rheumatologist can prevent joint damage. Drugs used for treatment include non-steroidal anti-inflammatory drugs, corticosteroids, disease-modifying anti-rheumatic drugs, and biologic response modifiers.	<i>There is no cure for SLE.</i> The aim of treatment is to control symptoms, reduce the number of flare-ups and prevent damage. Commonly used medications include analgesics, anti-inflammatory drugs, cortisone and disease-modifying anti-rheumatic drugs. Diet and exercise are also important in the management of lupus.	<i>There is no cure for AS.</i> Medications similar to those used for other types of arthritis are often prescribed to treat AS. Exercise is the cornerstone of AS management. If damage is severe, surgery may be considered.	<i>There is no cure for gout.</i> Non-steroidal anti-inflammatory drugs are often used to help reduce the pain and swelling of joints and decrease stiffness. Cortisone may also be used for this purpose. Drugs such as Allopurinol can be used on a long-term basis to reduce uric acid levels and prevent future attacks. Other methods for controlling gout include dietary changes, weight loss and exercise.

Data source: www.arthritis.ca [Arthritis in Canada ³]

Appendix C. Examples of Arthritis Programs and Services

The following seven program descriptions are examples of models of care that illustrate different approaches to managing arthritis.

The Arthritis Program (TAP)

I'm taking charge of my arthritis!

Physiotherapy/Occupational Therapy Practitioner Model of Care

Getting a Grip on Arthritis: A National Primary Health Care Community Initiative

Alberta Hip and Knee Replacement Pilot Project

Primary Therapist Model

Rheumatology Services in The Netherlands

The Arthritis Program (TAP)

The Arthritis Program provides individual interventions and disease-specific group education programs for people with arthritis.

Objectives

- To provide consumers with individual inter-disciplinary treatment of their disease
- To offer an education program to consumers, enabling them to become active participants in their health care
- To enable participants to monitor their own disease process and to recognize when professional intervention is required
- To provide on-going appropriate access to arthritis care
- To provide a vehicle for the team to develop standards, collect and evaluate research data in order to benefit future treatment and care

Target population

- Inflammatory joint diseases and related disorders
- Degenerative diseases and related joint disorders
- Osteoporosis
- Fibromyalgia
- Juvenile arthritis

Types of interventions

- Assessment
- Treatment, both group and individual
- Rheumatology clinics
- Education

Who delivers the interventions?

- Occupational therapists (1.8 FTE)
- Pharmacists (1.5 FTE)
- Physical therapists (1.7 FTE)
- Kinesiologist (1.0 FTE)
- Social worker (0.3 FTE)
- Dietician (0.05 FTE)
- Rheumatologists (3)

Referral mechanisms

As a regional community hospital, governed by the Ontario Public Hospital's Act, all referrals for treatment must be from a physician, including family physicians and rheumatologists.

Communication processes

All patients review the consent to communicate form. As a program standard, the following information is listed:

- Referring physician
- Specialist or family physician
- Pharmacy
- Consent to use aggregate data for research and CQI projects for submission as abstracts to scientific conferences

There is one chart per client. All disciplines chart on the same form, or same sheet if many disciplines are seeing the patient on the same day. For repetitive services, standardized flow sheets are used. Letters are sent to physicians to communicate changes in disease and outcomes.

Monitoring and measurement methods

- Each disease subset within TAP has a standardized monitoring system for change
- Impairment, disability, handicap, function and health status are monitored and measured, using reliable, validated assessment/outcome tools
- The data are calculated to understand the change
- Clinicians are evaluated for treatment content and style by the patients
- Programs are monitored for efficiency and effectiveness

How the service/program fits into the broader health care system

Effectiveness

The goal of TAP is to provide its clients with the tools:

- To understand the impact of their own disease process
- To become proficient in self-monitoring
- To have the skill to adjust their treatments within appropriate ranges
- To contact the health care team with the least impact on the overall system

Efficiency

- Workload is collected and measured by clinician, by disease group, by program
- Wait list and times are monitored, program adjusts as required to stay within standards
- Wait list is sub-divided by disease sub groups and each has its own management algorithm

Impact of service

Some TAP examples:

- Fiscal year 2004/05 TAP received 3000 referrals, generating 20,000+ attendances
- Pre-Diagnostic Clinic (The Change Foundation Project 2003/05) showed inter-validation of arthritis assessment skills between rheumatologists and

participating allied health (OT); wait times to see rheumatologist and initiate treatment are within 5 weeks of receiving referral

- Patient satisfaction with service is greater than 90%
- HAQ, Self Efficacy, SF 36 scores show improvement
- Increased treatment compliance
- Cost effectiveness: each subset program below 25 percentile

Strengths of service

- Early access to diagnosis and treatment
- One stop arthritis treatment access
- Multiple appointments during same attendance
- Rheumatology Clinics run daily; allied health are the “gate-keepers”, not the rheumatologists
- Types of Clinics: diagnostic, urgent, procedure, osteoporosis
- Rheumatologists cover each others clinics
- Inter-reliability of assessment skills
- Delegated acts

Tips for duplicating this approach

- Recognition of value and outcomes for service delivery by physicians
- Cooperation between physicians, not competition
- Formal allocation of resources for allied health arthritis management
- Program management model, not departmental
- Administrative and physician champions required
- Clear understanding of RHPA by the champions and its applications: public domain, generic, profession specific

Future initiatives

- Use of tele-health for distance triaging, clinics, group treatment
- TAP school: formal workshops for professionals to be able to duplicate the programs
- Linkage with universities for formal research initiatives

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The Arthritis Program

Southlake Regional Health Centre

Newmarket, Ontario

I'm taking charge of my arthritis!

Summary

I'm taking charge of my arthritis! is a self-management program for housebound older adults with arthritis, developed in collaboration of with the Department of Kinesiology, University of Montreal, the CSSS Cavendish, and the Arthritis Society. The program aims to improve self-management of arthritis symptoms and is intended for people with arthritis who are confined to their home and who have experienced a loss of autonomy.

Location

Québec (but available on-line and can be used outside of Québec)

Objectives

- To increase participants' knowledge and sense of control regarding the management of their arthritis
- To reinforce the fundamental belief that they will succeed in managing their symptoms
- To increase their commitment and perseverance to carry out self-selected interventions or ones suggested by their health care team

Target population

I'm taking charge of my arthritis! is designed for older adults with arthritis who have a loss of autonomy. The experimental version of the program showed that it works best for individuals:

- Whose arthritis is the primary reason for their loss of independence,
- Who are motivated to change their condition,
- Who have some capacity for self-critique and sufficient cognitive ability to benefit from the program, and
- Who are open to trying new methods.

Types of interventions

The program consists of six one-hour sessions delivered by a health professional either in a participant's home or in a small group. Session themes related to arthritis include pain and stiffness, medication, exercise, relaxation, emotions, communication, energy management and relationships with health professionals. Through a personal contract, the participant commits to reaching a specific objective related to his/her situation with arthritis for the following week. A participant's confidence level with respect to his or her ability to reach this objective is also evaluated. Educational material includes a participant manual with information on arthritis, personal contract forms and a logbook.

Who delivers the intervention?

Given the characteristics of participants and the nature of the issues addressed, it is recommended that the program be provided by a health professional (e.g. physiotherapist, occupational therapist, kinesiologist, nurse, social worker). The program can be offered in various settings such as CSSSs, day centres, rehabilitation centres, self-help centres or other organizations that work with arthritic clients with a loss of autonomy. The “coach” motivates, support, and reinforce participants’ actions. Participants who express needs that go beyond the program's mandate are referred to the appropriate resources (e.g. personal nutritional counseling, re-evaluation of medications).

Referral mechanisms

Health professionals who wish to implement the program obtain the educational manual in English or French via the website, www.myarthritis.ca. An optional training session is also available for potential facilitators. The health professional identifies clients in his/her caseload to participate. As part of a study on program implementation in the clinical setting, the program developers invite clinicians and interested organizations to complete a follow-up questionnaire as part of the evaluation.

Communication processes

Throughout program implementation, facilitators can consult with a program developer or program team member. The website is also an effective communication tool.

Monitoring and measurement methods

Two studies are being conducted:

1. Efficacy trial to verify the impacts of the program in a controlled environment under ideal conditions in 2000-2005 with the support of a grant from the Canadian Institutes for Health Research (CIHR).
2. A study of program implementation in a natural milieu to evaluate whether effectiveness prevails within a context of "real life" and unanticipated variables, started in 2006. A pilot is underway for the effectiveness trial.

How the service/program fits into the broader health care system

Most self-management programs are designed for people without mobility issues. However, some people with arthritis have such severe functional limitations that existing programs are less suitable for them. A number of health professionals, aware of the chronicity of these participants' arthritis symptoms, want to provide in-home or adapted alternatives to traditional interventions designed specifically for older adults.

Impact of service

A randomized control trial of 125 participants, referred by homecare case managers, were assigned to an experimental group (n=65) to receive the program in the first year from a health professional hired by the project or to a

control group (n=48) to receive the program in the second year. All participants complete a questionnaire four times during the course of the study (baseline, pre-intervention, post-intervention, post-intervention 2).

Results showed that a structured arthritis self-management program could have a positive impact on the physical, psychological, social and behavioural health of housebound older adults. In the short-term, this home-based arthritis self-management program significantly decreased perceptions of functional limitations and helplessness, and increased coping effectiveness. In addition, the program increased the frequency of physical exercise, relaxation activities, and confidence level in using the management strategies (outcome expectations). The impact on one's sense of helplessness was greater among participants who had increased their practice of physical health behaviours and their level of confidence during the program. The effect on functional limitations was significantly larger among participants with higher increase in confidence. In the long-term, eight months post-intervention, the increase in physical health behaviors is maintained. The significant impact on functional limitations is also maintained, but only among participants who received social reinforcement following the program.

Strengths of the service

- Based on a rigorous *theoretical model* and *evaluated* programs.
- The health professional receives *support* from a resource person.
- *Easy to use implementation guide*, including a structured facilitator's guide and participant's manual that can be copied for each new participant is available at no charge on the website of the program.
- *Multidisciplinary* nature of the program and diversity of people involved in developing/testing program.
- The program can be offered by a *variety of health professionals and settings*
- *Flexibility* in the sequence of program themes.
- The *website* provides information about the program and news and is an effective communication tool.

Tips for duplicating this approach

Originally, this program was developed to be administered on an individual basis. However, some facilitators are currently implementing the program with small groups of older adults with arthritis. If offered in a small group setting, extending the length of sessions or increasing the number of sessions would provide more time to cover topics. Also, offering sessions every two weeks, would allow participants more time to realize their action plans.

Health professionals from home care services may select specific clients to receive the program each year. It is not realistic to provide this program to all persons with arthritis on a caseload. However, it would be feasible to offer a few times during the year. Resources are limited in the health sector, but this

program has the potential to enhance a person's function and thus could be considered an intervention tool. Health professionals working in adult day care or rehabilitation centres will find it easier to offer the program as they already offer these types of interventions to the clientele that they serve.

Future initiatives

The program team is planning to evaluate the implementation of the program in "real world" settings. The team maintains contact with everyone offering the program to track how it is being used and how it can be enhanced. The team originally tested the program in an in-home setting. Now there are several health professionals who want to offer it to the same frail clientele but in a small group setting. The program team plans to apply for a CIHR grant in September 2006 to investigate the effectiveness of the program when offered in a natural milieu and the factors associated with those effects.

For further information:

www.myarthritis.ca

Reference: *I'm taking charge of my arthritis!* www.myarthritis.ca

Physiotherapy/Occupational Therapy Practitioner Model of Care

Location

The Hospital for Sick Children – Department of Rehabilitation Medicine and the Division of Rheumatology (ambulatory clinics and the Medical Day Care Unit [MDCU]).

Objectives

The role of the MDCU practitioner is to assess each patient and review laboratory investigations prior to receiving IV medications (e.g. Remicade, IVIG). The aim is to streamline these processes to ensure the following:

- Reduce the duration of visit,
- Identify those that may require change in therapy and refer back for interim medical assessment, and
- Flag those that may not be able to receive the treatment (i.e. due to abnormal laboratory tests, etc.). Again, those patients are identified by the practitioner and referred back to medical care.

Target population

Children diagnosed with Juvenile Idiopathic Arthritis (oligoarticular, polyarticular and systemic onset) with varied severity, including those receiving second line therapy and biologics. Other diagnoses include Juvenile Dermatomyositis, Enthesitis-related arthritis, Morphea, Fibromyalgia and Chronic Fatigue.

Types of interventions

- Assessment of new referrals in collaboration with responsible rheumatologist.
- Diagnosis is made by the rheumatologist and follow up care may then be triaged to primary practitioner care (Physical Therapy Practitioner (PTP) or Occupational Therapist Practitioner (OTP)).
- Ongoing follow up assessments via clinic, communication with family/community physician, specialists (e.g. orthopedic surgeon), other agencies (rehab facilities, Community Care Access Centres, school, pharmacist, government agencies).
- Ordering and conveying results of laboratory investigations (*under hospital approved medical directive) and musculoskeletal ultra-sound (*under hospital approved medical directive).
- Ordering other tests in consultation with physician with co-signature (X-rays, DEXA, MRI, CT).
- Patient education regarding condition, medication, roles, etc.
- Creating and carrying out management plans in collaboration with physician as appropriate (e.g. to alter medication dose or change medications, practitioners discuss with physician)

- Refer to other services as appropriate (e.g. social work, psychiatry, orthotics)

Who delivers the interventions?

- Assessment and ongoing follow up completed by PTP or OTP.
- PTP and OTP refer patients back to the rheumatologist to provide medical interventions (i.e. for final decision-making and prescription writing, for change in drug therapy, or completion of joint injections).

Referral mechanisms

- Patients are triaged to practitioner care after confirmed diagnosis made by responsible rheumatologist

Communication processes

- Consult with rheumatologist directly via pre-clinic meeting, or indirectly via telephone or written communication.
- All clinic visits are dictated by practitioner and electronically viewed by responsible rheumatologist.
- All Medical Day Care unit visits are documented on assessment sheets and in health record; a follow up summary of the MDCU visits are provided to the other pertinent team members involved (e.g. clinic nurse, rheumatologist).

Monitoring and measurement methods

- Collection of patient satisfaction data
- Identification and collection of critical indicators (i.e. duration of visit, compliance with treatment, investigations ordered and outcomes, frequency of referral to back to medical care); these are not yet fully collected, analyzed or published

How the service/program fits into the broader health care system

- This is a homegrown Sick Kids program but there are other similar programs now evolving outside of this hospital. The hope is that this and similar models of care will become part of the funding formula as a model of health care delivery in Ontario. The current challenge with this model in many facilities is billing of patient visits; if a medical doctor doesn't directly see a patient, only the practitioner, the physician cannot bill for the visit.

Impact of service

- Strengths of the service are continuity of care and comprehensive care (including education, rehabilitation, assessment with timely and appropriate triage back to medical care for intervention-specific needs). This allows fewer individuals to be involved in the care and more efficient delivery of care.

- This model frees up physician time for more complex patients, and other duties (academic, research); decreases wait list for new patients; and increases access to care for follow up patients.

Tips for duplicating this service

- Need to first have strong support of medical staff involved as well as support from an academic institution
- Strong, experienced candidates
- Liaise with programs already in place and adapt to unique needs of program as well as join forces for lobbying (i.e. medical directives to support expanded role)

Future initiatives

- Sick Kids has already initiated a training program and now employs advanced practice therapy models in the neo-natal follow clinic and a PTP in orthopedics (scoliosis clinic).
- We have liaised with other facilities that have undertaken or plan to undertake such training programs.
- We continue to work together to educate and advocate these roles (ie. to professional colleges).

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Getting a Grip on Arthritis: A National Primary Health Care Community Initiative

Introduction

In November 2003, The Arthritis Society and eight partners¹ received funding from the Primary Health Care Transition Fund, Health Canada to respond to the growing burden of arthritis in Canada. Over the period of November 3, 2003 to March 31, 2006 we implemented and evaluated an arthritis educational program for providers in primary health care organizations across Canada.

Goal

The goal of this project was to increase the ability of primary health care providers and people with arthritis to work together in managing arthritis. The project supported primary health care providers in their delivery of arthritis care by emphasizing prevention, early arthritis detection, collaborative care, more appropriate and timely referral to specialty care and self-management.

Overview

- Thirty MAINPRO-C accredited workshops on arthritis best practices (French and English) were delivered in urban and rural locations across Canada reaching 900 providers.
- Activities took place following the workshops to reinforce learning and build the capacity of the community.
- Educational tools, based on evidence in the literature, were developed for patients and providers.

Interventions

This project was comprised of three parts: a provider intervention, a patient intervention and a community intervention.

Provider intervention

Getting a Grip on Arthritis Educational Workshop

- Interactive educational sessions for providers on osteoarthritis and rheumatoid arthritis, musculoskeletal (MSK) examination techniques, and education regarding the optimal use of investigations, pharmacologic and non-pharmacologic management strategies, and the appropriate use and timing of referrals to other health providers and community programs
- A hands-on review of a MSK examination which was facilitated by patient educators, Patient Partners in Arthritis®

¹ Sunnybrook and Women's College Health Sciences Centre, Canadian Nurses Association (CNA), Arthritis Health Professions Association (AHPA), Canadian Rheumatology Association (CRA), Patient Partners® in Arthritis, Arthritis Community Research and Evaluation Unit (ACREU), Canadian Alliance of Community Health Centre Associations (CACHCA), Ontario Family Health Network

Intervention strategies within participating sites

- Local adaptation process for arthritis clinical practice guidelines
- Office-based reminder systems for appropriate prescribing (use of acetaminophen, risk factors for NSAIDs) and referral (indications for PT, OT, rheumatology, orthopaedic surgery)
- Reinforcement procedures such as a reflective practice exercise to determine utilization of arthritis best practices
- Visits from Arthritis Society therapists
- Train the trainer sessions on arthritis case management and education
- Patient Partners in Arthritis® demonstrations

Patient intervention

Educational messages to be given during health care visits or group programs focused on key themes: types of arthritis, arthritis prevalence and disability, self-management strategies (especially exercise, weight loss, and coping), medication use, when to see a doctor, when a specialist would be helpful, further sources of information and support, and appropriate community resources.

Community intervention

- An inventory of community arthritis resources for each participating site
- Donation of arthritis books and videos to a local library
- Community educational events such as public forums
- Educational messages were disseminated in site newsletters and local newspapers, radio, and television
- Involvement of local arthritis specialists as workshop faculty and facilitators

Impact of initiative

Follow-up surveys of primary health care providers participating in *Getting a Grip on Arthritis* have indicated that *Getting a Grip* has an impact on the following areas of arthritis care:

- Arthritis patient self-management
- Early arthritis detection
- Collaborative care for patients with arthritis
- Access to specialty care for patients with arthritis
- Arthritis prevention

Strengths of the initiative

- Team Model of Care/Team Learning
 - *“Learning with nurses, occupational therapists, physios, dietitians and social workers worked.”*
- Patient Partners®:
 - *“Excellent, phenomenal - amazing, reality, super educational”.*
- Linking with local resources:
 - *“Nice to have local speakers so you can have a resource here.”*

- Interactive Format:
 - “By changing styles, large, and small group format, by physically moving from sitting to exercise, and from room to room, it kept our interest. We listened, asked questions, and then brain-stormed in a focus group setting, and finally, wrote down what behaviour we are going to change.”

Tips for duplicating this approach

- Develop partnerships
- Establish a core team
- Foster communication

Future initiatives

- **Getting a Grip on Arthritis: Increasing Public Access to Clinical Practice Guidelines for Rheumatoid and Osteoarthritis**
Lucie Brosseau, a researcher at the University of Ottawa, just received CIHR funding for a grant to update clinical practice guidelines for rehabilitation interventions for osteoarthritis and rheumatoid arthritis, develop lay language versions of the guidelines, and disseminate these to the public through workshops for patients with arthritis and media communications. The workshops will be a modified version of the Getting a Grip on Arthritis workshop and will target influential members of arthritis patient groups.
- **Getting a Grip on Arthritis: Interprofessional Curriculum Development and Online Learning:** This project will be based on the content and key learnings from the implementation of the Getting a Grip on Arthritis national project. The partners in the new project will build on this experience by adapting the content and developing an interprofessional pre-licensure program for undergraduate /graduate health professional students at the University of Toronto and at Memorial University. The goal of the project is to consolidate and improve the knowledge, skills and attitudes of pre licensure health professionals to support collaborative practice in the assessment and treatment of arthritis.
- Getting a Grip on Arthritis partners have developed connections with stakeholders interested in developing proposals for Aboriginal and Pediatric adaptations of the initiative.

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Alberta Hip and Knee Replacement Pilot Project

The Alberta Bone and Joint Institute together with the provincial government, the Alberta Medical Association, and the Calgary, Capital and David Thompson Health Regions, have implanted a pilot project to improve access to hip and knee replacements within a targeted timeframe based on urgency.

Location

Three cities in Alberta - Edmonton, Red Deer and Calgary Health Region.

Objectives

The Alberta Hip and Knee Replacement Project will improve the way care is delivered, resulting in shorter waiting times and better health outcomes for patients. Objectives include:

- To improve access, cost-effectiveness and quality of patient care
- To increase the number of hip and knee surgeries performed in order to define (and later reach) an appropriate standard of access for all Albertans.
- To reduce the time it takes a person to get appropriate care for hip and knee pain including those who need to see an orthopedic specialist for assessment
- To see the most efficient use of resources across the continuum of care for all hip and knee patients.

Target population

Patients with hip and knee pain including those eligible for primary hip and knee replacement surgery

Types of interventions

During one visit at a central assessment clinic, patients who may require orthopaedic surgery are assigned a case manager and a team of healthcare providers, including nurses, therapists and physicians who facilitate appropriate access to care across various specialties. Through a shared care plan, patients who do not require surgery are identified earlier to prevent unnecessary waits for care. Those who do require surgery receive more support before and after their operation to ensure the best possible outcomes. For those patients waiting for surgery, an individualized surgical plan is put in place to reduce unnecessary waits, delays and last-minute surgical cancellations. The patient is scheduled for surgery at a time that works for their plan, the team and the system. Appropriate care needs (e.g. home care or physiotherapy that may be required after surgery) are booked in advance to avoid surprises and delays. Each surgeon works with a team to improve the efficiency and effectiveness of the operating room. By organizing all care requirements for patients in advance, and working with patients to ensure they are fit for surgery, patients can expect their length of stay in hospital and recovery time to be shorter.

In appropriate cases, the clinic arranges for home care services to provide additional support for the patient at home. These resources are scheduled prior to surgery. Patients who need to quit smoking can receive help pre-operatively, reducing their surgical risk and improving their health outcome. The goal is to ensure that patients get all the information and resources they need to have a successful outcome based on the world's best practices (synthesized from the literature).

Who delivers the interventions?

- 19 orthopaedic surgeons
- One assessment intake clinic in each city with a team of physicians, nurses, PTs and OTs
- Depending on the site, the case manager is a nurse, PT or OT

Referral mechanisms

Patients are referred by a physician through a single clinic and are triaged into an appropriate care pathway (surgery, non-surgery)

Communication processes

The case manager facilitates communication among health care providers and patients. Health care providers work together with the patient and the family as a team to create a specialized plan for the patient's unique needs. This enhances the system's ability to organize the appropriate care and resources the patient will require both before and after surgery, and ensure all the resources are in place prior to their surgery.

Monitoring and measurement methods

The new pathway is being evaluated on efficiency, effectiveness and other outcomes established by the Alberta Bone & Joint Health Institute. Patients' urgency for surgery is rated using the Western Canada Waiting List project's rating tools, one of the first practical evaluations of these tools in Canada. The clinics employ a multidisciplinary team that works with the surgeons and other specialists to perform pre-operative evaluations and provide an optimization plan for the patient. At the same time, a case manager works with the patient and the healthcare team to ensure the patient achieves specific clinical benchmarks across the entire care continuum.

How the service/program fits into the broader health care system

In this shared care model primary care physicians are more involved in preparing patients for surgery and caring for them after surgery. The central assessment of patients, using standardized criteria to determine suitability for surgery, is intended to reduce the number of inappropriately referred patients, particularly those not requiring surgery. By centralizing the booking function, patients are referred to the most appropriate surgeon with the shortest wait list unless they have preference (patient choice is always respected as a priority). This model results in realized efficiencies in the health system.

Impact of service

- This project has met its goal of ensuring patients receive surgery within four months of initial consultation. Outcomes after 8 months include:
- Decreased wait time for new patients to receive first orthopaedic consult: from 35 weeks to six weeks
- Decreased wait time from first orthopaedic consult to surgery: from 47 weeks to 4.7 weeks
- Decreased length of stay in hospital: from 6.2 days to 4.3 days
- Improved satisfaction among patients and physicians

Strengths of the service

- A multidisciplinary team specific to arthritis care
- Consistent clinical standards resulting in better, more appropriate and safer care
- Predictability with volumes and therefore, more controllable
- Cost-effectiveness being measured
- Heightened awareness of/focus on outcomes
- Empowerment of patients and providers
- More support for patients before and after surgery throughout the entire care pathway, including family involvement

Tips for duplicating this approach

A team approach to redesigning the continuum of care built on collaboration is essential (doctors and other providers, regions and government) to build the model. The change management is significant, so patience is required.

Future initiatives

The same concept is being generalized to all hip and knee replacements in Alberta with a sustainability model being built. Beyond that, based on evidence, the model will be rolled out in other areas of bone and joint health (spine care, etc).

For further information:

www.albertaboneandjoint.com

Primary Therapist Model

The Primary therapist model is instituted within The Arthritis Society in Ontario. Physical therapists and occupational therapists function as rheumatology trained multi-skilled professionals and assume the role of case managers. Primary therapists may consult their respective physical therapy or occupational therapy colleagues, rather than transferring the patient for treatment.

Location

Primary Therapist Model, The Arthritis Society, Ontario, Canada

Objectives

- To improve rehabilitation services for people with arthritis

Target population

Population varies across the province with the majority of clients presenting with inflammatory arthritis, and some clients with osteoarthritis and fibromyalgia.

Types of interventions

Service focuses on

- Education and consultation
- Splinting
- Exercise
- Work site assessments

Who delivers interventions

Primary therapists who are physical therapists or occupational therapists manage clients. Clients have access to social worker in the team.

Referral mechanisms

Clients are referred from family physicians, rheumatologists, rehabilitation therapists, home care and self-referrals.

Communication processes

Communication strategies vary across the regions but include:

- Face to face interaction and telephone/voicemail
- Discharge notes are sent to referring physicians; notes hand delivered with patients

Monitoring and measurement

- The primary therapist model has been compared to traditional treatment provided by a physiotherapy or occupational therapy generalist in a randomized control trial. The primary therapist model was associated with better outcomes in patients with rheumatoid arthritis, where 44.4% of clients were clinical responders compared to 18.8% in the traditional care group. Clinical responders were clients showing more than 20%

improvement in 2 outcome measures (Health Assessment Questionnaire, pain and visual analog scale, and Arthritis Community Research and Evaluation Unit RA Knowledge Questionnaire).

- In economic evaluation, the primary therapist model generated higher quality adjusted life years and higher mean costs compared to traditional care, although these differences were not statistically significant.

How fits into broader health care system

With the rheumatology, cross-disciplinary training, Primary therapists are equipped to provide a wide variety of services, from public education, rehabilitation treatment to patient advocacy. In remote regions in Ontario, these therapists are often the main health care providers and resources to people with arthritis.

Impact of service

Strengths of the service include:

- Positive client outcomes
- Potentially cost-effective as compared to the traditional model
- Decrease confusion and duplication of assessment / interventions – patients only deal with one rehab therapists

Tips for duplicating this service

- Adequate front-end training and on-the-job training (job shadowing, in-service, peer consultation)
- Organizational support to provide cross-disciplinary care
- Therapists restrict practice in arthritis rehabilitation (e.g., no rotation to work in other disease groups)

Future initiatives

- To evaluate if specially-trained rehabilitation therapist can adequately assess and identify people with inflammatory arthritis

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Rheumatology Services in The Netherlands

Location

Leiden University Medical Center, Department of Rheumatology, Leiden, The Netherlands

Types of interventions

Rheumatology services consist of several programs:

Outpatient clinic

Most patients are seen as outpatients in the department by the rheumatologist and referred to other professionals needed. Clinical nurse specialists work with patients on a one to one basis to provide: a) guidance with biologics and paperwork for funding; b) guidance in coping with the disease, education, and advice (i.e. regarding assistive devices); and c) services for the OA program. Apart from the clinical nurse specialist, a social worker is available at the outpatient clinic.

Day patient clinic

The day patient program provides services for patients who are having difficulty coping with the disease, medications and activities of daily living. Individual occupational therapy, physical therapy, nursing, social work and rheumatological services are provided as well as group hydrotherapy.

The vocational program consists of a team of providers who provide assessments of patients with arthritis and advice on workplace issues. After a structured assessment, patients are given information on the disease, how to adjust to the workplace and how to deal with colleagues.

The hand clinic is a multidisciplinary service where patients are seen only once or twice for a structured assessment and advice on a treatment plan.

Inpatient clinic

Inpatient care is restricted to patients with complications or co-morbidity or post surgery. Multidisciplinary team care is delivered in case of severe limitations of activities of daily living or societal participation and restricted to those patients who cannot make use of the day patient program because of their limitations or because the distance from their homes to the hospital is too large.

Objectives

The overall goal of our services is to provide comprehensive care for patients with rheumatic conditions. The other two goals, apart from care, are education and research.

Target population

Adults with arthritis, including rheumatoid arthritis, osteoarthritis, and psoriatic arthritis are treated in the various programs at the hospital. This includes clients with arthritis at all stages of the disease process.

Who delivers the interventions?

Occupational therapists, physiotherapists, social workers, nurses and clinical nurse specialists, rheumatologists, rehabilitation specialists, orthopaedic surgeons and occupational physicians are members of various teams in rheumatology.

Referral mechanisms

Clients are referred from family physicians to specialist care. The urgency level of the referral is judged by the rheumatologist based on the written or electronic referral. After initial examination by the rheumatologist or Junior doctors in training, clients are referred to other health care professionals in the team as needed.

Communication processes

- An electronic medical record for all health professionals is used. Client goals are recorded by all team members.
- Team conferences and meeting are used to communicate in teams.
- Standardized discharge letters are sent to health care providers in the community.
- There is access to a network of physiotherapists in the region. A website is available which identifies physiotherapists who have specific training as well as all relevant services in primary and secondary care in rheumatology.

Monitoring

- Extensive research has been conducted at the hospital comparing care delivered by a clinical nurse specialist, an inpatient team, and a day patient team for patients with rheumatoid arthritis. The results show that care delivered by a clinical nurse specialist appears to have similar clinical outcomes as the inpatient and day care patients. The patients in the clinical nurse specialist group were found to be slightly less satisfied.
- Evaluation of vocational rehabilitation showed that interventions did not affect maintenance of the job but increased quality of life for patients.
- The hand program and osteoarthritis program have conducted process evaluations.
- A routine system using the ICF is utilized for goal-setting with patients.

Strengths of the service

- There is a comprehensive array of services for all problems that allows individual choice for care.
- Regular evaluations of the services are conducted.
- Patient education programs are beneficial aspects of care.

Tips for duplicating this service

- For patients with complex problems, compact, tailored assessment and treatment programs in a day care setting, followed by care delivered by specialized health professionals in primary care appears to be an efficient way of providing rheumatology services.
- Working problems are hard to influence by a service delivered from the health care system only.

Future initiatives

- Develop decision tree for indicators of care to determine indicators of which type of program is required for which patients.
- Develop the scleroderma program.

For further information:

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Appendix D. Key Informant Interview Guide for Health Care Providers, Academics, and Administrators

A. Overview of Study

- purpose/objectives

B. Questions from Participant and Informed Consent

C. Interview Questions

1. Briefly describe your position and experience related to arthritis care.

- Role
- Setting (e.g. community vs. hospital)
- Years Experience (working in arthritis care)
- Education

2. Please describe your approach to provision of services (programs) to arthritis care.

- Who is target population (stage of disease, age)
- What interventions/services are provided/available (e.g. where services are delivered, best practices used)
 - Group interventions
 - Individual interventions
- Who delivers interventions
- Intake process
- Referral processes
 - referral into program/service
 - referrals to other services
- Long-term patient follow-up (how is follow-up initiated?)
- Communication processes
 - internal processes
 - external processes
- Evaluation
 - Program/model evaluation: what is evaluated and how is it evaluated
 - Evaluation of patients: what is evaluated and how is it evaluated
 - Outcome measures commonly used

3. Please describe the strengths of this model of care (services/programs for arthritis) (e.g. characteristics, structures and processes that are strengths of this model).

4. In your experience, what are the challenges or barriers in this model of care (in the delivery of these services/programs for arthritis)?

- Funding issues
- Access issues (geographical, health care provider shortages, direct access)

How can these challenges be overcome?

- 5. Please describe your perspective on ideal elements of any interdisciplinary care model for arthritis (e.g. characteristics, structures and processes)?**
- 6. Please tell me about any other approaches to the provision of services or programs that you think are feasible models of care for arthritis.**
- 7. Recommendations re. anyone else who can inform our study**

Appendix E. Key Informant Interview Guide for People Living with Arthritis

I. Overview of Study

- Review background information
- Review purpose and objectives

II. Obtain Informed Consent

III. Demographic Information

1. Have you been told by a health care provider that you have arthritis?

Yes
No

2. What type of arthritis do you have?

- Osteoarthritis
- Rheumatoid arthritis
- Psoriatic arthritis
- Unsure
- Other _____

3. When were you diagnosed with arthritis? _____

4. Do you have any other chronic illnesses?

Yes
No
Please list: _____

5. Do you live alone or with others?

Live alone
With others _____

IV. Interview Questions

Intro: Let's start the interview by discussing your arthritis.

1. Tell me about the impact that arthritis has on your life.

(Examples for probes, if necessary: Activities of daily living; function and mobility; participation in community, work and leisure; family life; coping/stress)

2. Tell me about some of the challenges you have faced living with your arthritis.

Probes:

- *Tell me about any challenges you face in getting access to health care professionals and resources (including referrals).*

3. Tell me about what you do to care for your arthritis.
(Examples for probes, if necessary: exercise, diet, planning, pacing, help, rest, medications, health care services)

4. a) Let's specifically discuss the care provided within the health care system.

Tell me about the kinds of help you need from the health care system for you to manage your arthritis effectively.

Probes:

- *What types of people do you go to when you require any type of care, treatment or advice for your arthritis?*

[For interviewer only – do not need to probe for each]

- Primary Care Physician
- Rheumatologist
- Orthopaedic Surgeon
- Physiotherapist
- Occupational therapist
- Nurse/nurse practitioner
- Social worker
- Pharmacist
- Dietitian
- Massage therapist
- Family/friends
- Other _____

Are there any other people that you think would be beneficial to go to for care, treatment or advice for your arthritis that you have not gone to before?

- *Does the location where you receive care matter (eg. at home or a doctor's clinic)? Can you tell me about a situation where you received or needed care but where it was not a suitable location?*

- *Tell me how often you seek help from the health care system (in the past year)?*

[For interviewer only]

- Weekly
- Monthly
- Yearly
- Other _____

- *When you need to see your health care provider(s), who would you prefer to initiate any follow-up appointments?*

[For interviewer only]

- a health care provider
 - If so, which provider _____
- yourself
- other _____

b) Tell me about any other services, programs or resources in the community that you think are important to help you care for your arthritis effectively that we haven't discussed already.

(Examples for probes, if necessary: pools, community exercise programs)

5. Arthritis care can be managed in different ways. We would like to ask you about a few of the approaches used to deliver arthritis care.
 - a) One way arthritis can be managed is by a team of health care providers working together with the person with arthritis. Tell me about how you prefer your arthritis care be delivered.
 - b) How would you feel if more of your arthritis care was delivered by someone who is not a physician but has received special training in managing arthritis? (For example, this might mean that a specially trained nurse, physiotherapist or occupational therapist would help manage more of your care.)
 - c) Telemedicine is another way care can be delivered. Telemedicine is the use of technology that allows a person with arthritis to be assessed by a health care provider that is located in a different location. The health professional, often a specialist, can see and talk to the person to help them with their health care needs by using telecommunications. How would you feel about having your health care delivered in this way?

6. We've talked about a lot of things related to arthritis care. Are there any other ways that you think the quality of care for your arthritis could be improved that we haven't discussed already?

If so, please tell me more about your ideas.

Other demographic information:

1. In what year were you born?
2. Record sex – DO NOT READ
3. What is the highest level of education that you have completed?
 - Less than high school
 - High school
 - Trades certificate/Diploma
 - College graduate
 - University graduate
4. Administer Modified Health Assessment Questionnaire (p.5)

Modified Health Assessment Questionnaire

In this section we are interested in learning how your illness affects your ability to function in daily life.

Please indicate the response which best describes your usual abilities OVER THE PAST WEEK. Please check (✓) one box for each item.				
Are you able to:	Without Any Difficulty	With Some Difficulty	With Much Difficulty	Unable To Do
1. Dressing and Grooming Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
2. Arising Get in and out of bed?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
3. Eating Lift a full cup or glass to your mouth?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
4. Walking Walk outdoors on flat ground?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
5. Hygiene Wash and dry your entire body?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
6. Reaching Bend down to pick up clothing from the floor?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
7. Gripping Turn faucets on and off?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4
8. Other Activities Get in and out of a car?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4