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ICES Institute for Clinical Evaluative Sciences

Information Strategy: Urgency Rating, Waiting List Management and Patient Outcomes Monitoring for Primary Hip/Knee Joint Replacement

August 2000

INFORMATION STRATEGY:

Urgency Rating, Waiting List Management and Patient Outcomes Monitoring for Primary Hip/Knee Joint Replacement

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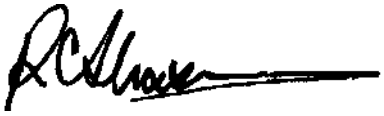
I am writing to you on behalf of the ICES Consensus Group on Waiting List Management for Total Joint Replacements. The Ministry of Health and Long Term Care asked the Institute for Clinical Evaluative Sciences (ICES) to form a consensus group for the purpose of recommending an information system for managing waiting lists for total joint replacements. The goal was to recommend a system to the Ministry of Health and Long Term Care and the Ontario Orthopaedic Association, for providing information on waiting lists, severity rating, wait times, and patient outcomes following primary total hip and knee replacements. Representatives from key stakeholder organizations joined the Consensus Group and participated in its deliberations.

I am pleased to present our final report and recommendations for waiting list management and monitoring of patient outcomes. The stakeholders represented on the Consensus Group have endorsed the recommendations of the report. The Consensus Group believes that the implementation of the recommendations will give health care providers the tools needed to prioritize patients with respect to their clinical condition, pain and degree of disability and thereby manage waiting lists for total joint replacement.

The report has been forwarded to the Ministry of Health and Long Term Care and the Ontario Orthopaedic Association. ICES and members of the Consensus Group are looking forward to working with the Advisory Committee of the Ontario Joint Registry to address the recommendations.

Sincerely,



Roger Sharman, Chair
ICES Consensus Group

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Executive Summary

Total hip and total knee replacements are the definitive treatments for reducing pain and disability caused by arthritic disease or injury of the lower limbs. Over the fiscal years 1993/94 to 1998/99, the number of total hip replacements in Ontario increased by 22 per cent, from 6,500 to 8,000 procedures, while total knee replacements increased by 52 per cent, from 6,000 to 9,200 procedures. Total joint replacements continue as a priority program for the Ontario Ministry of Health and Long Term Care. The Ministry has provided designated funds to support the increase in the number of hip/knee arthroplasties, in response to an increase in the demand for surgery. However, despite increases in volume, the waiting times for surgery in Ontario have continued to increase.

In January 1999, the Ministry requested that the Institute for Clinical Evaluative Sciences (ICES) form a Consensus Group to recommend an information infrastructure for managing waiting lists, focused on severity rating and patient outcomes using the Western Ontario McMaster Osteoarthritis Index (WOMAC), which is one of the leading clinical measures for assessing pain, stiffness and function of the hip and knee. The multidisciplinary Consensus Group, with representation from a broad range of stakeholder organizations, met five times, conducted feasibility studies with primary care physicians, orthopaedic surgeons, and hospitals; and, reached consensus on the recommendations included in this report. In March 2000, the Ministry of Health and Long Term Care announced the formation of the Ontario Joint Replacement Registry, to be based in London, Ontario. The recommendations regarding waiting lists, waiting times, and outcomes, included in this report, are intended to supplement and complement the information in the Ontario Joint Replacement Registry.

The key recommendations of the Consensus Group are as follows:

- Orthopaedic surgeons providing total hip and total knee replacements should be required to participate in the Registry;
- Orthopaedic surgeons should complete the standardized Consultation Note;
- All patients requiring primary hip/knee replacement should be requested to complete a WOMAC questionnaire on the date of consultation;
- When the surgeon and the patient both agree to proceed to surgery, a date should be booked and the Consultation Note and Patient WOMAC Questionnaire should be forwarded to the Registry for data entry and to place the patient on the waiting list; and,
- The Registry should mail a questionnaire to each patient, containing the WOMAC, 12 months following surgery for the assessment of outcomes.

The collection of data from orthopaedic surgeons and patients will provide information on:

- *Waiting lists* with standardized definitions for the entry/removal of patients from the list;
- *Waiting times* for consultation and for surgery, linked with clinical severity to allow for prioritization on the basis of urgency; and

- *Patient outcomes* in terms of reduction of pain, improvement in function and satisfaction with waiting times, hospital services and care provided by orthopaedic surgeons.

The Consensus Group also considered:

- A standard Referral Letter to be completed by primary care physicians when making referrals to orthopaedic surgeons;

- Collecting clinical information and WOMAC questionnaires at hospitals immediately before patients have surgery to assess changes in their clinical condition while in the queue; and,

- Following patients periodically beyond 12 months to assess longer-term outcomes.

The Consensus Group recommends that researchers and stakeholders assess the feasibility of gathering these data and the value of having the added information. The findings of these studies could be reported to the Ministry of Health and Long Term Care and the Advisory Board for the Registry.

The success of the Registry will be contingent on the full participation by all orthopaedic surgeons in the province. The Consensus Group recommended that orthopaedic surgeons be provided with a fee for submitting the required Consultation Note and the Patient WOMAC Questionnaire to balance the time they and their staff invest in the process. Further, it is acknowledged that the commitment of key stakeholders will be contingent upon the Ministry of Health and Long Term Care working with them to develop methods for responding to problems identified with respect to waiting lists and waiting times.

The Consensus Group reviewed processes for collecting the core data, confidentiality of data, access to data for research purposes, and the reporting of information on waiting lists, waiting times and outcomes. In addition to issuing the report to the Ministry of Health and Long Term Care and the Ontario Orthopaedic Association, the Consensus Group recommended that key members of the group meet with the Ontario Joint Replacement Registry team to discuss the recommendations and plans for collecting core information. The collaborative involvement of all stakeholders will be critical to meeting the objective of improved quality of care for patients awaiting total hip and total knee replacements in Ontario.

1.0 Introduction

Hip and knee arthroplasties, or total joint replacements, are the definitive treatment for reducing pain and disability caused by arthritic diseases or injury affecting the lower limb joints.[1] In a global review of the effectiveness of medical care[2] stated, "The widespread use of total joint replacements to relieve pain and restore function has been one of the great success stories of medical care today". Over the fiscal years 1993/94 to 1998/99, the number of total hip replacements in Ontario increased by 22 per cent, from 6,500 to 8,000 procedures, while total knee replacements increased by 52 per cent, from 6,000 to 9,200 procedures.

Total joint replacements continue as a priority program for the Ontario Ministry of Health and Long Term Care. In 1990, the Orthopaedic Committee, a subcommittee of the Tripartite Committee of the Ministry, Ontario Hospital Association and Ontario Medical Association, recommended the funding of hip and knee arthroplasties under the Life Support Program. The Ministry implemented the recommendation and provided funds to offset the cost of prostheses. In 1995/96, the Ministry transferred the funding of hip/knee implants to Hospital Operations and Priority Programs with the goal of bringing total hip/knee joint replacement rates as close to the provincial average as possible. Based on age-/sex-adjusted Ministry target rates per 100,000 population of 84.4 for hip replacement and 90.7 for knee replacement, hospitals set annual targets for the number of procedures to be performed.[3] Since 1995, the province has increased annual funding for the procedures by $10.2 million to about $43.6 million this fiscal year.

The Institute for Clinical Evaluative Sciences (ICES) has monitored the waiting times between date of orthopaedic consultation and date of surgery, from 1993 forward, for primary total hip and knee replacements. The waiting times have remained the same or increased. The median waiting time for hip procedures was approximately 115 days until 1998, jumping to 139 days over the last year. The median waiting time for knee procedures was in the range of 150 days from 1993 until the past year when the waiting time increased to 181 days. Data from 1996/97 clearly demonstrate geographic variations in rates of hip/knee procedures as well as median wait times. For example, less than 40 per cent of patients in Thames Valley District Health Council (DHC) waited more than three months for elective hip replacement while more than 75 per cent of patients in the Quinte, Kingston and Rideau DHC waited longer than three months.[4]

Joint replacement registries are now being implemented in a number of jurisdictions to address the demand for total hip and knee replacements (see Appendix A). The Canadian Institute for Health Information (CIHI)[5] is establishing a national joint replacement Registry in collaboration with the Canadian Orthopaedic Registry and with funding from Health Canada. This initiative led to the creation of the Southwestern Ontario Joint Replacement Pilot Project in 1999.[6,7] A group of orthopaedic surgeons from the Southwest region submitted data electronically on patient characteristics, surgical procedures, prostheses implanted, date of referral for consultation, date of consultation and date of surgery. The Ministry of Health and Long Term Care recently provided funding to extend the pilot project in Southwest Ontario to form the Ontario Joint Replacement Network, in concert with the Ontario Orthopaedic Association, the Ontario Hospital Association and the Ministry.

The Ministry of Health and Long Term Care asked ICES to form a consensus group to recommend an information system for managing waiting lists for total joint replacements. The intent has been to develop an information system that could be added to a Registry, not to develop the Registry per se. It is anticipated that the recommendations from the Consensus Group will complement plans underway for the Ontario Joint Replacement Network.

A *waiting list* is generally defined as a roster of patients awaiting a particular service.[8] *Waiting time* refers to the length of time a patient is enrolled on a list until he/she receives the service.[8]

In Appendix B, a national and international overview of waiting lists and registries is provided. There are basically three approaches to defining waiting times: self-reports from providers, use of administrative data and prospective data to mark the movement of patients through the health services system. The Fraser Institute[9] and the Ontario Orthopedic Association rely on reports of specialists to estimate the time from referral to consultation and from consultation to next available date for surgery. Nova Scotia[10], the Manitoba Centre for Health Policy and Evaluation and ICES have used medical claims data and hospital discharge data to determine the time between specialist consultation and the date of surgery. In British Columbia, the Ministry of Health reports on the median time people on hospital lists wait for surgery.[11]

The Cardiac Care Network of Ontario (CCN)[12] maintains a central waiting list and information on waiting times for patients awaiting coronary artery bypass surgery in Ontario. Patients are referred to cardiac surgeons by cardiologists, once catheterization laboratory results are known. If patients are appropriate candidates for surgery, the cardiac surgeon puts them on the waiting list, gives them an Urgency Rating Score and places them into one of three categories: urgent, semi-urgent, or elective. Each category has a Recommended Mean Waiting Time, and the Cardiac Care Network publishes hospital-specific reports every three months on the cases completed, median waits, and percentages of patients who had surgery within the recommended waiting times (www.ccn.on.ca/access/waitimes.html). CCN also monitors waiting lists for hospitals and facilitates the transfer of patients between centres if the wait times become too long. Working from the CCN experience, the goal of the Consensus Group is to propose an information system that encompasses wait lists, wait times, severity ratings, and outcomes for primary hip/knee replacements.

1.1 WOMAC

The Cardiac Care Network (CCN)[12] has developed rating systems and criteria for assessing patients both in terms of appropriateness for coronary artery bypass surgery and urgency categories with recommended waiting times for surgery.[13,14] An ICES expert panel developed criteria for rating the appropriateness and urgency of patients for hip and knee arthroplasty.[15] For appropriateness, the expert panel used the Delphi method developed by RAND[16, 17] for rating clinical scenarios of patients based on the functional classification system of the American College of Rheumatology: pain, candidacy for osteotomy and prosthesis survival time. The scenarios for the rating of urgency were based on pain at rest, problems encountered at work or in caregiving, and functional status. However, neither the concept of the Registry nor the use of the criteria for appropriateness and severity were deemed feasible at that time.

The development and widespread use of the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) provides a disease-specific measure that has the potential for

providing evidence and criteria for assessing the appropriateness and severity of arthritic disease in the hips and knees. The WOMAC includes 24 items on three dimensions: pain – five items; stiffness – two items; and function – 17 items. It captures the patients' perspectives of their condition. The WOMAC has been extensively tested; its reliability, validity and responsiveness have been demonstrated in a number of clinical settings.[18]

There are a number of clinical rating systems and measures used to assess patients for arthroplasty, but there is not consensus on the best measure. However, a recent survey conducted by the Canadian Orthopaedic Association indicates that most orthopaedic surgeons view the WOMAC as a valid measure and a preferred data collection instrument for assessing the clinical condition of candidates for total hip replacement surgery. The WOMAC is used widely for total knee arthroplasty as well. While there is a lack of consensus on which WOMAC score should be used for defining appropriateness for surgery, the Consensus Group believes the instrument can be used for defining the severity of patients' clinical conditions while waiting for surgery.

1.2 Multi-stakeholder Consensus Group – Mission

The mission of the Consensus Group was to recommend, to the Ontario Ministry of Health and Long Term Care and the Ontario Orthopaedic Association, an information strategy focused on numbers on the waiting list, severity rating, wait times and patient outcomes for primary total joint replacement of the hips and knees. The information strategy was to begin with referral from the primary care physician, include the consultation visit with the orthopaedic surgeon, booking information, surgery, and follow-up. The strategy should produce information on appropriateness for surgery, severity of condition, waiting list management, and the evaluation of outcomes at follow-up. More specifically, it should provide information to primary care physicians, surgeons, consumers, hospitals, government and researchers related to: access to services (waiting lists and waiting times), barriers to access (including resources), and, costs and outcomes over the short and long term.

1.3 The Objectives of the Consensus Group were to:

- Design an information system which will produce waiting list and waiting time data, using the following mechanisms:
    - develop and test a standardized referral letter to be used by physicians when referring patients to orthopaedic surgeons for hip or knee problems;
    - include information in the standardized referral letter, such as the WOMAC (Western Ontario and McMaster Universities Osteoarthritis Index, 1982), which can be used by the orthopaedic surgeon for assessing severity of condition and urgency for consultation;
    - develop and test a standardized form to assist orthopaedic surgeons in assessing severity or urgency for surgery for patients whom they deem appropriate for hip/knee arthroplasty. The form would encompass the WOMAC, other clinical factors and a statement indicating the patient's willingness to proceed with surgery as soon as possible;

- assess the feasibility for linking hospital booking systems for surgery with severity/urgency ratings of orthopaedic surgeons;

- assess the feasibility of collecting WOMAC and clinical data post-operatively for assessing outcomes;

- identify and compare alternative strategies and incentives for collecting requisite data elements from referring physicians, orthopaedic surgeons, hospitals and patients; and,

- identify and compare strategies for storing and managing the data and generating timely reports for all stakeholders.

- Address issues regarding ownership of and access to data, management of the information system, and protection of the privacy and confidentiality of patients and providers; and,

- Present a report on the issues and recommendations, which stem from the feasibility work, to the Ministry of Health and Long Term Care and Ontario Orthopaedic Association.

1.4 Consensus Group Process

The Consensus Group, formed in January 1999, met five times, from March 1999 to March 2000. The Consensus Group membership included a broad range of clinical expertise and stakeholder organizations. More specifically, the Consensus Group included representation from the following organizations and specialty groups:

- *Orthopaedic Surgeons* from: Hospital for Sick Children, Kingston General Hospital, London Health Sciences Centre, North York General Hospital, Sunnybrook and Women's College Health Sciences Centre, Thunder Bay Regional Hospital and University Health Network;

- *Rheumatologists* from: Sunnybrook and Women's College Health Sciences Centre and University Health Network;

- Family Physicians;

- *Stakeholder Organizations* including: Arthritis Community Research and Evaluation Unit (ACREU), Department of Physical Therapy (University of Toronto), Institute for Clinical Evaluative Sciences, Joint Planning and Policy Secretariat (JPPC), Loeb Health Research Institute, Ontario Ministry of Health and Long Term Care, Ontario Hospital Association (OHA), and Ontario Orthopaedic Association; and

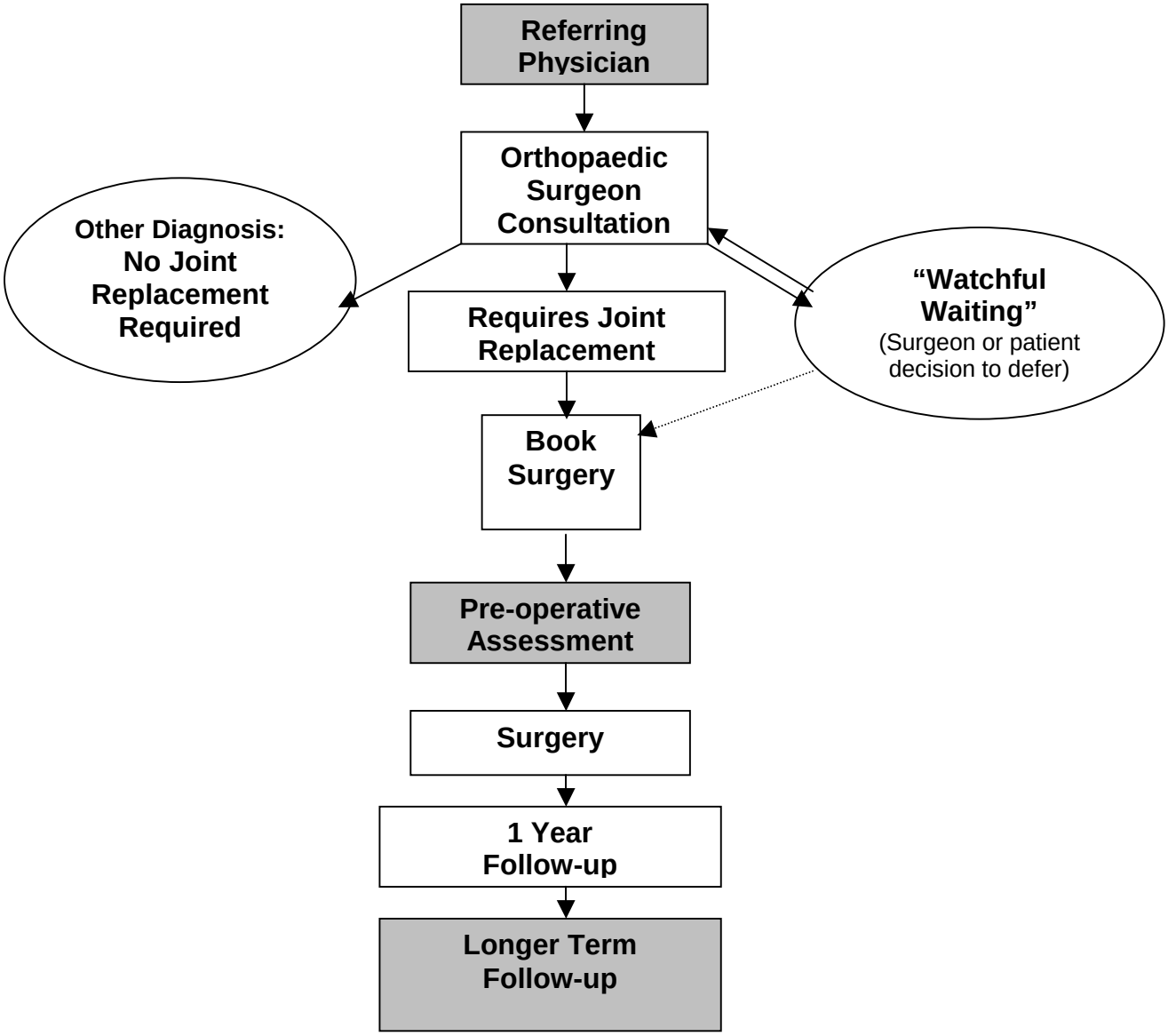
- *Canadian Joint Registry Initiatives* including: Southwestern Ontario Joint Replacement Registry Initiative and The Canadian Joint Replacement Registry of the Canadian Institute for Health Information (CIHI).

A working group, comprising three orthopaedic surgeons, a rheumatologist, a Ministry of Health and Long Term Care representative and two ICES' researchers, was formed in May,

1999 to conduct the feasibility work, develop detailed recommendations and report back to the Consensus Group at regular intervals.

The Consensus Group is pleased to present this final report to the Ministry of Health and Long Term Care and the Ontario Orthopaedic Association. The report includes broad recommendations for addressing the complex issues of waiting lists and waiting times for total joint replacement. The Consensus Group acknowledges that the implementation will be contingent on creating the right conditions and incentives for data collection, management and reporting. Collaborative involvement of all stakeholders will be critical for the collection and use of clinically important information for improving access to primary hip and knee arthroplasty and reducing waiting times. The recommendations are meant to complement plans that are already underway for the implementation of the Ontario Joint Replacement Registry.

Figure 1: Patient Flow Through the System



2.0 Feasibility Study

The goal of managing waiting lists and waiting times is to ensure timely access to surgery, resulting in optimal outcomes. The working group identified four critical points in time for assessing patients with total joint replacement, as indicated in Figure 1: Patient Flow Through the System. The date of referral by the primary care or other referring physician is the starting point for patients moving through the system. Referring physicians manage patients and decide with them when they should seek consultation with an orthopedic surgeon regarding surgery. The second key point in time is the consultation, during which the orthopaedic surgeon decides on the appropriateness of hip or knee arthroplasty, the severity of disease, and in consultation with the patient, whether the patient should be "booked" for surgery. The date of surgery is the third critical point in time. During future research, it will be important to determine if information about changes in the severity of disease or other changes in the patient's health can be collected pre-operatively. The assessment of outcome at follow-up is the endpoint marking the fourth critical time in the process.

It should be noted that the recommendations focus on the Consultation Note from the orthopaedic surgeon, the date of surgery, and the use of a patient questionnaire to assess outcomes and perspectives on care 12 months following surgery. The Consultation Note provides information on patients who are placed on waiting lists for surgery. It also provides information on the date of referral and the date of consultation, and when this is linked with date of surgery, the dates can be used to define the times between referral and consultation and consultation and surgery. The Patient Questionnaire provides the key information on patient outcomes.

Additional work and research is required for: developing and implementing a standard referral letter to be completed by primary care physicians; collecting standard information on the clinical status, severity of pain and disability prior to surgery; and deciding what information should be gathered for longer term follow-up. The shaded boxes in Figure 1 reflect areas for additional work and research.

The working group was directed to design and conduct a feasibility study and report back to the Consensus Group by November, 1999. It focused on the four key times outlined in Figure 1 to identify the points at which information could be obtained for managing waiting lists and waiting times.

2.1 Design of the Feasibility Study

The feasibility work was divided into three main components:

- Referral from family physicians and referring specialists to orthopaedic surgeons for consultation;
- Consultation for surgery by orthopaedic surgeons; and,
- Surgical booking for total hip/knee arthroplasty at Ontario hospitals.

Given the relatively short timeframe allotted for the feasibility work, it was determined that the optimal approach would be to conduct focus groups with family physicians, request orthopaedic surgeons to use the Consultation Note and the WOMAC with their patients for a one-month trial period, and send a survey to hospitals regarding their booking systems. The working group targeted physicians affiliated with 10 hospitals across the province, selected on the basis of annual hip/knee arthroplasty volumes and geographic distribution. The specific objectives, design and results for each component are detailed below.

2.1.1 Referral by Primary Care Physicians and Specialists to Orthopaedic Surgeons

Objectives

The objectives addressed through the Referral Letter from primary care physicians to orthopaedic surgeons were:

- to highlight therapy which might be considered prior to referring a patient to an orthopaedic surgeon for consideration of joint replacement;
- to standardize the demographic and clinical information provided to orthopaedic surgeons by referring physicians;
- to provide orthopaedic surgeons with an indication of clinical severity at time of referral to allow orthopaedic surgery consultations to be prioritized on the basis of clinical condition;
- to track wait times for orthopaedic surgery consultation; and,
- to collect quality of life data to track patient outcomes and assess issues such as change in clinical condition in the queue while awaiting consultation/surgery.

Design

To meet these objectives, the working group developed a standardized "Referral Letter" which included basic demographic and clinical information, indication as to whether specific therapeutic interventions had already been tried and the results of therapy, and a patient administered questionnaire highlighting pain and disability (24 item WOMAC) at the time of referral. In collaboration with the "WOMAC Working Group", we hoped to identify a small number of WOMAC items which could be used by the orthopaedic surgeon's receptionist to determine urgency, to allow for prioritization of consultation appointments on receipt of the Referral Letter.

The referring physician would be requested to complete the form, in place of his/her usual referral letter, for any patient who he/she thought might be a candidate for primary hip/knee arthroplasty. The patient would be instructed to complete the WOMAC prior to leaving the physician's office. Both the Referral Letter and the WOMAC would then be faxed to the orthopaedic surgeon's office and an appointment would be scheduled based on the clinical urgency reflected by specific WOMAC items. The WOMAC

completed by the patient at the time of referral would be the first in a series of outcome measures which could be analyzed to assess longitudinal changes in pain and disability. Similarly, the date on the Referral Letter, when combined with the date on the orthopaedic surgeon's consultation form, would allow tracking of wait times for consultation in different jurisdictions.

Each centre was contacted through an introductory letter and follow-up phone call to the Chief of Family Medicine, who took responsibility for working with ICES staff to recruit his/her colleagues for a focus group. Family physicians were each provided with an honorarium for participating in a one-hour focus group, organized at a time and location convenient to the physicians. A research coordinator from ICES and one of two family physicians on the Consensus Group facilitated each of the focus groups.

Results

We were able to arrange focus groups for family physicians in six of 10 centres originally targeted; another two communities were added to the list, providing us with input from eight communities (Appendix D) and a total of 65 family physicians.

The focus group discussion in each community centred on access to orthopaedic surgeons for consultation, the objectives and content of the standardized Referral Letter and WOMAC, the proposed process for collecting data, the information needs of family physicians in regard to waiting list data and the feasibility of implementing the process in their community.

With the exception of one group of family physicians, we received overall support for the implementation of a hip/knee joint Registry and for family physician participation in the data collection process. Additionally, we received a number of detailed and valuable suggestions for improving the content of the Referral Letter as well as some concerns regarding the process and use of the Referral Letter by orthopaedic surgeons. The revised Referral Letter, based on focus group input, is included in Appendix E.

A summary of the input/concerns, excluding specific suggestions regarding content, is included below:

- Some physicians expressed concern about the time required to complete yet another form, without any remuneration, while a number of others supported use of the form, indicating that it would take less time to complete than their existing referral letter. All physicians expressed concern about the time required by them and their staff to ensure that patients complete the WOMAC appropriately. Some suggested that if their current referral letter replicated the information on the first page of the standardized Referral Letter, they should be allowed to attach the second and third pages of the standardized Referral Letter to their usual one page referral letter.

- Many physicians expressed concern about their patients' ability to understand some of the questions in the WOMAC.

- Some physicians highlighted a concern that the Referral Letter seemed like the tip of an iceberg, with worry about a proliferation of forms in the future for each subspecialty group in medicine and surgery.

- If the standardized Referral Letter is implemented, it would need to be made available in hard copy, easy-to-use packages and in electronic format to accommodate the needs of all physicians.

- Physicians voiced concern about potential gaming of the system by patients in an attempt to decrease their wait times for consultation.

- In areas where waits for consultation are lengthy, physicians expressed skepticism in regard to whether orthopaedic surgeons would use patients' information on pain and disability to priorize appointment times for consultation, with many indicating that the current system of contacting surgeons directly by telephone works well for them. If orthopaedic surgeons accepted and used their information, many indicated they would support the use of objective data to priorize consults. If it were not used by orthopaedic surgeons, there would be no incentive to complete the forms. In geographic areas where waiting time for consultation is not a problem, there was no perceived benefit for family physicians to participate on a voluntary basis.

- Family physicians indicated that information provided by the Registry on wait times for consultation and surgery, by hospital centre and surgeon, would be useful to them and their patients. They highlighted their desire to use these data in altering referral patterns *if desired by the patient and physician*. Due to the volume of paper received by physicians in their offices, the family physicians indicated they would prefer a 1-800 number or a fax-on-demand service to provide information for a specified region, rather than receiving hard copy or electronic information on a routine basis for the entire province. Many indicated that they do not have Internet access in their offices. Some indicated that they would only alter referral patterns if they could be assured of quality, therefore requiring outcomes data to be tied to aggregate information on wait times.

- It was suggested that, if implemented, the standardized Referral Letter should be completed by *any* referring physician, not solely family physicians; this would generally include general internists and rheumatologists, as well as family physicians.

- Family physicians made two suggestions for encouraging participation in the process: 1) providing priority booking only for those patients for whom the orthopaedic surgeon receives the standardized Referral Letter/WOMAC; or 2) no consultation without receipt of the standardized Referral Letter.

2.1.2 Consultation by Orthopaedic Surgeons

Objectives

The objectives addressed through the use of a consultation note by the orthopaedic surgeons and a patient-completed WOMAC were:

- To develop centralized waiting lists for primary hip/knee replacement surgery;
- To track wait times for surgery;
- To standardize the point in time from which wait time for surgery is calculated;
- To collect information related to the patient's severity of condition to allow surgeons to priorize patients for surgery on the basis of clinical condition;
- To develop a database to provide sufficient data over the long term for the development of recommended wait times linked to ranges in patients' WOMAC scores;
- To collect information on patients' pain and disability to allow for patient outcomes to be monitored on a long-term basis; and,
- To provide information to support requirements for reallocation and/or additional resources for primary hip/knee replacement surgery.

Design

To meet these objectives, the working group developed a standardized Consultation Note for primary hip/knee joint replacement and a Patient Questionnaire which included the 24 item WOMAC. The Consultation Note included the following components:

- Patient name and health card number;
- Joint(s) for surgery and diagnosis for primary joint replacement;
- Past surgical history relating to hips/knees;
- Other symptomatic joints (hip/knee/spine);
- Recommended wait time for surgery (one month to more than one year);
- Indication as to whether the surgeon recommends that the patient proceed to surgery and that the patient has agreed to proceed; and,
- Indication as to whether the date of surgery has been booked, and if not, why (including patient preference).

The patient questionnaire included the following information:

- Basic demographics;
- Date completed;
- Highest level of education completed;
- Current employment status and any link with disability;
- Comorbid illness;
- An indication as to whether the patient would accept a surgery date within 12 weeks if recommended by the surgeon; and,
- The 24 item WOMAC.

If, during a patient consultation, the surgeon determines that a patient is a candidate for primary hip/knee joint replacement, he/she would complete the standardized Consultation Note and ask the patient to complete the Patient Questionnaire (including the WOMAC) in his/her waiting room before leaving the office. If the decision to proceed with surgery is made, by both the surgeon and the patient, the orthopaedic surgeon would be responsible for forwarding the patient's data (from the referring physician and the orthopaedic surgeon) to the Registry, if the decision to proceed has been deferred to a later date, the patient's data would be stored in the patient's file until there is a decision to proceed.

To assess the feasibility of using these forms in a surgeon's office, orthopaedic surgeons participating as members of the Consensus Group contacted colleagues at each of 10 Ontario hospitals to discuss the objectives and ask them if they would be willing to use the forms in their offices for a one-month period. Each surgeon was also informed that he/she would be required to complete a one- to two-page feedback form following the one-month trial period.

Results

Of 36 surgeons targeted for inclusion in the feasibility study, all but two agreed to participate. Sixteen surgeons (44%) sent back at least one Consultation Note and Patient Questionnaire, providing for a total of 89 sets of completed forms. Additionally, 22 surgeons (61%) sent back feedback forms. Input from a few surgeons suggested that the key reasons for not participating following initial agreement to do so were: 1) forgetting to complete the Consultation Note when an eligible patient attended the office for consultation; and, 2) being too busy to complete more paper work given their hectic office schedules.

From those who provided the Consensus Group with feedback, the following information was noted:

- All but one surgeon indicated that the content included in the Consultation Note was useful/appropriate; suggestions for change included adding more space to describe previous surgeries and adding the date booked for surgery (see Appendix E for modified Consultation Note and Patient Questionnaire);

- Slightly more than half of respondents indicated they would use the Consultation Note on an ongoing basis, with one of these indicating only if appropriately compensated for the additional work involved. Reasons for not using the Consultation Note on an ongoing basis included:

    - Too much time required for paperwork;

    - Practices where waiting times are not a problem;

    - Not wishing to carry forms back and forth between multiple consultation offices/clinics;

    - Not perceived as useful to physician or patient; and,

    - Surgeons who already have other systems for tracking wait times and bookings, and for priorizing patients for surgery.

- Less than half indicated they would use the WOMAC on an ongoing basis to assist them to manage their own waiting lists;

- Less than half indicated they would use information on clinical condition from the referring physician's Referral Letter to priorize patients for consultation;

- Approximately one-third indicated their patients encountered some difficulty in completing the WOMAC due to language barriers; and,

- All surgeons indicated they would like to receive aggregate information on waiting times and patient outcomes.

Reflecting on these results, the Working Group acknowledged the concerns raised but also suggested that, given the process used to quickly recruit surgeons into the feasibility study, a number of surgeons may not have fully appreciated the goals for establishing a Registry or the role of each of the various stakeholders in the proposed process. Due to the strong support provided for the concept of a Registry from the Ontario Orthopaedic Association, the Working Group suggested that these results be interpreted within the context of the quick timeframe allowed for the surgeon component of the feasibility work. The results suggest that education/training and appropriate incentives for gaining participation will be critical to meaningful involvement by the province's orthopaedic surgeons.

2.1.3 Survey of Hospitals

Objectives

The objectives addressed in sending the survey to hospitals were:

- To assess the amount of variation among hospitals in regard to policies for documenting and managing waiting lists for hip/knee replacement;
- To determine the electronic/manual systems used by hospitals for surgical bookings and to assess the flexibility of such systems for the addition of variables; and,
- To assess the willingness of hospitals to standardize systems for waiting list management and to enter three or four additional variables to their routine data entry for surgical bookings, if asked to do so.

Design

The survey was mailed to 10 hospitals, with specific questions relating to:

- Timeframe prior to surgery that a patient can be booked;
- Practice of keeping waiting lists beyond the timeframe within which a patient can be booked;
- Definition of "booked for surgery" at their hospital;
- Minimum and maximum timeframes prior to surgery for attendance at pre-operative clinic;
- Systems used for OR booking and variables included in the database;
- Use of waiting list variables already available in automated booking systems;
- Methods for removing patients from the system following surgery/death/cancellation, etc;
- The potential for adding variables, both from the perspectives of software flexibility and personnel time; and,
- Willingness to standardize the timeframe for booking prior to surgery.

Results

All 10 hospitals returned a completed survey. A summary of the responses to individual items follows:

- Booking timeframes vary from one- to two-weeks at some hospitals to one year at others (no limit at one hospital);
- Most hospitals do not maintain waiting lists beyond the booking timeframe; waiting lists are managed by individual surgeons in their offices;
- Surgeons assign dates and times for surgery at their offices and then notify the hospital of the bookings;
- Two hospitals are still using manual booking systems; at the remaining eight centres, a total of five different computerized software modules are being used;
- None of the hospitals reported using waiting list screens, even if available as part of the software module;
- A variety of methods were reported for removing patients from the booking system; and,
- Most indicated they would be agreeable to adding a few additional variables (assuming the cost for doing so would be covered by the Registry) and to standardizing the timeframe for booking patients for surgery; however, a number of hospitals raised concerns about the possibility of the timeframe being standardized to longer than a few weeks, as this would create the frequent need to rearrange/cancel bookings to accommodate emergencies.

3.0 Recommendations – Data Collection and Monitoring

The Consensus Group recommends the establishment of an information system for managing waiting lists and waiting times. The Consultation Note from the orthopaedic surgeon and the Patient Questionnaire provide the key information required for demarcating and managing the waiting lists. The patient questionnaire at one-year follow-up provides the key information for assessing outcomes and the impact of waiting times on patient satisfaction.

Ideally, information should be collected from the primary care and other referring physicians, and from the patient at the time of surgery, as this would add value to the analysis of the waiting lists and waiting times. However, the results from the feasibility study indicate that further work is required to develop the forms and test the feasibility of collecting this additional information on an ongoing basis.

Consequently, the following recommendations, which are based on the feasibility study and the deliberations of the Consensus Group, suggest focusing on orthopaedic surgeon participation at the outset and conducting smaller pilot/research studies to identify optimal strategies for gaining the participation of family physicians and referring specialists over the long term.

3.1 Orthopaedic Surgery Consultation

As advocates for their patients, orthopaedic surgeons would like to see increases in funding for joint replacements to resolve unmet need and reduce waiting times. Additionally, all orthopaedic surgeons expressed a desire to receive aggregate information on waiting times for surgery. The feasibility work suggests that, due to the time required by surgeons and their staff, additional provincial funding for hip/knee prostheses and funding to compensate for some of the time required to complete necessary forms may be critical to participation by orthopaedic surgeons.

It is therefore recommended that:

- ***Orthopaedic surgeons complete the standardized Consultation Note*** (see Appendix E) for all patients who they identify as candidates for primary hip/knee replacement;

- ***All patients recommended for primary hip/knee replacement be requested to complete a WOMAC on the date of consultation*** using the version included in the Patient Questionnaire in Appendix E;

- ***When the surgeon and the patient both agree to proceed to surgery, a date be booked and the Consultation Note and Patient Questionnaire be forwarded to the Registry for entry on the waiting list;***

    - If agreement to proceed to surgery has not been reached, the forms should remain in the patient's chart in the orthopaedic surgeon's office until such agreement is reached.

    - If the decision to proceed to surgery is deferred beyond the initial date of consultation and the patient returns to see the orthopaedic surgeon prior to the date of surgery, the

WOMAC completed closest to the date of surgery should be the WOMAC forwarded to the Registry with the Consultation Note.

- ***Orthopaedic surgeons who use the WOMAC score and other clinical factors listed below manage their own waiting lists:***

  - *Level of support in the home;*

  - *Occupational status; and*

  - *Underlying pathology of tumour.*

Ideally, there would be agreed upon categories for the WOMAC score that could be used to define recommended wait times related to severity of pain and loss of functioning. In the absence of such WOMAC categories and benchmarks for severity and recommended waiting times, the Consensus Group set the following preliminary benchmark.

- ***Orthopaedic surgeons schedule patients with WOMAC scores of 50 or higher for surgery within 3 months of the decision to proceed with surgery***.

In the future, information from the Registry database could be used to refine/develop the categories and benchmarks. The information on the patient's clinical condition, health status, level of support at home, work status and caregiving responsibilities may be considered in developing categories and criteria for appropriateness and urgency for surgery. This work will require study and development by a working group of stakeholders.

3.2 Referrals from Primary Care Physicians and Specialists to Orthopaedic Surgeons

As advocates for their patients, referring physicians will generally telephone an orthopaedic surgeon if they believe there is an urgent need for consultation. While not unanimous, many of the family physicians expressed satisfaction with the current system. Additionally, however, all family physicians expressed a desire to receive aggregate information on waiting times by hospital and by physician.

From the perspective of referring physicians, an incentive to complete the standardized Referral Letter would exist if they practised in a community where there are considerable waiting times for consultation by orthopaedic surgeons *and* if the information they provided were used by orthopaedic surgeons to expedite consultation appointments for those with the greatest clinical need *and* if they believed the use of the letter would save them time. In communities where there is not a perceived problem in accessing consultations with an orthopaedic surgeon, in the absence of some other enticement, the only incentive for voluntary participation would be the perceived benefit of receiving aggregate data on waiting times for consultation and waiting times for surgery. To be useful in altering existing referral patterns, referring physicians would require data reported at the level of individual surgeon.

The family physician focus groups highlighted a need to develop a shorter form of the WOMAC, which would be highly correlated with the 24 item WOMAC. The development of a short form

WOMAC was deemed necessary to address concerns about the amount of time required by patients (and office staff) to ensure the form is completed, and more importantly, to provide the orthopaedic surgeon's receptionist with a quick method for assessing urgency for consultation when the Referral Letter is faxed to the surgeon's office. Similarly, some family physicians indicated a desire for a quick, brief scoring method to allow them to track changes in patients' clinical condition between visits.

In response to this need, a WOMAC working group (see Appendix F) has developed a short form of the WOMAC with eight items, including three items from the pain dimension and five from the physical function dimension. Using Rasch methods to test item response characteristics, the short form retains clinically important items, has construct validity and is as responsive to interventions for hip/knee arthroplasty as the original WOMAC scores for pain and functioning.[19] The results of this work still need to be validated using new data collected prospectively for patients in the queue for surgery. Similarly, the prognostic value of the shortened WOMAC as a screening tool for triaging a waiting list of patients requiring total hip/knee replacement needs to be evaluated.

The following recommendations outline the process developed by the Consensus Group for family physician and referring specialist involvement in data collection for the Registry***. The process outlined should be pilot tested in one or two geographic areas to identify optimal strategies for involving referring physicians in the process over the longer term.***

- ***Researchers affiliated with the Registry and the WOMAC Working Group should test the reliability and validity of the WOMAC short form and assess its clinical use as a component of the standardized Referral Letter.***

- ***Referring physicians (primary care physicians, general internists, rheumatologists) complete the standardized Referral Letter*** (see Appendix E) for all patients who they identify as potential candidates for primary hip/knee replacement;

- ***Orthopaedic surgeons be requested to priorize patients for consultation, based on the severity of their clinical condition***, reflected by patient responses to items on the short-form WOMAC;

- ***Page 2 of the Referral Letter include Results of Therapy,*** intended to promote the use of conservative approaches to treatment prior to referral to the orthopaedic surgeon, thereby increasing the appropriateness of referrals, improving the quality of primary care and facilitating a decrease in wait times for consultation; and,

- ***Referring physicians be permitted to substitute their "usual" referral letter for page 1 of the three page standardized Referral Letter.***

3.3 Tracking Waiting Lists, Wait Times and Outcomes

The purpose of the proposed information system is to determine who is on the waiting list, calculate the waiting times, prioritize patients who are waiting (based on clinical condition), and assess outcomes of patients following surgery.

3.3.1 Tracking Waiting Lists

It is recommended that the Consultation Note and Patient Questionnaire submitted by the orthopaedic surgeon to the Registry provide the requisite information for the waiting list.

- ***Entry to the Waiting List:*** A patient will be added to the waiting list when the patient and the surgeon have made a decision to proceed to surgery and have agreed to book the surgery on the earliest available date.

- ***Exit from the Waiting List***: A patient will removed from the waiting list on the day of surgery, or alternatively, if a decision is made by either the patient or physician not to proceed or to delay surgery, or if the patient dies while in the queue.

3.3.2 Tracking Wait Times

It is recommended that the following data be used to track wait times:

- ***Wait for Consultation:*** time from Date of Referral to Date of Consultation (included on the Consultation Note).

  At the time of consultation, a surgeon may recommend that a patient receive more than one hip/knee joint replacement, to be conducted sequentially. As wait times for second joint replacement are not generally perceived to be a problem, it was decided that tracking wait times for the second or subsequent joint(s) should not be necessary.

- ***Wait for Surgery:*** time from Date Decision Made to Proceed with Surgery (included on the Consultation Note) to Date of Surgery (included as a variable in the database for the Ontario Joint Replacement Registry).

It will be important to monitor waiting times across hospitals and regions of Ontario to identify surgeons, hospitals and regions with long waiting times; similarly it will be important to assess reasons for long waits; and seek strategies for reducing them. Moreover, it will be important to determine if waiting times can be related to the severity of the patients' conditions and to other medical and demographic information. Reports on waiting lists, waiting times, and characteristics of patients clearing the waiting lists should be reported on a regular basis. Specifically, the reports should include information for each hospital and region, on the percentage of patients with WOMAC scores over 50 who clear the waiting list within three months after the date of consultation.

It is further recommended that follow-up research be conducted to determine the underlying causes for longer than recommended waiting times at specific hospital centres and regions. The information should be provided to the Ministry of Health and Long Term Care and other relevant stakeholders to ensure that future access to joint replacement is enhanced in the province.

3.3.3 Tracking Patient Outcomes

It will be important to systematically follow patients after surgery to determine the outcomes achieved and their satisfaction with care received. The outcomes should include adverse events, problems encountered in receiving care as well as reductions in pain, improvements in function and satisfaction with the total joint replacement.

- ***Patient outcomes subsequent to surgery***: Change in pain and function are major outcomes following total joint replacement. Surgeons vary in the process used for following patients after surgery in terms of recall period, follow-up assessment, and frequency of return visits over time. The Consensus Group agreed that the benefits of surgery are evident one year after surgery. Adverse outcomes including deaths, readmissions, complications and prosthesis failure within the first year should be reported as well.

  Therefore it is recommended that the Registry be responsible for mailing the WOMAC questionnaire to all patients at one year post-surgery and entering these data into the Registry database as part of the Minimum Data Set. The mailing should also include a questionnaire to obtain the patients' perspectives on the care they received, including waiting times and delays. Hospital discharge abstract data should be reviewed to identify adverse events within 12 months following surgery.

- ***Patient outcomes over time.*** The Consensus Group considered the feasibility of following patients over time to detect "significant" changes in quality of life over the long term. If feasible, WOMAC scores could be used to highlight arthroplasty failure and to provide for the early detection of patients who might be candidates for joint revision. However, additional investigation is still required to:

  - Research the utility of using WOMAC scores for the early detection of patients who might be candidates for joint revision;
  - Define a change in WOMAC score which would identify candidates for potential revision;
  - Assess issues related to liability which might result from monitoring patients using the WOMAC;
  - Determine the number of orthopaedic surgeons who schedule routine follow-up visits in their offices; and,
  - Assess the pragmatic limitations of following all patients who receive primary hip/knee arthroplasty on an ongoing basis.

The Consensus Group decided that these issues would have to be successfully addressed before the periodic follow-up of patients over time could be recommended.

- ***Changes in clinical condition while patients are in the queue:*** The Consensus Group acknowledged the ongoing debate as to whether patients' clinical conditions change while

they are in the queue, the clinical significance of any changes, and whether clinical changes in the queue alter patient outcomes. There is an expressed concern that undue waiting times for total joint replacements may be detrimental to long term outcomes. The extent to which a patient's clinical condition changes while waiting in the queue for surgery has not been well documented in the literature.

The Consensus Group considered collecting WOMAC and other data at the pre-operative clinic or at the time of admission to hospital to track changes in clinical condition after the date of the consultation, and to later relate these changes to patient outcomes at 12 months. From the feasibility study, it was learned that hospitals vary markedly in the policies and procedures they follow regarding pre-operative clinics. Therefore, procedures for collecting information from patients pre-operatively will have to be worked out with each hospital. It is recommended that researchers work with hospitals and the Registry to determine the feasibility of collecting pre-surgery data from patients at the hospital and undertake a pilot project to assess the significance of changes in clinical condition while patients are in the queue.

4.0 Recommendations for Ensuring Participation of Key Stakeholders

Incentives for participation by key stakeholders (referring physicians and orthopaedic surgeons) will be required to balance the investment of time required of them. The Consensus Group has agreed that, to succeed over the long term, there should be participation by all orthopaedic surgeons in the province. Further, the long term success of the Registry will be dependent on physicians' initial perceptions of the Registry's sophistication and ability to meet its stated objectives.

To facilitate the participation of stakeholders, ***it is recommended that:***

- ***Orthopaedic surgeons providing total hip and total knee replacements be required to participate in the Registry;***

- ***Orthopaedic surgeons be provided with a form completion fee (as per Appendix F, Schedule of Benefits, Ontario Ministry of Health, 1997) to compensate them for completion and submission of the Consultation Note and Patient Questionnaire[20];***

- ***The Ministry of Health and Long Term Care, in conjunction with the Registry and stakeholders, address identified problems with access to hip/knee replacement surgery to ensure that access to required care is enhanced across the province;***

- ***Strategies for gaining the participation of referring physicians be developed and evaluated; and,***

- ***Once a strategy has been identified to involve referring physicians in the data collection process, the Registry work with the Ontario Orthopaedic Association and primary care physicians to implement the use of the standardized Referral Letter.***

5.0 Data Collection Process

The funding of the Ontario Joint Replacement Registry was announced by the Ontario Ministry of Health and Long Term Care (MOHLTC) near the end of the Consensus Group's deliberations. Dr. Robert Bourne and his colleagues are building on their experience from the pilot project in Southwestern Ontario in addressing the issues of data collection and management. These issues are also being addressed in the contract between the MOHLTC and the Registry. The Consensus Group has heard reports on the evaluation of the pilot project and on plans for the provincial Registry, but there have been no direct discussions between the groups regarding the information system and data collection. The suggestions and recommendations of the Consensus Group are independent of the Ontario Joint Replacement Registry, but they are to be forwarded to the management team of the Registry for consideration and discussion.

There are a number of possible methods for collecting the data necessary to meet the objectives of the Consensus Group. These include:

- Hard copy data collection forms which could be mailed, couriered or faxed to a central location by orthopaedic surgeons; or,

- Electronic collection through "point of care" computerized devices.

Regardless of the method ultimately selected, it will be necessary, at the outset, to collect hard copy data or use an alternate method for verifying the data collected electronically to ensure data integrity and quality.

It is recommended that a consultant with expertise in computerized methods for data collection develop an optimal plan for data collection and entry. The system selected should be based on the following principles:

- *Quick and simple to use;*

- *Integrate data for a single patient from various providers, collected over time, without duplication of variables in order to streamline data collection; and,*

- *Provide a clinical record for physicians to place in patients' charts, simultaneous with the entry of data for the Registry.*

The database will need to include the following key variables that have been identified as the "***Minimum Data Set***":

- Date of referral from the referring physician;

- Date of consultation by the orthopaedic surgeon;

- Date of agreement to proceed with surgery (made by the surgeon and the patient), if different from the Date of Consultation;

- Date of surgery;
- WOMAC data:
  - Most recent WOMAC prior to surgery; and,
  - One year post-surgery.
- Specified patient demographics (including name, date of birth, address, health card number and gender);
- Specified provider demographics (including name and billing number of referring physician and orthopaedic surgeon); and,
- Clinical factors including diagnosis, index joint for surgery, past surgical history, other symptomatic joints, surgeon's recommendation re: ideal wait time for surgery, patient's preference for timing of surgery, date on which surgery has been booked if available, and reason(s) for no booking if no date has been scheduled.

The patient's health card number and date of birth will be used to link data collected at various points in time.

Additional data will be required for the targeted research studies outlined in this report. These data will include a number of variables from the Referral Letter and Consultation Note, as well as WOMAC questionnaires for subgroups of patients collected: 1) at time of referral to the orthopaedic surgeon; 2) at time of pre-operative clinic or date of admission for surgery; and 3) at specified intervals after the first year post-op, such as every other year. If justified through research, these data may be added to the Minimum Data Set over the long term.

6.0 Confidentiality of Data and Information Reporting

6.1 Data Confidentiality

The Ontario Joint Replacement Registry will be developing detailed policies related to patient privacy and confidentiality of information collected. In making recommendations to the Ontario Ministry of Health and Long Term Care and the Ontario Orthopaedic Association, the Consensus Group acknowledges the importance of ensuring that patient-specific information remains confidential and that mechanisms be put into place to ensure the privacy and protection of patient data.

6.2 Requests for Data for Research Purposes

The organizational structure for the Ontario Joint Replacement Registry will include an Advisory Board and a Research Committee. Guidelines will be developed by these groups to allow researchers to apply for access to data for research purposes. The Consensus Group stressed the importance of access to Registry data for research purposes.

6.3 Routine Reporting of Data

Ministry of Health and Long Term Care personnel, physicians, hospital administrators, associations (such as the Ontario Orthopaedic Association) and researchers will seek access to information on wait times (by region, by hospital and by physician) to make decisions on resource allocation and referral patterns. Similarly, the same stakeholders will wish information on patient outcomes to evaluate clinical care and promote enhancements to quality of care for the future. However, due to issues of accuracy and buy-in, and the need to adjust data to consider illness severity, the Registry is likely to gain broader support if data are initially reported in aggregate form by region and hospital, only, with data by surgeon (wait times and outcomes) provided only to the individual surgeon submitting the data with access via an individually assigned password. ***Thus, it is recommended that stakeholder requirements for data be addressed through short and long term goals. The short term goal should be to provide aggregate data on wait times by region and hospital for the purpose of informing resource allocation decisions; these initial data should be made accessible to stakeholder organizations (e.g. MOHLTC, OOA, OHA), hospitals and to physicians. Additionally, using an individually assigned password, individual surgeons should have the ability to access his/her own data reported at the level of individual surgeon. The advisability of providing more liberal access to data at the individual surgeon level will need to be determined at a later date, with input provided by all stakeholders.***

7.0 Implementation Plan

Following submission of this report to the Ministry of Health and Long Term Care and to the Ontario Orthopaedic Association, the following steps are recommended to facilitate integration of the Consensus Group's recommendations with the plans of the Ontario Joint Replacement Registry.

- ***That members of the Consensus Group meet with members of the Ontario Joint Replacement Registry to review the Consensus Group report, discuss the recommendations and develop plans for integrating the recommendations.***

It is important for all stakeholders to fully appreciate the rationale for the establishment of the Registry, including recommendations stemming from the Consensus Group. The long term success of the Registry will be dependent on the initial communication with physicians, the incentives integrated into the data collection process and the sophistication of the systems designed for data collection and reporting.

8.0 Summary

The Consensus Group has developed recommendations for: developing an information system for defining lists of patients waiting for total hip and total knee replacements; the monitoring of waiting times between referral and consultation and consultation and surgery; and, assessing outcomes and the patients' perspective of care at 12 months following surgery. The recommendations seek to provide health care providers with the tools necessary to prioritize patients on the basis of clinical severity, based on the underlying principle of wanting to ensure that those with the greatest need for the intervention are serviced first. The information infrastructure provides for the development of waiting lists and allows patients on the list to be characterized using a number of variables including clinical severity. As well, the data collected will allow for calculation of waiting time on the list prior to surgery, a key indicator both clinically and in terms of public perception.

The Group has developed a core set of recommendations for the Ministry of Health and Long Term Care. As well, a number of targeted research studies have been identified for future completion.

8.1 Unique Characteristics of the Consensus Group's Proposal

As noted in the introduction and detailed in the appendices, most hip/knee joint replacement registries collect data related to prosthesis type, approach to surgery, cement used, and other variables relevant to surgery and seek to identify factors associated with cases which end in revision. Some registries track waiting lists and waiting times for surgery, although the definitions for both are not always clear or consistent.

This proposal, which focuses on the management of waiting lists and waiting times for hip/knee replacement, includes the following unique characteristics:

- ***Defines waiting lists and identifies when patients enter and exit the list***, thereby allowing standardized rates of clearance to be calculated;

- ***Standardizes the definition of wait time for surgery and allows orthopaedic surgeons to rank patients on the basis of clinical severity*** - allows waiting lists for surgery to be based on severity of condition as documented by the WOMAC, and provides decision makers with information needed to improve resource allocation for hip/knee replacement surgery; and

- ***Collects patient outcome data and perspectives on the care they received.***

Additionally, the Consensus Group has identified a number of topics for research. Some of the areas identified include:

- Assessing the feasibility of ***standardizing the information flowing from referring physicians to orthopaedic surgeons for patients deemed to be candidates for hip/knee replacement***. This would include a standardized Referral Letter and a short form of the WOMAC to be completed by the patient at the time of referral. Collection of these data would provide information on: 1) conservative treatment provided prior to referral; and 2)

patient pain and functional disability at the time of referral. These additional data would serve as a baseline for studies related to patient outcome, would allow further assessment of the utility of the short form WOMAC as a screening instrument and would provide orthopaedic surgeons with clinical information to prioritize patients for consultation. The first step will be to assess strategies to promote widespread participation of referring physicians across the province.

- ***Determining changes in patients' pain and functional disability while they are in the queue waiting for surgery.*** By implementing the short form WOMAC at the time of referral and then requesting a subgroup of patients to complete a WOMAC at pre-operative clinic or on admission to hospital, this research question can be addressed.

- ***Determining the impact of surgical delay on long term patient outcomes.***

The collaborative involvement of all stakeholders at each phase of implementation will be critical to meeting the objective of improved quality of care for patients awaiting primary hip/knee replacement in Ontario.

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Appendix A

Waiting Lists/Registries – Covering the Landscape

A1.0 Introduction

In recent months, there has been considerable interest in the management of waiting lists at both a provincial and national level. Although waiting lists are an inherent part of any publicly funded health care system, they also serve as a means of evaluating the accessibility of health care services. However, the ability to reliably measure waiting list activity is somewhat difficult as there can be considerable variation on the definition, measurement and response to wait list issues.[1] In 1998, a commissioned report by Health Canada reported, "With rare exceptions, wait lists in Canada, as in most countries, are non-standardized, capriciously organized, poorly monitored, and (according to most informed observers) in grave need of retooling. There is consequently an urgent need for a concerted investment in this country in the design and development of information and management systems that can provide the public with a greater sense of confidence about access to, and quality of, care".[2]

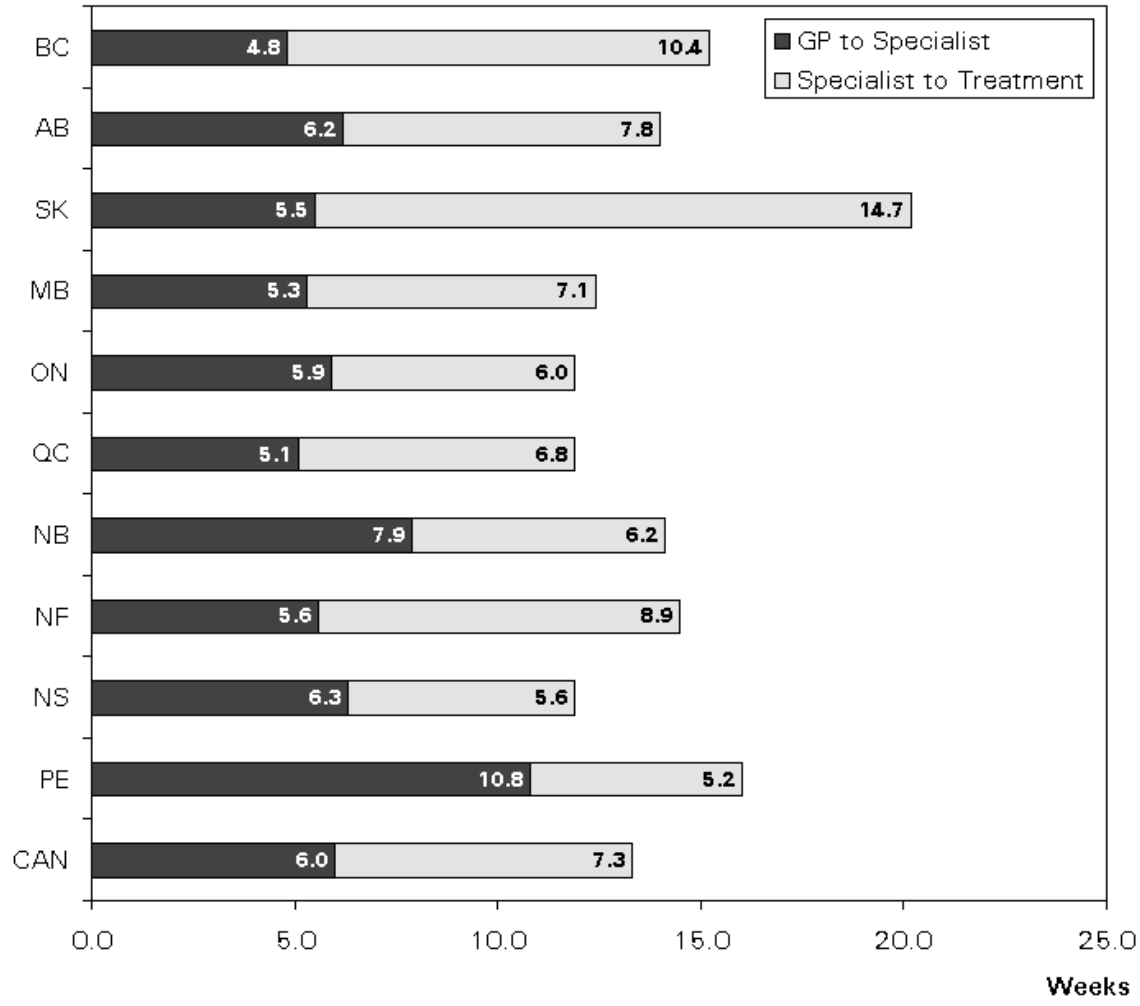
The purpose of this report is to outline the current Canadian and international experiences associated with waiting list management.

A2.0 The Canadian Experience

A2.1. The Fraser Institute

Over the past several years, the Fraser Institute has reported annually on surgical and diagnostic waiting times.[3] The Institute obtained its information from self-reported surveys that ask surgeons to provide the estimated average length of time between referral and consultation and the time between consultation and the procedure. In 1998, as part of its ninth edition of *Waiting Your Turn – Hospital Waiting Lists in Canada,* the Institute reported "Not only were there more people waiting for treatment than in 1997, but those patients were waiting longer to receive treatment – 13.3 weeks, or more than three months – between referral to a specialist by a general practitioner (GP) and the receipt of treatment. In 1997, patients waited 11.9 weeks. Waiting times have increased a dramatic 43 per cent since 1993, when the total waiting time for Canadians to receive treatment was 9.3 weeks. The total wait in 1998 varied from 11.9 weeks in Ontario, Quebec, and Nova Scotia, to 20.2 weeks in Saskatchewan".

Figure A1: Provincial Waiting Times



Source: Waiting Your Turn: Hospital Waiting Lists in Canada, September 1999
(http://www.fraserinstitute.ca/publications/critical_issues/1999/waiting_your_turn/)

A2.2 Waiting Lists – Web-based Reporting Initiatives

In 1998, the British Columbia Ministry of Health implemented a controversial public web-site (http://www.hlth.gov.bc.ca/waitlist/) that reports surgical waiting times. The Wait List Registry includes data from about 1,000 doctors at 33 of British Columbia's largest hospitals, including large community hospitals, major referral hospitals and the large teaching hospitals. The Registry will be expanded this year to include another 15 to 18 hospitals. At that time, the Registry will include data for 95 per cent of all of scheduled surgery in the province. Waiting times are calculated based on the median wait time, in weeks. The provincial median wait times and the wait times listed for individual hospitals and surgeons on this website are calculated from the wait times for surgeries and procedures performed over the most recent three months.[4]
The British Columbia Medical Association has published a report (http://www.bcma.org/concerns/waitlist.asp) which presents the total time patients must wait for services, including the wait from general practitioner visit to specialist consultation and the wait from consultation to procedure. Measuring the wait for a consultation and the wait for a procedure more accurately represents the true amount of time patients must wait in British Columbia. The report shows that regional differences in the length of time people must wait are significant.[1]

Similar initiatives are underway in Quebec and Ontario. In Quebec, the Régie Régionale de la Santé et des Services Sociaux de Montréal-Centre is currently using the Internet to provide information on waiting list size and waiting times for cardiac surgery in Montreal.[5] The website provides a weekly update regarding the number of patients waiting for surgery for each of the eight Montreal Hospitals providing cardiac surgery. The Régie Régionale is planning to post wait list information on the Internet for additional procedures including orthopedic surgery and ophthalmology surgery.

In November 1999, the Southeast Academic Medical Organization (SEAMO) received funding from the Change Foundation to develop and implement an information system that will include web-based reporting of waiting lists and waiting times. The purpose of this initiative is to better inform the public, allowing them to make informed choices about their referral preferences, based on the publication of waiting times by surgeon.

A2.3 The Manitoba Centre for Health Policy and Evaluation

In 1998, the The Manitoba Centre for Health Policy and Evaluation used administrative data to estimate the magnitude of waiting times for elective surgery, and to determine if waits had changed in recent years. A pre-operative visit to the surgeon was chosen as the "flag" to mark the commencement of the waiting time.[6] The Centre reviewed waiting times for nine elective surgical procedures from 1992/93 to 1996/97 inclusive.[6] The Centre's findings suggested:

- Over the five-year period, waits for only two procedures increased – varicose vein and carpal tunnel repair. For cholecystectomy, TURP and tonsillectomy, waits decreased;

- The system seemed to do a good job of providing equal access to different groups. For some procedures – varicose veins, carpal tunnel release, and TURP – patients over 65 years of age had an advantage over younger people; and,

- There were differences in the public sector wait depending on whether or not the surgeon also had a private practice. Patients whose surgeons also had a private practice could anticipate longer waits than patients of surgeons who operated exclusively in the public sector could; in 1996/1997, the difference between the two was 13 weeks. The reasons for these differences were not clear.

The Centre reported that findings using data from 1997/98 and 1998/99 suggest waiting times for elective surgery might be increasing.

A2.4 The Western Canada Wait List Project[7]

In 1998, a major study sponsored by Health Canada,*"Waiting Lists and Waiting Times for Health Care in Canada - More Management!! More Money??"*[2] concluded, among other things, that "…there are no standardized sources of data currently available for compiling national information on waiting lists", and that "…there is widespread interest in standardizing data and coordinating and integrating waiting lists". The Western Canada Waiting List Project has begun this work. The project, comprising a consortium of four medical associations, seven regional health authorities, the four western provincial ministries of health, and four health research centres, received funding from Health Canada's Health Transition Fund to address some of the key issues associated with waiting lists in Canada. Over the past few years, there has been increasing media coverage of the length of time patients wait for access to needed medical services. These "waiting periods" are often pointed to as indications of underfunding of Canada's health care system.

There are three major concerns about waiting lists in Canada. The first is that the waiting lists aren't fair—by the luck of the draw or because of inadequate management, some people or groups are better served than others. The second is that some people end up waiting so long that their health status or ability to benefit from service is diminished. Thirdly, there is concern that standardized and transparent methods do not exist for collecting and comparing information about the clinical status of patients on waiting lists—including the extent of any suffering, disability and premature mortality. Nor is much known about how doctors take into account the expected outcomes of services in determining relative priority. Currently, there are no mechanisms built into our health care system to address these problems. In recent years, calls have increased for assessment and accountability in health care. Measures and tools such as those to be developed in this project are anticipated to demonstrate progress in addressing political and public demands for accountability and transparency in the methods by which waiting lists are managed.

The Western Canada Waiting List Project's major objective is to improve the fairness of the system. They propose to do this by developing valid and reliable clinical measures of patients' relative priority for wait-listed services. These measures will reflect the severity of patients' clinical conditions, including the extent of pain, reduction in function, threat of premature mortality, and potential to benefit from the service or procedure in question. Using these measures, it will be possible to assess and compare clinical profiles and expected outcomes of patients within and across waiting lists. The measures will be developed by panels of clinical experts, based on evidence of service effectiveness and clinical need.

The five clinical areas chosen for this project incorporate a broad range of diagnostic and therapeutic procedures and one where the main issue is access to consultation. They are: MRI scanning; hip and knee replacement; cataract surgery; all general surgery procedures; and, children's mental health services. In addition, the Project will endeavor to develop generic measures that will permit comparison of urgency, benefit and relative priority across these five clinical areas. Five regional health authorities in Western Canada will each host a multidisciplinary clinical panel to conduct research and provide recommendations on health care waiting lists in each specific clinical area. Each panel will consist of a cross-section of clinicians who are involved in and who refer patients for the five procedures.

A2.5 Nova Scotia and Health Performance Reporting[8]

In 1996, the province commissioned a study called *Reporting Health Performance – Elective Procedure Waiting Times in Nova Scotia 1992-1996,* which tracked elective surgery waiting times using physician billing data. The last specialist visit was used as a proxy measure for placing patients on the waiting list. Waiting times were defined as the period between the last specialist visit (the time the decision to perform an elective procedure was likely made) to the day the procedure was performed. Waiting times were compared from one year to the next to determine trends. Some of the findings of the report include:

- most waiting times have decreased; patients are waiting less time for elective procedures than they were four years ago;

- overall, the number of procedures performed in the province has increased over the past four years, from 67,000 in 1992/93 to approximately 72,000 last year; and,

- many factors can affect wait times: e.g. government policy, decision-making at hospitals, the supply and distribution of specialists, referral patterns from family doctors to specialists, an aging population, changes in technology, new options for treatment and societal expectations.

A2.6 Cardiac Care Network of Ontario[9]

Ontario experienced a significant mismatch between the demand for and supply of coronary artery bypass graft surgery (CABG), resulting in long waiting lists in 1987/88.[10] As an outcome of this situation, an urgency ranking system for patients referred for surgery was developed. It is managed by the Cardiac Care Network of Ontario (CCN). CCN was founded in 1990 and is one of the few functioning prioritization systems in the world. The Registry includes all 14 hospitals in Ontario that perform adult cardiac catheterization or cardiac surgery and is engaged in two main areas of activity:

- Coordinating the provision of advanced cardiac services for adults province-wide, with the aid of a computerized patient Registry for cardiac surgery. This database is used to facilitate and monitor access to cardiac surgery, thus contributing to equitable, timely and appropriate access to services by patients and their physicians; and,

- Advising the Ontario Ministry of Health on matters related to adult cardiac services. Using data- and consensus-driven methods, CCN offers planning advice for the future of cardiac

services and the provision of high-quality care in collaboration with the Ministry of Health and others.

The Metropolitan Toronto Cardiovascular Triage and Registry Program, CCN's forerunner, used a rigorous consensus process to develop guidelines for ranking the urgency of bypass surgery to ensure that patients whose need for surgery is most urgent will get surgery first. The guidelines were intended to aid clinical judgment, not replace it. A simple scoring system, called the Urgency Rating Score (URS), was derived to allow the consensus panel's recommended ratings to be readily estimated. Based on the URS computed for each patient, patients are currently grouped into four categories for surgical priority:

Emergency	-	Surgery without delay
Urgent	-	Surgery within 14 days
Semi-urgent	-	Surgery within 15 to 42 days
Elective	-	Surgery within 43 to 180 days

The timeframes attached to the categories are guidelines only. The primary purpose of categorizing patients is to facilitate and monitor access to surgery in a system with limited resources. When a patient requires cardiac surgery, the referring physician contacts a coordinator at one of the 14 cardiac centres who then collects patient information and locates a suitable cardiac surgeon. Each time a surgeon accepts a patient for bypass surgery, the continuous process of determining priorities reasserts itself. If patients' symptoms significantly change before their surgery, priorities must be redetermined. The CCN's computerized patient Registry is available to support surgeons in exercising this responsibility. From June to August 1998, 77 per cent of emergency/urgent cases received care within two weeks; 71 per cent of semi-urgent cases received care in 15 to 42 days; and 74 per cent of elective cases were treated in 43 to 180 days.[5]

A2.7 The Ontario Joint Policy and Planning Committee

In May 1999, the Senior Committee of the Joint Policy and Planning Committee (JPPC) requested that a review of waiting lists in the province of Ontario be undertaken. The purpose of this review was to develop an understanding of how to effectively manage waiting lists and improve access to health care services. Central to this issue is the development of a methodology that fairly prioritizes patients, ensures timely access to services, is applicable across levels of care and is acceptable to all stakeholders. In light of this, there are two initiatives with which the JPPC has been directly involved. The first initiative is the Western Canada Waiting List Project, which is developing a priority scoring methodology for general surgery, MRI, hip/knee replacement surgery, cataracts and children's outpatient mental health services. These tools are to be completed by September 2000, at which time the JPPC has offered to pilot test them in Ontario. The second initiative is being coordinated by ICES and is the topic of this report. The JPPC has been invited to participate in a third project, based in Kingston, Ontario, that involves the development of a web-based waiting list system for elective surgery.

In December 1999, the JPPC hosted a one-day conference at which key stakeholders and opinion leaders concerned with waiting list management identified the JPPC as key in developing methodological rigor and providing implementation guidance in the province of Ontario.

Four major issues were raised:

- What should the focus of the JPPC be in relation to waiting list management?
- How do waiting lists contribute to better resource allocation?
- What clinical areas should be priorities for waiting list management?
- What tools should be employed to better manage waiting lists?

A discussion paper and recommendations on waiting list management is under development and will be completed by March 31, 2000.

A3.0 The International Experience

A3.1 Modernizing the National Health Service: Booking Patients for Hospital Care[11]

Since the 1997 British general election, ministers have launched a series of initiatives to improve access to National Health Service (NHS) services. In the case of primary care, these initiatives include NHS Direct, a nurse-led telephone helpline, and walk-in primary care centres. As far as hospitals are concerned, the National Patients' Access Team (NPAT) was established in 1998 to support Trusts and Health Authorities to achieve reductions in waiting lists and to help redesign elective patient processes. Consequently, considerable efforts have been made to implement booking systems as a waiting list management strategy for elective procedures including joint replacement. This involves the introduction of a National Booked Admissions Program that will pilot a range of approaches to enable patients to pre-book their appointments or treatments. The Program is designed to make the NHS more accessible and convenient, and to use resources more efficiently. Ministers have said that, in the future, they wish hospital bookings to become as easy as booking travel tickets and hotel reservations.

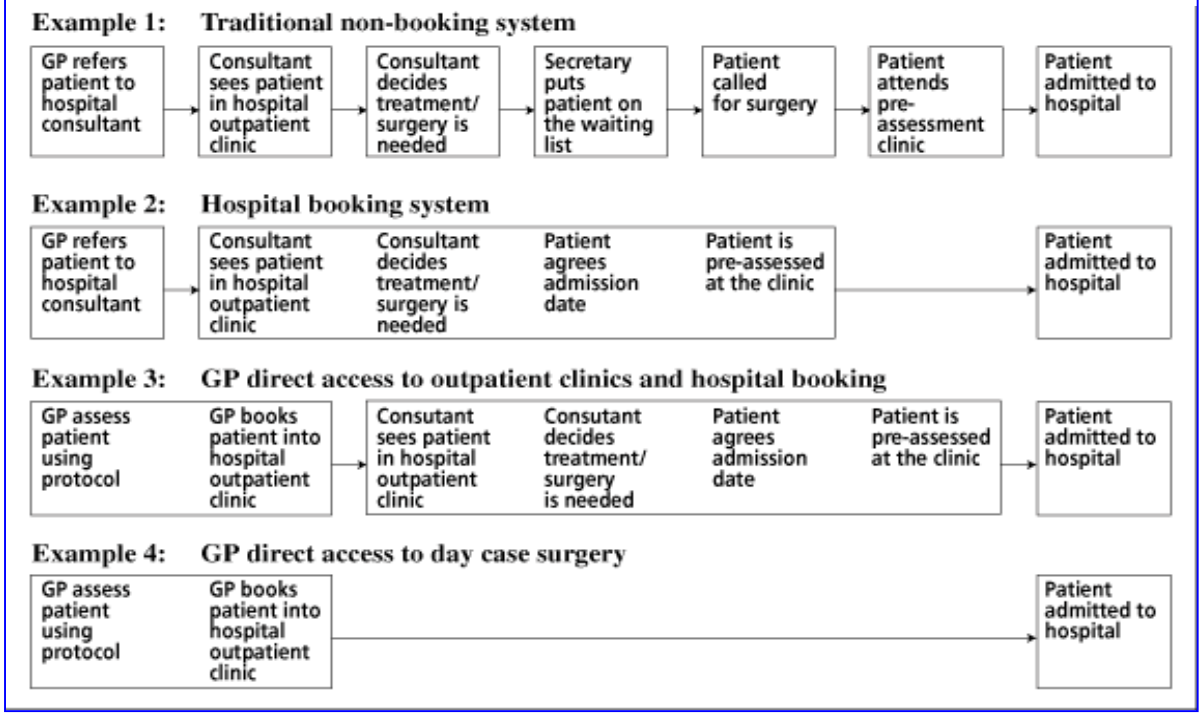
An evaluation of the program has recently been published. The main lessons for action on booked admissions are:

- The introduction of booking systems requires strong project management;
- Consultant [specialist] commitment is key to the implementation of booking systems;
- An investment in training and development has eased the introduction of booking systems;
- The close involvement of Health Authorities and Primary Care Groups (PCGs) is essential in securing widespread ownership of booking systems;
- Although not dependent on information technology solutions, booking may require changes in existing systems and additional investment in hardware and software;
- General practitioner direct access is a feature of some of the pilots and appears to be most likely to succeed where there is effective communication between GPs and consultants, including the adoption of referral protocols;
- Patients appear to welcome the certainty of booked appointments and the opportunity to choose a convenient date, although not all wish to agree upon a date for their treatment at the time of consultation; and,
- The extension of booking to inpatients enables managers and clinicians to address the redesign of patient care as whole and, in the process, is opening up a challenging agenda for the future.

Booking systems reduce unnecessary stages in the process of diagnosis and treatment, increase the patient's sense of certainty, and enable resources to be used more efficiently.

Figure A2 below illustrates the use of booking systems versus waiting lists (Kipping, 1999).[11]

Figure 2: Examples of Access to Hospital Services



A3.2 The New Zealand Experience with Priority Scoring Systems[12]

New Zealand restructured its health system in 1992 with the aim of achieving greater levels of assessment and accountability in the publicly funded health sector. The National Health Committee recommended that surgical services should move away from a system of waiting lists and toward a system of specific booking times, so that patients would know (within reasonable limits) when they would receive their operation, resulting in waiting lists being replaced by booking systems. In addition, the Committee called for greater transparency and consistency in the process used to decide priority for elective surgery. The national priority criteria were considered to serve the following purposes:

- To ensure that the process used to define priority is fair and consistent across New Zealand;
- To permit the assessment and comparison of need, case mix and severity;
- To assist the regional health authorities in developing new booking strategies, including target booking times for patients with defined levels of priority;
- To permit comparison of waiting times across regional health authorities;
- To ensure that social values are integrated into the decision making process in an appropriate and transparent manner;

- To provide the framework for the national health committee to define maximum acceptable waiting times for patients with defined levels of priority, as well as core levels of each service; and,

- To make possible national studies on the health outcomes experienced by patients who do or do not receive the services.

On May 8, 1996, the Minister of Health announced the creation of a new NZ$130m (£57m; US$90m) fund for the express purpose of reducing waiting times and clearing waiting lists. Access to the funds was contingent on the use of explicit clinical priority criteria. Response to the new waiting list initiative has generally been positive. In particular, doctors are pleased with the new initiative. They claim that thousands of patients on waiting lists will now be provided with the surgery that they would otherwise not have received.

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Appendix B

Experience with Management of Total Joint Replacement Registries in Other Jurisdictions Since 1990

B1.0 Experience with Management of Total Joint Replacement Registries in Other Jurisdictions Since 1990

B1.1 Waiting Lists and Registries

A waiting list is a roster of patients in a queue for specific health services.[1] Active management of waiting lists ensures patients are properly assigned based on the urgency of the their condition and the Registry can be made to function in a more predictable manner.[2] Waiting list queues are usually managed through registries or booking systems. Registries are instruments with mixed information for balancing various interests.[3] These interests encompass various perspectives such as:

- Surgeons' needs concerning implant and surgical procedure information;
- Health policy on how the Registry tracks appropriateness, urgency and waiting times (such as referral to consultation, consultation to booking, consultation to surgery date), in addition to co-ordination of services, costs and outcomes, and planning and management;
- Physician requirements for improved access, referral, resources, services and accountability;
- Hospitals' needs concerning financial incentives, improved booking and reduced waiting times;
- Government requirements for planning, management, financing and accountability;
- Research perspectives addressing clinical, epidemiological and health services research; and,
- Consumer and public perspectives addressing need, urgency, waiting times, prognosis and outcomes.

Potential difficulties in implementing a Registry include noncompliance, funding, finding appropriate staff to collect the data and comparability of data.[4] Furthermore, to make a national Registry work, all hospitals and surgeons have to contribute their data to it. Principles and procedures for security of data have to be developed and strictly adhered to in order to respect the privacy of users and providers and to protect data/databases against loss, destruction or unauthorized use. Physicians and hospitals require assurance that data not be used for political or legal purposes.

In general, there are two functions served by joint registries. A majority collect clinical information on surgery and implants; other registries also collect information related to waiting lists with the objective of improving waiting list management, either through urgency ranking or by reallocating resources to respond to variations in wait time. Models for managing total joint replacement registries have been established in Sweden, Norway and Finland. Recently, registries have also been developed in the United Kingdom, Australia, New Zealand and Canada. The former registries tend to focus on clinical and implant data while the latter-noted registries combine both clinical and waiting list management functions.

B2.0 The Joint Replacement Registry Experience in Canada

B2.1 The Canadian Joint Registry (CJR) – 2000

In Canada, the demand for total hip and knee replacement creates a perception among orthopaedic surgeons that waiting lists are too long and that revision rates are higher than they should be.[5] In 1995, orthopaedic surgeons, under the auspices of the Canadian Orthopaedic Association, proposed a national joint Registry. In 1997, the Registry was piloted; funded by Health Canada. It is intended to operate through the Canadian Institute for Health Information (CIHI). In June 1999, CIHI published its final report concerning the national Registry, which includes 60 data elements. It will and will be operational and ready to accept data by July 2000. The Registry (CJR) will be high level, collecting information on demographics, surgical factors and implants for joint replacement. Quality of life indicators, radiographic information or patient satisfaction data will not be collected. Plans include information transfer from provincial registries to the CJR; however, it is acknowledged that provincial registries will collect other, more detailed data which will not be standardized across the country and will not be forwarded to CJR. A provincial Registry has been established in British Columbia and in Ontario; developmental work continues in other provinces such as Alberta.

B2.2 The Southwestern Ontario Joint Replacement Pilot Project – 1999 [6]

In 1996/97, there were 6,375 total hip and 7,540 total knee arthroplasties conducted in Ontario. Hospital costs per procedure ranged from $7,000 to $10,000 with medical costs at about $2,000. The Health Services Restructuring Commission (HSRC) identified joint replacement as a high priority, projecting over 14,000 knee procedures and 12,000 hip procedures by 2016. In Ontario, there is currently no mechanism to identify and track patient, surgical or implant data. In 1999, Southwestern Ontario was selected to pilot a provincial joint Registry. The Southwestern Ontario Joint Replacement Pilot Project was a cooperative venture between the Ontario Ministry of Health and Long Term Care and orthopaedic surgeons from the Ontario Orthopedic Association.

The pilot project implemented point of care electronic data collection and transmission resulting in timely data collection and reporting of patient demographics, revision rates and surgical approach. In addition, “waiting time data from referral to consult, consult to surgery and total wait were collected and were available for viewing on a secured website”.[6] Provider and patient satisfaction data were included in the data collection process. Implementation of an Ontario total joint replacement Registry has recently been announced, with Ministry funding of $2 million annually to support the Ontario Joint Replacement Network based in Southwest Ontario.

The work of the ICES Consensus Group, is detailed in the body of this report.

The recommended information strategy is intended to allow for waiting list management based on clinical urgency, to provide detailed information upon which to base resource allocation decisions and to provide the data necessary to assess short- and long-term patient outcomes.

B2.3 The British Columbia Joint Replacement Waiting List [7]

The British Columbia government has recently published waiting times for 42 surgical procedures on a public website. The site includes names of surgeons and hospitals and their respective wait times. The site does not provide information concerning patient outcomes. There has been considerable resistance from the medical community concerning the accuracy of the wait times. The BC Medical Association has responded with concerns that median wait times are not an accurate measure of access to care.

B3.0 The International Experience with Joint Replacement Registries

B3.1 The New Zealand Experience – 1997[8]

In 1997, the New Zealand Orthopedic Association agreed to establish a national hip and knee Registry. The program, which involves 42 hospitals throughout New Zealand, was implemented in 1999. It is not evident if this Registry will also provide insight into waiting times and waiting list management. Furthermore, it will be at least five years before there is sufficient data for meaningful analysis to occur.

B3.2 The Australia Experience – 1998[9]

In 1998, a pilot study of the Australian Orthopedic Association (AOA) National Joint Replacement Registry was initiated. In August 1999, the Australian government approved funding to establish the Registry which is to be implemented in a staged manner, state by state. The government indicated that the Registry is a quality assurance activity, and therefore, the data collected is to be controlled and made available at the discretion of the AOA.

Data capture reported in the pilot project ranged from 98.4 per cent for primary total and revision hip procedures and 91.4 per cent for primary total and revision knee procedures. The complete joint replacement data set will be a combination of Registry, hospital, state health department and orthopedic company data which is hoped to identify 100 per cent of patients undergoing hip or knee replacement surgery. Surgeons are requested to provide primary operation and revision data, on a paper form available through their associated hospitals.

A coordinator at each hospital is responsible for updating staff on the Registry development, maintaining continuity of data collection and liaising with the Registry project coordinator. The implementation model is similar to that used by CCN in Ontario. Annual reports will be made available and will not include patient, surgeon or institution names. In addition to the survival rates of different prostheses, patient demographics, diagnoses, number of primary and revision procedures will be examined.

B3.3 The United Kingdom Experience

Since 1990, there have been localized efforts to develop joint replacement registries to track patient outcomes of hip and knee surgery.[4] The contributions of these registries in managing waiting lists have not been described. A regional hip and knee Registry for joint replacement in Trent is funded by the Department of Public Health to look at outcomes of total hip replacement.

As at 1996, the Royal College of Surgeons had commenced a national audit of primary total hip replacements which could be considered a pilot for a national Registry. Booking systems have become the primary focus of managing waiting lists in the UK. The relationship between joint replacement registries and booking systems is not yet clear.

B3.4 The Scandinavian Experience

The Scandinavian joint replacement Registries have proved successful at monitoring patient demography and have allowed direct comparison of the cumulative revision rates of different implants.[10] This has enabled Swedish surgeons to identify and avoid certain specific complications and to eliminate inferior implants from the market. Other factors such as cementation technique have recently been analyzed, with valuable results that have altered clinical practice after a mean follow-up duration of 3.2 years. [10] These registries focus on epidemiological management of joint replacement and do not provide information on waiting times.

B3.5 The Norwegian Joint Registry

The Norwegian Joint Registry was established in 1987 by the Norwegian Orthopedic Association as a hip Registry but has been expanded to include all joints since January 1994. More than 60,000 total hip replacements have been registered thus far, including both primary operations and revisions. The Registry "…links revisions to the primary operation and performs survival analyses of the implants, with adjustment for potential confounding by factors such as age**,** gender and diagnosis".[11] Reasons for revisions are captured by the Registry and assessment of the rate of revision can be analyzed according to aseptic loosening of the stem or cup, infection, dislocation, wear, osteolysis or other reasons. Surgeons names are not recorded and hospital results are confidential. The operating cost of the Registry is approximately $18 (US) per registered implant. The Registry provides reliable data concerning implants with several brands of uncemented prostheses and two brands of cement having been withdrawn from the market as a result of findings from the Registry.[11]

B.3.6 The Swedish Joint Registry

The Swedish Registry has provided data from 1976 through 1992, on 30,003 primary knee arthroplasties and their revisions.[12] The Registry focuses on epidemiological trends and addresses identified concerns. However, information as to their effectiveness in managing waiting lists or waiting times does not seem to be a major focus of the Registry activities.

B3.7 The United States Experience

Waiting lists do not appear to be a concern in the United States due to excess capacity in the health care system; however, joint registries have been developed to meet objectives other than waiting list management. These registries provide information to assess the effectiveness of total hip arthroplasty related to implant design, surgical technique and patient selection. The Mayo Clinic in Rochester, Minnesota has maintained a computerized database for all joint replacements for over 25 years.[13] The Registry contains 56,000 arthroplasties of which 30,000 involve the hip. The Registry has been instrumental in communicating with patients through routine follow-up at one, two and five years post-operatively and then every 5 years via

examination, letter or telephone questionnaire. The annual budget for the Registry is $400,000 US per year and the Registry employs five full-time employees, including computer and statistical support. The Registry is currently under pressure to demonstrate cost-effectiveness, validation of data collection tools and adequate patient follow-up.[13]

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Appendix C

Membership – ICES' Consensus and Working Groups

C1.1 Consensus Group Members

- Ms. Susan Adolph – Managing Director, Ontario Joint Replacement Registry, London Health Sciences Centre, London, Ontario.
- Dr. Elizabeth Badley – Director & Senior Scientist, Arthritis Community Research & Evaluation Unit (ACREU), Toronto, Ontario.
- Dr. Maurice Bent – Orthopaedic Surgeon, North York General Hospital, Toronto, Ontario.
- Ms. Paula Blackstien-Hirsch – Research Coordinator, Institute for Clinical Evaluative Sciences, Toronto, Ontario.
- Dr. Alex E. M. Borgiel – Family Physician, Apple Hills Medical Associates, Mississauga, Ontario.
- Dr. Robert Bourne – Orthopaedic Surgeon, Advisory Committee Chair and Medical Director, Ontario Joint Replacement Regisitry, London Health Sciences Centre, London, Ontario.
- Dr. James Edney – Family Physician and Medical Director, Castleview Wychwood Towers, Toronto, Ontario.
- Dr. Jeffrey D. Gollish **–** Orthopaedic Surgeon, Sunnybrook and Women's College Health Sciences Centre (Orthopaedic and Arthritic site), Toronto, Ontario.
- Ms. Ricki Grushcow – Manager, Priority Programs Unit, Ministry of Health and Long Term Care, Toronto, Ontario.
- Dr. Duncan Gordon – Rheumatologist, University Health Network, Toronto Western Division, Toronto, Ontario.
- Dr. Henry W. Hamilton – Past-President, The Ontario Orthopaedic Association, Thunder Bay, Ontario.
- Dr. Gillian Hawker – Rheumatologist, Sunnybrook and Women's College Health Sciences Centre (Women's College site), Toronto, Ontario.
- Dr. Hans Kreder – Orthopaedic Surgeon, Sunnybrook and Women's College Health Sciences Centre (Sunnybrook site), Toronto, Ontario.
- Dr. Andreas Laupacis – Director, Clinical Epidemiology Unit, Loeb Health Research Institute, Ottawa, Ontario.
- Dr. Katie Lundon – Department of Physical Therapy, University of Toronto, Toronto, Ontario.
- Ms. Anne Marie MacLeod – Program Director, Orthopaedic and Arthritic Institute, Musculoskeletal Program, Sunnybrook & Women's College Health Sciences Centre, (Orthopaedic and Arthritic site) and Representative, Ontario Hospital Association, Toronto, Ontario.
- Dr. Nizar Mahomed – Orthopaedic Surgeon, University Health Network, Toronto Western Division, Toronto, Ontario.
- Dr. David R. Pichora – President, The Ontario Orthopaedic Association, and Orthopaedic Surgeon, Kingston General Hospital, Kingston, Ontario.
- Ms. Maureen Provencher – Program Consultant, Priority Program's Unit, Ministry of Health and Long Term Care, Toronto, Ontario.
- Ms. Caroline Rafferty – Technical Planning Consultant, Joint Planning & Policy Secretariat, Toronto, Ontario.
- Dr. Edward Rumble – Orthopaedic Surgeon, North York General Hospital, Toronto, Ontario.
- Dr. Joseph Schatzker – Orthopaedic Surgeon, Sunnybrook & Women's College Health Sciences Centre, Toronto, Ontario.

- Mr. Roger Sharman (Chair) – Acting Chief Executive Officer, Halton Healthcare Services Corporation, Oakville, Ontario.
- Ms. Mona Shaw – Administrative Assistant, Institute for Clinical Evaluative Sciences, Toronto, Ontario.
- Dr. J. Ivan Williams – President and Chief Executive Officer, Institute for Clinical Evaluative Sciences, Toronto, Ontario.
- Dr. James G. Wright – Orthopaedici Surgeon, The Hospital for Sick Children, Toronto, Ontario.

C1.2 Working Group Members

- Ms. Paula Blackstien-Hirsch – Research Coordinator, Institute for Clinical Evaluative Sciences, Toronto, Ontario.
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- Dr. Nizar Mahomed – Orthopaedic Surgeon, University Health Network, Toronto Western Division, Toronto, Ontario.
- Dr. J. Ivan Williams – President and Chief Executive Officer, Intitute for Clinical Evaluative Sciences, Toronto, Ontario.

Appendix D

Hospital Centres Participating in Feasibility Study

D1.0 Hospital Centres Participating in the Feasibility Study

D1.1 Family Physician Focus Groups

- Community Memorial Hospital, Port Perry
- Grand River Hospital, Kitchener
- Halton Healthcare Services Corporation, Oakville
- North York General Hospital, Toronto
- Queensway Carleton Hospital, Nepean
- Timmins and District Hospital, Cochrane Hospital, Kirkland Lake Hospital
- Trillium Health Centre, Mississauga
- University Health Network, Toronto Western Division, Toronto

D1.2 Orthopaedic Surgeons' Offices Completing Surveys

- Halton Healthcare Services Corporation, Oakville
- Hotel Dieu Hospital, St. Catharines
- North York General Hospital, Toronto
- Queensway Carleton Hospital, Nepean
- Thunder Bay Regional Hospital, Thunder Bay
- Trillium Health Centre, Mississauga
- University Health Network, Toronto Western Division, Toronto
- Sunnybrook and Women's College Health Sciences Centre, Orthopaedic and Arthritic Site, Toronto

D1.3 Hospitals Completing Surveys

- Grand River Hospital, Kitchener
- Halton Healthcare Services Corporation, Oakville
- Hotel Dieu Hospital, St. Catharines
- Kingston General Hospital, Kingston
- North York General Hospital, Toronto
- Queensway Carleton Hospital, Nepean
- Thunder Bay Regional Hospital, Thuder Bay
- Trillium Health Centre, Mississauga
- University Health Network, Toronto Western Division, Toronto
- Sunnybrook and Women's College Health Sciences Centre, Orthopaedic and Arthritic Site

Appendix E

Revised Referral Letter,Consultation Note and Patient Questionnaire

Insert pages 62, 63, 64, 65, 66, and 67 here – no headers/footers or Pg#.
Next page picks up where this section leaves off on page 68

Appendix F

Reduction of the WOMAC Using Rasch Methodology

F1.0 Reduction of the Womac Using Rasch Methodology

F1.1 Introduction

The Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) questionnaire is one of the most widely used patient-based outcome measures for patients undergoing total hip arthroplasty (THA) or total knee arthroplasty (TKA).[1-4] The measure was developed to evaluate clinically important, patient-relevant changes in health status as a result of treatment intervention.[4] The WOMAC evaluates three dimensions: pain, stiffness, and physical function with five, two and 17 questions respectively. The reliability, validity and responsiveness of the WOMAC based on traditional clinimetric and psychometric methods have been reported by numerous authors.[1-4] The Likert version of the WOMAC may be a valuable questionnaire for evaluating severity of disability in patients who need referral to an orthopaedic surgeon or who are waiting for TKA or THA. However, the current 24 question version is too long for completion in an office setting as a component of data collected for triaging the waiting list.

Rasch analysis [6,7] is a probablistic mathematical model that places the items of a questionnaire on a hierarchy of difficulty analogous to equally spaced rungs on a ladder. Some items may be of equal difficulty and hence at the same position on the ladder indicating that there is item redundancy. Hence, only one of the questions is required to obtain the requisite information. Further, depending on the degree of discrimination required, items can be omitted from a questionnaire, analogous to widening the distance between the rungs on the ladder. Based on these properties of Rasch analysis, the WOMAC was evaluated using this methodology to determine if a short version that maintained face validity, construct validity and responsiveness could be created. A shortened WOMAC would be feasible as a screening tool for triaging patients on a waiting list.

F1.2 Methods

Secondary analysis was performed using data from a community sample (n=773) with hip and knee complaints from two counties in Ontario and from preoperative and one-year postoperative THA and TKA patients (n=1151) treated at various tertiary care centres in Toronto and London. Sample demographics are presented in Table 1. Each of the community samples, the preoperative and one-year postoperative arthroplasty samples were analyzed independently for the five pain and 17 physical dimension items of the WOMAC using *Bigsteps*, *Winsteps* software version 2.81.[8]

The Rasch model estimates item difficulty on interval-level scaling based, on a logit function. For the WOMAC, items are calibrated on a hierarchy of easiest to most difficult on a positive to negative scale; that is, more difficult items are negative. Items “fit” the Rasch model (i.e. the scale is unidimensional) when the mean square (MNSQ) infit and outfit statistics are in the range of 0.80 to 1.20.[8] Fit statistics in the wider range of 0.70 to 1.30 are acceptable when the measure is not used in critical decisions.

Unidimensionality of the WOMAC data was further confirmed by analyzing the residuals (or the data variance remaining after extracting the data component modeled by Rasch analysis) using principal component analysis. If the data is truly unidimensional, the analysis of the residuals should not produce a factor structure.

Differential item functioning may result in misfitting items. Differential item functioning occurs when items have different levels of difficulty based on a sample characteristic such as gender. For example, if item difficulty varies by gender, items may need to be calibrated separately by the Rasch model for males and females. Differential item functioning based on gender, hip versus knee, sample and time were evaluated using the method of Andrich (1988). Items were considered to be free of differential item functioning if the item logits fell within approximately two standard deviations of the logit unity line.

Stability of item order for the preoperative and one-year postoperative surgical sample was similarly confirmed using the method of Andrich.[9] The Wilcoxon test was also calculated to confirm that there was no statistically significant difference in the order of the items based on the logits.

Item redundancy was evaluated by comparing the clustering of items based on item logits. When one or more items clustered around a logit value, one item was selected for the shortened scale based on fit statistics, lack of differential item functioning, maintenance of rank order of difficulty and range of the logit values for the five response options for the item. The fit of the shortened pain and physical dimensions was evaluated as outlined above.

To evaluate face and content validity of the shortened WOMAC, the importance ratings of the all of the WOMAC items, as previously published by Bellamy[1,10], were evaluated to ensure that the items selected represented the range of clinically important items. The pain and physical dimension scores based on Rasch analysis were calculated and compared graphically to the long version WOMAC scores based on summated ratings.[5] Pearson correlation coefficients were also calculated. Responsiveness of the short WOMAC from preoperative to one-year postoperative was calculated by the standardized response mean and compared to that of the long WOMAC by calculating the relative efficiency by a ratio of these effect sizes.

F1.4 Results

The five item-pain dimension did not fit the Rasch model in that the one-year postoperative data demonstrated misfit for the item “night pain” (outfit of 1.30). There was differential item functioning for pain on standing in the preoperative sample, with the item more difficult for women than men with logits of –1.21 versus 0.15 for women and men respectively. Pain walking on flat ground and pain standing did not maintain order across the three samples, with pain walking on flat ground easier than pain standing for the community and one-year postoperative samples and the order reversed in the preoperative arthroplasty sample. Pain going up and down stairs was the most “difficult” in all three datasets. However, there was no statistically significant difference in the rank order of the item difficulty check ($p=0.90$ for all pair-wise comparisons).

Based on model misfit of night pain and gender bias for pain on standing, the pain dimension was reanalyzed with only three items: pain sitting or lying, pain walking on a flat surface and pain going up and downstairs. Pain sitting or lying had marginally high infit and outfit statistics for each of the datasets (Table 2). Principal component analysis of the residuals for each of the datasets confirmed unidimensionality. There was no differential item functioning and the ranking of the items based on difficulty (estimated by the logits) demonstrated stability of the model across samples and over time. Pain going up and down stairs was the most difficult item, followed by pain walking on a flat surface, with pain sitting or lying the easiest item. The p-value based on pair-wise comparison of the datasets was 1.0.

The mean importance ratings based on a scale of 0 to 4 for the five pain items were invariant with a range of 2.51 to 2.63[1,10] such that omission of the night pain and pain standing items did not represent exclusion of clinically important items.

In order to standardize the scoring for responsiveness evaluation, the preoperative and postoperative data sets were calibrated by anchoring to the community sample. Comparison of the scores based on a three item versus five-item WOMAC were highly correlated (Pearson r=0.94 for all samples). The standardized response means were equivalent, 0.87 and 0.88 for the three and five item pain scales respectively (relative efficiency 0.99).

F1.5 Physical Dimension

Based on the analysis of the 17-item physical dimension, three items (heavy domestic duties; getting in and out of the bath; and getting on and off the toilet) consistently misfit the Rasch model and had instability of level of difficulty across the three data sets. Getting on and off the toilet had both high infit and outfit statistics (1.34 and 1.32 respectively) for the community sample and heavy domestic duties and getting in and out of the bath had very high infit and outfit statistics (>1.37) for the one-year post-arthroplasty sample.

Factor analysis of the residuals did not demonstrate a factor pattern confirming the unidimensionality of the physical function dimension. There was differential item functioning for the preoperative sample on descending stairs, putting on socks and taking off socks for hip versus knee subjects. Although not significantly different statistically (p=0.89), the rank order of the item difficulty based on the logit values demonstrated instability over the three samples. Heavy domestic duties (ranks of 10, 17, 17 for the community, preoperative and one year postoperative surgical samples respectively), getting on and off the toilet (ranks of 17, 4, 5 for the community, preoperative and one year postoperative surgical samples respectively), and getting in and out of the bath (ranks of 10, 11, 15 for the community, preoperative and one year postoperative surgical samples respectively) varied from a rank of the easiest to the most difficult items across the data sets.

Based on the analysis of the 17-item physical dimension, heavy domestic duties; getting in and out of the bath; and getting on and off the toilet were omitted in the subsequent analysis in an attempt to improve the fit of the data to the Rasch model. Although some items had marginal fit statistics with the 14-item analysis (Table 3) none of the items demonstrated differential item functioning based on gender on pair-wise comparison of the community, THA or TKA samples. Similar to the 17-item model described above, knee subjects found descending stairs to be a more difficult item than hip subjects preoperatively (logits of –1.21 and –0.01) and at one year post operatively (logits of –1.08 and –0.19). There is improved stability of the order of item difficulty based on the logits across the datasets based on ranks with the 14 item physical model. There is no statistically significant difference between the item ranks (p=1.00 for all pair-wise comparisons).

Based on a 14-item physical dimension, item clustering was evaluated to determine if there was item redundancy. Based on the decision rules outlined in the methods, a five-item physical dimension including lying in bed, rising from bed, getting in and out of a car, light domestic duties and ascending stairs was created. (Walking on flat ground and rising from bed were

equivalent items based on the selection criteria and can be interchanged.) All five items had fit statistics within the range of 0.80 to 1.20 and there was minimal differential item functioning with only light domestic duties more difficult at one year than preoperatively. Table 4 shows the logit values and rank ordering of the items for the three data sets. There is stability in the rankings and analysis of the residuals confirmed that data was unidimensional.

Evaluating the five items selected in relation to the clinical importance ratings reported by Bellamy, the five items maintained had the higher mean importance ratings.[1,10] Again there was relative invariance in the importance ratings (range of 2.26 to 2.60).

The scores for the five-item physical WOMAC correlated to the 17-item scale at 0.94 preoperatively and 0.96 one year postoperativley. The standardized response mean from preoperatively to one year postoperatively was 0.62 for the five-item physical score and 0.65 for the 17-item score with a relative efficiency of 0.94.

F1.6 Summary

In analysis of a community sample, a preoperative and one-year postoperative total hip and total knee arthroplasty samples, the WOMAC pain and physical dimensions have been shortened from five and 17 questions to three and five questions respectively using Rasch methodology. In summary, the three-item pain WOMAC fits the Rasch model, maintains clinically important items, has construct validity and is as responsive to TKA and THA intervention as the five-item pain scale. The five-item physical WOMAC fits the Rasch model, maintains clinically important items, has construct validity and is as responsive to TKA and THA intervention as the 17-item physical scale.

F1.7 Additional Evaluation of the WOMAC

There are three additional primary analyses required for the WOMAC.

1. The WOMAC has a Likert and visual analogue scale (VAS) format, both of which are in frequent use. The current analyses have evaluated only the Likert scaled data. There is currently one dataset with repeated measures available with VAS data consisting of approximately 250 cases. Solicitation of further data for adequate sample size will be required for analysis of VAS data.

2. The results of the current work with Likert version WOMAC data need to be validated on a new dataset with a minimum of 200 hip and 200 knee cases with repeated measures data.

3. An evaluation must be done of the prognostic value of the shortened WOMAC scales as a screening tool for triaging a waiting list of patients requiring total hip or knee replacement.

References – Appendix F

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Table 1: Sample Characteristics

	Community Sample		*Surgical Sample* Total Hip and Knee Arthroplasty	
	Hips N = 234	**Knees n = 539**	**Hips n = 592**	**Knees n = 559**
Age: mean (sd)	69.8 (8.6)	70.2 (9.1)	62.9 (13.8)	71.3 (8.6)
Sex: Men	181	373	273	232
Women	53	166	319	327

Table 2: Pain Dimension Based on Rasch Model of Three Items

	Community Sample					*Preoperative*					*One-year Postoperative*				
Item	**Logit**	**SE**	**Infit MNSQ**	**Outfit MNSQ**	**Rank based on logit**	**Logit**	**SE**	**Infit MNSQ**	**Outfit MNSQ**	**Rank based on logit**	**Logit**	**SE**	**Infit MNSQ**	**Outfit MNSQ**	**Rank based on logit**
Pain sitting or lying	1.27	0.06	1.22	1.32	1	1.70	0.05	1.20	1.27	1	1.07	0.09	1.27	1.38	1
Pain walking on flat ground	0.11	0.06	0.84	0.84	2	-0.04	0.05	0.84	0.84	2	0.56	0.09	0.75	0.71	2
Pain up/downstairs	-1.38	0.06	0.81	0.80	3	-1.60	0.06	0.94	0.94	3	-1.63	0.09	0.97	0.97	3
Mean logit	0.00					0.00					0.00				
Standard deviation	1.33					1.37					1.17				

Table 3: Physical Dimension Based on Rasch Model of 14 Items

	Community Sample					*Preoperative*					*One-year Postoperative*				
Item	**Logit**	**SE**	**Infit MNSQ**	**Outfit MNSQ**	**Rank based on logit**	**Logit**	**SE**	**Infit MNSQ**	**Outfit MNSQ**	**Rank based on logit**	**Logit**	**SE**	**Infit MNSQ**	**Outfit MNSQ**	**Rank based on logit**
Ascending stairs	-1.04	0.05	0.94	0.94	14	-0.87	0.04	0.98	0.97	14	-0.86	0.07	0.98	1.01	13
Descending stairs	-0.79	0.05	1.09	1.08	13	-0.53	0.04	1.24	1.23	9	-0.62	0.07	1.22	1.27	12
Bending to the floor	-0.76	0.05	1.23	1.24	12	-0.61	0.04	1.24	1.20	10	-1.25	0.06	1.44	1.50	14
Rising from sitting	-0.54	0.06	0.81	0.81	11	-0.40	0.04	0.84	0.83	8	-0.16	0.07	0.80	0.80	8
Going shopping	-.028	0.05	1.04	1.06	10	-0.67	0.04	0.88	0.88	13	-0.47	0.06	0.84	0.86	9
Light domestic duties	-0.20	0.05	1.05	1.07	9	-0.66	0.04	0.94	0.93	12	0.06	0.07	0.91	0.90	6
Getting in/out of car	-0.07	0.05	0.91	0.91	8	-0.64	0.04	0.87	0.86	11	-0.56	0.07	1.01	0.98	10
Standing	0.11	0.05	1.02	1.01	7	0.13	0.04	1.07	1.07	6	0.29	0.07	0.95	0.95	5
Putting on socks/ stockings	0.25	0.05	0.86	0.84	6	-0.19	0.04	1.09	1.08	7	-0.56	0.06	1.19	1.21	11
Rising from bed	0.35	0.05	0.78	0.75	5	0.24	0.04	0.84	0.84	3	0.49	0.07	0.82	0.80	4
Walking on flat	0.38	0.06	1.03	1.07	4	0.16	0.04	0.95	0.94	5	0.79	0.07	0.71	0.67	3
Lying in bed	0.61	0.06	1.04	1.06	3	1.12	0.04	1.13	1.19	2	1.47	0.08	0.96	1.27	1
Sitting	0.73	0.05	0.92	0.90	2	1.38	0.04	0.97	0.97	1	1.36	0.08	1.03	0.95	2
Taking off socks/ stockings	1.24	0.06	1.26	1.58	1	0.22	0.04	1.00	0.99	4	0.01	0.07	1.10	1.03	7
Mean logit	0.00					0.00					0.00				
Standard Deviation	0.63					0.67					0.78				

Table 4: Five-Item Physical Dimension Based on Removing Redundant Items

	Community		Combined Hip/Knee Preoperative		Combined Hip/Knee 12 months Postoperative	
Item	**Logit**	**Rank**	**Logit**	**Rank**	**Logit**	**Rank**
Lying in Bed	0.84	1	1.23	1	1.71	1
Rising from Bed	0.52	2	0.31	3	0.53	2
Getting In/Out of Car	0.00	3	-0.84	4	-0.77	4
Light Domestic Duties	-0.14	4	0.65	*2	-0.17	3
Ascending Stairs	-1.22	5	-1.34	5	-1.31	5

*light domestic duties are more difficult at one year than preoperatively