

Tooling Up For Early Osteoarthritis: Measuring What Matters

Osteoarthritis (OA) is not a normal part of ageing

– that's the message lead investigators Dr. John Esdaile, a rheumatologist, and Dr. Monique Gignac, a public health scientist, together with their team of leading Canadian arthritis researchers, want to get out to the public about their new arthritis research program, "Tooling Up For Early Osteoarthritis: Measuring What Matters".

Funded by the Canadian Institutes of Health Research and the Canadian Arthritis Network, the main goal of the Tooling Up For Early Osteoarthritis research team is to learn how health care professionals can do a better job of identifying OA at the earliest possible stages. If OA can be detected early, the health care system will be better able to respond to the needs of people living with the disease, helping them:

- maintain a healthy lifestyle
- live with less pain
- suffer less joint damage
- stay employed, and
- improve their overall quality of life with their families and in their communities, throughout their entire lifetime.

One in ten Canadians has OA. Most do not seek medical care until symptoms, pain and activity limitations are already well established, resulting in damage that could have been prevented with early intervention. Current treatment strategies focus on established disease only.

The team of researchers or "investigators" involved with the Tooling Up for Early Osteoarthritis program come from leading arthritis research institutes and organizations from across Canada. The team includes experts in diagnostic blood tests for osteoarthritis, state-of-the-art X-ray scanners, treatment of osteoarthritis and measurement



Dr. Monique Gignac



Dr. John Esdaile

OsteoArthritis and You: "Your Link to Osteoarthritis Research in Canada"

People living with osteoarthritis "put up with" the symptoms, whether they are just getting it or have lived with it for many years. Along with some family physicians, many people with osteoarthritis believe that nothing can be done to ease the pain, suffering, and loss of function and daily activities caused by this disease. But the latest osteoarthritis research is rapidly changing this view, and those who conduct and participate in the research are eager to share their "breaking news" with you.

Osteoarthritis and You is a new quarterly newsletter written by people living with osteoarthritis and leading Canadian arthritis researchers. It will focus on getting the latest research information about osteoarthritis out to family physicians, the health research community, people with osteoarthritis and the public, as quickly as possible. By getting the latest information about the disease out to those affected by it, the disease can be better managed by health care professionals and people living with it can enjoy improved quality of life.

With a distribution to approximately

15,000 family physicians across Canada (in both French and English), Osteoarthritis and You will also serve as a link between researchers and people living with the disease who want to be more informed and educated about osteoarthritis as well as participate in short surveys, get involved in focus groups or "pilot" studies, or participate in clinical trials.

Project Team Members:

Paul Clarke	Dr. Monique Gignac
Dr. John Esdaile	Cheryl Koehn
Jay Fiddler	Jean Légaré
Anne Fouillard	Pamela Montie

What do you want to know?

Osteoarthritis and You will be an invaluable information source. We encourage you to read this issue and to tell us what you think about it. We welcome your ideas for articles in future issues.

Please email your comments and ideas for future issues to:

oandyou@arthritisresearch.ca

Thank you.

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The Investigators:

The columns beside each investigator represent the projects currently underway. Investigators not yet associated with projects will be involved in future projects. We are also pleased to acknowledge the many other researchers who are contributing to the projects, but are not specifically part of the New Emerging Teams (NET) investigator list. For a complete list please refer to the web site at www.arthritisresearch.ca.

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Abrahamowicz, Michal – PhD

James McGill Professor, Department of Epidemiology and Biostatistics, McGill University; Division of Clinical Epidemiology, Montreal General Hospital

● ●

Anis, Aslam – PhD

Associate Professor and Director, Masters of Health Administration Program, University of British Columbia; Director, Health Economics, BC Centre for Excellence in HIV/AIDS; Research Scientist, ARC

○

Backman, Catherine – PhD, OT(C)

Research Scientist, Rehabilitation, ARC; Associate Professor, Occupational Therapy, School of Rehabilitation Sciences, University of British Columbia

Badii, Maziar – MD, FRCP(C)

Research Scientist, Rheumatology, ARC

● ●

Badley, Elizabeth – PhD

Professor, Public Health Sciences, University of Toronto; Head, Outcomes and Population Health; Director, Arthritis Community Research/Evaluation, UHN, Toronto Western Research Institute

●

Bombardier, Claire – MD, FRCP(C)

Professor and Head, Division of Rheumatology, University of Toronto; Canada Research Chair; Director, Clinical Decision-Making and Health Care, TGRI, UHN

○ ● ● ○

Cibere, Jolanda – MD, PhD, FRCP(C)

Research Scientist, Rheumatology, ARC; Assistant Professor of Medicine, Rheumatology, University of British Columbia

● ○

Davis, Aileen – BScPT, MSc, PhD

Senior Scientist, Toronto Rehabilitation Institute; Associate Professor, University of Toronto

● ● ● ●

Esdaile, John – MD, MPH, FRCP(C)

Scientific Director, Arthritis Research Centre of Canada; Professor and Head, Division of Rheumatology, University of British Columbia

●

Fiddler, Jay – MA

Co-chair, Consumer Advisory Council of Canadian Arthritis Network (CAN); Member, Consumer Advisory Board, ARC

Fortin, Paul – MD, MPH, FRCP(C)

Director of Clinical Research, Arthritis Centre of Excellence; Associate Professor of Medicine, University of Toronto

●

Fouillard, Anne – MEd

Consumer Member of CAC/CAN; Member, Canadian Arthritis Patient Alliance (CAPA)

○ ●

Gignac, Monique – PhD

Assistant Professor, Department of Public Health Sciences, University of Toronto; Outcomes & Population Health, Toronto Western Research Institute; Adjunct Scientist, Institute for Work & Health, Toronto

○ Team Leader
● Team Member

Projects Underway:

These brief profiles cover the projects that have been approved and are underway. For more detail on each project, please check the web site www.arthritisresearch.ca. We will be profiling individual projects in future issues, to help people understand more about the research and its importance in daily living.

#1 Evaluation and standardization of the hip examination in osteoarthritis

The hip examination is an important component for assessing people with hip osteoarthritis both in a clinical setting and in research. The hip examination can be conducted using different assessments including:

- examinations for pain on movement
- end-of-range stress pain
- range of motion
- muscle strength and
- gait.

There is little information on how reliable or comparable the findings of a hip examination are among different examiners. The objective of this study is to determine which hip examination techniques can be consistently performed and reliably assessed by expert rheumatologists and orthopaedic surgeons.

These findings will be applied in a subsequent study that aims to develop a tool for the diagnosis of early hip osteoarthritis.

#2 Pharmacist identification of new, diagnostically-confirmed, osteoarthritis (PHIND-OA)

Pharmacists working in community pharmacies are often the first point of contact with the healthcare system – indeed, people visit their pharmacist 5-8 times more frequently than their physician. The purpose of this study is to find out if a screening program to identify people with previously undiagnosed knee osteoarthritis by pharmacists is accurate and feasible. The pharmacist will use two simple questionnaires to identify people who may have undiagnosed knee osteoarthritis and, if they qualify, they will be offered the opportunity to be examined by a rheumatologist. They will receive an expert evaluation of their knee condition in a timely manner and will be able to begin managing their disease more quickly.

#3 Assessing health-related quality of life in early OA: Development and application of a web-based computerized adaptive measurement system

The purpose of the project is to develop a web-based computerized adaptive system for measuring health-related quality of life in people with early OA. The system will be designed, building on previous work in this area already undertaken with the financial assistance of Canadian Arthritis Network and the Workers' Compensation Board of British Columbia. The questionnaire will be evaluated in terms of its measurement properties, and will also be compared with a similar questionnaire that can be administered without a computer, as well as compared to other standard methods for measuring functional outcomes in people with OA. Study participants will be recruited from an existing database at Arthritis Research Centre of Canada (ARC), primary physicians, arthritis community groups, general advertising, and random sampling from the general population.

#4 Early hip OA MRI pilot study

In this pilot study the clinical and Magnetic Resonance Imaging (MRI) assessments of early hip OA will be developed and tested on a small group of study participants. The objectives of the study are:

- 1) to develop a standardized assessment of subjects with hip pain including comprehensive clinical and risk factor evaluation;
- 2) to develop standardized protocols for plain radiography and MR imaging of the hip; and
- 3) to evaluate how reliably and consistently different clinicians interpret hip MRI readings.

The results of this study will guide the development of a full research proposal.

#5 Tooling up for early osteoarthritis: Measuring what matters – participation

The impact of osteoarthritis on many areas of life has been poorly recognized in the past. These include:

- participating in work;
- home and social life;
- sports; and
- other leisure activities.

A new diverse group representing consumers, researchers, and clinicians with a range of expertise, sharing an interest in the broader impact of OA on the lives of people living with this condition, will investigate. Objectives are:

- 1) define where early OA has an impact in people's lives and assess changes over time;
- 2) assess existing questionnaires used for people with early OA and design studies to improve and evaluate them; and
- 3) assess relevant personal and environmental factors such as people's perceptions of their condition and preferences for OA treatment and its relationship to the progression of OA.

#6 Arthritis outcomes over 5 years: Is it patient improvement or instrument instability?

Is our assumption that osteoarthritis always gets worse over time correct? If so, why do some people report an improvement in their condition over time? Is there an underlying problem with the tools and techniques used to assess change over time? Understanding if we have instrumentation problems is critical as we attempt to identify biomarkers of change in OA over time. The overall purpose of this study is to determine if the observed changes in hip/knee OA represent true change over five years of follow-up or whether these changes represent item instability and inherent instrument problems.

This project will provide information about the measurement properties of the Western Ontario McMaster Universities Arthritis Index (WOMAC), a commonly used patient-based measure for hip and knee OA.

#7 Osteoarthritis and You: "Your Link to Osteoarthritis Research in Canada"

The project involves getting the word out about the osteoarthritis research being undertaken under the New Emerging Teams (NET) umbrella. Please read the article on the first page for details of this project. ☺

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Greidanus, Nelson – MD, MPH, FRCS(C), PhD
Candidate
Research Scientist, Orthopedics, ARC; Assistant Professor, Department of Orthopedic Surgery, University of British Columbia

Hawker, Gillian MD, MSc, FRCP(C)
F.M. Hill Chair in Academic Women's Medicine, Women's College Campus of Sunnybrook & Women's College Health Sciences Centre; Associate Professor of Medicine, Faculty of Medicine, University of Toronto

Koehn, Cheryl
President, Arthritis Consumer Experts (ACE); Arthritis consumer

Kopec, Jacek – MD, PhD
Research Scientist, ARC; Assistant Professor, Department of Health Care and Epidemiology, University of British Columbia

Lacaille, Diane – MD, MHSc, FRCP(C)
Research Scientist, Rheumatology, ARC; Assistant Professor of Medicine, Rheumatology, University of British Columbia

Légaré, Jean
Member, Canadian Arthritis Patient Alliance (CAPA); Consumer Advisory Council (CAN); Patient Partners in Arthritis®; Arthritis consumer

Mahomed, Nizar N. MD ScD
Associate Professor, Surgery, U of Toronto; Smith & Nephew Chair in Orthopaedic Surgery; Director, Musculoskeletal Health and Arthritis Program, University Health Network

Marra, Carlo – PharmD, PhD
Head, Health Economics Program at the Centre for Clinical Epidemiology and Evaluation, University of British Columbia; Assistant Professor, Pharmaceutical Sciences, University of British Columbia; Research Scientist, ARC

McKiel, George – PhD
Arthritis consumer

Montie, Pamela
Member: Patient Partners in Arthritis Program; Canadian Arthritis Patient Alliance; Advisory Board, ARC; Advisory Board, Arthritis Consumer Experts; Arthritis Consumer

Perruccio, Anthony
Doctoral student, Department of Public Health Sciences, University of Toronto

Poole, A. Robin – PhD, DSc
Co-Director, Canadian Arthritis Network; Co-chair of the Research Advisory Committee (RAC); Professor, Surgery, McGill; Director, Joint Diseases Lab., Shriners Hospitals for Children

Power, Denise – MHSc, PhD Candidate
Doctoral student in Epidemiology, University of Toronto

Seboldt, Rolf J. – MD, CM, FRCP(C), FACP
Associate Clinical Professor of Medicine and of Clinical Epidemiology & Biostatistics, McMaster; President, Clinforma Data Systems and Project Management, A division of Fig.P Software Inc.

Living with Osteoarthritis

By Sandy Lockwood, a person with arthritis

Where would we be without research?

Without research, change and progress would not happen. For example, research gives us the opportunity to see if what currently exists is optimal or a new product is more effective. Both consumers and researchers play an integral part in progress. Consumers are the users of products and doctors users of the procedures that result from research – new diagnostic tools, new medications and health treatment regimes, new and / or improved surgical procedures all come from research.

Without research I would not have been given my quality of life back. I have had bilateral hip replacements within the last three years. The surgery was performed due to osteoarthritis and was at the point where bone was rubbing on bone. Walking up to the surgical area the day of my last surgery was almost impossible. I am young to have had this kind of surgery, generally given to people age 65 and older. It is the result of hip replacement research that I have longer lasting, quality replacement hardware. This model is expected to last twenty years – maybe my lifetime.

I have some limitations such as no running, skiing, or horse riding but my limitations were much greater prior to surgery. Carrying even a small light load was difficult, walking just for pleasure impossible. This year I was able to participate in the 10 kilometre Sun Run/Walk after three years of not being able to.

The most frustrating part of this whole procedure was the time involved in getting a diagnosis. It took at least eight years to get a diagnosis and the medications available were

*“not knowing ...
is scarier than challenging
the problem”*

of little help in reducing my pain and disability.

Up to now there has not been any standardized, diagnostic procedures for osteoarthritis for hips. I am excited to hear there is now research in this area. This will help people who were like me ten years ago. I hope with the results of the research that general practitioners are provided with this diagnostic training as well as the specialists for arthritis. An earlier diagnosis means an earlier



treatment plan and a better quality of life.

It's not knowing that is scarier than challenging the problem or health concern. It's also important that family and friends understand what a person with osteoarthritis is going through and their limitations even post surgery. For me the psychosocial effects of osteoarthritis with pain, limping, feeling inadequate because of my increasing limitations due to limited mobility and pain was sometimes worse than the physical pain I was living with.

I know that because I have been diagnosed with osteoarthritis in my hips, I am more susceptible to getting osteoarthritis in other parts of my body, like my knees. I want to know what I can do to prevent or slow down my potential for further osteoarthritis. However, I don't know where to get this information. I do know pain is my body's way of telling me something is wrong but what can I do before that happens? For me, I would do whatever it takes not to see an operating room for at least 20 years or so, maybe forever.

Osteoarthritis is a painful, slowly progressing disease that affects every aspect of our daily lives. Standardized testing procedures can only help people with osteoarthritis have a better quality of life through early intervention treatment plans. Research can make diagnosis for early osteoarthritis a reality for many Canadians along with improving their quality of life. ☺

Tooling Up... Continued

of important aspects of the disease such as limitations on activities, costs and psychological consequences.

A unique and important part of the Tooling Up For Early Osteoarthritis research team is a group of people living with Osteoarthritis. They will work closely with the researchers to help ensure that the goals of the various projects being undertaken are relevant to people living with the disease. They will help to identify priority research areas and help to get the research results out to the arthritis community, public and health policy-makers as quickly as possible. This is the first time a group of people living with arthritis has participated in the design, execution, and dissemination of Health Canada-funded arthritis research in Canada. ☺

Thanks

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Contact Information:

Paul Clarke, Research Coordinator
Arthritis Research Centre of Canada
895 West 10th Avenue
Vancouver, BC V5Z 1L7
Website: www.arthritisresearch.ca
Email: oaandyou@arthritisresearch.ca

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