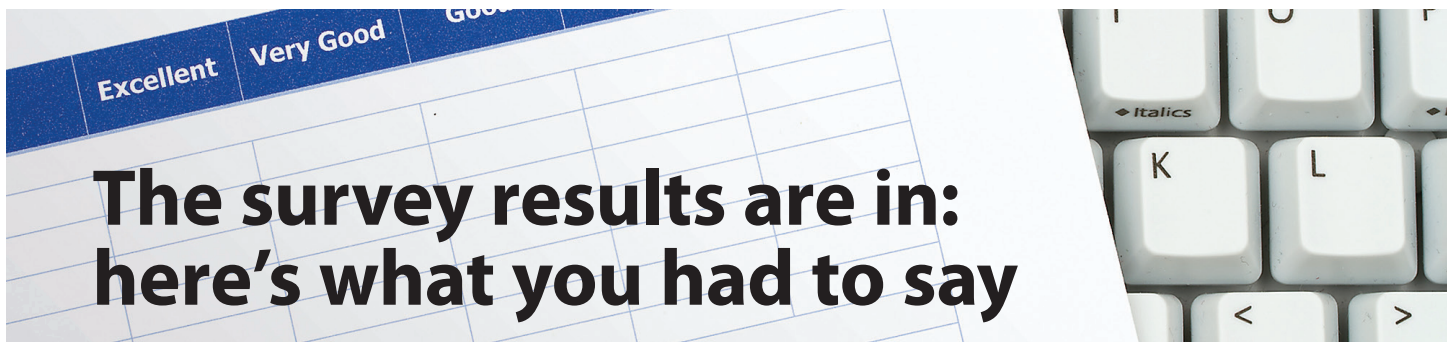


JointHealth[™] monthly

Arthritis research, education and advocacy news : March 2012



The survey results are in: here's what you had to say

Early this year, Arthritis Consumer Experts (ACE) ran a survey to find out how satisfied you, our members and JointHealth[™] subscribers, are with the information and the communications tools we provide. We are pleased to report the survey findings in this issue of JointHealth[™] monthly.

Purpose of the survey

Every year we set goals to increase consumer satisfaction. Since 2007, ACE has conducted JointHealth[™] Program Satisfaction and Interest surveys so that we can find out what you want and need from us. The information we gather measures our relationships with consumers and spotlights areas where we need to focus more attention. Using the valuable input we receive from the public, consumers, subscribers and volunteers, we aim to improve our programs, activities and communications tools. Sometimes, the survey

leads to the development of focus groups and follow-up surveys, which help dig more deeply into consumer issues.

What did the survey ask?

The ACE 2012 JointHealth[™] Programs Satisfaction and Interest survey was conducted via the Internet, allowing us to collect feedback from consumers worldwide. You rated the importance of JointHealth[™] programs, JointHealth[™] website pages, and various arthritis issues on a 5-point scale, from "not important at all" to "extremely important". Survey respondents were also given the opportunity to make suggestions for what they would like to see in future JointHealth[™] programming.

The survey asked participants the following:

- As a person living with arthritis, to rate the challenges the disease poses to working, child care, driving, leisure and athletic activities, physical intimacy, managing medications, talking with their doctor, and public drug plan coverage for the medications they take.
- To rate the importance of getting information on arthritis disease, arthritis medications, government health policy developments related to arthritis, diet and exercise, latest arthritis research, how to be an arthritis advocate, donating to arthritis research, and connecting with others who live with arthritis.
- To rate the importance of ACE and JointHealth[™] programs, such as the website, the monthly newsletter (online and print versions), breaking

news by email, web workshops, podcasts, the JointHealth[™] Report Card on provincial formulary reimbursement listings for biologic response modifier, the medications guide, surveys, **arthritisID apps**, and social media.

- To rate the importance of areas of the **JointHealth[™] website**, such as "About Arthritis", which spotlights a few different types of arthritis, "Getting Better Healthcare", "Taking Action", "Media", "Resources", "About Us", and "Contact".

What were the survey results?

We are very pleased with the participation in the ACE 2012 JointHealth[™] Programs Satisfaction and Interest survey. The input on our JointHealth[™] programs and related projects was positive and constructive.

Overall, our highest number of respondents were female (84%) and were born in the 1950s (32%) or 1940s (28%). From their feedback, we have a greater insight into what programs are the most important and what people would like to see us focus on in future projects.

The most important challenge was leisure and athletic activities.

The most important challenge was leisure and athletic activities. This challenge is particularly alarming when considering the evidence-based research from organizations, like the Arthritis Research Centre of Canada (ARC), that show being physically active can potentially prevent the onset of some types of arthritis and ease the pain associated with many, if not all, types of arthritis.



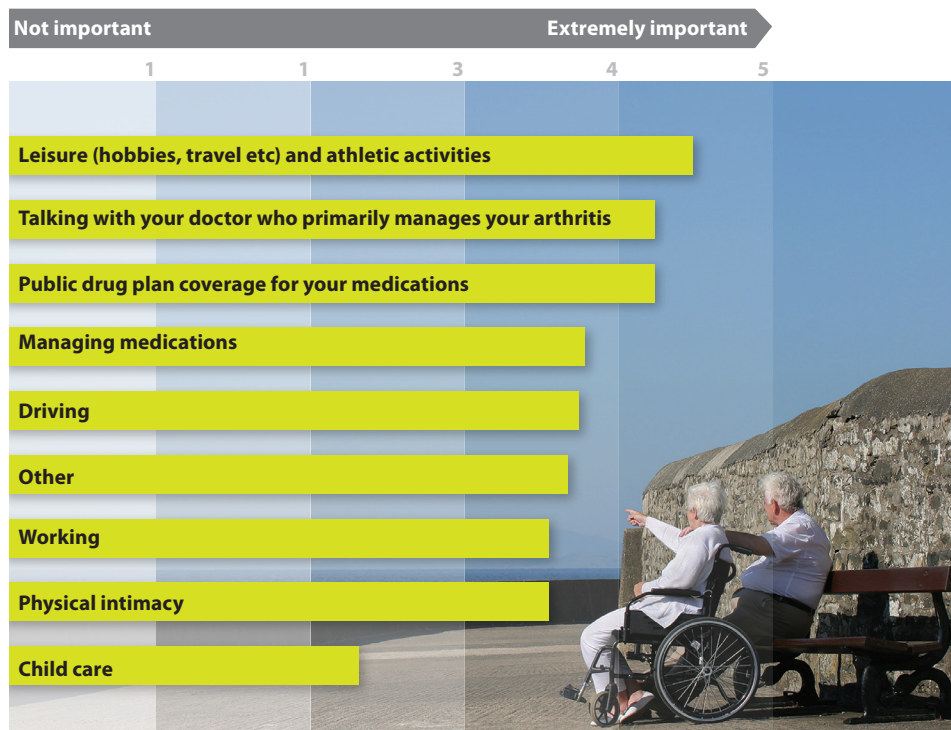
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Q If you are a person living with arthritis, please rate the following challenges that arthritis poses in your life. If you live with someone with arthritis, please feel free to answer this question to the best of your ability



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Even though exercise is very important in the prevention and management of arthritis, the “Life with Arthritis in Canada” report from the Federal Government pointed out that in 2007-2008 many individuals with arthritis were physically inactive during their leisure time compared to those without arthritis (59% and 49%, respectively). Furthermore, 63% of Canadians aged 18 years and over with arthritis were overweight or obese compared to 49% of those without arthritis.

The second most important challenge was considered to be talking to the doctor mainly responsible for managing their arthritis. ACE has consistently advocated the need for improvement in the arthritis consumer and physician partnership. In previous surveys, ACE has found that the highest levels of consumer satisfaction with healthcare providers come from patients who have a rheumatologist as one of their healthcare providers. On average, getting access to public drug plan coverage for arthritis medications was the third most important challenge to someone living with arthritis. The fact that consumers continue to face the challenges of not being able to talk to their doctor and to be reimbursed for their medications, demonstrates much needs to be done to improve access to arthritis treatment and care in Canada.

Survey participants said that the topics they felt were most important for ACE to focus on were

arthritis medications, research, and government health policy developments related to arthritis. Diet and exercise, arthritis diseases, and evidence based information on non-medicinal therapies were also rated as extremely important by a majority of respondents. Many of our readers reported fair or poor general and mental health and the need for help with daily activities in addition to limitation in work, community, social and civic life.

In response to the needs established in this survey, ACE will focus more attention on helping people become more active, providing evidence-based information on mainstream and complementary treatments, continuing to advocate to improve access to medications, and giving you the tools and opportunities to advocate for your own healthcare.

The most important programs that ACE has to offer were considered to be the JointHealth™ medications guide, the JointHealth™ monthly newsletter, the JointHealth™ express (email alerts with breaking arthritis news), and the JointHealth™ website. The areas on the JointHealth™ website that survey respondents said were a priority are “Getting better healthcare”, “Taking Action”, and “About Arthritis”, and “Resources”. We are very pleased that you are happy with our core programs and we commit to continuing to provide high quality, evidence-based arthritis information.

Learning from the Survey

We were very pleased to learn that our members and subscribers are generally very satisfied with the communication tools we use to deliver arthritis news and information with the JointHealth™ medications guide, JointHealth™ express, JointHealth™ monthly and JointHealth™ website rated the most important ACE programs.

The positive feedback received from the survey will inform ACE’s efforts this year, as well as those for the **National Arthritis Awareness Program** (co-led by ACE and the Arthritis Research Centre of Canada), which is entering its third year.

Overall, the wide ranging information needs of our survey respondents reveal there are different levels of arthritis understanding and awareness among Canadians in different provinces. There is, however, an increasing wave of consumers researching and looking to online materials for credible and accessible symptom identification, medical information and self-treatment strategies. The traditional provider-centric healthcare model that focuses on the medical disease, with the healthcare professional (HCP) viewed as the ‘knowing’ expert and the patient a ‘passive’ recipient, is becoming obsolete. Patients are taking a more active role in their disease management. In this case, both arthritis patients and HCPs are experts: patients are experts on their lives and experiences living with arthritis, and HCPs are experts on the art and science of medicine.



If arthritis consumers are taking more ownership of their disease and engaging more with ACE and other arthritis program, then one of ACE’s objectives for 2012 is to give Canadians the tools to connect even better. Enter the Arthritis Broadcast Network—a media rich (text, audio, video, photos) network made up of five programs that will become a primary source of arthritis news

Healthcare and Arthritis Reform: Coming soon to a Government near you

We are giving you this policy update because survey respondents said that information about government health policy developments are a priority . . .

In the past two months, Canadians have watched and listened to their federal and provincial governments meaningfully discuss options to reform the delivery of healthcare.

In January, provincial and territorial premiers met in Victoria, B.C. to discuss healthcare policy in the context of the Federal Government’s announcements in December on a new funding formula for the National Health Accord. The Premiers announced the formation of a Health Care Innovation Working Group, composed of all the country’s health ministers, whose purpose will be to identify ways to improve patient care and save money in Canada’s healthcare system. The Working Group will look at scope of practice for healthcare professionals and figure out what is working and what barriers to care need fixing.

In February, the Ontario Government released the Drummond Report, which calls for extensive spending reductions in public service delivery. Of the 362 recommendations contained in the report, more than 100 focus on healthcare. The report focuses on “patient-centred care” (i.e. moving patients away from hospital care to less costly forms of home-based care) and on a move toward lower cost healthcare professionals, such as pharmacists, nurse practitioners and personal support workers instead of doctors.

The report represents not just a potential turning point for Ontario’s

healthcare system but also a blueprint of long-term chronic disease management for other provinces to follow.

What do these reforms, at the federal and provincial levels, mean for Canadians living with arthritis? ACE is currently meeting with government representatives to determine the answers to this question. In our meetings we are recommending key interventions and strategies that, if implemented, would result in significant direct cost savings of valuable healthcare dollars and indirect cost savings to the economy, and more importantly, reduce the burden and consequences of the disease on Canadian consumers living with arthritis. We are using the results from the survey about your healthcare challenges to help inform our recommendations.

The current national debate presents the perfect opportunity for the arthritis community to provide patient perspective and participation, which are critical at all levels of our healthcare system so that it can respond effectively to chronic disease.

As a member of the Arthritis Alliance of Canada (AAC), ACE is taking a leading role to help the AAC promote a National Framework for Arthritis that will increase the efficiency of care and management of people living with the disease; implement effective measures to prevent disease onset; increase awareness of the full cost of arthritis to the individual and society; and, establish priorities for ongoing research. The National Framework is a response to the findings in **The Impact of Arthritis in Canada**, which identified four potential arthritis interventions to mitigate the burden of the disease and manage the impact arthritis could have, if left unchecked, over the next three decades. Implementing these interventions is expected to save the healthcare system more than \$700 million over the next 30 years.

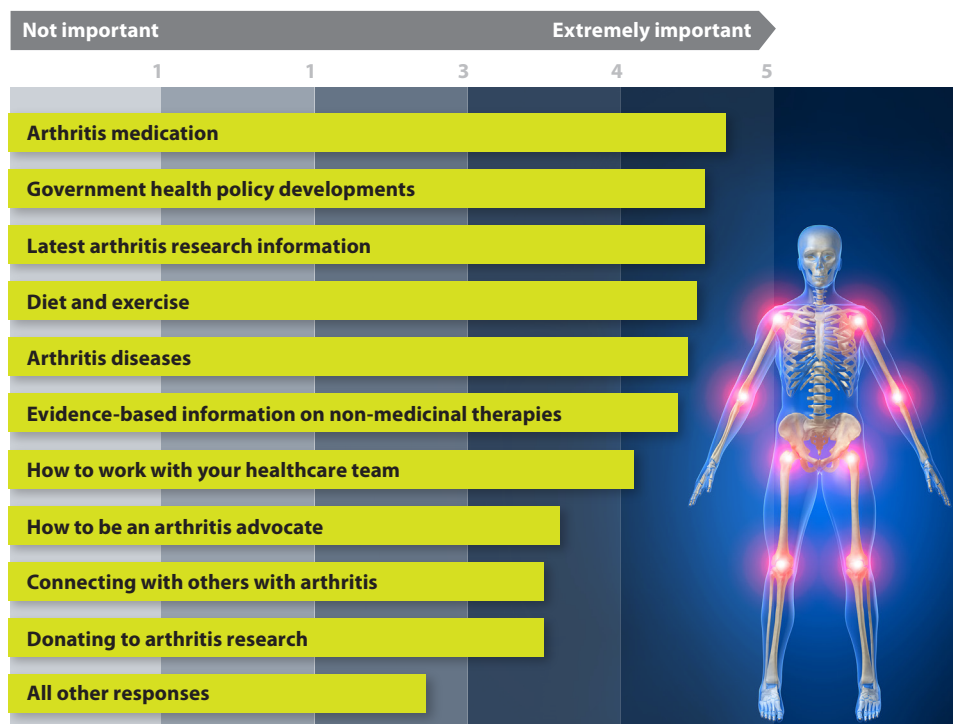
To be successful, we need your support. In the recent survey, the area on the website you rated as being one of the most important is the **“Taking Action”** area of the JointHealth™ website. Here is where you can get information on what ACE is doing to advocate for people who live with arthritis and on how you can be a part of the process. In the next few months, ACE will be suggesting ways you can participate and provide your valuable perspective to ensure arthritis successfully positions itself in the ongoing national debate over the future of healthcare in Canada.



and information in Canada and a place where our grassroots community creates and shares arthritis stories.

We will have more updates on the Arthritis Broadcast Network and other communications efforts ACE is undertaking to ensure we continue to provide you the information you need to meet the challenges you have identified in our ACE 2012 JointHealth™ Programs Satisfaction and Interest survey.

Q Please rate how important the following information areas are to you



Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit www.jointhehealth.org

Guiding principles and acknowledgement

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a

practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities, and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and healthcare providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.

Thanks

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada, Arthritis Research Centre of Canada, AstraZeneca Canada, Canadian Institutes of Health Research, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck & Co. Canada, Novartis Canada, Pfizer Canada, Sanofi-aventis Canada Inc., Takeda Canada, Inc., and UCB Canada Inc. ACE also receives unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks these private and public organizations and individuals.

Disclaimer

The material contained in this newsletter is provided for general information only. It should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Should you have any healthcare related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter.


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