

Raise your voice: patient participation in research

Research into arthritis and related conditions is an incredibly interesting, complex, and exciting field. Every day, research teams are working to learn more about arthritis, and understand the experiences of people living with the disease. Some of the things researchers are trying to discover and understand include:

- A cure for the more than 100 types of arthritis disease
- Effective treatments to slow or halt disease progression
- Causes of arthritis and related conditions
- Early signs of arthritis disease, and patients' awareness of these signs and symptoms
- Effective self-management techniques, to help people cope with arthritis
- The role of diet and exercise in arthritis prevention and treatment
- The impact of arthritis on participation in paid employment, family life, and leisure activities

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ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

While the research questions and methods for answering them vary widely from project to project, the ultimate goal is the same: to improve the lives of people living with arthritis. To do this, researchers often need significant input from real people living with real disease.

People with arthritis play a very significant role in research. This participation takes many different forms, including:

- Answering questionnaires and surveys
- Participation in individual or group interviews with researchers
- Participation in clinical medication trials
- Involvement with research decision-making, on advisory boards or councils.

Participation in questionnaires, surveys, and interviews

One of the easiest ways people with arthritis can participate in research is through answering questionnaires and surveys. This type of participation allows people with arthritis to contribute to research without leaving home, on

their own schedule and at their own pace.

Questionnaires and surveys also offer researchers the opportunity to gain input from large numbers of people living with arthritis. This level of input is critical to developing research around arthritis prevention, treatment, and care from the patient perspective.

Individual and group interviews are another way that researchers can learn about patients' experiences. Because these interviews are conducted in person, the results are sometimes more in-depth and spontaneous. On the other hand, participation in this type of research usually requires that patients attend interviews outside of their homes, which can be difficult for people living with disability.

Participation in clinical trials

A clinical trial is a study designed to test a new medication therapy. Clinical trials study new or "experimental" therapies, as well as older therapies to be used in a new way or at a different dosage.

In order to receive government approval for widespread use in a specific disease, a new medication or experimental therapy must first pass three phases of clinical testing: Phase I, Phase II, and Phase III.

During Phase I, the medication is tested by a group of healthy people, to see if the medication is well-tolerated and to see if participants develop side effects not observed in animals during "pre-clinical" laboratory testing. This phase usually lasts several months.

In Phase II, which lasts anywhere from several months to two years, a larger group (80-300) of people living with disease test the medication, to assess its effectiveness and to develop dosage guidelines for its use.

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In Phase III, the experimental medication is tested against a placebo in 1000-3500 people living with the disease this experimental therapy is to treat. This phase takes between one and four years.

After a therapy has been approved for use in the treatment of a disease, it may undergo Phase IV testing. This phase is commonly known as a “post-marketing” trial. During this phase, long-term benefits and side effects are studied.

Participation in research decision-making

Many research organizations have consumer advisory bodies that help to guide the type of research being conducted. The Consumer Advisory Board of the Arthritis Research Centre (ARC) of Canada is one example of such a body.

By participating in such a group, people with arthritis help to ensure that the types of research being conducted are relevant to the people they are designed to help: those living with disease.

Participation on research decision-making bodies like these can be daunting. People with disease who are new to the process can feel intimidated by the presence of scientific researchers and may worry that they have little of importance to contribute, but nothing could be further from the truth. Patient participation in research decision-making is a critically important component of designing studies with real-world relevance.

For more information, you can listen to a conversation between consumer advocate Jay Fiddler and ACE president Cheryl Koehn in the podcast entitled “People with arthritis and

arthritis research decision-making”. This podcast is available for download at www.jointhehealth.org.

Why participate in research?

People with disease who participate in research do so for a number of different reasons. Some say they gain satisfaction from helping improve arthritis treatment and care, others hope to gain a better personal understanding of their disease, and many people actually enjoy the research experience.

Participation in clinical trials has benefits and drawbacks. People may want to participate for a number of reasons: they may wish to access a promising new medication before it is licensed for use in their country, they may need assistance affording expensive medications being studied, and they may wish to contribute to the discovery of new treatments for their disease. Drawbacks include the risk of side effects, and interference in the trial subject’s lifestyle—for example, the medication may need to be taken at an inconvenient time, diet or activities may be restricted, or more complex medical testing may be required.

Participation in non-clinical studies, like surveys and interviews, carries a different set of benefits. When considering participation in research, it is important to remember that because of the debilitating symptoms and devastating nature of arthritis disease, too often people who live with arthritis are forced to stop participating in the things that have made them who they are—family activities, work, and leisure pursuits. Effectively, this can cause people with serious arthritis to simply “disappear”.

Participation in questionnaire, interview, and survey work lets the voices of these people be heard. Researchers, clinicians, health policy decision-makers and media are just some of the people whose understanding of arthritis disease can be shaped by this type of research.

How to participate

Finding a research project to get involved with is the first step to participating in arthritis research. The National Data Bank for Rheumatic Diseases is a terrific example of a research project that is changing the face of arthritis research in North America. For more information about the project please see the article entitled “National Data Bank for Rheumatic Diseases” in this issue of JointHealth™ monthly, and visit www.jointhehealth.org or www.arthritis-research.org for more information.

In Canada, the Arthritis Research Centre (ARC) of Canada is a good resource for information about clinical trials and ongoing non-clinical research. Their website is www.arthritisresearch.ca.

In the United States, The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) is a good resource for information about clinical trials and patient research registries. You can visit their website at www.niams.nih.gov.

For information about patient recruitment for research projects, consider subscribing to JointHealth™ express. These breaking news bulletins bring information about patient recruitment for studies into the inboxes of subscribers. You can subscribe at www.jointhehealth.org. ☺

National Data Bank for Rheumatic Diseases

Arthritis Consumer Experts is pleased to announce an exciting new partnership with the National Data Bank for Rheumatic Diseases (NDB). Based in Wichita, Kansas, the NDB is the largest patient-reported research data bank for rheumatic disorders in the United States.

The NDB undertakes critically important work in arthritis research by conducting surveys in order to collect data about rheumatic diseases directly from people living with them. The stated goals of the NDB project are to “advance knowledge about the causes, outcomes, costs, treatments, and results of treatments related to rheumatic conditions”.

Research findings from NDB surveys are regularly presented at the major scientific conferences, and in peer-reviewed rheumatology publications. This means that through these presentations, the voices of people with arthritis—true experts in living with disease—are

being heard by the scientists and health care decision-makers.

Please add your voice to the project and help improve the lives of people with arthritis.

Participation in survey work like this represents an important opportunity for people with arthritis to have an impact on arthritis research. Too often, people with arthritis are unable to volunteer in conventional settings, due to fatigue, joint damage and disability, and other effects of arthritis. By participating in research, people with arthritis can contribute to efforts to improve the lives of others living with arthritis.

Participation in the NDB is easy and only requires participants to answer a questionnaire once every six months. Questionnaires are quite in-depth and take, on average, about an hour to complete. Questions focus on information relating directly to the experience of living with arthritis, including:

- Pain
 - Functional ability
 - Work ability
 - Disability
 - Joints that are affected
 - Symptoms
 - Treatments with medications and surgery
 - Side effects of treatments
 - Other illnesses
 - How you manage your disease
 - Questions about who you are
- If you are not already involved in NDB research, please contact ACE to express your interest in joining us in this vitally important work. You can call us toll-free at 1-866-974-1366, or email us at feedback@jointhehealth.org.

By participating in arthritis research, and this partnership between JointHealth™ and the National Data Bank, you truly are helping to change arthritis. ☺

organization spotlight

Arthritis Consumer Experts

JointHealth™ is pleased to present a new feature of JointHealth™ monthly: organization spotlights. In this new feature, we will profile some of the organizations in the arthritis world working to make a difference in the lives and futures of people living with disease.

In this first organization spotlight, we present information about the organization behind JointHealth™: Arthritis Consumer Experts (ACE). While many of our readers are familiar with ACE, JointHealth™ has experienced a dramatic increase in readership over the past year and many newer readers may not know the “ACE story”.

History

Arthritis Consumer Experts was founded in November of 2000 by Cheryl Koehn. A nineteen-year survivor of rheumatoid arthritis, Koehn is a strong believer in the power of the consumer (person with arthritis) to make change and have a positive impact on health care decision-making processes. Noting a significant unmet need in the arthritis community, Koehn founded ACE with three organizational objectives:

- To inform, educate and empower people with arthritis to help them take control of their disease and improve their quality of life.
- To provide evidence-based information in reader-friendly language to people with arthritis, the public, governments and media.
- To provide research decision-making training to people with arthritis to help them participate meaningfully in research organizations and in consultations with government.

Since it formed, ACE has delivered face-to-face arthritis education to 3,000 people with arthritis in North America, mentored dozens of its community members to become involved in research and health care decision-making, and delivered invited talks from the consumer perspective in Canada, the United States, Australia and the United Kingdom.

Programs

Today, ACE provides a variety of free education and information programs to people with arthritis through the JointHealth™ family of programs. These include:

- JointHealth™ monthly, an online and in-print monthly publication providing evidence-based information, education, and arthritis news

to people with arthritis, their families and friends, and elected officials. JointHealth™ monthly is delivered for free to approximately 27,000 people in Canada, the United States, and around the world.

- Jointhealth.org, providing evidence-based information about arthritis for people with arthritis in an easy-to-navigate format. In addition to in-depth disease and treatment information, the website houses all of the online JointHealth™ programs, along with news about ACE's government advocacy programs, media activities, and community partners.
- JointHealth™ express, providing email updates about breaking arthritis news right to the inboxes of online subscribers.
- JointHealth™ workshops, including on-line and in-person slide presentations and web-based videos designed to give people with arthritis access to the latest information about different aspects of arthritis. Workshops cover a wide range of topics, and are presented by leading researchers, rheumatologists, and advocates for people with arthritis.
- JointHealth™ surveys, designed to capture the experiences, needs and desires, and expertise of people living with arthritis. Survey results are analyzed and reported back to the arthritis consumer and research communities. As well, results are used to inform provincial, state, and federal elected officials and media about the experiences of real people living with disease.
- JointHealth™ podcasts, providing the listener with interesting and important arthritis information on topics ranging from arthritis research to effective and safe exercise for people living with arthritis. JointHealth™ podcasts feature interview-style conversations with leading Canadian rheumatologists,

arthritis research scientists and consumer advocates.

- JointHealth™ report card on provincial formulary listings for biologic response modifiers, a ground-breaking tool designed to provide patients and elected officials with information about access to gold-standard arthritis medications.

Advocacy

Formed as a private-sector company, ACE operates like any other non-profit group—on unrestricted grants from public and private sector organizations, as well as individual donations. Free from the influence of government and non-partisan, ACE is able to effectively advocate on behalf of its community members and the public living with arthritis.

In the past year, ACE has met with elected officials from coast to coast, providing education on arthritis and advocating for real change to improve the lives of people with disease. These efforts have met with great success; more and more elected officials are beginning to understand the impact of arthritis and speak out about treatment and care for people with disease.

As well, ACE works to raise the profile of arthritis in the media. Through press releases, press conferences, letters to the editor, and interviews on radio, television and in print, ACE media activities are focused on challenging commonly-held misperceptions about arthritis and informing the public about the reality of the disease.

Looking forward

Arthritis Consumer Experts continues to break new ground in terms of innovative program delivery and advocacy. Founded in Canada, the organization's reach is expanding to new countries—the online version of JointHealth™ monthly is read in the United States, Europe, Australia and Asia—and people around the world are looking to ACE to inform, educate, and empower them in their journey to take control of their disease and take action in health care decision-making.

To subscribe to the JointHealth™ family of programs, or for more information about ACE and JointHealth™ visit www.jointhealth.org or call 1-866-974-1366. ☎

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 health care 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

Health care is a human right. Those in health care, 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 health care 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 web site, 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™.



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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 health care 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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