
Models of Care in Action: Implementation into Practice

1) Identification

Patients and the Primary Care Provider

A New Patient Charter Outlines Arthritis Patients' Rights and Responsibilities

By Dawn P. Richards, PhD; Linda Wilhelm; and Laurie Proulx

The Canadian Arthritis Patient Alliance (CAPA) undertook a grassroots campaign in 2014 to update the Canadian Arthritis Patient Bill of Rights.¹ The goal was to bring new life to this important document, which largely served as an advocacy piece, and to emphasize the key role of arthritis patients in recognizing symptoms and accessing care.²

The Arthritis Patient Charter was a collaborative effort spearheaded by CAPA with input and feedback from over 730 community stakeholders from across Canada. From

its initial draft to its final inception, the Arthritis Patient Charter took only eight months to complete, a testament to the Canadian arthritis community's enthusiasm and ability to mobilize its resources.

The Arthritis Patient Charter is available at CAPA's website (arthritispatient.ca/projects/arthritis-patient-charter/) in English and French, in an easily accessible format.³

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References:

1. Canadian Arthritis Bill of Rights, 2001. Available at www.arthritis.ca/document.doc?id=565.
2. Richards DP. The Arthritis Patient Charter. CRAJ 2014; 24(4):8-9.
3. Canadian Arthritis Patient Alliance. Arthritis Patient Charter, 2014. Available at www.arthritispatient.ca/projects/arthritis-patient-charter/.

The Patient's Perspective

Patient Experiences of Rheumatoid Arthritis Models of Care: An International Survey

By Cheryl Koehn

In 2016, Arthritis Consumer Experts led the formation of a global network of 18 patient organizations working on behalf of people living with rheumatoid arthritis (RA). To complement the Arthritis Alliance of Canada (AAC) Inflammatory Arthritis Models of Care (IA MOC) work, the network's first project was an online survey aimed at uncovering RA Models of Care (RA MOC) gaps by surveying patients living with the disease.

The survey, which was the first crowd-sourced research of its kind, was conducted in Canada and 24 other countries from March-June 2017. Questions focused on five domains of the AAC's own IA MOC work: 1) patients recognize symptoms and seek care; 2) access to a specialist; 3) medical management; 4) shared care; and 5) patient self-management.

Several RA MOC gaps were identified among the 2,690 respondents, including:

- 51% reported a delay of 4-6 months to over 2 years from symptom onset to receiving an RA diagnosis;
- 93% reported they helped their rheumatologist diagnose

their RA through their description of symptoms; only 57% reported having a thorough joint and skeletal system examination;

- 58% were currently treated with methotrexate only;
- 30% said it took from 4 months to "never" for an effectiveness review of their first initiated medication;
- Approximately half lacked knowledge when describing their current treatment as biological or not;
- 14-45% needed more disease information or would like to talk with other patients or their rheumatologist about their RA;
- 82% and 46% reported their main source of RA information was through internet searches or social networks, respectively.

These survey results will guide the Global RA Network's development of pan-country and specific country initiatives to work towards closing RA MOC gaps at the patient level. For more information, please visit globalranetwork.org.

Ms. Cheryl Koehn, President, Arthritis Consumer Experts, Vancouver BC, on behalf of the Global RA Network

Reference:

Koehn C et al. Patient experiences of rheumatoid arthritis models of care: an international survey. Poster presented at the 2017 ACR Annual Meeting, 3-8 November 2017, San Diego, CA. Abstract #353.