

Background

In 2014, the Canadian Arthritis Patient Alliance (CAPA) led the creation of an Arthritis Patient Charter¹. This was an update of the Arthritis Society's 2001 Canadian Arthritis Patient Bill of Rights². In the nearly 15 years since the Bill's original development, the landscape of arthritis and its care has changed significantly. CAPA wishes to provide patients, their families, and their healthcare providers with a new tool to stimulate conversation, hopefully improve their partnership with their healthcare providers, and ultimately result in better outcomes for patients.

We felt that it was time to update the original Bill in ways that reflect our current world. While the original Bill had responsibilities, we chose to further emphasize these for patients. We also developed the Charter in multiple formats (online, print, long and abbreviated versions) to make it more accessible, and we hope that the Charter continues to evolve with time.

Objectives

This poster undertakes to:

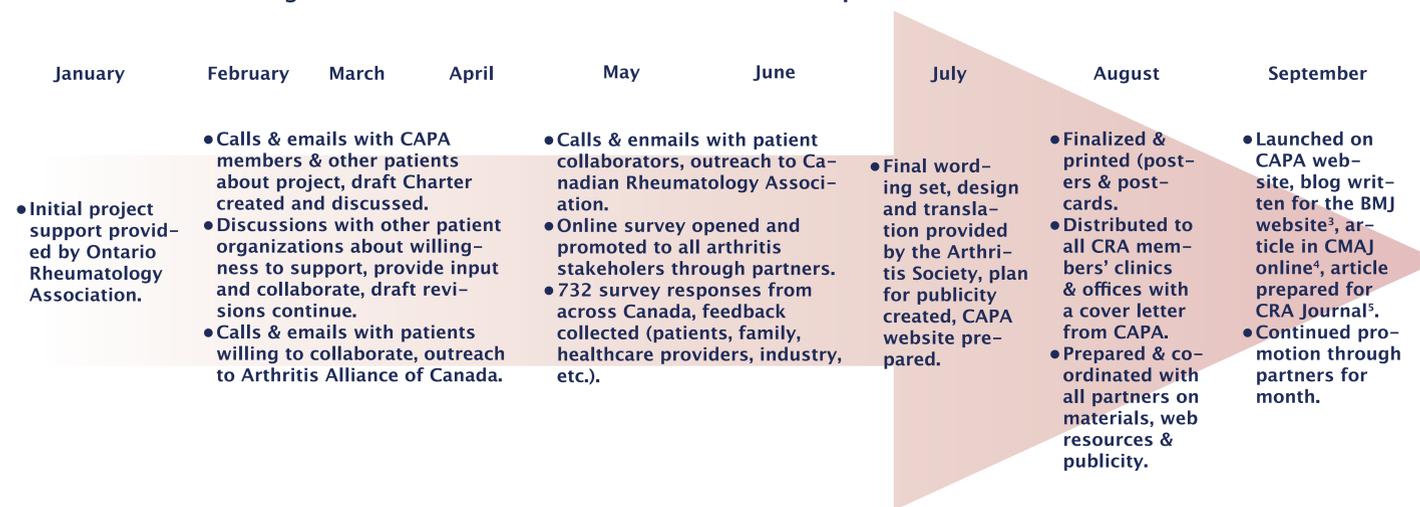
1. Inform of the process (including collection of input from all arthritis stakeholders) and timeline undertaken to develop and launch the Arthritis Patient Charter in Arthritis Month in September 2014;
2. Share the final Arthritis Patient Charter;
3. Explain how the Arthritis Patient Charter can be used in conversation between patients and their healthcare providers; and,
4. Communicate next steps in our continued efforts to raise awareness of the Charter and ensure that patients and their caregivers have access to the Charter.

Methods

From the beginning of the project, CAPA sought to gain input from multiple arthritis stakeholders to update the Bill. Originally supported by the Ontario Rheumatology Association's Models of Care Committee, support (in-kind and financial) grew to include the Arthritis Society, the Arthritis Alliance of Canada, the Canadian Rheumatology Association, Arthritis Consumer Experts, the Canadian Spondylitis Association, Patient Partners, and some individual patients. One CAPA Board member acted as the project manager. Figure 1 shows the timeline and process for the development of the Charter.

Methods (continued)

Figure 1. Timeline and methods utilized to develop the Arthritis Patient Charter.



Results

Figure 2. Poster versions of the Arthritis Patient Charter (English & French).

From our partnership with numerous arthritis organizations and our survey of stakeholders across Canada, we developed two versions of the Arthritis Patient Charter (both in English and French). Figure 2 shows the poster versions (long versions) of the Charter which were mailed to CRA members' clinics and offices across Canada. Accompanying these posters were abbreviated postcard versions of the Charter which patients could view/take away from the waiting room. All versions of the Charter, an explanation of its development, and a history as well as link to the original Arthritis Patient Bill of Rights is found on the CAPA website in English and French¹.

Arthritis Patient Charter

People with arthritis have the right to:

- **Be treated with dignity, respect and consideration.** This includes being heard by healthcare providers who respect privacy and confidentiality.
- **A timely and accurate diagnosis.** Arthritis leads to significant joint damage when left undiagnosed and untreated.
- **Timely access to all types of high-quality care.** This includes access to all qualified healthcare providers and professionals.
- **Readily available current information, education and support programs about arthritis and evidence-based arthritis care.** People living with arthritis have the responsibility to learn about arthritis and arthritis care.
- **Be informed and participate with their healthcare providers in all treatment decisions.** This includes discussing treatment risks and benefits and timely access to medical records. People with arthritis have a responsibility to live a healthy lifestyle, speak openly with their healthcare providers, ask questions about treatment and follow the agreed upon course of treatment.
- **Equal public reimbursement and timely access in all provinces and territories to available medication and non-medication treatments.** Surgery and rehabilitation therapy that improve activities of daily living and quality of life should not be considered elective.
- **Live their lives fully without discrimination.** Enjoying life to its fullest potential includes taking part in family, social activities, school and employment. This may require removal of barriers and access to disability programs.
- **See that research is underway to find a cure and improve quality of life.** Arthritis research must be funded to an amount equal to other chronic illnesses and include people with arthritis to help set priorities, participate as research partners or in clinical trials and benefit from its discoveries.
- **Be included in the development of health policies and programs that affect them.** The voices of people living with arthritis must be considered to develop the most relevant and meaningful policies and programs.

This charter can be found online at: <http://arthritispatient.ca/projects/arthritis-patient-charter/>

Charte des personnes atteintes d'arthrite

Les personnes atteintes d'arthrite ont droit à ce qui suit :

- **Être traitées avec dignité, respect et considération.** Il incombe par ailleurs aux fournisseurs de soins de santé de les écouter en toute confidentialité et de respecter leur vie privée.
- **Recevoir un diagnostic exact en temps opportun.** Lorsqu'elle n'est pas diagnostiquée et traitée, l'arthrite peut causer des lésions articulaires graves.
- **Avoir accès rapidement à divers types de soins de grande qualité,** y compris l'accès à des professionnels de la santé et à des fournisseurs qualifiés.
- **Avoir facilement accès à de l'information actuelle, à des ressources éducatives et à des programmes de soutien liés à l'arthrite ainsi qu'à des soins fondés sur des données probantes.** Il est de la responsabilité des personnes atteintes d'arthrite de se renseigner sur la maladie et sur les soins disponibles.
- **Être informées et participer avec leurs fournisseurs de soins de santé à toutes les décisions concernant leur traitement.** Cela suppose des discussions sur les risques et les avantages de divers traitements ainsi que l'accès opportun aux dossiers médicaux. Les personnes atteintes d'arthrite ont la responsabilité de mener un mode de vie sain, de parler ouvertement avec leurs fournisseurs de soins de santé, de poser des questions sur leur traitement et de suivre les traitements convenus.
- **Avoir accès en temps opportun aux soins et traitements disponibles et bénéficier d'un remboursement public des médicaments et autres traitements au même taux dans toutes les provinces et tous les territoires.** Les interventions chirurgicales et les services de réadaptation qui facilitent les activités de la vie quotidienne et améliorent la qualité de vie ne devraient pas être considérés comme facultatifs.
- **Mener une vie bien remplie sans discrimination,** notamment en prenant part à une vie familiale, à des activités sociales, à des études ou à un emploi. Cela peut supposer l'élimination d'obstacles et l'accès à des programmes de gestion de l'invalidité.
- **Savoir que des projets de recherche sont menés en vue de trouver un moyen de guérir la maladie et d'améliorer la qualité de vie.** La recherche sur l'arthrite doit recevoir un financement égal à celui accordé à la recherche sur d'autres maladies chroniques et faire appel à des personnes arthritiques – les bénéficiaires des découvertes – pour établir des priorités et participer à des essais cliniques ou à titre de partenaires de recherche.
- **Jouer un rôle dans l'élaboration des politiques et des programmes qui les concernent.** Les personnes arthritiques doivent avoir voix au chapitre pour assurer la mise en place de politiques et de programmes des plus pertinents et bénéfiques.

Vous pouvez consulter la charte à l'adresse suivante: <http://arthritispatient.ca/projects/arthritis-patient-charter/>

Discussion

Through hundreds of volunteer hours, coordinated efforts of arthritis organizations and input from hundreds of Canadian stakeholders, CAPA was able to drive the update of the Arthritis Society's 2001 Arthritis Patient Bill of Rights. A grassroots approach to publicity and awareness included promotions in partners' newsletters, websites, blogs, and journals. Partner support allowed the Charter to be CAPA-branded and permanently housed on the CAPA website to which all others point.

The Charter is meant to create dialogue between patients, their families, and their healthcare providers. Its aim is to complement and increase patients' knowledge of their arthritis management, and to prompt them to ask more questions of our healthcare system and our providers. It was also updated with the realization that as patients we also have responsibilities in our life with arthritis – although there is a lot we can't control, we do have responsibilities to take action where we can. It is our hope that this has stimulated thoughtful discussions and a better partnership between patients and their caregivers. We will also continue to build on the Charter through development of document which may answer some questions that the Charter has prompted and which can be used by all arthritis stakeholders. In the end, CAPA hopes that the Charter and its various accompanying documents will create better outcomes for patients and a better overall health care.

Conclusions

Through a multistakeholder partnership, CAPA drove the update of the 2001 Arthritis Bill of Rights, which is now called the Arthritis Patient Charter. Importantly CAPA aims to educate patients about their journey with arthritis, and help build dialogue with their families and healthcare providers about their care, and how their own actions can benefit their life with arthritis. The Charter and its accompanying resources will continue to evolve over time.

References

1. <http://arthritispatient.ca/projects/arthritis-patient-charter/>, accessed Jan 24, 2015.
2. <http://www.arthritis.ca/document.doc?id=565>, accessed Jan 26, 2015.
3. <http://blogs.bmj.com/bmj/2014/09/09/dawn-richards-a-canadian-arthritis-patient-charter/>, accessed January 26, 2015
4. <http://www.cmaj.ca/content/186/17/E646.extract>, accessed Jan 26, 2015
5. <http://www.craj.ca/archives/2014/English/Winter/Richards.html>, accessed Jan 26, 2015

Acknowledgements

CAPA thanks all of its partners who contributed generously to this project, including: the Ontario Rheumatology Association, the Arthritis Society, Arthritis Alliance of Canada, the Canadian Rheumatology Association, Arthritis Consumer Experts, Canadian Spondylitis Association, Patient Partners, and the following individual patients (without affiliation): Jennifer Boyle, Cathy Hoffstetter, Annette McKinnon.