

May 6, 2024

Re: Response to pan-Canadian Health Data Content Framework consultation

To whom it may concern,

On behalf of the Canadian Arthritis Patient Alliance, we are writing to you to provide our feedback on the consultation related to the [pan-Canadian Health Data Content Framework](#). We have reviewed the proposed data content standard and information model from the perspective of people who live with or who are affected by arthritis, a chronic health condition that affects close to six million people in Canada.

For people living with arthritis, the pan-Canadian Health Data Content Framework is an important step towards creating a common Canada-wide digital health record. We understand that many of the provincial health transfer agreements have included provisions related to digital health priorities and the [2023 Canada Health Accord](#) prioritized patients accessing their own electronic health

information. We hope that this Framework will inform the work of the provinces and territories in creating the right systems that support patient access to their digital health records.

Accessing health data is an important part of managing arthritis and can help in a variety of ways, like:

- self-managing arthritis
- monitoring medication effects
- monitoring the disease activity and the progression of arthritis
- managing comorbidities like cardiovascular and lung diseases
- maintaining good health like accessing vaccines, and
- coordinating health care among many providers including pharmacists and other allied health care professionals.

The Canadian Arthritis Patient Alliance is a grassroots, patient driven, independent, national organization with members across Canada and supporters in Canada and beyond. We believe the first expert on arthritis is the individual who lives with the condition. We provide a strong voice and concerted effort to promote the well-being of people living with arthritis and we assist our members to become advocates not only for themselves but for all people with arthritis. The organization is a small virtual organization and powered by volunteers who all live with various forms of arthritis.

We will share our perspective as patients, or people with lived experience, in the remainder of this letter to describe in what ways this health data can be used and how it can benefit patients.

How do people with arthritis want to use their own data?

Many patients know that accessing their own or a loved one's health information can bring peace of mind. People can feel like they are losing control when diagnosed with a chronic condition like arthritis and they are faced with additional barriers when receiving care in a health care system that does not share power with them. Accessing their own health records and information can facilitate and support a shift in power dynamics where patients have the least amount of power in the relationship with their health care provider. Many patients in our community expressed the need to have access to all of their health data in one location without having to re-login into separate systems and navigate complex registration and access portals.

Living with arthritis can bring additional complexity to a person's life particularly when comorbidities, or related health conditions need to be managed. For example, beyond affecting the joints and connective tissues, inflammatory arthritis is a systemic disease which can cause increased comorbidities like cardiovascular disease, diabetes and metabolic syndrome, lung conditions, and eye-related conditions like uveitis and scleritis. This often means that people need to coordinate care among different physician specialists and health care providers given the lack of direct and regular communication amongst these providers. Accessing their own health information can help coordinate this care, which is a responsibility currently placed on patients, instead of the healthcare system as a whole. In addition, pharmacists are becoming increasingly involved in managing a patient's health and they need access to patient medical records to provide the best care.

People with arthritis also wish to access their own health data on an ongoing basis. It must be comprehensive, rigorously entered by various health care providers and become available immediately for patients. In the Appendix to this letter, we have identified a number of specific data elements people with arthritis wish to access so they manage their health. When information is made available, it should be accompanied by a simple, easy to understand, plain language version of the meaning of the data element. Typically, health information should be written at a grade eight reading level in order to be accessible to patients. For further context, we developed an educational resource for people living with arthritis called "[Know Your Numbers](#)" which explains many of the tests used in managing inflammatory arthritis.

Whose data is it anyway?

There is also concern among patients that they cannot easily access their own data and health

information when they wish. Some have noted that they are asked to pay expensive fees (over \$200) to receive hard copy versions of medical records from physician offices. In addition, many patient organizations may wish to use this data available throughout the health care system to advocate for and support patient needs. Patient organizations often need to create their own data sources or pay to access patient's health care data. There should be a democratization of this data where it can be available free of charge to patient communities.

Many patients cannot add their own personal information to health records without the approval of a healthcare provider. Patients have very little personal input and stewardship of their own personal health data and must rely on these records to receive the care they need. The lack of patient control over their health information shifts the power towards health care providers and supports paternalistic treatment decisions. In contrast, many patients value [shared decision making](#) which is *"a process by which both patients and healthcare professionals make a joint decision, consider the best evidence of available options, and the patient's values and preferences."* To make high-quality decisions, especially complex decisions, patients require information, help to clarify what is important to them, and ongoing support to make a decision. Some of the information patients need is available through health records. Patients wish to make shared treatment decisions though there is [evidence](#) that it remains difficult and even less accessible for vulnerable patient populations.

Disability and social determinants of health

Many people living with arthritis live with pain and limitations in physical function and daily activities. There is a stigma that can be associated with these limitations and disability, and we questioned who is entering this disability data, how it is being collected, and how it might be used in their health care. A focused effort needs to be taken to better understand how this data is collected and will be used which considers the history of disability in Canada and the fears that this information may be misused and lead to differential treatment and disparities in health care. Similarly, the data around the social determinants of health shares similar concerns that can further cause poor treatment and outcomes of equity deserving communities, such as diverse ethno-cultural communities, Indigenous Peoples, and the 2SLGBTQ+ community.

Next steps

The proposed pan-Canadian Health Data Content Framework represents an opportunity to meaningfully engage patients and patient groups in developing and maintaining the Framework. This engagement can ensure that the pan-Canadian Health Data Content Framework responds to the needs of people with lived experience. There are [leading practices](#) for engaging patients in digital design which can guide this work. As a start, we ask that you

offer a webinar to patient groups and patient partners so they can be introduced to this topic and become engaged in the work.

In closing, we ask that you work with us, people with lived experience, and other patient groups to understand how you can actively and meaningfully consider the role of patients into the work of CIHI and how this fits within the broader health care ecosystem. We thank you for the opportunity to provide our perspective on behalf of people living with arthritis.

Sincerely,



Linda Wilhelm
President



Laurie Proulx
Managing Director

Appendix

We have completed the “Response Prep Sheet” in Word format, as noted in the instructions provided by employees of CIHI.

Submitter information	
Name	Laurie Proulx
Organization	Canadian Arthritis Patient Alliance
Job title	Managing Director
Email address	director@arthritispatient.ca
Role	<input type="checkbox"/> General public <input type="checkbox"/> Allied health care provider (e.g., physiotherapist, social worker) <input type="checkbox"/> Clinician (doctor, nurse practitioner, registered nurse) <input type="checkbox"/> Leadership team/administrator <input type="checkbox"/> Researcher <input type="checkbox"/> Government (e.g., health system decision-maker/policy-maker) <input type="checkbox"/> Standards development organization <input type="checkbox"/> Non-governmental organization or pan-Canadian health organization <input type="checkbox"/> Vendor <input checked="" type="checkbox"/> X Other, please specify: patient organization
<p>Do you self-identify as First Nations, Inuit or Métis?</p> <p>We are asking this question so that we can better understand the data and information needs of First Nations, Inuit and Métis Peoples.</p>	<input type="checkbox"/> Yes, I am First Nations <input type="checkbox"/> Yes, I am Inuk <input type="checkbox"/> Yes, I am Métis <input checked="" type="checkbox"/> X No <input type="checkbox"/> Prefer not to answer
Country	<input checked="" type="checkbox"/> X Canada <input type="checkbox"/> United States <input type="checkbox"/> Other, please specify:

Submitter information

Province, territory or state

- Newfoundland and Labrador
- Prince Edward Island
- Nova Scotia
- New Brunswick
- Quebec
- Ontario
- Manitoba
- Saskatchewan:
- Alberta
- British Columbia
- Yukon
- Northwest Territories
- Nunavut
- Other, please specify:

Suggestion 1	
Are you suggesting changes to the data content standard or information model?	<input type="checkbox"/> X Data content standard <input type="checkbox"/> Information model
Section name (e.g., Person information)	Diagnostic information - Clinical tests
What should we change and why?	<p>People with arthritis need access to a variety of information to help manage co-morbidities associated with inflammatory arthritis, like rheumatoid arthritis, spondyloarthritis, systemic lupus erythematosus, and vasculitis. Also, people living with osteoarthritis can also experience comorbidities which can present additional challenges to managing their health. Patients need access to the following tests: Hemoglobin A1C, Cholesterols and triglycerides, Vitamin D, Ferritin, blood pressure, weight and Bone Mineral Density and DEXA Scans.</p>
What should we change it to?	<p>At the moment, there are few details about the specific clinical tests included in the frameworks. The next iteration of the data model must include specific information above the above-noted tests.</p>
If you have files with supporting information, please describe them or provide links here	<p>In 2023, we developed a Know Your Numbers educational resource to help people living with arthritis understand and better self-manage their health. It provides additional context about the need for this information and describes each of these tests in further detail.</p>

Suggestion 2	
Are you suggesting changes to the data content standard or information model?	<input checked="" type="checkbox"/> X Data content standard <input type="checkbox"/> Information model
Section name (e.g., Person information)	Diagnostic information - clinical tests and laboratory tests
What should we change and why?	People with arthritis need access to test results to monitor the effects of medications on their bodies, such as albumin, kidney and liver function tests, and eye exam results.
What should we change it to?	At the moment, there are few details about the specific clinical tests included in the frameworks. The next iteration of the data model must include specific information above the above-noted tests.
If you have files with supporting information, please describe them or provide links here	In 2023, we developed a Know Your Numbers educational resource to help people living with arthritis understand and better self-manage their health. It provides additional context about the need for this information and describes each of these tests in further detail.

Suggestion 3	
Are you suggesting changes to the data content standard or information model?	<input checked="" type="checkbox"/> X Data content standard <input type="checkbox"/> Information model
Section name (e.g., Person information)	Diagnostic information - medical imaging
What should we change and why?	People with arthritis need access to their medical imaging results so they can track the progression of their health over time, such as x-rays of various joints, and Ct Scan and MRI results.
What should we change it to?	At the moment, there are few details about the specific clinical tests included in the frameworks. The next iteration of the data model must include specific information above the above-noted imaging results.
If you have files with supporting information, please describe them or provide links here	In 2023, we developed a Know Your Numbers educational resource to help people living with arthritis understand and better self-manage their health. It provides additional context about the need for this information and describes each of these tests in further detail.

Suggestion 4	
Are you suggesting changes to the data content standard or information model?	<input checked="" type="checkbox"/> X Data content standard <input type="checkbox"/> Information model

Suggestion 4	
Section name (e.g., Person information)	Immunizations
What should we change and why?	Immunizations are an important part of managing the health of people living with various forms of arthritis. Most importantly, people with inflammatory arthritis like systemic lupus erythematosus, rheumatoid arthritis, and juvenile idiopathic arthritis, take medications that suppress their immune systems which puts them at increased risk of infection overall. It is well documented that people who are moderately to severely immunocompromised are at higher risk of severe outcomes of COVID-19 yet had difficulties accessing vaccines in the early days of the COVID-19 pandemic. Similar issues were experienced during the H1N1 outbreak in 2009. To prevent future access challenges for people with inflammatory arthritis, we ask that a new identifier be included in the data content standard to identify their status as “immunocompromised persons” consistent with the terminology used by the National Advisory Committee on Immunization (NACI).
What should we change it to?	Add a new identifier called “immunocompromised persons” to vaccination data
If you have files with supporting information, please describe them or provide links here	We have written and shared many letters to various levels of government about the experiences of people with arthritis in accessing COVID-19 vaccines , masking in health care facilities, and the exclusion of immunocompromised people from life in a world with COVID-19. These issues highlight the barriers faced in health care by people who are immunocompromised in a world with COVID-19.

Suggestion 5	
Are you suggesting changes to the data content standard or information model?	<input type="checkbox"/> X Data content standard <input type="checkbox"/> Information model
Section name (e.g., Person information)	Not applicable or noted in the documents
What should we change and why?	There should be additional information available about doing skin exams for people living with arthritis. Currently, we do not see any information captured in the current information model and data context standard focused on skin. Many people that live with arthritis experience comorbidities relating to the skin, specifically those that live with systemic lupus erythematosus, vasculitis, and Sjogren's syndrome.
What should we change it to?	Although we do not have specific recommendations around the terminology to be used, whatever information is provided should be in a language that is accessible to patients or people living with arthritis.
If you have files with supporting information, please describe them or provide links here	

Suggestion 6	
Are you suggesting changes to the data content standard or information model?	<input type="checkbox"/> X Data content standard <input type="checkbox"/> Information model

Suggestion 6	
Section name (e.g., Person information)	Not applicable or noted in the documents
What should we change and why?	The physician or other health care providers typically write up summary notes during a visit with a patient. These medical summaries contain useful information that can be helpful for people with arthritis to confirm their understanding of the visit and reflect on the next steps. Although we can see a “health concerns” data element, it is unclear if any of the data elements include this kind of a summary report which is typically available in digital health records.
What should we change it to?	Although we do not have specific recommendations around the terminology to be used, whatever information is provided should be in a language that is accessible to patients or people living with arthritis.
If you have files with supporting information, please describe them or provide links here	