








Priorities for High-quality Care in Rheumatoid Arthritis: Results of Patient, Health Professional, and Policy Maker Perspectives

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ABSTRACT. Objective. To elucidate the essential elements of high-quality rheumatoid arthritis (RA) care in order to develop a vision statement and a set of strategic objectives for a national RA quality framework.

Methods. Focus groups and interviews were conducted by experienced qualitative researchers using a semi-structured interview or focus group guide with healthcare professionals, patients, clinic managers, health-care leaders, and policy makers to obtain their perspectives on elements essential to RA care. Purposive sampling provided representation of stakeholder types and regions. Recorded data was transcribed verbatim. Two teams of 2 coders independently analyzed the deidentified transcripts using thematic analysis. Strategic objectives and the vision statement were drafted based on the overarching themes from the qualitative analysis and finalized by a working group.

Results. A total of 54 stakeholders from 9 Canadian provinces participated in the project (3 focus groups and 19 interviews). Seven strategic objectives were derived from the qualitative analysis representing the following themes: (1) early access and timeliness of care; (2) evidence-informed, high-quality care for the ongoing management of RA and comorbidities; (3) availability of patient self-management tools and educational materials for shared decision making; (4) multidisciplinary care; (5) patient outcomes; (6) patient experience and satisfaction with care; and (7) equity, the last of which emerged as an overarching theme. The ultimate vision obtained was “ensuring patient-centered, high-quality care for people living with rheumatoid arthritis.”

Conclusion. The 7 strategic objectives that were identified highlight priorities for RA quality of care to be used in developing the National RA Quality Measurement Framework.

Key Indexing Terms: quality improvement, quality of health care, rheumatoid arthritis

Rheumatoid arthritis (RA) affects approximately 1% of the population^{1,2} and is a leading cause of long-term disability^{3,4}. It is also the most costly form of arthritis, with projected cumulative

(from 2010 to 2030) direct and indirect costs of \$162 billion (2010 Canadian dollars) by 2030⁵. The rates of mortality associated with RA are 2-fold higher compared to the general

Funding for this study was provided by a Project Grant from the Canadian Institutes of Health Research (CIHR) PJT 153265. DAM is supported through a Canada Research Chair in Health Systems and Services Research, and the Arthur J.E. Child Chair in Rheumatology Outcomes Research. DL is supported by the Mary Pack Chair in rheumatology research from The Arthritis Society of Canada and the University of British Columbia.

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Accepted for publication October 29, 2020.

population^{6,7,8}. Given the importance of early and targeted treatment in RA, the Arthritis Alliance of Canada (AAC) developed a validated set of system-level performance measures that report on access to rheumatology care and treatment⁹. The measures were tested in 5 Canadian provinces and are vital in identifying important gaps in care to drive quality improvement^{10,11,12,13}. Building upon this work, we have partnered with the Canadian Rheumatology Association (CRA; representing rheumatologists) and the AAC¹⁴ (representing over 36 arthritis organizations) to develop a comprehensive framework for quality measurement in RA encompassing patient-level outcomes. The framework's development was modeled after the Kaplan and Norton Balanced Scorecard (BSC) Framework¹⁵. BSC is a tool that helps translate the vision for quality improvement into strategic objectives and goals along multiple domains. It also includes different stakeholder perspectives and performance measures to monitor progress towards quality improvement targets¹⁶.

The objective of the present study was to elucidate the elements of high-quality RA care through focus groups and interviews with rheumatology healthcare providers (HCP), managers, healthcare leaders and policy makers, and persons living with RA. This work was used to develop a vision statement and a set of strategic objectives for a national quality improvement framework for RA.

MATERIALS AND METHODS

Design. This project was part (phase 1 of 3) of a larger, nationally scoped, mixed-methods program of research aimed at developing, testing, and implementing a quality improvement framework for RA. In this study, focus groups and semistructured interviews were used to identify elements of high-quality RA care.

Participants and recruitment. Stakeholders with expertise, knowledge, or experience in RA care (rheumatologists and allied health professionals [AHP]), people living with RA, clinic managers, regional/provincial healthcare leaders, and policy makers were recruited between December 2017 and June 2018. Participants were recruited through different means depending on participant type. Rheumatology leaders (e.g., presidents of regional rheumatology societies and/or rheumatology divisional heads) from all provinces were asked to identify rheumatologists and clinic managers from both academic and community clinics as well as regional healthcare leaders/policy makers in their region for recruitment. AHP were invited to participate by directors of regional arthritis rehabilitation and therapy programs, and the national Arthritis Health Professions Association. People living with RA were recruited through advocacy organizations including the Arthritis Patient Advisory Board, the Canadian Arthritis Patient Alliance, Arthritis Consumer Experts, and The Arthritis Society. We used purposive sampling to ensure a broad representation of participants from various stakeholder types and regions of work or residence across Canada.

Focus group and interview objectives. The objective of the focus groups and interviews was to obtain participant perspectives on RA care to inform the development of a vision statement and strategic objectives for quality improvement, which represent the foundation of a quality measurement framework. Participants were asked to define "quality of care" for RA care and identify areas of priority for quality improvement. In addition, participants were also asked to describe an ideal model of care, and to identify any barriers and facilitators for care.

Three semistructured focus group and interview guides tailored to participant type were developed based on the research questions (Supplementary Data, available from the authors on request). The facilitators followed the guides with questions and probes to assess the objectives, and encouraged

participants to share their views. Focus groups and interviews were digitally recorded and transcribed verbatim by a transcriptionist.

Focus groups and interviews. An experienced qualitative researcher and a research associate trained in qualitative methods cofacilitated the focus groups. Separate focus groups were held for different stakeholder types (e.g., healthcare professionals, people living with RA) to avoid dominance of the discussion by a single participant type and to ensure all voices were heard. Individual and small group interviews (also by participant type) were conducted by teleconference for those stakeholders unable to participate in focus groups due to constraints with scheduling or travel.

Data analysis. Transcripts were deidentified and imported into QSR International NVivo 12 software for data management and analysis. A 6-step thematic analysis^{17,18} guided an iterative and reflective process involving grouping of responses and arranging information, making sense of the data, examining relationships within the data, and making comparisons between participants and different groups. Four coders (2 teams of 2) independently (1) reviewed the transcripts to familiarize themselves with the data, then (2) inductively created provisional codes. Weekly meetings between the coders helped to (3) refine and (4) ensure mutual understanding of the codes. Coders then (5) independently reexamined each transcript and assigned sections of text to codes, representing themes. Finally, the coders (6) produced a report on the themes and associated quotes. Through this process, it was also determined that data saturation had been achieved (i.e., no new additional themes emerged)¹⁹.

Trustworthiness. We took multiple steps to meet the Lincoln and Guba²⁰ concept of trustworthiness, which included dependability, credibility, confirmability, and transferability. Dependability is the extent that the study could be duplicated by other researchers and the findings would be similar. Two independent teams of 2 team members reviewed the decision-making record and made sure the process was logical and controlled for biases. The coding teams met for peer debriefing and feedback on coding and analysis. To ensure dependability and confirmability, we used an audit trail to document decisions made throughout the analysis process. As well, many team members were trained in multiple disciplines (quality of care, rheumatology, nursing, qualitative methods), providing balanced perspectives. Credibility was established with frequent updates to and discussion of findings with the CRA Quality Care Committee and the AAC during scheduled teleconferences. Transferability was accomplished through rich descriptions of findings with selected quotations, so that those seeking to apply the learnings to their own site could judge the generalizability of the results¹⁷.

Development of the vision and strategic objectives for the quality framework. Following qualitative analysis, 4 members of the research team involved in the qualitative data collection and analysis reviewed the qualitative results, identified the main themes relating to quality of care, and drafted the vision and strategic objectives for the quality improvement framework. Members of the research team, including 2 patient partners (KT, KE), involved in overall study inception, design, and execution, iteratively reviewed the draft and finalized the wording. The development of the vision statement and strategic objectives represents the first phase in the development of a measurement framework prior to populating the framework with performance measures to drive quality improvement.

Ethical considerations. Ethical approval was granted by the University of Calgary's Conjoint Health Research Ethics Board (REB16-0556) and all participants provided written informed consent.

RESULTS

Participants. We conducted 3 focus groups with 6–10 participants each, 13 1:1 interviews, and 6 smaller focus groups of 2–4 people. Focus groups lasted 90–120 minutes and interviews lasted 45–90 minutes. Table 1 outlines the participant types and regional distributions. In total, 54 people participated in either

Table 1. Participant type and regional distribution.

Province ^a	PT	RN	Social Worker	Pharmacist	Patient	Rheumatologist	Manager	Regional/Provincial Healthcare Leaders and Policy Makers	Total
British Columbia		1	1		9 ^b	1			12
Alberta	2	8		1	1	1	1	3	17
Manitoba						1	1		2
Ontario	6					3	2	1	12
Quebec		1			1	1			3
Nova Scotia						1		1	2
Prince Edward Island								1	1
Newfoundland and Labrador	1								1
New Brunswick					1			3	4
Total	9	10	1	1	12	8	4	9	54

^aWe had no participants from Saskatchewan, the Northwest Territories, Nunavut, or the Yukon. ^bOne patient participated in both an interview and the patient focus group. PT: physiotherapist; RN: registered nurse.

a focus group or interview. Three separate face-to-face focus groups were conducted including AHP at a rheumatology clinic (registered nurses and a physiotherapist, n = 10), AHP (registered nurses, physiotherapists, and a pharmacist) at the CRA Annual Scientific Meeting (n = 9), and one with patients at the same meeting (n = 6). In addition, 30 people participated in interviews (2 in 1:1 face-to-face interviews and the rest by telephone) and smaller focus groups of 2–4 people by teleconference (8 rheumatologists, 7 patients, 4 clinic managers, 9 healthcare leaders/policy makers, and 2 allied healthcare professionals).

Perspectives on RA quality of care informing a vision and strategic objectives. Seven main themes were derived from participants' responses that are important to consider when developing a quality of RA care framework. These included (1) access to care, (2) evidence-informed, high-quality, patient-centered care for patients with RA including care for other coexisting comorbidities, (3) patient education and access to information, (4) multidisciplinary care, (5) improving patient outcomes, (6) the patient experience of care, and (7) equity in the delivery of healthcare. Overall results are summarized in Table 2.

The main themes were used to develop a vision for RA care: "Ensuring patient-centered, high-quality care for people living with rheumatoid arthritis." The 7 main themes, discussed in detail below with supporting quotations on Table 3, Table 4, and Table 5, were used to develop strategic objectives for quality improvement (Figure 1).

Access. Access to rheumatology care was of primary importance to all participant types, with many highlighting the importance of early diagnosis and early disease management in improving patient outcomes. A number of HCP discussed the CRA's wait time benchmarks for rheumatology consultation, which suggest a maximum time between referral and rheumatologist appointment²¹. A number of participants highlighted that the wait time measures were suboptimal because they do not capture the time from patient symptom onset. Further, HCP expressed concern that the wait time benchmarks were not

easily achievable due to the large volume of referrals received in their centers. A frequently cited reason for prolonged wait times was the mismatch between "supply and demand" (IG6, IG10). This mismatch was perceived to be more prevalent in rural areas. Use of alternative models of care were cited as potential resources for increasing provider capacity, thereby reducing wait time.

A lack of expertise among some referring physicians was seen as contributing to delays in access, as were poor quality of referrals wherein information was not adequate for appropriate triage. Central access and triage models were described by some HCP as an approach of improving access, with some models including AHP with advanced musculoskeletal training assisting with triage. However, challenges in incentivizing and funding new models of care in some provinces were described as barriers to uptake of this approach. Patients also reported the ongoing need for timely access to their specialist team (e.g., to manage disease flares).

Evidence-informed, high-quality, patient-centered care. Concepts central to the theme of evidence-informed, high-quality, patient-centered care included measuring RA-related outcomes (e.g., disease activity and functional status) and addressing comorbidities. However, the role of rheumatologists in the screening and/or management of comorbidities was controversial. Some HCP described specialized risk clinical and online tools they used to help screen and manage comorbidities on a systematic basis, while acknowledging this could lead to a "longer visit" (IG1), thus affecting provider availability for others. Other HCP felt strongly that management of comorbidities reduced time spent managing issues specific to a rheumatologist's scope of practice. At a minimum, some HCP acknowledged the need to help educate primary care providers and patients about the need for screening for comorbid conditions such as heart disease and osteoporosis. Patients and HCP also viewed access to medications as important, including wait time from date of decision to escalate therapy to start of advanced therapy and between

Table 2. Themes defining high-quality RA care, descriptions of an ideal clinic, areas for improvement, and examples of potential solutions.

Theme	Ideal Clinic/Care Principle	Areas for Improvement	Potential Solutions
Access to care	Timely access to rheumatology care	<ul style="list-style-type: none"> - Reducing time from symptom onset to rheumatology care - Rheumatology workforce shortages and/or mismatch between supply and demand - Referral quality - Incentivizing new MOC 	<ul style="list-style-type: none"> - Central triage and access - Alternative MOC to increase capacity (i.e., nurse-led, ACPAC)
Evidence-informed, high-quality, patient-centered care for patients with RA including comorbidity care	<ul style="list-style-type: none"> - Timely ongoing care - Timely treatment (DMARD, advanced therapies) - Comorbidity screening/management 	<ul style="list-style-type: none"> - Challenges with timely access for flares - Delays for advanced therapy starts and switches - Challenges in finding time/expertise for comorbidity screening/management - Gaps in addressing mental health and wellness 	<ul style="list-style-type: none"> - Alternative MOC to increase capacity (i.e., nurse-led, ACPAC) and assist with screening/management for comorbidities - Specialized risk assessment clinics
Patient education and access to information	<ul style="list-style-type: none"> - Right amount of information at the right time - High-quality educational materials 	<ul style="list-style-type: none"> - Challenges with volume of information - Information overload (following diagnosis) 	<ul style="list-style-type: none"> - Patient/peer navigator - List of high-quality resources - Alternative MOC to assist with education (e.g., nurse-led) - Education while on waitlist - Online materials/videos
Multidisciplinary care	Access to rheumatology care including PT, OT, social work, vocational counseling, and pharmacy, among others	<ul style="list-style-type: none"> - Access to other professionals - Funding - Expertise and training in inflammatory arthritis for other professionals 	<ul style="list-style-type: none"> - Advanced training in musculoskeletal care (ACPAC) - Funding MOC to ensure allied health professionals are accessible
Improving patient outcomes	<ul style="list-style-type: none"> - Time to remission or lower disease activity state - Measuring pain, fatigue, disease activity, functional status 	Challenges with measuring outcomes consistently	<ul style="list-style-type: none"> - Alternative models of data collection to assist with measuring and monitoring outcomes - Electronic medical records
Improving patient experience	<ul style="list-style-type: none"> - Holistic care - Understanding patients on a personal level - Trust - Appropriate communication 	Lack of standardized measurement of patient experience	Alternative MOC to improve patient experience
Equity in healthcare delivery	Equitable access to linguistically appropriate, culturally safe, and culturally competent care	<ul style="list-style-type: none"> - Access to rheumatology care in rural/remote regions and underserved populations - Language barriers - Culturally safe and culturally competent care for some populations - Training and education of providers and patients around telehealth 	<ul style="list-style-type: none"> - Satellite clinics/mobile clinics - Telehealth - Alternative MOC to increase capacity in rural/remote regions - Provider education and advocacy skills

ACPAC: Advanced Care Practitioner in Arthritis Care; DMARD: disease-modifying antirheumatic drug; MOC: model of care; OT: occupational therapist; PT: physiotherapist; RA: rheumatoid arthritis.

switches in advanced therapies, as well as time from diagnosis to the first disease-modifying antirheumatic drug (DMARD; Table 4). Additional gaps identified by patients and HCP were in addressing mental health issues, as well as lifestyle, exercise, and dietary changes.

Information and educational materials. Access to information and educational materials was cited as an element of high-quality care, with patients emphasizing the need to receive the right amount of information at the right time. For example, having a list of where to access high-quality information about arthritis was suggested as a strategy to improve patient care.

Patients also described the high volume of information available (which was at times overwhelming, especially early after diagnosis) and suggested ways to better navigate the information. The concept of a “buddy system” (Patient FG1) or peer

navigation to facilitate information gathering and/or the health system itself was also discussed by patients.

HCP also noted that at early diagnosis a more coordinated approach could be offered for patient education. In 1 focus group, AHP suggested that education could even begin while patients are awaiting their initial appointment.

The use of alternative models of care was also discussed, including, but not limited to, nursing models to assist with delivering educational materials and ensuring patients were comfortable with the medical plan. Patients suggested that more innovative resources for education could include online materials and videos. HCP also noted a need to develop resources that were culturally and linguistically appropriate.

Multidisciplinary care. Multidisciplinary and team-based care were highlighted as important to high-quality RA care given

Table 3. Sample quotations from the “Access” theme.

Access (general importance)	<p>“I guess the first thing is you have to have access to the care. Before you can have quality, you have to have access.” (HCP FG2)</p> <p>“The biggest change is being able to dramatically change patient access, so that these patients can be identified first and then get them out to those resources. But we have to deal with this first before we can even think about tackling the rest.” (HCP FG2)</p> <p>“When you’re down, it’s harder to climb out and I keep thinking to myself when I’m waiting and I’m waiting and I’m waiting and it’s like oh my god, don’t make me wait too long, because it hurts so badly. Am I going to get back to where I was?” (Patient IG11)</p>
Symptom onset not captured in existing wait time measures	<p>“So I can strive to have a good wait time from that period of time, but really, the overall bigger picture is the wait time from the time that the patient first developed symptoms. And so, yes, the measurement is important, but I don’t think it gives the whole picture.” (HCP IG15)</p>
Challenge with meeting benchmarks wait times	<p>“We all strive to meet the benchmarks, but I don’t think many of us achieve them very consistently in spite of for best efforts, just because of the huge volumes that we’re facing.” (HCP IG6)</p> <p>“We have such lengthy wait times and we also hear through the grapevine that some family physicians don’t even refer because they say your wait time is like 2 years, 5 years, or whatever.” (HCP IG12)</p>
Mismatch between supply and demand	<p>“The problem is that we have a significant maldistribution of rheumatologists across the country. Downtown (City X), you’re twiddling your thumbs to find inflammatory arthritis, whereas (Small center Y), you’re up to your eyeballs in only inflammatory arthritis.” (HCP IG10)</p>
Poor quality referrals/lack of expertise in primary care	<p>“It probably speaks to the amount of time that’s devoted to rheumatology in medical school or whatever health care training.” (HCP IG15)</p> <p>“We get a ton (of patients) that come in late having been managed by other people.” (HCP FG3)</p> <p>“I’ve only been diagnosed for the last 5 years and I chased it down for probably 4 or 5 years, not knowing what was going on, and finally they sent me to a rheumatologist and after some RA tests were done and my numbers kept going up, so they finally sent me to a rheumatologist. And once I got in there, my doctor put me on medication and life was good again.” (Patient IG2)</p>
Potential solutions: Alternative models of care and central access and triage	<p>“I think that we should have advance nursing practice...like using those resources so much more efficiently, so that our rheumatologists can do what they do best and actually see new patients.” (Manager IG19)</p> <p>“It behooves us to have well-trained individuals at the front door, right? And that saves a lot of money, as opposed to hopping around from profession to profession to find out what’s wrong with me. You need someone who actually has the eyes to get you to that gold standard in the most expedited way.” (HCP IG9)</p>
Challenges in funding new models of care to improve access	<p>“But why are we not offering solutions to the waitlists? Why are we talking about things that should happen after the patient is seen? And there again is our inability to think about our part of this bottleneck. And how we can make a difference and it just requires doing things differently and we are not encouraged to do that.” (HCP FG2)</p>
Ongoing timely access for flares	<p>“And that (the care) is timely..., especially in the case of rheumatoid arthritis. It’s very episodic, so that I’m seen within a timely manner.” (Patient IG8)</p> <p>“So when I’m in trouble, 6 months is a long time to be waiting.” (Patient IG11)</p>

FG: focus group; HCP: healthcare provider; IG: interview group.

the complex needs of patients with RA. Unfortunately, access to multidisciplinary care was highlighted as lacking in many centers and described as an important area for resource development. Additionally, beyond access to physiotherapists and occupational therapists for management of disease, HCP discussed the need for access to social workers to help patients navigate financial concerns relating to access to medications, vocational counselling, and assistance with income support programs. In addition to lack of funding for AHP, human resource shortages of AHP with expertise in inflammatory arthritis was also noted as a deficit. In contrast, the Advanced Clinician Practitioner in Arthritis Care program²² was cited as an important innovation in the training of extended role practitioners in arthritis care, which is necessary for expanding and optimizing the rheumatology workforce through alternative models of care.

Improving patient-reported outcomes. A variety of outcomes including disease activity, pain, fatigue, and functional status were discussed by HCP and patients as important to monitor

and serve as guides in disease management. Challenges with measuring and monitoring these outcomes were discussed, given different availabilities of electronic health records and challenges with standardized collection of patient measures during routine clinical care. HCP in particular also emphasized that time to remission or lower disease activity are important concepts when considering the measurement of patient outcomes.

Patient experience and satisfaction with care. Patient experience of the care transaction and relationship with their provider was very important to patients and HCP when they were defining high quality of care. While this concept was infrequently measured using satisfaction or experience surveys, key defining features included emotional support and understanding and acknowledging who the patient was beyond their disease and the effect the disease had on their lives (Table 5). Central to the patient experience was approaching patient care with a more holistic approach, having trust in their physician and appropriate communication, and a sense of feeling “heard” (IG8).

Table 4. Sample quotations from themes of “high-quality, patient-centered care,” “information and educational materials,” and “patient outcomes.”

Theme: High-quality, patient-centered care	
Comorbidity care and lifestyle (controversial)	<p>“When we’re asked to do things that other people could do, that takes away from the time that we can spend using the specific expertise that we have for that person in front of us.” (HCP FG2)</p> <p>“I always, always have a very clear note when I see my patients at every visit that I return to the family doctor with my recommendation. But there’s a lot of ignorance in the community about the cardiovascular disease in arthritis.” (HCP IG4)</p> <p>“A lot of times, patients will want some dietary changes that they can make and lifestyle changes that they can make that would help, so that maybe they could have a little bit less medication. If we could actually spend time providing each patient with that, that would be ideal care, I think, for patients.” (HCP FG3)</p>
Access to medications	<p>“The duration from the time at the appointment where you’ve made the decision that you’re switching medications, or starting a new medication until the date you first pick up and start the new medication. That would be a wonderful thing to track as far as quality.” (Patient FG1)</p> <p>“It would be how long did it take them to get the sick person to a DMARD? Time to DMARD or biological or whatever the magic potion is. That’s the biggest metric of all. Time to DMARD.” (HCP IG9)</p>
Theme: Information and educational materials	
Right information, right time	<p>“Not all of us need the same amount of information. For some people, they don’t want to know.” (Patient FG1)</p> <p>“We live with the disease by ourselves more than we live with the disease with the people who help us with the disease. To have that information when you need it, in the way you need it...” (Patient FG1)</p>
Navigation of health information	<p>“There’s so much information. Because there’s so much information, what would be really helpful is having a roadmap for that information, having some guidance, so helping establish that credibility but not forcing a particular direction. It’s like a roadmap but then somebody to help you navigate it.” (Patient FG1)</p>
Importance of information early on and coordinated approach	<p>“I think we need to have a more coordinated approach to our newly diagnosed patients with respect to a how we handle their first visits and the education we provide.” (HCP FG3)</p>
Models of care to support delivery of information and education	<p>“It would be lovely to have that RN able to look at their sheet that we provide from when they’re leaving clinic, that does hopefully have a bit of a plan written out for them to make sure they don’t have any questions regarding that plan.” (HCP FG3)</p>
Theme: Patient outcomes	
Outcomes	<p>“It’s about trying to get them in remission or lower disease activity as quickly as possible, and also with the least burden on the system in terms of medications and access to care all the time.” (HCP FG2)</p>

FG: focus group; HCP: healthcare provider; IG: interview group; RN: registered nurse.

Equity. Equity in the provision of rheumatology services emerged as an overarching theme. Participants noted gaps in geographic access to care, in particular, access for rural and remote areas, as well as for Indigenous populations. Challenges were also identified in providing linguistically and culturally appropriate and safe care to Indigenous and other population groups.

The stratification of measurement based on region or socio-economic status was suggested by a policy maker as a means of measuring and monitoring equity in healthcare delivery. A number of potential solutions for models of care delivery to rural and remote regions were suggested, including traveling clinics and telehealth. Potential barriers that were discussed included patient buy-in for telehealth compared to a traditional in-person clinic visit, as well as the need for well-trained individuals to conduct physical exams and facilitate appropriate care at the remote site. In contrast, travel grants to allow patients to travel for healthcare appointments at distant academic centers were not always viewed by HCP as the most effective use of healthcare resources.

DISCUSSION

This work is part of a larger project to develop a framework for monitoring, measuring, and optimizing RA care in Canada with the central vision of improving patient-centered, high-quality

care for persons living with RA. This qualitative study provides important stakeholder perspectives on elements constituting high-quality RA care, promoting 7 main themes. There was near universal agreement on these main themes identified with the only area of potential controversy being the role of rheumatologists in comorbidity management. Six of these were used to develop strategic objectives for quality of care (Figure 1), while the 7th (equity) remains an overarching theme that needs to be considered when evaluating and addressing the other 6 objectives.

Our study’s results resonate with other qualitative studies evaluating perceptions on specific aspects of RA care. For example, a 2018 qualitative study by Barton, *et al*²³ explored clinician and patient perspectives on treatment goals and revealed patient knowledge and psychosocial dynamics (stress) as 2 major domains that have some overlap with our identified themes, including those pertaining to information and educational materials and patient experience with care. A recent qualitative study of barriers and facilitators for screening for hyperlipidemia among patients with inflammatory arthritis²⁴ highlights the need for improved communication around screening for this comorbidity, as well as the potential role of peer coaching, similar to the peer navigation concept discussed by our participants. Other relevant qualitative work has further explored domains identified by our work, including access to care²⁵ and shared decision making²⁶.

Table 5. Sample quotations from the themes of “multidisciplinary care,” “patient experience and satisfaction with care,” and “equity.”

Theme: Multidisciplinary care	
Multidisciplinary care	<p>“So each person taking a different chunk of the pie, so that feeling that my portion of the pie is much smaller because everyone has provided me a perspective of different things that I can try.” (Patient describing their use of different members of their care team IG8)</p> <p>“Because it really isn’t all about access to a rheumatologist. It’s access to rheumatology care.” (Patient IG11)</p> <p>“Just having a complete allied health team within the clinical setting... I think you have a stronger team because the rheumatologist...is kind of quarterbacking this and has a trusted team around him or her.” (HCP IG19)</p>
Gap in access to multidisciplinary care	<p>“If I want to go to see my rheumatologist, I can go see her. But the only thing I don’t really understand is why I’m on disability and it doesn’t cover things like physiotherapy, which would benefit my illness.” (Patient IG19)</p> <p>“Funding for the total patient care would be important and it doesn’t exist right now.” (Manager IG7)</p>
Social work	<p>“It’s important that we have the access to the expertise to help manage these situations because often I don’t have the expertise to counsel in terms of employment or what resources financially are available to patients.” (HCP FG2)</p>
Theme: Patient experience and satisfaction with care	
Patient experience and satisfaction with care	<p>“The element of emotional support which involves relationships, listening, building relationship, understanding who the person is in relation to themselves, their families, their work, their leisure, and all of that, and the impact as it’s unfolding from diagnosis and as it moves forward.” (HCP FG2)</p> <p>“I think in my experience, quality care would be where I feel that my issues and my concerns and my questions have been heard and they’ve been answered.” (Patient IG8)</p>
Theme: Equity	
Equity	<p>“And I think quality means that you have, not equal, but equitable service. So if you live in a rural community there are different ways of getting to that care. It’s not the same cookie cutter approach.” (HCP IG9)</p> <p>“We have no ability to provide for equity because we just don’t have the resources available for translation or delivering culturally appropriate care. We’re just sort of cut off at the knees from that perspective.” (HCP IG17)</p> <p>“Look at our regional breakdown, our subregional breakdown. It may be by facility if the data [are] available. It may be by age, sex, like it might be by income, neighborhood income if that’s what is available. So that would be something we would do routinely. And urban/rural...” (Policy maker IG13)</p> <p>“I think rural areas are underserved and I think that they... will have overall worse outcomes because they’re less likely to be able to come as frequently.” (HCP IG1)</p>

FG: focus group; HCP: healthcare provider; IG: interview group.

Other studies have evaluated RA care from a more general perspective. In a study of the UK National Rheumatoid Arthritis Society membership, the stories of 22 patients with RA were “mapped” to compare patients’ experiences with guidelines and recognized standards of care²⁷. Five themes that overlapped extensively with those from our study were identified, including primary care access and initial treatment; the effect/significance of time between seeing a consultant rheumatologist and receiving DMARD or biologic treatment; disease management and individualized care plans; access to multiprofessional teams; and access to patient education²⁷. In another UK-based study, patient views of RA healthcare were obtained with the aim of using these perspectives to help tailor service delivery through a total quality management framework²⁸. The results centered around the following themes: past experiences with the healthcare system, personal health beliefs, professional issues (secondary specialist care and primary care), strategies for interacting with healthcare staff, interaction with different types of health professionals, and organizational issues (visits and blood tests, clinic organization).

A unique aspect of the present study is the use of these qualitative data to inform strategic objectives for our RA quality framework²⁹. While other standards of RA care exist, including

the European League Against Rheumatism patient-centered standards for care for RA³⁰, these were developed based on practice guidelines combined with expert opinion using a modified Delphi panel that involved patient partners but included no apparent qualitative inquiry. Interestingly, the standards of care, including 16 statements, overlap thematically with the present study’s themes and strategic objectives, highlighting the transferability of our findings as areas of importance in high-quality RA care.

While our study represents a comprehensive qualitative evaluation of Canadian RA quality of care, there are a number of limitations. First, it is possible that the participants’ experiences and views are not typical of all participant types. This may be especially true for persons living with RA in our study because they were recruited through advocacy organizations, and individuals engaged in these organizations may have different sociodemographic characteristics than a general RA clinic population. Clinic recruitment was unfortunately not feasible given the national scope of this project. The majority of our patient participants were female, and no other demographic data were collected such as age or socioeconomic status; this may have affected results. It is likely that different elements of high quality of care may be important to different populations, for example,

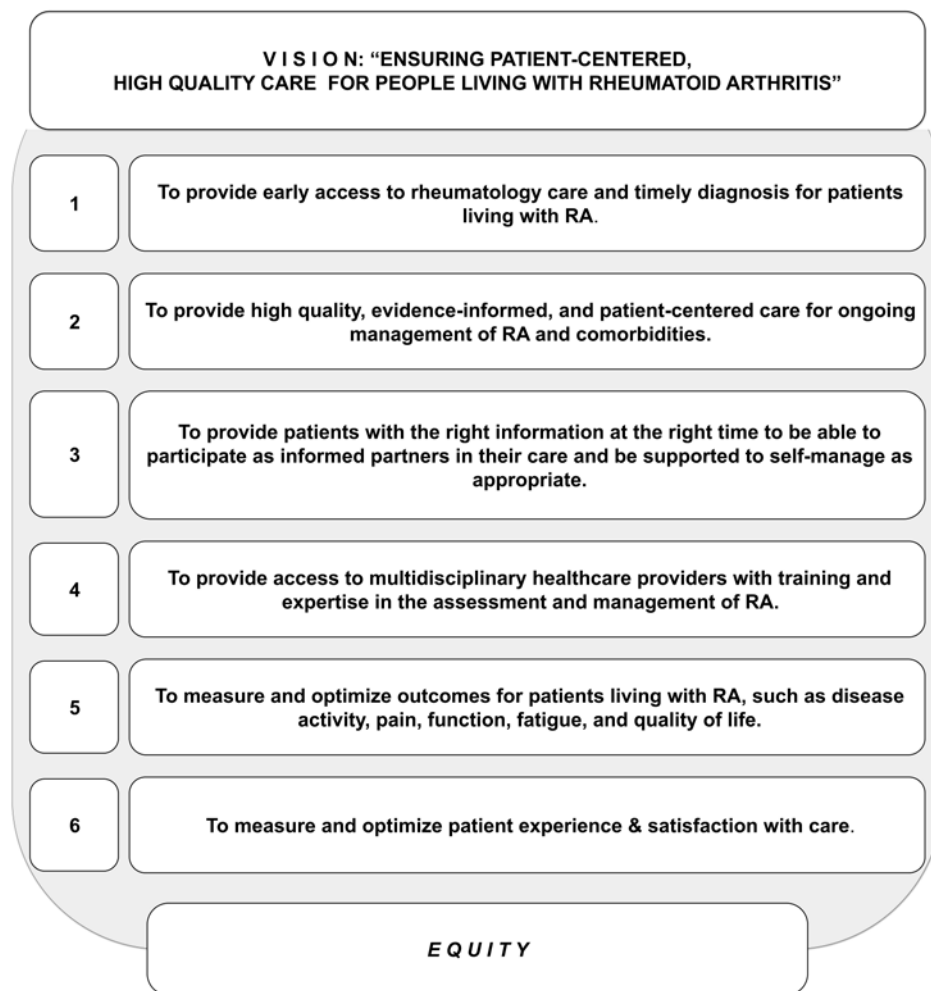


Figure 1. Vision statement and strategic objectives for quality improvement for RA. RA: rheumatoid arthritis.

Indigenous populations³¹. We suggest that future studies consider evaluation of these strategic objectives for high quality of care and their relevance to different patient populations across Canada. While a diverse sampling of HCP, managers, and health-care leaders was sought from across the country, it is possible that those participating in the study may have had more experience in developing models of care for arthritis and measurement frameworks, which could have influenced the themes arising. Analyses did not specifically elicit between-province comparisons. We also did not distinguish in our analysis of HCP between rheumatologists and other types of arthritis HCP (e.g., nurses or physiotherapists), because many of these individuals had advance practice roles. Future study could be undertaken to better understand different HCP perspectives on these topics; in particular, comorbidity screening arose as the most controversial topic.

Early access to rheumatology care, ongoing high-quality care, the right information and educational materials at the right time, access to multidisciplinary care, and optimizing patient experience and outcomes all emerged as important themes from this work; these represent the foundation for the RA quality framework. Health equity was an overarching theme across all

strategic objectives, with particular attention paid to improving access to care and outcomes for patients living in rural and remote regions, as well as in underserved patient populations. In future work, performance measures will be selected to address the strategic objectives and populate the measurement framework, which will then be tested in different settings. Ongoing patient participation and arthritis provider involvement will be important as the measures are selected to address the strategic objectives.

ACKNOWLEDGMENT

The authors would like to acknowledge the support from the Canadian Rheumatology Association (CRA) in helping provide a venue for the focus groups and an online platform for public comment for this work. We would also like to acknowledge the CRA and the Arthritis Alliance of Canada for supporting this work through updates to their committees and membership.

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