

Priorities for High Quality Care in Rheumatoid Arthritis: Results of Patient, Health Professional, and Policymaker Perspectives

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Objectives: 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, healthcare 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 de-identified 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, and 6) patient experience and satisfaction with care, and 7) Equity, 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 seven strategic objectives identified highlight priorities for RA quality of care to be used in developing the National RA Quality Measurement Framework.

INTRODUCTION

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 2010-2030) direct and indirect costs of \$162 billion by 2030 (5). The rates of mortality associated with RA are two-fold higher compared to the general population (6-8). 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 treatment (9). The measures were tested in five Canadian provinces and are vital in identifying important gaps in care to drive quality improvement (10-13). Building upon this work, we have partnered with the Canadian Rheumatology Association (CRA) representing rheumatologists, and the AAC (14) representing over 36 arthritis organizations, to develop a comprehensive framework for quality measurement in RA encompassing patient-level outcomes. The framework's development was modelled after Kaplan and Norton's Balanced Scorecard (BSC) Framework (15). A 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 targets (16).

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 (HCPs), 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.

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 semi-structured interviews were used to identify elements of high-quality RA care.

Participants & Recruitment

Stakeholders with expertise, knowledge, or experience in RA care (rheumatologists and AHPs), people living with RA, clinic managers, regional/provincial healthcare leaders and policy makers were recruited between December 2017 to 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. Allied health professionals (AHP) were invited to participate by directors of regional arthritis rehabilitation and therapy programs and the national Arthritis Health Professions Association (AHPA). People living with RA were recruited through advocacy organizations including the Arthritis Patient Advisory Board (APAB), the Canadian Arthritis Patient Alliance (CAPA), Arthritis Consumer Experts (ACE), and The Arthritis Society (TAS). 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 & Interview Objectives

The objectives of the focus groups and interviews were 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 as well as any barriers and facilitators for care.

Three semi-structured focus group and interview guides tailored to participant type were developed based on the research questions (see Appendix for sample questions). The facilitators followed the guides with questions and probes assessing the objectives and encouraged participants to share their views. Focus groups and interviews were digitally recorded, and transcribed verbatim by a transcriptionist.

Data Collection

Focus Groups and Interviews

An experienced qualitative researcher and a research associate trained in qualitative methods co-facilitated the focus groups. Separate focus groups were held with 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 de-identified and imported into QSR International NVivo 12 software for data management and analysis. A six-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; and 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 re-examined 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 Lincoln and Guba's (20) 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 reviewed the decision-making record and made sure the process was logical and control 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), which provided balanced perspectives. Credibility was established with frequent updates and

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discussion of findings to the CRA Quality Care Committee and the AAC during scheduled teleconferences. Transferability was accomplished through rich descriptions of findings with selected quotations so those seeking to apply the learnings from the work to their own site could judge the generalizability of the results (17).

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 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 three focus groups with 6-10 participants each, 13 1:1 interviews, and 6 smaller focus groups of 2-4 people were conducted. Focus groups lasted 90-120 minutes and

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interviews lasted 45-90 minutes. Table 1 outlines the participant types and regional distributions. In total, 54 people participated in either a focus group or interview. Three separate face to face focus groups were conducted including: AHPs at a rheumatology clinic (registered nurses and a physiotherapist, n=10), AHPs (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 via telephone) and smaller focus groups of 2-4 people by teleconference (8 rheumatologists, 7 patients, 4 clinic managers, 9 healthcare leaders/policy makers, 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 including: 1) access to care, 2) evidence-informed high-quality patient centered care for patients with RA including care for other co-existing 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 3-5, were used to develop strategic objectives for quality improvement (shown in Figure 1).

Access

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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 HCPs discussed the CRA's wait time benchmarks for rheumatology consultation, which suggest a maximum time between referral and rheumatologist appointment (21). A number of participants highlighted that the wait time measures were suboptimal as they do not capture the time from patient symptom onset. Furthermore, HCPs expressed concern that the wait time benchmarks were not easily achievable due to the large volumes of referrals received in their centers. A frequently cited reason for prolonged wait times was the mismatch between "supply and demand" (IG 6). 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 which did not contain adequate information for appropriate triage. Central access and triage models were described by some HCPs as an approach of improving access, with some models including allied HCPs 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

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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 HCPs 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” thus impacting provider availability for others. Other HCPs felt strongly that management of comorbidities reduced time spent managing issues specific to a rheumatologists’ scope of practice. At a minimum, some HCPs 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 HCPs also viewed access to medications as important, including wait time from date of decision to escalate therapy to start of advanced therapy and between switches in advanced therapies, as well as time from diagnosis to the first disease modifying anti-rheumatic drug (DMARD). Additional gaps identified by patients and HCPs were in addressing mental health issues, as well as lifestyle, exercise and dietary changes.

Information & 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” or peer navigation to facilitate information

gathering and/or the health system itself was also discussed by patients.

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

The use of alternative models of care including, but not limited to, nursing models to assist with delivering educational materials and ensuring patients were comfortable with the medical plan was also discussed. Patients suggested that more innovative resources for education could include online materials and videos. HCPs 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 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, HCPs 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 allied health providers, human resource shortages of AHPs with expertise in inflammatory arthritis was also noted as a deficit. In contrast, the ACPAC program (22) was cited as an important innovation in the training of extended role practitioners in arthritis care, 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 HCPs 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. HCPs 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 HCPs 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 impact 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”.

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 and also 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 socioeconomic 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 travelling clinics and telehealth. Buy-in from the patient in the process of telehealth compared to a traditional in-person clinic visit was discussed as a potential barrier as was the need for individuals well trained in physical exam at the remote site to facilitate appropriate care. In contrast, travel grants to allow patients to travel for healthcare appointments at distant academic centers were not always viewed by HCPs 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 which 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 arthritis (24) 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 care (25) and shared decision-making (26).

Other studies have evaluated RA care from a more general perspective. In a study of United Kingdom (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 care (27). Five themes that overlapped extensively with those from our study were identified including: primary care access and initial treatment, the impact/significance of time to seeing a consultant rheumatologist and receiving DMARD or biologic treatment, disease management and individualized care plans, access to multi-professional teams, and access to patient education (27). In another UK-based study, patient views of RA health care were obtained with the aim of using these perspectives to help tailor service delivery through a total quality management framework (28). 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 health care 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 this qualitative data to inform strategic objectives for our RA quality framework. While other standards of RA care exist, including the European League Against Rheumatism (EULAR) patient-centered standards for care for RA (29). These were developed based on practice guidelines combined with expert opinion using a modified Delphi panel including 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 to high quality RA care.

While our study represents a comprehensive qualitative evaluation of Canadian RA quality of care, there are a number of limitations. Firstly, 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 as 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 which may have impacted results. It is likely that different elements of high quality of care may be important to different populations, for example Indigenous populations (30). We suggest that future studies could 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 HCPs, manager and healthcare leaders was sought from across the county, 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. Analysis did not specifically elicit

between province comparisons. We also did not distinguish in our analysis of HCPs between rheumatologists and other types of arthritis HCPs (e.g. nurses or physiotherapists) as many of these individuals had advance practice roles. Future study could be undertaken to better understand different HCPs perspectives on these topics and in particular comorbidity screening, which arose as the most controversial topic.

Conclusion

Early access to rheumatology care, ongoing high-quality care, the right information and educational materials at the right time, access to multidisciplinary care, optimizing patient experience and outcomes all emerged as important themes from this work, and 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 and 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.

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REFERENCES

1. O'Donnell S, McRae L, Toews J, Pelletier L, CDDSS Arthritis Working Group. National Surveillance of Arthritis in Canada, Results from the Canadian Chronic Disease Surveillance System (CCDSS). Proceedings of the Canadian Rheumatology Association Annual Scientific Meeting 2019.
2. Public Health Agency of Canada. Canadian Chronic Disease Surveillance System (CCDSS). 2018 [updated 2018; cited 2019 May 17]; Available from: <https://infobase.phac-aspc.gc.ca/CCDSS-SCSMC/data-tool/>.
3. Burton W, Morrison A, Maclean R, Ruderman E. Systematic review of studies of productivity loss due to rheumatoid arthritis. *Occup Med (Lond)* 2006;56:18-27.
4. Lacaille D. Arthritis and employment research: where are we? Where do we need to go? *J Rheumatol Suppl* 2005;72:42-5.
5. Bombardier CH, G.; Mosher, D. The Impact of Arthritis in Canada: Today and Over the Next Thirty Years. Arthritis Alliance of Canada; 2011 [updated 2011; cited 2015 March 25]; Available from: www.arthritisalliance.ca.
6. Mikuls TR, Fay BT, Michaud K, Sayles H, Thiele GM, Caplan L, et al. Associations of disease activity and treatments with mortality in men with rheumatoid arthritis: results from the VARA registry. *Rheumatology (Oxford)* 2011;50:101-9.
7. England BR, Sayles H, Michaud K, Caplan L, Davis LA, Cannon GW, et al. Cause-Specific Mortality in Male US Veterans With Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)* 2016;68:36-45.
8. Gonzalez A, Maradit Kremers H, Crowson CS, Nicola PJ, Davis JM, 3rd, Thorneau TM, et al. The widening mortality gap between rheumatoid arthritis patients and the general population. *Arthritis Rheum* 2007;56:3583-7.
9. Barber CE, Marshall DA, Mosher DP, Akhavan P, Tucker L, Houghton K, et al. Development of System-level Performance Measures for Evaluation of Models of Care for Inflammatory Arthritis in Canada. *J Rheumatol* 2016;43:530-40.
10. Barber C, Lacaille D, Faris P, Mosher D, Katz S, Homik J, et al. Reporting of Arthritis Alliance of Canada (AAC) System-Level Performance Measures for Patients with Rheumatoid Arthritis (RA) in Alberta. *Journal of Rheumatology* 2019;46:801-.
11. Barber C, Marshall D, Szefer E, Thompson D, Lacaille D, editors. Evaluating the Quality of Care for Rheumatoid Arthritis. Annual European Congress of Rheumatology; 2018; Amsterdam.
12. Barber CEH, Thorne JC, Ahluwalia V, Burt J, Lacaille D, Marshall DA, et al. Feasibility of Measurement and Adherence to System Performance Measures for Rheumatoid Arthritis in 5 Models of Care. *J Rheumatol* 2018;45:1501-8.
13. Barber CEH, Schieir O, Lacaille D, Marshall DA, Barnabe C, Hazlewood G, et al. High Adherence to System-Level Performance Measures for Rheumatoid Arthritis in a National Early Arthritis Cohort Over Eight Years. *Arthritis Care Res (Hoboken)* 2018;70:842-50.
14. Arthritis Alliance of Canada. Arthritis Alliance of Canada. [cited December 19, 2019]; Available from: <http://arthritisalliance.ca/en/>.
15. Kaplan RS, Norton DP. Translating strategy into action-The Balanced Scorecard. Boston, Massachusetts: Harvard Business School Press; 1996.

16. Kaplan RS, Norton DP. The balanced scorecard--measures that drive performance. *Harvard business review* 1992;70:71-9.
17. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *Int J Qual Meth* 2017;16.
18. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3:77-101.
19. Glaser BG, Strauss A. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine Pub. Co.; 1967.
20. Lincoln Y, Guba EG. *Naturalistic Inquiry*. Newbury Park, CA: Sage; 1985.
21. Wait Time Alliance (WTA). *Time to Close the Gap: Report Card on Wait Times in Canada* (2014). 2014 [updated 2014; cited 2015 February 23]; Available from: <http://www.waittimealliance.ca/wta-reports/2014-wta-report-card/>.
22. Lunden K, Shupak R, Sunstrum-Mann L, Galet D, Schneider R. Leading change in the transformation of arthritis care: development of an inter-professional academic-clinical education training model. *Healthc Q* 2008;11:62-8.
23. Barton JL, Hulen E, Schue A, Yelin EH, Ono SS, Tuepker A, et al. Experience and Context Shape Patient and Clinician Goals For Treatment of Rheumatoid Arthritis: A Qualitative Study. *Arthritis Care Res (Hoboken)* 2018;70:1614-20.
24. Navarro-Millan I, Young SR, Shurbaji S, McDavid C, Cornelius-Schechter A, Johnson B, et al. Barriers and facilitators for screening and treatment of hyperlipidemia among patients with inflammatory arthritis. *BMC Rheumatol* 2020;4:26.
25. Suter LG, Fraenkel L, Holmboe ES. What factors account for referral delays for patients with suspected rheumatoid arthritis? *Arthritis Rheum* 2006;55:300-5.
26. Binder-Finnema P, Dzurilla K, Hsiao B, Fraenkel L. Qualitative Exploration of Triangulated, Shared Decision-Making in Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)* 2019;71:1576-82.
27. Oliver S, Bosworth A, Airoidi M, Bunyan H, Callum A, Dixon J, et al. Exploring the healthcare journey of patients with rheumatoid arthritis: a mapping project - implications for practice. *Musculoskeletal care* 2008;6:247-66.
28. Lempp H, Scott DL, Kingsley GH. Patients' views on the quality of health care for rheumatoid arthritis. *Rheumatology (Oxford)* 2006;45:1522-8.
29. Stoffer MA, Smolen JS, Woolf A, Ambrozic A, Bosworth A, Carmona L, et al. Development of patient-centred standards of care for rheumatoid arthritis in Europe: the eumusc.net project. [10.1136/annrheumdis-2013-203743]: *Ann Rheum Dis*. 2013 Aug 6;; 2013 [updated 2013; cited]; Available from: <http://dx.doi.org/10.1136/annrheumdis-2013-203743>.
30. Thurston WE, Coupal S, Jones CA, Crowshoe LF, Marshall DA, Homik J, et al. Discordant indigenous and provider frames explain challenges in improving access to arthritis care: a qualitative study using constructivist grounded theory. *Int J Equity Health* 2014;13:46.

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

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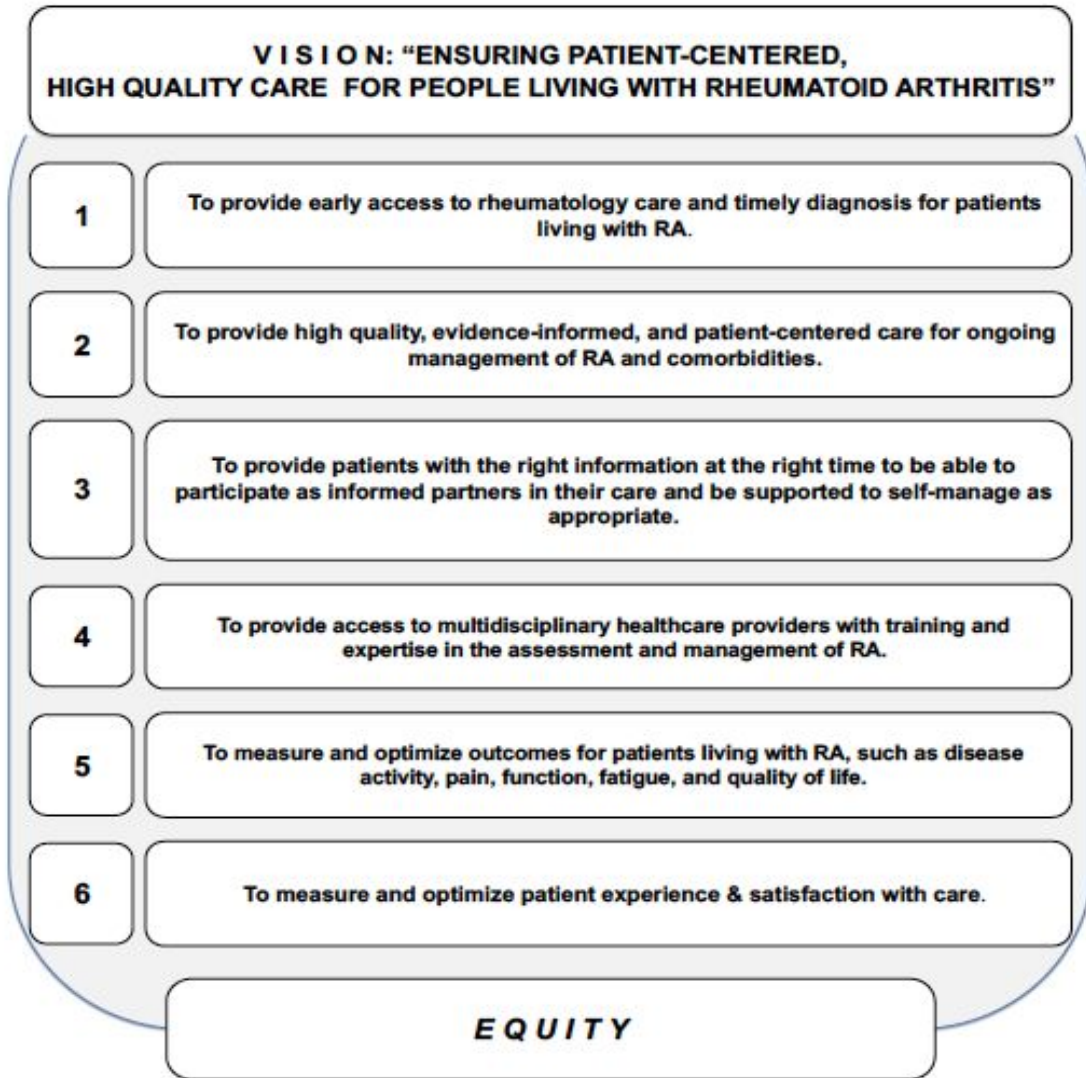


Table 1. Participant type and regional distribution.

Province ¹	PT	RN	Social Worker	Pharmacist	Patient	Rheumatologist	Manager	Regional/provincial healthcare leaders and policy makers	Total
British Columbia		1	1		9 ²	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

Physiotherapist (PT), Registered Nurse (RN)

¹ We had no participants from Saskatchewan, the Northwest Territories, Nunavut or the Yukon.

² One patient participated in both an interview and in the patient focus group

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Table 2. Themes defining high quality rheumatoid arthritis 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	-Reducing time from symptom onset to rheumatology care -Rheumatology workforce shortages and/or mismatch between supply and demand -Referral quality -Incentivizing new MOC	-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	-Timely ongoing care -Timely treatment (DMARDs, advanced therapies) -Comorbidity screening/management	-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 & wellness	-Alternative MOC to increase capacity (i.e., nurse led, ACPAC) and to assist with screening/management for comorbidities -Specialized risk assessment clinics
Patient education and access to information	-Right amount of information at the right time -High quality educational materials	-Challenges with volume of information -Information overload (following diagnosis)	-Patient/peer navigator -List of high-quality resources -Alternative MOC to assist with education (e.g., nurse-led) -Education while waiting on wait list -Online materials/videos
Multidisciplinary care	Access to rheumatology care including PT, OT, social work, vocational counselling, pharmacy among others.	-Lack of access to other professionals -Funding -Lack of expertise and training in inflammatory arthritis for other professionals	-Advanced training in musculoskeletal care (ACPAC) -Funding MOC to ensure allied health professionals are accessible
Improving patient outcomes	-Time to remission or lower disease activity state -Measuring pain, fatigue, disease activity, functional status	Challenges with measuring outcomes consistently	-Alternative models of data collection to assist with measuring and monitoring outcomes -Electronic medical records
Improving patient experience	-Holistic care -Understanding patients on a personal level -Trust -Appropriate communication	Lack of standardized measurement of patient experience	Alternative MOC may improve patient experience
Equity in the delivery of healthcare	Equitable access to linguistically appropriate and culturally safe and culturally competent care	-Access to rheumatology care in rural/remote regions and in underserved populations -Language barriers -Culturally safe and culturally competent care for some populations is currently lacking -Training and education of providers and patients around telehealth	-Satellite clinics/mobile clinics -Telehealth -Alternative MOC to increase capacity in rural/remote regions Provider education and advocacy skills

Advanced Care Practitioner in Arthritis Care (ACPAC), Disease Modifying Anti-rheumatic drugs (DMARD); Model of Care (MOC); Physiotherapy (PT); Occupational Therapist (PT)

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

Access (general importance)	<p><i>“I guess the first thing is you have to have access to the care. Before you can have quality, you have to have access.”</i> (Healthcare provider FG2).</p> <p><i>“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.”</i> (Healthcare provider FG2)</p> <p><i>“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?”</i> (Patient IG 11)</p>
Symptom onset not captured in existing wait time measures	<p><i>“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.”</i> (Healthcare provider IG15)</p>
Challenge with meeting benchmarks for wait times	<p><i>“We all strive to meet the benchmarks, but I don’t think many of us achieve them very consistently in spite of best efforts, just because of the huge volumes that we’re facing.”</i> (Healthcare provider IG6)</p> <p><i>“... 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 two years, five years or whatever”</i> (Healthcare provider IG12)</p>
Mismatch between supply and demand	<p><i>“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.”</i> (Healthcare provider IG10)</p>
Poor quality referrals/lack of expertise in primary care	<p><i>“...it probably speaks to the amount of time that’s devoted to rheumatology in medical school or whatever healthcare training.”</i> (Healthcare provider IG15)</p> <p><i>“We get a ton that come in just late having been managed by other people.”</i> (Healthcare provider FG3)</p> <p><i>“I’ve only been diagnosed for the last five years and I chased it down for probably four or five 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.”</i> (Patient IG2)</p>
Potential solutions: Alternative models of care and central access and triage	<p><i>“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...”</i> (Manager IG19)</p> <p><i>“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.”</i> (Healthcare provider IG9)</p>

Challenges in funding new models of care to improve access

"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."
(Healthcare provider FG2)

Ongoing timely access for flares

"And that its timely I think is responsive especially in the case of rheumatoid arthritis. It's very episodic, so that I'm seen within a timely manner...." (Patient IG8)

"So when I'm in trouble, six months is a long time to be waiting" (Patient IG11)

Interview group (IG); Focus Group (FG)

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)

“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.” (Healthcare provider FG2)

“I always, always have a very clear note when I see my patients at every visit. That return to the family doctor with my recommendation. But there’s a lot of ignorance in the community about the cardiovascular disease in arthritis....” (Healthcare provider IG4)

“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.” (Healthcare provider FG3)

Access to medications

“...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)

“It would be how long did it take them to get the sick person to a DMARD? Time to DMARD or biologic or whatever the magic potion is. That’s the biggest metric of all. Time to DMARD.” (Healthcare provider IG9)

THEME: INFORMATION & EDUCATIONAL MATERIALS

Right information right time

“...not all of us need the same amount of information. For some people, they don’t want to know.” (Patient FG1)

“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)

Navigation of health information

“...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)

Importance of information early on and a coordinated approach

“I think we need to have a more coordinated approach to our newly diagnosed patients with respect to how we handle their first visits and the education we provide.” (Healthcare provider FG3)

Models of care to support delivery of information and education

“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.” (Healthcare provider FG3)

THEME: PATIENT OUTCOMES

Outcomes

“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.” (Healthcare provider FG2)

Interview group (IG); Focus Group (FG)

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

THEME: MULTIDISCIPLINARY CARE**Multidisciplinary care**

“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)

“Because it really isn’t all about access to a rheumatologist. Its access to rheumatology care...” (Patient IG11)

“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.” (Healthcare provider IG19)

Gap in access to multidisciplinary care

“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)

Social work

“Funding for the total patient care would be important and it doesn’t exist right now.” (Manager IG7)

“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...(Healthcare provider FG2)

THEME: PATIENT EXPERIENCE & SATISFACTION WITH CARE**Patient experience and satisfaction with care**

“...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.” (Healthcare provider FG2)

“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)

THEME: EQUITY**Equity**

“And I think quality means that you have not equal, but equitable service. So if you live in a rural community there a different ways of getting to that care. It’s not the same cookie cutter approach.” (Healthcare provider IG9)

“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...” (Healthcare provider IG17)

“...look at our regional breakdown, our sub-regional breakdown. It may be by facility if the data is available. It maybe 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)

“I think rural areas are under-served and I think that they... will have overall worse outcomes because they’re less likely to be able to come as frequently...” (Healthcare provider IG1)

Interview group (IG); Focus Group (FG)