# Models of Arthritis Care: A Systems-level Evaluation of Acceptability as a Dimension of Quality of Care

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ABSTRACT. Objective. To describe a systems-level baseline evaluation of central intake (CI) and triage systems in arthritis care within Alberta, Canada. The specific objectives were to (1) describe a process for systems evaluation for the provision of arthritis care; (2) report the findings of the evaluation for different clinical sites that provide arthritis care; and (3) identify opportunities for improving appropriate and timely access based on the findings of the evaluation.

*Methods.* The study used a convergent mixed methods design. Surveys and semistructured interviews were the main data collection methods. Participants were recruited through 2 rheumatology clinics and 1 hip and knee clinic providing CI and triage, and included patients, referring physicians, specialists, and clinic staff who experienced CI processes.

**Results.** A total of 237 surveys were completed by patients (n = 169), referring physicians (n = 50), and specialists (n = 18). Interviews (n = 25) with care providers and patients provided insights to the survey data. Over 95% of referring physicians agreed that the current process of CI was satisfactory. Referring physicians and specialists reported issues with the referral process and perceived support in care for wait-listed patients. Patients reported positive experiences with access and navigation of arthritis care services but expressed concerns around communication and receiving minimal support for self-management of their arthritis before and after receiving specialist care.

*Conclusion.* This baseline evaluation of CI and triage for arthritis care indicates satisfaction with the service, but areas that require further consideration are referral completion, timely waiting lists, and further supporting patients to self-manage their arthritis. (First Release May 1 2020; J Rheumatol 2020;47:1431–9; doi:10.3899/jrheum.190501)

Key Indexing Terms: OSTEOARTHRITIS HEALTH SERVICE RESEARCH

Hip and knee osteoarthritis (OA) and rheumatoid arthritis (RA) are significant contributors to the global disability burden<sup>1,2</sup>. In Canada it is estimated that the prevalence of diagnosed OA is 14.2% (15.6% among women, 12.4% among men)<sup>3</sup>, causing a reduced quality of life due to chronic

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pain, a loss of independence in activities of daily living, and poorer mental health<sup>4</sup>. A number of factors appear to be accelerating the rising prevalence of OA including obesity and an ageing population<sup>3</sup>.

OA is the most common presentation of arthritis, and with

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no cure, endstage OA is primarily managed through surgical intervention<sup>5</sup>. RA has an autoimmune etiology requiring timely diagnosis and pharmaceutical intervention to prevent extensive joint damage6,7. In Canada, waiting times for joint replacement surgeries, such as hip and knee, continue to grow<sup>8,9</sup>, yet doctors are performing more of these procedures than previously reported<sup>8</sup>. Similar trends can be observed for patients referred for RA<sup>10,11</sup>, where benchmark waiting times are rarely achieved, even for urgent referrals<sup>10,12</sup>. Incomplete referrals, variability in waiting times for different rheumatologists, and geographic location all affect waiting times in primary and specialty care<sup>11</sup>. One recommended strategy to manage high-volume referrals for specialty care, such as orthopedics and rheumatology services, is central intake (CI) and triage systems, which pool referrals to streamline triage and allow for timely specialist review based on urgency<sup>13,14,14a</sup>. CI are usually a central part of an overall model of care that provides a particular type of health service, informed by theory evidence and defined standards<sup>15</sup>. These defined core components provide a structure for the implementation and subsequent evaluation of care.

Systems-level quality improvement (QI) initiatives in healthcare and healthcare service provision frequently focus on the principles of "co-design"<sup>16,17</sup> and partnerships<sup>18,19,20</sup>. Co-design enables patients, families, and practitioners to design improvement initiatives together, in partnership<sup>17</sup>. These approaches draw feedback and perspectives from multiple participants as a means of enacting effective QI change in complex service pathways<sup>21,22</sup>. Common overarching goals of these system QI interventions include (1) the improvement of the experience for all involved, and (2) more equal distribution of the control and design of service delivery among them.

The initial introduction of CI systems to manage arthritis care referrals in Alberta was a QI initiative to shorten waiting lists and enhance access to specialists<sup>14,23,24</sup> by engaging patients in service improvement research and implementation of QI initiatives in care delivery<sup>25,26</sup>. Developing performance measures for use in arthritis research and QI efforts has been a central component for the provision of arthritis care<sup>27</sup>. Twenty-eight key performance indicators (KPI; Table 1) measuring healthcare service delivery in OA and RA were developed using RAND ExpertLens, a modified Delphi process<sup>28</sup>. This QI measurement framework was based on the Health Quality Council of Alberta's Alberta Quality Matrix for Health<sup>28,29</sup>, with 6 dimensions of quality of care: acceptability, accessibility, appropriateness, safety, effectiveness, and efficiency<sup>28</sup>.

This report describes a systems-level baseline evaluation of the current CI and triage systems across 3 different sites of arthritis care in Alberta, Canada, focusing on the acceptability KPI of different patient and caregiver experiences<sup>29</sup>. The specific objectives of this manuscript are to (1) describe a process for systems evaluation for the provision of arthritis care (patients with OA, patients with RA, referring physicians, specialist physicians, and clinic staff); (2) report the findings of the evaluation for different clinical sites that provide arthritis care; and (3) identify opportunities for improving appropriate and timely access based on the findings of the evaluation.

## MATERIALS AND METHODS

The study design was a convergent mixed methods evaluation, where quantitative data from surveys and qualitative data from semistructured interviews were simultaneously collected and analyzed to develop a comprehensive understanding of the CI process in arthritis care within Alberta<sup>30</sup>.

*Setting.* Alberta Health Services has 16 specialized Strategic Clinical Networks (SCN) to facilitate collaboration between systems administrators, frontline clinicians, researchers, and patients to promote innovative, evidence-based care and improve the patient experience and health outcomes<sup>31,32</sup>. In Alberta, there are about 2500 new cases of RA per year and about 10,000 surgical patients (hip and/or knee replacements) annually. In consultation with the Bone and Joint Health SCN, 3 established CI sites eligible for evaluation were identified. At the time of the study there were only 2 rheumatology sites and 1 orthopedic site with CI.

Site A serves as a CI for hip and knee arthroplasty for southern Alberta, averaging 1200 referrals per year with 4 specialists (orthopedic surgeons). Referrals and diagnostic radiographs are received electronically or by fax and reviewed by nursing staff for completion and urgency. Site B receives referrals resulting in rheumatology diagnoses and uses a CI system model where 2800 to 4000 total referrals are received by fax per year and triaged by 11 specialists (rheumatologists). Site C has 29 specialists (rheumatologists) and receives 6000 referrals by fax per year, triaged manually by nursing staff and mainly nurse-led<sup>24</sup>.

Sites B and C have an on-call rheumatologist for primary care physicians (PCP) to call for advice and referral expediting. They manage 70% of all arthritis patients and referrals for the province. All sites require a referral from the patients' PCP.

Surveys. Surveys were developed for each group informed by the previously developed KPI<sup>31</sup>, local referral guidelines<sup>33</sup>, and recommendations from the literature (Supplementary Data 1, available with the online version of this article). Our purpose was not to undertake lengthy survey development but to use previously developed tools such as the Patient Experience Survey instrument for the Canadian Institute for Health Information and the Primary Health Care Survey project<sup>34</sup>. These were collaboratively adapted and contextualized to enable them to work in our environment. The survey selection was based on its application of measurement concepts (i.e., things we were told to measure to see whether CI could enable improvement on these areas). Additionally, the KPI development workgroup provided feedback on which questions to include from which survey. For example, for the Patient Experience Survey instrument, we used prior research that had collectively identified what was important for people living with OA and RA<sup>35,36</sup>, to inform the decisions regarding survey items for inclusion. The patient experience survey had 23 items that included experiences from initial consultation with the family physician, the referral process, and care at the clinic. The specialist physician survey included 5 items to measure experience with various components of CI (e.g., the quality of the referring physician's referral). The referring physician survey had 23 items and included components of CI (e.g., the referral requirements, treatment effect on the patient, access). Each group had the opportunity to comment on the survey for face validity prior to finalization and the surveys appear in Supplementary Data 1 (available with the online version of this article).

*Interviews*. Semistructured interview protocols for CI clinic staff examined implementation successes and challenges, to determine how the various structures and processes were working (Supplementary Data 1, available with the online version of this article). Patient interviews revealed their

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*Table 1*. Key performance indicators (KPI; n = 28) for CI in arthritis care in Alberta<sup>30</sup> according to the Health Quality Council of Alberta's Dimensions of Quality<sup>31</sup>.

Dimensions of Quality Care	RA KPI	OA KPI		
Acceptability				
Health services are respectful	Patient experience with centralized intake			
and responsive to user needs,	Referring clinician's experience with centralized intal			
<i>preferences and expectations.</i> MSK specialty care provider experience with centralized intake				
Accessibility	Administrative staff and allied health professional experience	with centralized intake		
Accessibility Health services are obtained in	Time from RA referral receipt to referral completion for	Time from OA referral receipt to referral completion for		
the most suitable setting in a reasonable time and distance.	initially incomplete referrals	initially incomplete referrals		
	Waiting times for patients with established RA	Time from receipt of complete OA referral to MSK appointment		
	Percentage of patients who receive information available for management while waiting for fir			
Appropriateness				
Health services are relevant to	Percentage of patients with new-onset RA with at least	Percentage of OA referrals scored using Western		
user needs and are based on accepted or evidence-based practice Effectiveness	1 visit to a rheumatologist in the first year of diagnosis   e. Percentage of referrals rejected or redirected when	Canada Waiting List priority referral criteria en received at centralized intake		
Health services are based on scientific knowledge to achieve desired outcomes.	Percentage of RA patients treated with a DMARD during the measurement year	Distribution of OA referrals in each urgency category (as scored using the Western Canada Waiting List referral tool)		
	Agreement of centralized intake suspected diagnosis vs confirmed diagnosis of RA	Agreement of centralized intake suspected diagnosis of severe OA cases (e.g., patients who are candidates for hip or knee joint replacements) vs confirmed diagnosis of severe OA		
Efficiency				
Resources are optimally used in achieving desired outcomes.	Percentage of RA referrals received with complete information	Percentage of OA referrals received with complete information		
	Waiting times for rheumatologist consultation for patients with new-onset RA	Ratio of patient flow to estimated clinic capacity of OA teams participating in centralized intake		
	Rheumatologists per 100,000 population Ratio of patient flow to clinic capacity of RA teams participating in centralized intake	Operating room time for arthroplasty surgeons in Alberta		
	Percentage of musculoskeletal appointments completed as scheduled			
	Percentage of specialist providers participating in centralized intake No. referrals received through centralized intake			
Safety				
•	Time to DMARD therapy for patients with new-onset RA	Percentage of OA referrals triaged as highest urgency based on high Western Canada Waiting List priority criteria scores seen within Wait Time Alliance benchmarks		

RA: rheumatoid arthritis; OA: osteoarthritis; MSK: musculoskeletal; DMARD: disease-modifying antirheumatic drug.

experiences with primary care, the CI clinic and the referral process, and care provided by specialists and the specialist clinic. Digitally recorded interviews took place either in person or by phone by one of the researchers. *Data collection*. Ethics approval was obtained prior to recruitment and all participant involvement was voluntary (University of Calgary Conjoint Health Research Ethics Board ID: REB13-0822). CI clinics recruited high-volume referring PCP and specialists, as well as patients, on behalf of the researchers. CI clinic staff were approached by the research team at the CI clinic sites to potentially participate in a recorded semistructured interview. PCP and specialists were contacted by e-mail and mail to complete the survey through an online link by Research Electronic Data Capture (REDCap) or by completing a hard copy of the survey. Informed consent was collected by password-protected e-mail and electronic documents as well as through sealed mail. Data were collected between September 2016 and December 2017.

*Analysis*. Survey results were analyzed using descriptive statistics with SPSS v.24 software (IBM Corp.). To compare survey results across the 3 sites (A, B, and C) where the response rates from each group were different, weighted averages rather than simple averages were used to accurately portray comparisons between sites with different participant numbers<sup>35</sup>. Weighted averages were calculated by multiplying the specific response rate for a survey item by the percentage of participants recruited at the site. The weighted average (e.g., strongly agree, disagree) for each survey item and ranked for frequency. To provide further understanding of the quantitative data, interviews from patient and CI clinic staff were transcribed and then analyzed using a thematic approach<sup>36</sup>. The analysis was iterative, in that additional themes may emerge or be revised, but essentially the themes were similar to the interview topics<sup>37</sup>. Open text

comments from the surveys were included in the analysis to provide supplementary understanding.

## RESULTS

A total of 237 surveys were completed by patients (n = 169), referring physicians (n = 50), and specialists (n = 18; Table 2). Eleven interviews were conducted with CI staff (Site A, n = 4; Site B, n = 6; Site C, n = 1) and 14 interviews with patients (Site A, n = 7; Site B, n = 3; Site C, n = 4).

Patient recruitment was done by clinic staff at each site, but no record was kept of how many patients were approached for the study. From the surveys, patients who initially agreed to be interviewed but did not respond or declined when contacted were as follows: Site A: 7/16 (44%), Site B: 3/10 (30%), and Site C: 4/13 (31%). Response rates for CI staff interviews at Site A were 4/4 (100%); Site B, 6/11 (55%); and at Site C, due to workload demands, only 1 individual was interviewed from the 2 key participants.

All specialists at each site were contacted to complete the survey, resulting in the following response rates: Site A: 4/4 (100%), Site B: 8/11 (73%), and Site C: 6/29 (21%). The response rate for referring physicians was Site A: 9/100(9%), Site B: 5/120 (4%), and Site C: 36/151 (24%). The results are presented according to each group (Table 2).

*Referring physicians*. Over 95% of referring physicians agreed that the current process of CI was satisfactory (Table 3). Across all sites, several aspects of care were consistently rated well and included recommendations of care made by the clinic (100%), that treatment had a positive effect on their patient (97–100%), the provider explained their role (89–100%), and they received information related to their patient (78–100%; Table 4). These were supported by additional comments provided in surveys:

I am 100% happy with the excellent care provided my patients. (Referring Physician 12)

Specialists and referring physicians at Site C reported the most dissatisfaction with the quality of referrals and support received from specialist clinics, respectively (Table 5). The areas that were less highly evaluated were specialist access, communication of referral response outcomes (accepted or

Table 2. Evaluation survey and interview participants across groups.

		Participants			
	Groups	Site A	Site B	Site C	Total
Surveys	Patients	82	36	51	169
	Referring physicians	9	5	36	50
	Specialists	4	8	6	18
Interviews	Total	95	49	93	237
	Patients	7	3	4	14
	Clinic staff and care providers	4	6	1	11
	Total	11	9	5	25

denied), and information about alternative services if referral is denied. However, just over half the referring physicians disagreed that they felt supported by the clinic for patients awaiting a consultation (52%), and 36% disagreed they were satisfied with the current access to a specialist (Table 3 and Table 5). From a completed survey:

> I find it difficult to get my patient to see the rheumatologist they have previously seen. If I send a letter w/ concerns it gets to central triage and then often asks for repeat blood, X-rays as if it's an initial referral. The standard testing required for initial referral sometimes doesn't fit the clinical problem [...] I feel I phone (harass) specific rheumatologist while waiting for referrals and they are great but there is not a really easy way to get consistent advice. (Referring Physician 25)

Specialists. Of the specialists receiving referrals, about 70% or higher of participating specialists appeared to be satisfied with the quality of care and services provided by CI (Table 4). All specialists, across each of the sites, agreed that the process for referral, screening, and triaging identified the right patient for their assessment (Table 4). However, key issues for specialists seem to be that initial referrals by referring physicians were often incomplete, with 41% of specialists disagreeing with the statement that for the majority of the time, referring clinicians' initial referral was complete (Table 3). From the survey:

Quality of referral is poor and digging for info is very labour intensive. Patients often wait longer due to low quality referrals. (Specialist 6)

*CI clinic staff and care providers*. Clinic staff and care providers (CI clinic managers, triage nurses, booking clerks) were interviewed regarding the successes and challenges they experienced in CI service provision. Common successes across the sites included efficiency of care and the ability to proficiently connect specialists with urgent referrals, but this often meant longer waiting times for non-urgent referrals due to a shortage of available specialists. From interviews with care providers:

I mean that's one factor that fluctuates a little and that bottleneck is if the volume is high, then the routines can be six months. (Care Provider B1)

And there are a number of patients [...] we're just unable to see because we don't

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#### Table 3. Highest scoring survey items across groups.

Group	Strongly Agree/Agree	est Scoring Survey Items for Groups <sup>1</sup> Strongly Disagree/Disagree vey Item No.: Weighted Average, % <sup>2</sup> )	Not Applicable
Patients	The care providers at the clinic <sup>§</sup> responded to all my questions or concerns in a way I could understand. (S11: 94)	It was difficult to reach the care providers at the clinic <sup>§</sup> . (S3: 78)	The information I received on peer support groups for arthritis <sup>§</sup> was useful. (S21: 44)
	Overall, I was treated with respect while I was at the clinic <sup>§</sup> . (S22: 93)	I received information on other options to manage my arthritis <sup>§§</sup> (e.g., physiotherapy, acupuncture, chiropractor, nonmedical wellness strategies). (S18: 27)	I received information on other options to manage my arthritis <sup>§§</sup> (e.g., physiotherapy, acupuncture, chiropractor, nonmedical wellness strategies). (S18: 19)
Specialists	The process for referral, screening, and triaging at my clinic identifies the right patient for my assessment. (S4: 100)	The majority of the time, referring clinicians' initial referral is complete. (S1: 41)	The majority of the time, referring clinicians' initial referral is complete. (S1: 6) <sup>3</sup>
	The process for referral, screening, and triage at my clinic allows me to see the most urgent patients in a timely manner. (S5: 88)	Referrals almost always contain specific questions for patient assessment. (S2: 41)	
Referring physicians	I am satisfied with the recommendations made for my patient(s) by the clinic <sup>§</sup> . (S11: 100)	I feel supported by the clinic <sup>§</sup> for patients awaiting a consultation. (S15: 52)	If the referral is denied, alternative services and directions to recommended care for the patient are suggested by the clinic <sup>§</sup> . (S6: 10)
	The treatment provided by the clinic <sup>8</sup> has had a positive impact on my patient. (S9: 98)	I feel satisfied with the current access to a specialist for my patient. (S12: 36)	If the referral is denied, a provider from the clinic <sup>8</sup> provides a reason(s). (S5: 10)

<sup>1</sup>Highest scoring survey items were tabulated per response categories (strongly agree/agree, strongly disagree/disagree, and not applicable). Some survey items (S18 and S1) scored highest across more than 1 response category, repeating in the table. <sup>2</sup>Weighted averages were calculated using cumulative sample sizes of groups compared across sites. <sup>3</sup>Only 1 survey item (S1) received "Not Applicable" responses from the Specialists group. <sup>§</sup>Rheumatology or hip/knee clinic. <sup>§§</sup>Osteoarthritis or rheumatoid arthritis.

Table 4. Highest scoring survey items for strongly agree and agree responses across groups.

Groups and Survey Items (Survey Item #: Weighted Average % <sup>1</sup> )		Site A	Site B N (%) [SA%, A%]	Site C		
Patients	The care providers at the clinic <sup>§</sup> responded to all my questions or concerns in a way					
	I could understand. (S11: 94)	78 (95)	32 (89)	49 (96)		
		[34, 61]	[47, 42]	[65, 31]		
	Overall, I was treated with respect while I was at the clinic <sup>§</sup> . (S22: 93)	74 (90)	35 (97)	48 (94)		
		[55, 44]	[66, 34]	[73, 22]		
	The care providers at the clinic <sup>§</sup> explained the proposed treatment plan to me in a					
	way I could understand. (S12: 90)	74 (90)	32 (89)	46 (90)		
		[34, 62]	[42, 47]	[59, 31]		
Specialists	The process for referral, screening, and triaging at my clinic identifies the right					
	patient for my assessment. (S4: 100)	4 (100)	7 (100)	6 (100)		
		[25, 75]	[43, 57]	[17, 83]		
	The process for referral, screening, and triage at my clinic allows me to see the most					
	urgent patients in a timely manner. (S5: 88)	4 (100)	7 (100)	4 (67)		
		[25, 75]	[57, 43]	[0,67]		
	I have access to the patients' relevant medical history for assessing the patient. (S3: 82)	3 (75)	6 (86)	5 (83)		
		[0, 75]	[14, 71]	[17,67]		
Referring	I am satisfied with the recommendations made for my patient(s) by the clinic <sup>§</sup> .					
physicians	(S11: 100)	9 (100)	5 (100)	36 (100)		
		[0, 100]	[60, 40]	[31, 69]		
	The treatment provided by the clinic <sup>§</sup> has had a positive impact on my patient. (S9: 98)	9 (100)	5 (100)	35 (97)		
		[11, 89]	[60, 40]	[39, 58]		
	The provider(s) at the clinic <sup>§</sup> explained their role(s) in followup care for my patient.					
	(\$10: 94)	8 (89)	5 (100)	34 (94)		
		[11, 78]	[60, 40]	[29, 65]		

<sup>1</sup>Weighted averages were calculated using cumulative sample sizes of groups compared across sites. <sup>§</sup>Rheumatology or hip/knee clinic. SA: strongly agree; A: agree.

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Table 5. Highest scoring survey items for strongly disagree and disagree responses across groups.

Groups and Survey Items (Survey Item #: Weighted Average % <sup>1</sup> )		Site A	Site B N (%) [SDA%, DA%]	Site C
Patients	It was difficult to reach the care providers at the clinic <sup>§</sup> . (S3: 78)	65 (81), m = 2	29 (81)	36 (72), m = 1
	T	[48, 34]	[36, 44]	[38, 34]
	I received information on other options to manage my arthritis <sup>§§</sup>			
	(e.g., physiotherapy, acupuncture, chiropractor, nonmedical wellness	10 (24)	12 (26)	12 (20)
	strategies). (S18: 27)	18 (24), m = 6	13 (36)	13 (26), m = 1
		[4, 20]	[14, 22]	[2, 24]
	The care providers at the clinic <sup>§</sup> gave me information on how to	15 (24)	10 (22)	= 4 0
	self-manage my arthritis <sup>§§</sup> . (S19: 23)	17 (24), m = 10	12 (33)	7 (14)
		[4, 19]	[11, 22]	[0, 14]
Specialists	The majority of the time, referring clinicians' initial referral is complete.			
	(S1: 41)	0 (0)	3 (43)	4 (67)
		[0, 0]	[0, 43]	[33, 33]
	Referrals almost always contain specific questions for patient assessment.			
	(S2: 41)	1 (25)	2 (29)	4 (67)
		[0, 25]	[0, 29]	[33, 33]
	The process for referral, screening, and triage at my clinic allows me to			
	see the most urgent patients in a timely manner. (S5: 12)	0 (0)	0 (0)	2 (33)
		[0,0]	[0, 0]	[0, 33]
Referring physicians	I feel supported by the clinic <sup>§</sup> for patients awaiting a consultation. (S15: 52)	2 (22)	0 (0)	23.5 (67), m = 1
		[0, 22]	[0, 0]	[17, 50]
	I feel satisfied with the current access to a specialist for my patient. (S12: 36	) 2 (22)	0 (0)	16 (44)
		[0, 22]	[0, 0]	[14, 31]
	The decision to accept or deny a request is communicated to me within a time commensurate with the urgency of the request, but no longer than			
	fourteen (14) days after the request was received. (S4: 28)	0 (0)	0 (0)	14 (39)
		[0,0]	[0,0]	[17, 22]

<sup>1</sup>Weighted averages were calculated using cumulative sample sizes of groups compared across sites. <sup>§</sup> Rheumatology or hip/knee clinic. <sup>§§</sup> Osteoarthritis or rheumatoid arthritis. SDA: strongly disagree; DA: disagree; m: missing responses.

have the capacity. [...] we definitely have a shortage of rheumatologists, there's been a shortage across the country for years. (Care Provider C1)

Clinic staff and care providers across the sites also echo that known bottlenecks in care are incomplete or erroneous referrals made by referring physicians:

> Therefore, if the referral letter says arthritis, questions mark, they get a low priority referral. (Care Provider B5)

Interestingly, sites managed incomplete referrals differently; for example, 1 site assigned incomplete referrals as "pending" and they kept their place in the system, whereas another site returned the incomplete referral and treated them as "new" on resubmission.

*Patients*. Across all sites, about 80% or higher of patients agreed that they were respectfully treated and their arthritis well cared for by healthcare professionals (Table 3). Three aspects of care across the sites received good evaluations (89–97% of patients strongly/agreeing across the sites):

explaining treatment, respecting their wishes, and addressing patient concerns with care (Table 4):

I am grateful for the doctor's quick response and medication received so that I could function. There was a lot of information received upon initial visit, it took a while to digest. Booklets and written information was [sic] very helpful. The staff really try to expedite patients for their treatments and take the time needed. I appreciate the help I received and very thankful they could help me. (Patient 9RC – Survey)

The staff provided much information that made a complicated medical condition understandable. (Patient 23 – Survey)

Very impressed with this department. (Patient 36 – Survey)

Conversely, patients appear to receive minimal or no education for self-management of their condition, and reported

little to no support of options to manage symptoms through nonpharmacological means (47%), such as through peer-topeer support groups (Table 3). In addition, survey comments and patient interviews revealed gaps in communication during their care, especially related to waiting times:

> Right, so...yeah, nobody ever called me... and I was told that the process was...you wait and if you did not make your appointment they would call you or email you a letter...Or mail you a letter...and say, 'Your appointment is on this day,' and I never got one. (Patient 1 – Interview)

> The people were excellent, friendly, and it really feels like they care and want to help, however clear communication and wait times are of major issues. (Patient 40 – Survey)

## DISCUSSION

This systems-level baseline evaluation of CI and triage systems in arthritis care from multiple participants was generally positive regarding service quality and patientcentered care, but several issues warrant discussion. Specifically, these relate to referral requirements and waiting lists, patient support, and participation.

Systems-level service evaluations can identify gaps in service provision and contextualizing QI initiatives to address these gaps more effectively<sup>17,38,39,40</sup>. Most importantly, a systems approach to QI also affords some flexibility in QI methods, allowing initiative leads to focus on overall QI goal(s) versus stringency in method<sup>16</sup>. For this baseline evaluation, a systems approach to QI allowed for a comparative multiparticipant view on the differences and similarities of service provision across sites. A strength of this study was the evaluation processes developed to assess the model of care. In addition, the use of a mixed methods approach, with both quantitative and qualitative data, allowed a richer and more complete understanding of the CI process in arthritis care. This approach could be used for the evaluation of other models of care in the context of complex systems.

A major challenge across all sites, for referring physicians and specialist clinicians, was the referral process. Referring physicians reported frustration at the information requirements and long waiting times, and both triage nurses and specialists expressed irritation with missing data required for triage. Complex referral requirements and differing processes for managing non-urgent, incomplete referrals seem to be prominent obstacles for efficient and timely triage. It has been reported that a shortage of rheumatologists is a major contributing factor for lengthy waiting lists in some parts of Alberta for RA and other rheumatologic conditions, and indeed across Canada<sup>41</sup>. Overall, patients were very satisfied with the care they received but gaps in their care were apparent, such as support in the everyday management of their condition<sup>42</sup>. Several systematic reviews have identified patient needs around health information on self-management, nonpharma-cological interventions, and emotional, social, and practical support needs<sup>43,44,45</sup>. Effective self-management of chronic conditions is essential for patient maintenance of health and longterm quality of life<sup>46</sup>, yet often remains absent in the provision of care. In our study, general communication and support for patients to self-manage their arthritis were 2 key opportunities for service improvement in arthritis care.

A systems approach to service QI can also help to identify and engage smaller, less vocal groups that have been overlooked or neglected within a system<sup>19</sup>. Key members of each group who had been engaged in the development of the KPI measures also helped recruit participants from their respective groups<sup>34</sup>. Acquiring equal feedback when groups have varying levels of buy-in and relative gains from participating can be challenging<sup>17,19</sup>. Specific to this evaluation, there was disproportionate feedback from groups due to differing levels of engagement and participation in the study. Across all 3 sites, patients appeared to be more engaged than some of the other groups (e.g., referring physicians), perhaps indicating the importance of the topic - a phenomenon identified in other system-level healthcare service improvement initiatives<sup>47</sup>. Survey completion by referring physicians and specialists was a significant challenge, despite many reminders, but is not unusual<sup>48</sup>. Site C seemed particularly affected and this might have been due to unusual service demands at the time of data collection. Adopting a systems approach to QI in this baseline evaluation created complex, time-intensive data collection, requiring multiple ethics modifications to overcome the institutional requirements from the many gatekeepers of critical information.

Bias was possible because response rates for patients were not known and were generally low across all groups. However, this is less of a concern when the data are to be used locally<sup>48</sup>. Site C, the largest group, had significant challenges in participation, raising concerns regarding the validity/reliability of the results for this site. The study did not include other sites for comparison, and although this can be seen as a weakness, this was not the intention for this study; rather, the intention was to describe a process for systems evaluation from multiple groups for the provision of arthritis care. The response rate might have been improved but the data collection phase of 16 months was defined by the funding timeline and minimal surveys being returned following reminders.

Overall, this systems-level baseline evaluation of CI and triage systems in arthritis care from multiple groups identified overall satisfaction with the service. But referral completion, timely waiting lists, and further supporting patients to self-manage their arthritis are areas that require

further consideration. The identification and understanding of these gaps ultimately will inform alternative models of care to optimize the provision of care and service delivery. In the current environment of complex healthcare service delivery systems, adopting a systems-level perspective in service evaluation may help increase uptake and longterm success of service improvement initiatives.

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## **ONLINE SUPPLEMENT**

Supplementary material accompanies the online version of this article.

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