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

Eloise C.J. Carr^(D), Mia M. Ortiz, Jatin N. Patel^(D), Claire E.H. Barber, Steven Katz, Jill Robert, Dianne Mosher, Sylvia R. Teare, Jean Miller, Joanne Homik, Kelly Dinsmore, and Deborah A. Marshall^(D)

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^{1,2}. In Canada it is estimated that the prevalence of diagnosed OA is 14.2% (15.6% among women, 12.4% among men)³, causing a reduced quality of life due to chronic

From the Faculty of Nursing, University of Calgary; Strategic Clinical Networks, Alberta Health Services; Division of Rheumatology, and Community Health Sciences, Cumming School of Medicine, University of Calgary; Surgery, and Bone and Joint Health Strategic Clinical Networks, Alberta Health Services, Calgary; Department of Medicine, Division of Rheumatology, University of Alberta, Edmonton; Chinook Bone and Joint Clinic, Lethbridge, Alberta, Canada.

This study was supported by the Alberta Innovates Health Solutions, Partnership for Research and Innovation in the Health System Grant: "Optimizing Centralized Intake to Improve Arthritis Care for Albertans"; The Arthritis Society, Models of Care Catalyst grant: "Creating an optimal model of care for the efficient delivery of appropriate and effective arthritis care"; Canadian Institute for Health Research Planning Grant (funded through Priority Announcement Health Services and Policy Research): "Evidence based planning of an optimal triaging strategy for arthritis care in Alberta"; and Alberta Health Services, Research Grant (through the Bone and Joint Health Strategic Clinical Network): "Optimizing Centralized Intake to Improve Arthritis Care for Albertans". E.C. Carr, RN, PhD, Professor, Faculty of Nursing, University of Calgary; M.M. Ortiz, RN, BN, Faculty of Nursing, Professional Faculties Building,

RHEUMATOID ARTHRITIS MODELS OF CARE

pain, a loss of independence in activities of daily living, and poorer mental health⁴. A number of factors appear to be accelerating the rising prevalence of OA including obesity and an ageing population³.

OA is the most common presentation of arthritis, and with

University of Calgary; J.N. Patel, MBT, Pan-SCN Manager, Strategic Clinical Networks, Alberta Health Services; C.E. Barber, MD, FRCPC, PhD, Division of Rheumatology, Cumming School of Medicine, University of Calgary; S. Katz, MD, Associate Professor, Department of Medicine, Division of Rheumatology, University of Alberta; J. Robert, BSCN, Surgery, and Bone and Joint Health Strategic Clinical Networks, Alberta Health Services; D. Mosher, MD, Division of Rheumatology, Cumming School of Medicine, University of Calgary; S.R. Teare, BSCN Med, Community Health Sciences, Cumming School of Medicine, University of Calgary; J. Miller, PhD, Community Health Sciences, Cumming School of Medicine, University of Calgary; J. Homik, MD, MSc, Professor, Department of Medicine, Division of Rheumatology, University of Alberta; K. Dinsmore, MSc, Chinook Bone and Joint Clinic; D.A. Marshall, MHSA, PhD, Professor, Community Health Sciences, Cumming School of Medicine, University of Calgary.

Address correspondence to E.C. Carr, Professor, Faculty of Nursing, University of Calgary, PF 2237, 2500 University Drive NW, Calgary, Alberta T2N 1N4, Canada. E-mail: ecarr@ucalgary.ca Accepted for publication October 30, 2019.

no cure, endstage OA is primarily managed through surgical intervention⁵. 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^{8,9}, yet doctors are performing more of these procedures than previously reported⁸. Similar trends can be observed for patients referred for RA^{10,11}, where benchmark waiting times are rarely achieved, even for urgent referrals^{10,12}. Incomplete referrals, variability in waiting times for different rheumatologists, and geographic location all affect waiting times in primary and specialty care¹¹. 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^{13,14,14a}. 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 standards¹⁵. 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"^{16,17} and partnerships^{18,19,20}. Co-design enables patients, families, and practitioners to design improvement initiatives together, in partnership¹⁷. These approaches draw feedback and perspectives from multiple participants as a means of enacting effective QI change in complex service pathways^{21,22}. 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^{14,23,24} by engaging patients in service improvement research and implementation of QI initiatives in care delivery^{25,26}. Developing performance measures for use in arthritis research and QI efforts has been a central component for the provision of arthritis care²⁷. Twenty-eight key performance indicators (KPI; Table 1) measuring healthcare service delivery in OA and RA were developed using RAND ExpertLens, a modified Delphi process²⁸. This QI measurement framework was based on the Health Quality Council of Alberta's Alberta Quality Matrix for Health^{28,29}, with 6 dimensions of quality of care: acceptability, accessibility, appropriateness, safety, effectiveness, and efficiency²⁸.

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 experiences²⁹. 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 Alberta³⁰.

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^{31,32}. 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-led²⁴.

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 KPI³¹, local referral guidelines³³, 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 project³⁴. 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^{35,36}, 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

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2020. All rights reserved.

The Journal of Rheumatology 2020; 47:9; doi:10.3899/jrheum.190501

Table 1. Key performance indicators (KPI; n = 28) for CI in arthritis care in Alberta³⁰ according to the Health Quality Council of Alberta's Dimensions of Quality³¹.

Dimensions of Quality Care	RA KPI	OA KPI		
Acceptability Health services are respectful and responsive to user needs, preferences and expectations.	Patient experience with centralized intake Referring clinician's experience with centralized intak MSK specialty care provider experience with centralized Administrative staff and allied health professional experience w	Patient experience with centralized intake ring clinician's experience with centralized intake ecialty care provider experience with centralized intake e staff and allied health professional experience with centralized intake		
Accessibility Health services are obtained in the most suitable setting in a reasonable time and distance.	Time from RA referral receipt to referral completion for initially incomplete referrals	Time from OA referral receipt to referral completion for initially incomplete referrals		
	Waiting times for patients with established RA Percentage of patients who receive information available for management while waiting for first	Time from receipt of complete OA referral to MSK appointment regarding resources and tools		
Appropriateness	available for management while waiting for ma	st wisk specially contact		
Health services are relevant to user needs and are based on accepted or evidence-based practice	Percentage of patients with new-onset RA with at least 1 visit to a rheumatologist in the first year of diagnosis 2. Percentage of referrals rejected or redirected whe	Percentage of OA referrals scored using Western 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	Percentage of RA referrals received with complete	Percentage of OA referrals received with complete		
achieving desired outcomes.	information	information		
	Waiting times for rheumatologist consultation for	Ratio of patient flow to estimated clinic capacity of OA		
	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	C			
Mitigate risks to avoid unintended or harmful results.	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 numbers³⁵. 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 approach³⁶. The analysis was iterative, in that additional themes may emerge or be revised, but essentially the themes were similar to the interview topics³⁷. 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
Irveys	Patients	82	36	51	169
	Referring physicians	9	5	36	50
Sc	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

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2020. All rights reserved.

The Journal of Rheumatology 2020; 47:9; doi:10.3899/jrheum.190501

Table 3. Highest scoring survey items across groups.

Group	High Strongly Agree/Agree (Sur	est Scoring Survey Items for Groups ¹ Strongly Disagree/Disagree vey Item No.: Weighted Average, % ²)	Not Applicable
Patients	The care providers at the clinic [§] 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 [§] . (S3: 78)	The information I received on peer support groups for arthritis [§] was useful. (S21: 44)
	Overall, I was treated with respect while I was at the clinic [§] . (S22: 93)	I received information on other options to manage my arthritis ^{§§} (e.g., physiotherapy, acupuncture, chiropractor, nonmedical wellness strategies). (S18: 27)	I received information on other options to manage my arthritis ^{§§} (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) ³
	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 [§] . (S11: 100)	I feel supported by the clinic ⁸ 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 [§] . (S6: 10)
	The treatment provided by the clinic [§] 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 [§] provides a reason(s). (S5: 10)

¹Highest 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. ²Weighted averages were calculated using cumulative sample sizes of groups compared across sites. ³Only 1 survey item (S1) received "Not Applicable" responses from the Specialists group. [§]Rheumatology or hip/knee clinic. ^{§§}Osteoarthritis or rheumatoid arthritis.

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

Groups and (Survey Iter	Survey Items n #: Weighted Average % ¹)	Site A	Site B N (%) [SA%, A%]	Site C
Patients	The care providers at the clinic [§] 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 [§] . (S22: 93)	74 (90)	35 (97)	48 (94)
		[55, 44]	[66, 34]	[73, 22]
	The care providers at the clinic [§] 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 [§] .			
physicians	(S11: 100)	9 (100)	5 (100)	36 (100)
		[0, 100]	[60, 40]	[31, 69]
	The treatment provided by the clinic [§] 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 [§] explained their role(s) in followup care for my patient.			
	(S10: 94)	8 (89)	5 (100)	34 (94)
		[11,78]	[60, 40]	[29, 65]

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

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2020. All rights reserved.

Carr, et al: Effective arthritis care

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

Groups and Su (Survey Item #	irvey Items #: Weighted Average % ¹)	Site A	Site B N (%) [SDA%, DA%]	Site C	
Patients	It was difficult to reach the care providers at the clinic [§] . (S3: 78)	65(81), m = 2	29 (81)	36(72), m = 1	
	I received information on other options to manage my arthritis ^{§§}	[48, 54]	[30, 44]	[38, 34]	
	strategies). (S18: 27)	18 (24), m = 6 [4, 20]	13 (36) [14, 22]	13 (26), m = 1 [2, 24]	
	The care providers at the clinic [§] gave me information on how to	C / J	ι / ι	(/ J	
	self-manage my arthritis ^{§§} . (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	I feel supported by the clinic [§] for patients awaiting a consultation. (S15: 52)	2 (22)	0 (0)	23.5 (67), m = 1	
physicians		[0, 22]	[0,0]	[17, 50]	
	I feel satisfied with the current access to a specialist for my patient. (S12: 36	b) 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]	

¹Weighted averages were calculated using cumulative sample sizes of groups compared across sites. [§] Rheumatology or hip/knee clinic. ^{§§} 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^{17,38,39,40}. 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 method¹⁶. 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 Canada⁴¹. 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 condition⁴². Several systematic reviews have identified patient needs around health information on self-management, nonpharma-cological interventions, and emotional, social, and practical support needs^{43,44,45}. Effective self-management of chronic conditions is essential for patient maintenance of health and longterm quality of life⁴⁶, 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 system¹⁹. Key members of each group who had been engaged in the development of the KPI measures also helped recruit participants from their respective groups³⁴. Acquiring equal feedback when groups have varying levels of buy-in and relative gains from participating can be challenging^{17,19}. 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 initiatives⁴⁷. Survey completion by referring physicians and specialists was a significant challenge, despite many reminders, but is not unusual⁴⁸. 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 locally⁴⁸. 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.

ACKNOWLEDGMENT

The authors acknowledge the following team members and their contribution to the study: Andrea Emrick, Martina Stevenson, Glen Hazlewood, Liam Martin, Jane Squire Howden, Yolanda Martens-Vanhilst, Linda Slocombe, Terri Lupton, Melissa DeBelser, Tracey Wasylak, and Linda Woodhouse.

ONLINE SUPPLEMENT

Supplementary material accompanies the online version of this article.

REFERENCES

- Woolf AD. Global burden of osteoarthritis and musculoskeletal diseases. BMC Musculoskelet Disord 2015;16 Suppl 1:S3.
- Cross M, Smith E, Hoy D, Nolte S, Ackerman I, Fransen M, et al. The global burden of hip and knee osteoarthritis: estimates from the global burden of disease 2010 study. Ann Rheum Dis 2014;73:1323-30.
- Birtwhistle R, Morkem R, Peat G, Williamson T, Green ME, Khan S, et al. Prevalence and management of osteoarthritis in primary care: an epidemiologic cohort study from the Canadian Primary Care Sentinel Surveillance Network. CMAJ Open 2015;3:E270–5.
- Bombardier C, Hawker G, Mosher D. The impact of arthritis in Canada: today and over the next 30 years. [Internet. Accessed March 30, 2020.] Available from: www.arthritisalliance.ca/images/ PDF/eng/Initiatives/20111022_2200_impact_of_arthritis.pdf
- 5. Katz JN, Earp BE, Gomoll AH. Surgical management of osteoarthritis. Arthritis Care Res 2010;62:1220-8.
- Smolen JS, Aletaha D, Bijlsma JW, Breedveld FC, Boumpas D, Burmester G, et al; T2T Expert Committee. Treating rheumatoid arthritis to target: recommendations of an international task force. Ann Rheum Dis 2010;69:631-7.
- Upchurch KS, Kay J. Evolution of treatment for rheumatoid arthritis. Rheumatology 2012;51 Suppl 6:vi28-36.
- Canadian Institute for Health Information. Wait times grow for joint replacements and cataract surgeries in Canada, more procedures being done. [Internet. Accessed March 30, 2020.] Available from: www.cihi.ca/en/wait-times-grow-for-joint-replacements-andcataract-surgeries-in-canada-more-procedures-being-done
- CBC News. Wait times for hip and knee replacements grow in Canada. [Internet. Accessed March 30, 2020.] Available from: www.cbc.ca/news/health/ hip-knee-replacement-wait-times-1.4615531
- Widdifield J, Bernatsky S, Bombardier C, Paterson M. Rheumatoid arthritis surveillance in Ontario: monitoring the burden, quality of care and patient outcomes through linkage of administrative health data. Healthc Q 2015;18:7-10.
- Widdifield J, Bernatsky S, Thorne JC, Bombardier C, Jaakkimainen RL, Wing L, et al. Wait times to rheumatology care for patients with rheumatic diseases: a data linkage study of primary care electronic medical records and administrative data. CMAJ Open 2016; 4:E205-12.
- Barber CE, 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.

- Lopatina E, Damani Z, Bohm E, Noseworthy TW, Conner-Spady B, MacKean G, et al. Single-entry models (SEMs) for scheduled services: towards a roadmap for the implementation of recommended practices. Health Policy 2017;121:963-70.
- Hazlewood GS, Barr SG, Lopatina E, Marshall DA, Lupton TL, Fritzler MJ, et al. Improving appropriate access to care with central referral and triage in rheumatology. Arthritis Care Res 2016;68:1547-53.
- 14a. Arthritis Alliance of Canada. Joint Action on Arthritis: a framework to improve arthritis prevention and care in Canada. [Internet. Accessed March 30, 2020.] Available from: www.arthritisalliance. ca/images/PDF/eng/Initiatives/201209171000_framework_EN_588. pdf
- 15. Blackwell RW, Lowton K, Robert G, Grudzen C, Grocott P. Using experience-based co-design with older patients, their families and staff to improve palliative care experiences in the emergency department: a reflective critique on the process and outcomes. Int J Nurs Stud 2017;68:83-94.
- Fucile B, Bridge E, Duliban C, Law MP. Experience-based co-design: a method for patient and family engagement in system-level quality improvement. Pat Exp J 2017;4:1-10.
- Hamilton AB, Brunner J, Cain C, Chuang E, Luger TM, Canelo I, et al. Engaging multilevel stakeholders in an implementation trial of evidence-based quality improvement in VA women's health primary care. Transl Behav Med 2017;7:478-85.
- Leviton LC, Melichar L. Balancing stakeholder needs in the evaluation of healthcare quality improvement. BMJ Qual Saf 2016;25:803-7.
- Pandi-Perumal SR, Akhter S, Zizi F, Jean-Louis G, Ramasubramanian C, Freeman RE, et al. Project stakeholder management in the clinical research environment: how to do it right. Front Psychiatry 2015;6:71.
- Bell D, McNaney N, Jones M. Improving health care through redesign: it's time to shift from small projects to whole systems. BMJ 2006;332:1286-7.
- Wheat H, Horrell J, Valderas JM, Close J, Fosh B, Lloyd H. Can practitioners use patient reported measures to enhance person centred coordinated care in practice? A qualitative study. Health Qual Life Outcomes 2018;16:223.
- Carpenter T, Katz SJ. Review of a rheumatology triage system: simple, accurate, and effective. Clin Rheumatol 2014;33:247-52.
- 23. Suter E, Birney A, Charland P, Misfeldt R, Weiss S, Howden JS, et al. Optimizing the interprofessional workforce for centralized intake of patients with osteoarthritis and rheumatoid disease: case study. Hum Resour Health 2015;13:41.
- Marlett N, Shklarov S, Marshall D, Santana MJ, Wasylak T. Building new roles and relationships in research: a model of patient engagement research. Qual Life Res 2015;24:1057-67.
- 25. Shklarov S, Marshall DA, Wasylak T, Marlett NJ. "Part of the team": mapping the outcomes of training patients for new roles in health research and planning. Health Expect 2017;20:1428-36.
- 26. Desai SP, Yazdany J. Quality measurement and improvement in rheumatology: rheumatoid arthritis as a case study. Arthritis Rheum 2011;63:3649-60.
- 27. Barber CE, Patel JN, Woodhouse L, Smith C, Weiss S, Homik J, et al. Development of key performance indicators to evaluate centralized intake for patients with osteoarthritis and rheumatoid arthritis. Arthritis Res Ther 2015;17:322.
- Health Quality Council of Alberta. The Alberta quality matrix for health. [Internet. Accessed March 30, 2020.] Available from: hqca. ca/about/how-we-work/the-alberta-quality-matrix-for-health-1
- Creswell JW, Plano Clark VL. Designing and conducting mixed methods research. Thousand Oaks: Sage Publications Ltd.; 2011:70-6.
- 30. Alberta Health Services. Transformational roadmap summary.

Personal non-commercial use only. The Journal of Rheumatology Copyright © 2020. All rights reserved.

The Journal of Rheumatology 2020; 47:9; doi:10.3899/jrheum.190501

[Internet. Accessed March 30, 2020.] Available from: www.albertahealthservices.ca/assets/about/scn/ ahs-scn-roadmap-summary.pdf

- Alberta Health Services. Strategic clinical networks (SCNs). [Internet. Accessed March 30, 2020.] Available from: www. albertahealthservices.ca/scns/scn.aspx
- College of Physicians & Surgeons of Alberta. CPSA standards of practice: Referral consultation. [Internet. Accessed March 30, 2020.] Available from: www.cpsa.ca/standardspractice/ referral-consultation
- 33. Wong ST, Haggerty HJ. Measuring patient experiences in primary health care: A review and classification of items and scales used in publicly-available questionnaires. [Internet. Accessed March 30, 2020.] Available from: open.library.ubc.ca/cIRcle/collections/ facultyresearchandpublications/52383/items/1.0048528
- 34. Bell BA, Onwuegbuzie AJ, Ferron JM, Jiao QG, Hibbard ST, Kromrey JD. Use of design effects and sample weights in complex health survey data: a review of published articles using data from 3 commonly used adolescent health surveys. Am J Public Health 2012;102:1399-405.
- 35. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. Int J Qual Methods 2006;5:80-92.
- Crabtree B, Miller W, editors. Doing qualitative research. Thousand Oaks: Sage Publications Ltd.; 1999:127-43.
- Barber CE, Jewett L, Badley EM, Lacaille D, Cividino A, Ahluwalia V, et al. Stand up and be counted: measuring and mapping the rheumatology workforce in Canada. J Rheumatol 2017;44:248-57.
- Crowe S, Knowles R, Wray J, Tregay J, Ridout DA, Utley M, et al. Identifying improvements to complex pathways: evidence synthesis and stakeholder engagement in infant congenital heart disease. BMJ Open 2016;6:e010363.
- 39. Elwy AR, Bokhour BG, Maguire EM, Wagner TH, Asch SM, Gifford AL, et al. Improving healthcare systems' disclosures of large-scale adverse events: A Department of Veterans Affairs

leadership, policymaker, research and stakeholder partnership. J Gen Intern Med 2014;29:895-903.

- 40. Piper D, Iedema R, Gray J, Verma R, Holmes L, Manning N. Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study. Health Serv Manage Res 2012;25:162-72.
- 41. Miller JL, Teare SR, Marlett N, Shklarov S, Marshall DA. Support for living a meaningful life with osteoarthritis: a patient-to-patient research study. Patient 2016;9:457-64.
- Chou L, Ellis L, Papandony M, Seneviwickrama KLMD, Cicuttini FM, Sullivan K, et al. Patients' perceived needs of osteoarthritis health information: a systematic scoping review. PLoS One 2018;13:e0195489e.
- Connelly K, Segan J, Lu A, Saini M, Cicuttini FM, Chou L, et al. Patients' perceived health information needs in inflammatory arthritis: a systematic review. Semin Arthritis Rheum 2019; 48:900-10.
- 44. Zuidema RM, Repping-Wuts H, Evers AW, Van Gaal BG, Van Achterberg T. What do we know about rheumatoid arthritis patients' support needs for self-management? A scoping review. Int J Nurs Stud 2015;52:1617-24.
- 45. Heijmans M, Waverjin G, Rademakers J, van der Vaart R, Rijken M. Functional, communicative and critical health literacy of chronic disease patients and their importance for self-management. Patient Educ Couns 2015;98:41-8.
- Burke M, Hodgins M. Is 'dear colleague' enough? Improving response rates in surveys of healthcare professionals. Nurse Res 2015;23:8-15.
- 47. Taylor T, Scott A. Do physicians prefer to complete online or mail surveys? Findings from a national longitudinal survey. Eval Health Prof 2018 Nov 1 (E-pub ahead of print).
- Coulter A, Locock L, Ziebland S, Calabrese J. Collecting data on patient experience is not enough. BMJ 2014;348:g2225.