Accepted Article

Original Manuscript Submission

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

Corresponding Author:

Eloise C. J. Carr[1], RN PhD; Orchid: 0000-0003-1870-4244

Professor, Faculty of Nursing, University of Calgary

PF 2237, 2500 University Drive NW, Calgary, Alberta, Canada T2N 1N4

Phone: 403-220-6267; Fax: 403-284-4803; Email: ecarr@ucalgary.ca

Departments and institutions

Co-Authors:

Mia M. Ortiz[1], RN BN

Faculty of Nursing, Professional Faculties Building, University of Calgary, 2500 University Drive NW, Calgary, ABT2N 4N2

Jatin N. Patel[2], MBT; Orchid ID: 0000-0002-7077-3012

Pan-SCN Manager, Strategic Clinical Networks, Alberta Health Services, Calgary, AB

Claire E. H. Barber[3], MD FRCPC PhD

Division of Rheumatology, Cumming School of Medicine, University of Calgary, Calgary, AB

This article has been accepted for publication in The Journal of Rheumatology following full peer review. This version has not gone through proper copyediting, proofreading and typesetting, and therefore will not be identical to the final published version. Reprints and permissions are not available for this version. Please cite this article as doi 10.3899/jrheum.190501. This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Steven Katz[4], MD

Associate Professor, Department of Medicine, Division of Rheumatology, University of Alberta, Edmonton, AB

Jill Robert[5], BScN

Surgery and Bone & Joint Health Strategic Clinical Networks, Alberta Health Services, Calgary, AB.

Dianne Mosher[3], MD

Division of Rheumatology, Cumming School of Medicine, University of Calgary, Calgary, AB

Sylvia R. Teare[6], BScN Med

Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, AB

Jean Miller[6], PhD

Community Health Sciences, Cumming School of Medicine, University of Calgary, Calgary, AB

Joanne Homik[4], MD MSc

Professor, Department of Medicine, Division of Rheumatology, University of Alberta, Edmonton, AB

Kelly Dinsmore[7], MSc

Chinook Bone and Joint Clinic, Lethbridge, AB

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Deborah A. Marshall[6], MHSA PhD; Orchid ID: 0000-0002-8467-8008

Professor, Community Health Sciences, Cumming School of Medicine, University of Calgary

Key Indexing Terms: Osteoarthritis, Rheumatoid arthritis, Health Service Research, Models of Care

Funding:

Alberta Innovates Health Solutions, Partnership for Research and Innovation in the Health System (PRIHS) 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 (CIHR) Planning Grant (funded through Priority Announcement Health Services and Policy Research): "Evidence based planning of an optimal triaging strategy for arthritis care in Alberta"; Alberta Health Services, Research Grant (through the Bone and Joint Health Strategic Clinical Network): "Optimizing Centralized Intake to Improve Arthritis Care for Albertans".

Disclosure of Interest:

The authors confirm that there is no financial support or other benefits from commercial sources for the work reported on in the manuscript. There are also no financial interests that the authors may have which could create a potential conflict of interest with regards to the work in the manuscript.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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: 1) describe a process for systems evaluation from multiple stakeholders 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 semi-structured interviews were the main data collection methods. Participants were recruited through two rheumatology and one hip and knee clinics 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 waitlisted 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 referral completion, timely waitlists and further supporting patients to self-manage their arthritis are areas that require further consideration.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

INTRODUCTION

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 osteoarthritis is 14.2% (15.6% among women, 12.4% among men) (3), causing a reduced quality of life due to chronic pain, a loss of independence in activities of daily living, and poorer mental health (4). A number of factors appear to be accelerating the rising prevalence of OA including obesity and an ageing population (3).

OA is the most common presentation of arthritis, and with no cure, end-stage OA is primarily managed through surgical intervention (5). RA has an autoimmune etiology requiring timely diagnosis and pharmaceutical intervention to prevent extensive joint damage (6, 7). In Canada wait 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 reported (8). 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 wait times for different rheumatologists, and geographic location all affect wait times in primary and specialty care (11). 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). CI's are usually a central part of an overall model care that provides a particular type of health service, informed by theory evidence and defined standards (15). These defined core components provide a structure for the implementation and subsequent evaluation of care.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Systems-level quality improvement (QI) initiatives in healthcare and healthcare service provision frequently focus on the principles of "co-design" (16, 17), and stakeholder partnerships (18-20). Co-design enables patients, families and practitioners to co-design improvement initiatives together, in partnership (17). These approaches draw feedback and perspectives from multiple stakeholder groups as a means of enacting effective QI change in complex service pathways (21, 22). Common overarching goals of these system QI interventions include (a) the improvement of stakeholder experience and (b) distribute the control and design of service delivery more equally among stakeholders.

The initial introduction of CI systems to manage arthritis care referrals in Alberta was a QI initiative to mobilize waitlists 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 quality improvement efforts has been a central component for the provision of arthritis care (27). Twenty-eight key performance indicators (KPIs) (Table 1) measuring healthcare service delivery in OA and RA were developed using RAND ExpertLens, a modified Delphi process (28). This QI measurement framework was based on the Health Quality Council of Alberta's Alberta Health Quality Matrix for Health (28, 29) with six dimensions of quality of care: *acceptability*, *accessibility*, *appropriateness*, *safety*, *effectiveness*, and *efficiency* (28).

This manuscript describes a systems-level baseline evaluation of the current CI and triage systems across three different sites of arthritis care in Alberta, Canada, focusing on the *acceptability* KPIs of different stakeholder experiences (29). The specific objectives of this

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

manuscript are to: 1) describe a process for systems evaluation from multiple stakeholders 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 semi-structured interviews were simultaneously collected and analyzed to develop a comprehensive understanding of the CI process in arthritis care within Alberta (30).

Setting

Alberta Health Services has 16 specialized Strategic Clinical Networks (SCNs) to facilitate collaboration between systems administrators, frontline clinicians, researchers, and patients to promote innovative, evidence-based care and improve patient experience and health outcomes (31, 32). In Alberta, there are approximately 2,500 new cases of RA per year and about 10,000 surgical patients (hip and/or knee replacements) annually. In consultation with the Bone & Joint Health Strategic Clinical Network, three established CI sites eligible for evaluation were identified. At the time of the study there were only two rheumatology sites, and one orthopedic site with CI.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Site A serves as a CI for hip and knee arthroplasty for southern Alberta, averaging 1,200 referrals per year with 4 specialists (orthopedic surgeons). Referrals and diagnostic X-rays are received electronically or via 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 2,800-4000 total referrals via fax per year and triaged by 11 specialists (rheumatologists). Site C has 29 specialists (rheumatologists) and receives 6,000 referrals via fax per year and triaged manually by nursing staff and it is mainly nurse-led (24).

Sites B and C have an on-call rheumatologist for primary care physicians 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' primary care physician.

Surveys

Surveys were developed for each stakeholder group informed by the previously developed KPIs [31], local referral guidelines (33), and recommendations from the literature (see Supplementary data: Appendix A). 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 (CIHI) and the Primary Health Care Survey project (34). 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 our stakeholders told us we needed to measure to see if central intake could enable improvement on these areas). Additionally, the KPIs development workgroup provided feedback on which question

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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 impact on the patient, and access. Each stakeholder group had the opportunity to comment on the survey for face validity prior to finalization and appears in Appendix A (Supplementary data).

Interviews

Semi-structured interview protocols for CI clinic staff explored implementation successes and challenges how the various structures and processes were working (see Supplementary data: Appendix A). Patient interviews explored their experiences with primary care, the CI clinic and 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 primary care physicians and specialists, as well as patients, on behalf of the researchers. CI clinic staff were approached by the research team at the CI clinic

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

sites to potentially participate in a recorded semi-structured interview. Primary care physicians and specialists were contacted via email and mail to complete the survey through an online link via Research Electronic Data Capture (REDCap) or by completing a hard-copy of the survey. Informed consent was collected via password-protected email and electronic documents as well as through sealed mail. Data was collected between September 2016 and December 2017.

Analysis

Survey results were analyzed using descriptive statistics using IBM SPSS v. 24 software. To compare survey results across the three Sites (A, B, and C), where the response rates from each stakeholder group were different, weighted averages rather than simple averages were used to accurately portray comparisons between sites with different participant numbers (35). 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 response rates from all three sites were then summed to calculate a weighted average (e.g. strongly agree, disagree, etc.) 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 (36). The analysis is iterative, in that additional themes may emerge or be revised, but essentially were similar to the interview topics (37). Open text comments from the surveys were included in the analysis to provide supplementary understanding.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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 made by clinic staff at each site but no record was made 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: 4/4 (100%); Site B: 6/11 (55%) and at Site C, due to workload demands, only one individual was interviewed from the two key stakeholders.

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: Site A: 9/100 (9%); Site B: 5/120 (4%); and Site C: 36/151 (24%). The results are presented according to each stakeholder group.

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 impact 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:

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

> 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 well evaluated were: specialist access, communication of referral response outcomes (accepted or 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 (Tables 3, & 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, approximately 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

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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 with respect to the successes and challenges they experienced in CI service provision. Commonly successes across the sites included efficiency of care and the ability to proficiently connect specialists with urgent referrals, but this often meant longer wait 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 bottle neck 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 have the capacity. [...] we definitely have a shortage of rheumatologists, there's been a shortage across the country for years. [Care Provider C1]

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Clinic staff and care providers across the sites also echo that a known bottleneck 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, one 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, approximately 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 evaluated well (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 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]

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

> 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 non-pharmacological means (47%), such as through peer-to-peer support groups (Table 3). In addition, survey comments and patient interviews revealed gaps in communication during their care, especially related to wait 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 central intake (CI) and triage systems in arthritis care from multiple stakeholders was generally positive with regards to service quality and patient-

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

centered care, but several issues warrant discussion. Specifically, these relate to referral requirements and wait lists, patient support, and stakeholder participation.

Systems-level service evaluations can identify gaps in service provision and contextualizing QI initiatives to address these gaps more effectively (17, 38-40). 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 method (16). For this baseline evaluation, a systems approach to QI allowed for a comparative multi-stakeholder 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.

Referral Requirements and Wait Lists

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 wait 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 bottlenecks for efficient and timely triage. It has been reported that a shortage of rheumatologists is a major contributing factor for lengthy waitlists in some parts of Alberta for RA and other rheumatologic conditions, and indeed across Canada (41).

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Patient Support

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 (42). Several systematic reviews have identified patient needs around health information on self-management, non-pharmacological interventions, emotional, social and practical support needs (43-45). Effective self-management of chronic conditions is essential for patient maintenance of health and long-term quality of life (46) yet often remains absent in the provision of care. In our study, general communication and support for patients to self-management of their arthritis, were two key opportunities for service improvement in arthritis care

Stakeholder Participation

A systems approach to service QI can also help to identify and engage smaller, less vocal stakeholder groups within a system that have been overlooked or neglected (19). Key members of each stakeholder group who had been engaged in the development of the KPI measures also helped recruit participants from their respective stakeholder groups (34). Acquiring equal feedback from stakeholder groups 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 stakeholder groups due to differing levels of engagement and participation in the study. Across all three sites, patients appeared to be more engaged than some of the other stakeholder groups, e.g. referring physicians, perhaps indicating the importance of the topic; a phenomenon identified in other system-level healthcare service improvement initiatives (47). Survey completion by referring physicians and specialists was a significant challenge, despite multiple reminders, but is not unusual (48). Site C seemed particularly

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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.

Limitations

Bias was possible as response rates for patients were not known and were generally low across all stakeholder groups. However, this is less of a concern when the data is to be used locally (49). 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 but rather to describe a process for systems evaluation from multiple stakeholders 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.

Conclusion

Overall, this systems-level baseline evaluation of central intake (CI) and triage systems in arthritis care from multiple stakeholders identified overall satisfaction with the service but referral completion, timely waitlists 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

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

delivery. In the current environment of complex healthcare service delivery systems, adopting a systems-level perspective in service evaluation may help increase uptake and long-term success of service improvement initiatives.

Acknowledgements:

The authors would like to 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.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

References

1. Woolf AD. Global burden of osteoarthritis and musculoskeletal diseases. *BMC Musculoskelet Disord*. 2015;16(Suppl 1):S3.

2. Cross M SE, Hoy D, Nolte S, Ackerman I, Fransen M, Bridgett L, 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.

3. Birtwhistle R, Morkem R, Peat G, Williamson T, Green M E, 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

4. Bombardier C, Hawker G, Mosher D. The impact of arthritis in canada: Today and over the next 30 years. [Internet. Accessed 25 April, 2019] Available from: http://www.arthritisalliance.ca/images/PDF/eng/Initiatives/20111022_2200_impact_of_arthritis.pdf

5. Katz J. N. EBE, Gomoll A. H. . Surgical management of osteoarthritis. Arthritis Care Res 2010;62:1220-8.

6. Smolen JS AD, Bijlsma JW, Breedveld FC, Boumpas D, Burmester G, Combe B, *et al.* Treating rheumatoid arthritis to target: Recommendations of an international task force. Ann Rheum Dis 2010;69:631-7.

7. Upchurch K. S. KJ. Evolution of treatment for rheumatoid arthritis. Rheumatology (Oxford) 2012;51:28-36.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

8. Canadian Institute for Health Information. Wait times grow for joint replacements and cataract surgeries in canada, more procedures being done. Ottawa, ON: Canadian Institute for Health Information; 2018.

9. CBC News. Wait times for hip and knee replacements grow in Canada. [Internet. Accessed 25 April, 2019]. Available from: https://www.cbc.ca/news/health/hip-knee-replacement-wait-times-1.4615531

10. 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.

11. Widdifield J BS, Thorne JC, Bombardier C, Jaakkimainen RL, Wing L, Paterson JM, *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-e12.

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. Lopatina E. DZ, Bohm E., Noseworthy T., Conner-Spady B., MacKean G., Simpson C., et al. Single-entry models (sems) for scheduled services: Towards a roadmap for the implementation of recommended practices. Health Policy 2017;121:963-70.

14. 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.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

14a Arthritis Alliance of Canada. Joint Action on Arthritis: A Framework to improve arthritis prevention and care in Canada. [Internet. Accessed August 27, 2019] http://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.

16. 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.

17. Hamilton AB, Brunner J, Cain C, Chuang E, Luger TM, Canelo I, Rubenstein L, Yano EM. 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.

18. Leviton LC, Melichar L. Balancing stakeholder needs in the evaluation of healthcare quality improvement. BMJ Qual Saf 2016;25:803-7.

19. Pandi-Perumal SR, Akhter S, Zizi F, Jean-Louis G, Ramasubramanian C, Freeman RE, Narasimhan M. Project stakeholder management in the clinical research environment: How to do it right. Front Psychiatry 2015;6:1-18.

20. 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.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

21. 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.

22. 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, Hendricks J, *et al.* Optimizing the interprofessional workforce for centralized intake of patients with osteoarthritis and rheumatoid disease: Case study. Hum Resour Health 2015;13:1-12.

24. 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 CEP, 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;17:1-12.

28. Alberta Health Quality Council. The Alberta quality matrix for health user guide. [Internet. Accessed August 27, 2019]Available from:

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

https://hqca.ca/about/how-we-work/the-alberta-quality-matrix-for-health-1/

29. Creswell JW & Plano Clark VL. Designing and conducting mixed method designs. Thousand Oaks, California: Sage Publications Ltd; 2011. p. 70-6.

30. Alberta Health Services. Transformational roadmap summary. [Internet. Accessed 25 April, 2019] Available from: https://www.albertahealthservices.ca/assets/about/scn/ahs-scn-roadmap-summary.pdf

31. Alberta Health Services. Strategic clinical networks (SCNs). [Internet. Accessed 25 April, 2019] Available from: https://www.albertahealthservices.ca/scns/scn.aspx

32. College of Physicians & Surgeons of Alberta. CPSA standards of practice: Referral consultation. [Internet. Accessed 25 April 2019]. Available from: http://www.cpsa.ca/standardspractice/referral-consultation/

33. Wong S. T. HJ. Measuring patient experiences in primary health care: A review and classification of items and scales used in publicly-available questionnaires. [Internet. Accessed 25 April 2019]. Available from: https://open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0048528

33a. 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

33b 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;10:1547-53

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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. American J of 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.

36. Miller W. L. CBJ. In: B. F. Crabtree WLM, editor. Doing qualitative research. Thousand Oaks, California: Sage Publications Ltd.; 1999. p. 127-43.

37. 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 Rheum2017;44:248-57.

38. 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.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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.

42. 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.

43. 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 48:900-910

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.

46. 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;1.

48. Coulter A, Locock L, Ziebland S, Calabrese J. Collecting data on patient experience is not enough. BMJ 2014;348:15-7.

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table legends

Table 1. Key performance indicators (KPIs, *n*=28) for CI in arthritis care in Alberta [30] according to the Health Quality Council of Alberta's Dimensions of Quality [31]

Table 2. Evaluation survey and interview participants across stakeholder groups

Table 3. Highest scoring survey items across stakeholder groups

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table 4. Highest scoring survey items for strongly agree (SA) and agree (A) responses across stakeholder groups

Table 5. Highest scoring survey items for strongly disagree (SDA) and disagree (DA) responses across stakeholder groups

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table 1. Key performance indicators (KPIs, *n*=28) for CI in arthritis care in Alberta [30] according to the Health Quality Council of Alberta's Dimensions of Quality [31].

DIMENSIONS OF QUALITY CARE	RHEUMATOID ARTHRITIS (RA) KPIS	OSTEOARTHRITIS (OA) KPIS
ACCEPTABILITY *Health services are respectful and responsive to user needs, preferences and expectations.*	▪ Patient experience with centralized intake ▪ Referring clinician's experience with centralized intake ▪ Musculoskeletal specialty care provider experience with centralized intake ▪ Administrative staff and allied health professional experience with centralized intake	
ACCESSIBILTY *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. ▪ Waiting times for patients with established RA	▪ Time from OA referral receipt to referral completion for initially incomplete referrals ▪ Time from receipt of complete OA referral to musculoskeletal appointment
	▪ Percentage of patients who receive information regarding resources and tools available for management while waiting for first musculoskeletal specialty contact	

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

APPROPRIATENESS *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 one visit to a rheumatologist in the first year of diagnosis	▪ Percentage of OA referrals scored using Western Canada Waiting List priority referral criteria
	▪ Percentage of referrals rejected or redirected when received at centralized intake	
EFFECTIVENESS *Health services are based on scientific knowledge to achieve desired outcomes.*	▪ Percentage of rheumatoid arthritis patients treated with a disease-modifying anti-rheumatic drug during the measurement year ▪ Agreement of centralized intake suspected diagnosis versus confirmed diagnosis of RA	▪ Distribution of OA referrals in each urgency category (as scored using the Western Canada Waiting List referral tool) ▪ Agreement of centralized intake suspected diagnosis of severe OA cases (e.g. patients who are candidates for hip or knee joint replacements) versus

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

		confirmed diagnosis of severe OA
EFFICIENCY *Resources are optimally used in achieving desired outcomes.*	▪ Percentage of RA referrals received with complete information ▪ Waiting times for rheumatologist consultation for patients with new-onset rheumatoid arthritis ▪ Rheumatologists per 100,000 population ▪ Ratio of patient flow to clinic capacity of RA teams participating in centralized intake	▪ Percentage of OA referrals received with complete information ▪ Ratio of patient flow to estimated clinic capacity of OA 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 ▪ Number of referrals received through centralized intake	
SAFETY *Mitigate risks to avoid unintended or harmful results.*	▪ Time to disease-modifying anti-rheumatic drug therapy for patients with new-onset RA	▪ Percentage of OA referrals triaged as highest urgency based on high Western

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

		Canada Waiting List priority criteria scores seen within Wait Time Alliance benchmarks

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table 2. Evaluation survey and interview participants across stakeholder groups.

		PARTICIPANTS			
STAKEHOLDER 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**
	TOTAL	**95**	**49**	**93**	**237**
INTERVIEWS	**Patients**	**7**	**3**	**4**	**14**
	Clinic Staff & Care Providers	**4**	**6**	**1**	**11**
	TOTAL	**11**	**9**	**5**	**25**

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table 3. Highest scoring survey items across stakeholder groups.

HIGHEST SCORING SURVEY ITEMS FOR STAKEHOLDER GROUPS[1]			
Stakeholder Group	**Strongly Agree/Agree** (Survey Item #: Weighted Average %[2])	**Strongly Disagree/Disagree** (Survey Item #: Weighted Average %[2])	**Not Applicable** (Survey Item #: Weighted Average %[2])
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, non-medical wellness strategies). (S18: 27)	I received information on other options to manage my arthritis[§§] (e.g. physiotherapy, acupuncture, chiropractor, non-medical wellness strategies). (S18: 19)

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

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 allow 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[§] 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	I feel satisfied with the current access to a	If the referral is denied, a provider from the

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

	positive impact on my patient. (S9: 98)	specialist for my patient. (S12: 36)	clinic[§] provides a reason(s). (S5: 10)

[1] 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 one response category, repeating in the table. [2] Weighted averages were calculated using cumulative sample sizes of stakeholder groups compared across sites. [3] Only one survey item (S1) received "Not Applicable" responses from the Specialists stakeholder group. [§] rheumatology or hip/knee clinic, [§§] osteoarthritis or rheumatoid arthritis

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table 4. Highest scoring survey items for strongly agree (SA) and agree (A) responses across stakeholder groups.

STRONGLY AGREE (SA)/AGREE (A): HIGHEST SCORING SURVEY ITEMS				
Stakeholders and Survey Items (Survey Item #: Weighted Average %[1])		**Site A** N (%) [SA%, A%]	**Site B** N (%) [SA%, A%]	**Site C** N (%) [SA%, A%]
Patients	The care providers at the clinic[§] responded to all my questions or concerns in a way I could understand. (S11: 94)	78 (95) [34, 61]	32 (89) [47, 42]	49 (96) [65, 31]
	Overall, I was treated with respect while I was at the clinic[§]. (S22: 93)	74 (90) [55, 44]	35 (97) [66, 34]	48 (94) [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) [34, 62]	32 (89) [42, 47]	46 (90) [59, 31]
Specialists	The process for referral, screening, and triaging at my clinic identifies the right patient for my assessment. (S4: 100)	4 (100) [25, 75]	7 (100) [43, 57]	6 (100) [17, 83]

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

	The process for referral, screening, and triage at my clinic allow me to see the most urgent patients in a timely manner. (S5: 88)	4 (100) [25, 75]	7 (100) [57, 43]	4 (67) [0, 67]
	I have access to the patients' relevant medical history for assessing the patient. (S3: 82)	3 (75) [0, 75]	6 (86) [14, 71]	5 (83) [17, 67]
Referring Physicians	I am satisfied with the recommendations made for my patient(s) by the clinic[§]. (S11: 100)	9 (100) [0, 100]	5 (100) [60, 40]	36 (100) [31, 69]
	The treatment provided by the clinic[§] has had a positive impact on my patient. (S9: 98)	9 (100) [11, 89]	5 (100) [60, 40]	35 (97) [39, 58]
	The provider(s) at the clinic[§] explained their role(s) in follow up care for my patient. (S10: 94)	8 (89) [11, 78]	5 (100) [60, 40]	34 (94) [29, 65]

[1] weighted averages were calculated using cumulative sample sizes of stakeholder groups compared across sites, [§] rheumatology or hip/knee clinic, *m* = missing responses

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Table 5. Highest scoring survey items for strongly disagree (SDA) and disagree (DA) responses across stakeholder groups.

STRONGLY DISAGREE (SDA)/DISAGREE (DA): HIGHEST SCORING SURVEY ITEMS				
Stakeholders and Survey Items (Survey Item #: Weighted Average %[1])		**Site A** N (%) [SDA%, DA%]	**Site B** N (%) [SDA%, DA%]	**Site C** N (%) [SDA%, DA%]
Patients	It was difficult to reach the care providers at the clinic[§]. (S3: 78)	65 (81), *m*=2 [48, 34]	29 (81) [36, 44]	36 (72), *m*=1 [38, 34]
	I received information on other options to manage my arthritis[§§] (e.g. physiotherapy, acupuncture, chiropractor, non-medical wellness 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 self-manage my arthritis[§§]. (S19: 23)	17 (24), *m*=10 [4, 19]	12 (33) [11, 22]	7 (14) [0, 14]

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

Accepted Article

Specialists	The majority of the time, referring clinicians' initial referral is complete. (S1: 41)	0 (0) [0, 0]	3 (43) [0, 43]	4 (67) [33, 33]
	Referrals almost always contain specific questions for patient assessment. (S2: 41)	1 (25) [0, 25]	2 (29) [0, 29]	4 (67) [33, 33]
	The process for referral, screening, and triage at my clinic allow me to see the most urgent patients in a timely manner. (S5: 12)	0 (0) [0, 0]	0 (0) [0, 0]	2 (33) [0, 33]
Referring Physicians	I feel supported by the clinic§ for patients awaiting a consultation. (S15: 52)	2 (22) [0, 22]	0 (0) [0, 0]	23.5 (67), *m*=1 [17, 50]
	I feel satisfied with the current access to a specialist for my patient. (S12: 36)	2 (22) [0, 22]	0 (0) [0, 0]	16 (44) [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]	0 (0) [0, 0]	14 (39) [17, 22]

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org

[1] weighted averages were calculated using cumulative sample sizes of stakeholder groups compared across sites, [§] rheumatology or hip/knee clinic, [§§] osteoarthritis or rheumatoid arthritis, *m* = missing responses

Accepted Article

This accepted article is protected by copyright. All rights reserved.

Downloaded on April 19, 2024 from www.jrheum.org