

Variations in Pediatric Rheumatology Workforce and Care Processes Across Canada

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ABSTRACT

Objective. To examine Canadian pediatric rheumatology workforce and care processes.

Methods. Pediatric rheumatologists and allied health professionals (AHPs) participated. A designee from each academic centre provided workforce information including number of providers, total and breakdown of full-time equivalents (FTE), and triage processes. We calculated the clinical care FTE (cFTE) available per 75,000 (recommended benchmark) and 300,000 (adjusted) children using 2019 census data. The national workforce deficit was calculated as the difference between current and expected cFTEs. Remaining respondents were asked about ambulatory practices.

Results. The response rate of survey A (workforce information) and survey B (ambulatory practice information) was 100% and 54%, respectively. The majority of rheumatologists (91%) practiced in academic centres. The median number of rheumatologists per centre was 3 (IQR:3) and median cFTE was 1.8 (IQR:1.5). The median cFTE per 75,000 was 0.2 (IQR:0.3) with a national deficit of 80 cFTEs. With the adjusted benchmark, there was no national deficit but a regional maldistribution of rheumatologists. All centres engaged in multidisciplinary practices with a median of 4 different AHPs, although the median FTE for AHPs was ≤ 1 . Most centres (87%) utilized a centralized triage process. Of 9 (60%) centres that used an electronic triage process, 6 were able to calculate wait times. Most clinicians integrated quality improvement practices, such as pre-visit planning (68%), post-visit planning (68%), and periodic health outcome monitoring (36-59%).

Conclusion. This study confirms a national deficit at the current recommended benchmark. Most rheumatologists work in multidisciplinary teams, but AHP support may be inadequate.

INTRODUCTION

Rheumatic conditions are prevalent globally, contributing to a tremendous burden both at individual and societal levels (1, 2). Children with rheumatic diseases, such as juvenile idiopathic arthritis (JIA), contribute a proportion of this burden and are at risk of reduced health-related quality of life and functional disability (3, 4). The majority of pediatric rheumatic conditions require ongoing treatment and monitoring through adulthood. Timely access to the necessary medical resources and quality care by health professionals are critical for the optimization of both short-term and long-term outcomes (5, 6).

Improving health care quality and delivery may be one way to optimize the clinical outcomes for individuals with chronic disease (7). In response to studies identifying disparities in health care access and significant deficits in adherence to care recommendations, improving care quality is recognized as an important initiative by stakeholders including governments, hospitals, and patient groups (8, 9). Similar deficiencies have been demonstrated within adult rheumatology care (10-12), including care provision disparities by geography or socioeconomic status (13), long wait times with delays to rheumatology consultation (14, 15), and low number of available rheumatologists per province (13).

Quality of care can be assessed by measuring health outcomes, processes, and the structure of care (9). Given that most pediatric rheumatologists develop their practices locally, no Canadian-wide study has described the national differences in care processes and structures. Therefore, the objectives of this study were to examine the variations in pediatric rheumatology practice across

Canada with respect to workforce, triage and referral practices, and delivery of clinical rheumatology services.

METHODS

Survey Instrument Development. The survey instrument was constructed after a review of the literature. Two versions of an electronic survey were developed, in order to decrease duplication of information and survey length and burden. Survey version A included 42 questions and version B included 22 questions (Supplementary). Both surveys were created and stored in REDCap (Research Electronic Data Capture) (16). To ensure acceptability of the instruments, both versions were pretested by members of the Canadian Rheumatology Association (CRA) Pediatrics Human Resources subcommittee.

Survey version A included workforce estimates, triage processes, and emergency medical coverage at each centre, and was completed by one designee from 15 eligible academic centres (the divisional director or nominated delegate). Workforce questions included both number of providers (clinicians and AHPs) and total full-time equivalents (FTEs) dedicated to pediatric rheumatology. We asked respondents to comment on the breakdown of total FTE within their division according to four responsibilities: clinical, educational, research, and administrative. A full-time FTE of 1.0 was defined as five working days (40 hours) per week. Clinical FTE (cFTE) was defined as the time spent on direct patient care. Given that academic centres often assign the FTE breakdown within employment contracts, the survey did not define these responsibilities further.

All other respondents completed a truncated survey (version B) which focused on outpatient ambulatory care practices and perceived level of access to rheumatology resources. Most items were multiple choice questions allowing for single answer responses, with subsequent questions cascading, where relevant. There were opportunities for respondents to provide free-text responses for additional information. Community-based pediatric rheumatologists were asked to fill survey version B. Since version B did not fully capture their workforce data, and because many community-based pediatric rheumatologists practice a mix of general pediatrics, the study team followed up with these respondents to determine their rheumatology clinical FTEs.

Respondents. Canadian pediatric rheumatologists and rheumatology-affiliated AHPs were invited to participate. A Canadian pediatric rheumatologist was defined as a physician working in Canada with a pediatric rheumatology and/or general pediatrics certification with at least one clinic weekly devoted to pediatric patients (≤ 18 years of age) with rheumatic diseases. An AHP was defined as a health care professional with dedicated FTE in rheumatology in an academic centre. AHPs include registered nurses (RN), physiotherapists (PT), occupational therapists (OT), physician assistants (PA) and advanced clinical practitioners in arthritis care (ACPAC). ACPAC are PT, OT, or RN who obtain additional post-licensure training for extended roles in rheumatology care (17). Dietitians, social workers, pharmacists, and psychologists were not included as their care practices were likely different and thus a majority of the survey questions would not apply.

Survey Dissemination. Eligible physicians were identified from the CRA Pediatric Committee membership list. Rheumatology-affiliated AHPs were identified by consulting division directors.

Survey version A was distributed to all 15 division directors. The remaining rheumatologists and AHPs were sent version B. Surveys were sent out to respondents electronically from September 1, 2019 until February 1, 2020. To maximize responses, a number of strategies were used, including: two follow-up e-mail reminders, advertisement through the CRA, and regular updates at rheumatology meetings.

Statistical Analysis. Analyses were performed using SAS University Edition (18). Survey respondent and centre characteristics were summarized with frequencies and percentages for categorical variables and medians (interquartile range [IQR]) for non-parametric continuous variables. Baseline characteristics were grouped to protect respondent anonymity for small cell sizes (<6). We calculated the number of cFTE required in each province/territory to achieve the benchmark threshold of 1 cFTE for every 75,000 Canadians (children and adults) with a modification to capture the population ≤ 19 years of age (13, 19). This benchmark was previously established and recommended by the CRA and has been used in subsequent Canadian rheumatology related workforce studies (Oral communication with Human Resources committee in 2021 and in previous communication in 2010 as described by Kur et al (19)). To ensure accurate reflection of a consistent referral practice observed in Eastern Canada, 3 provinces (Nova Scotia, Prince Edward Island and New Brunswick) were grouped together as the Maritime Provinces. Provincial populations stratified according to age were acquired through Statistics Canada census 2019 data (20). Two sensitivity analyses were performed: 1) cFTE per capita was re-calculated according to additional referral practices and catchment areas, and 2) the benchmark was modified to reflect the assumed lower prevalence of pediatric rheumatic disease when compared to adult rheumatic diseases, and was set to 1 cFTE for every 300,000 (21).

Ethics. Research Ethics Board approval (#1000063501) was obtained from SickKids, Toronto, Ontario prior to commencement of the study. Respondents implied consent when completing the survey.

RESULTS

Response Rates. Survey A had a response rate of 100%; 15/15 divisional directors responded. Survey B had a response rate of 54% (76/142). Of the 74 eligible pediatric rheumatologists, we achieved a response rate of 72% (n=53). Of 68 eligible AHPs, we achieved a response rate of 34% (n=23).

Respondent Characteristics. Sixty-seven percent (n=53) were rheumatologists, 15% (n=12) were RN, and 11% (n=9) were ACPAC, OT, or PT. **Table 1** reports respondents according to role and practice region.

Physician Workforce Estimates. Most pediatric rheumatologists (n=48, 91%) worked in academic centres. The median number of rheumatologists per centre was 3 (IQR:3.0, range:1-10) and the median total FTE per centre was 3 (IQR:1.8). The median cFTE was 1.9 (IQR:1.5). Only one centre in central Canada did not provide the breakdown of total FTE. For academic rheumatologists, the median percentage of time allocated to clinical practice was 62% (IQR:18.2), research was 16% (IQR:7.0), administrative activities were 8% (IQR:3.5) and teaching was 10% (IQR:1.4) (**Figure 1**). For community-based rheumatologists (n=5), the median percentage of time allocated to pediatric rheumatology clinical care was 23% (IQR:27.5).

With the recommended benchmark of 1 cFTE per 75,000, no Canadian provinces/territories achieved this threshold (**STable 1**). The median cFTE per 75,000 age ≤ 19 was 0.2 (IQR:0.3), with a national deficit of 80 cFTEs. When adjusted to reflect additional referral practices (**STable 2**), the cFTE per capita did not drastically change. **Table 2 and Figure 2** provides the cFTE per 300,000 children and youth per province/territory. With this modified benchmark, 6 provinces (British Columbia, Alberta, Maritimes, and Newfoundland) achieved this threshold. The median cFTE per 300,000 was 0.8 (IQR:1.1). There was no national deficit, but a surplus of 1.3 cFTEs nationally.

AHP Workforce Estimates. All academic centres engaged in a multi-disciplinary team practice, with a median of 4 (IQR:1.5) different AHP. All centres included either a RN and/or a nurse practitioner as part of the clinical team. The median number of RN per centre was 2 (IQR:1) and the median FTE was 1 (IQR:0.8). The majority of centres had at least one PT (80%), OT (60%), and social worker (80%), but the median FTE for each profession was considerably less than 1 (**Table 3**).

Only a few centres employed ACPAC, dietitians, pharmacists, or psychologists with dedicated time for rheumatology patients; no centre employed PA. Most respondents felt that additional AHPs were accessible through their affiliated hospital, including interpreters (n=69, 95%), child life specialists (n=65, 89%), and pharmacists (n=56, 77%). However, some respondents commented on barriers to access. For example, a pharmacist may only be available to patients during a hospitalization.

Triage processes. Most centres (n=13, 87%) utilized a centralized triage process to coordinate intake and prioritization of referrals according to urgency and availability. At the majority of centres, referrals (n=14, 93%) were reviewed and triaged by physicians. Two centres used a multi-disciplinary team to triage referrals.

Nine centres used an electronic process. Only four centres reported having published waitlist recommendations (e.g. Wait Time Alliance (22)) visible on their system as a guide for triaging referrals. Six centres were capable of calculating wait times, 4 centres used average wait time of referrals as a performance measure, and 3 centres retroactively calculated average wait times for specific diagnoses.

Medical Emergency Care. Fourteen centres (93%) had rheumatologists participate in medical coverage for emergency/urgent needs for established patients or patients with suspected rheumatologic disease. Of these centres, 9 centres (64%) received direct calls from patients/families, and all centres received calls from other health providers. There were variations with respect to duration of call coverage: 2 centres (14%) provided coverage at only pre-specified times on weekdays, 2 centres (14%) provided weekday and weekend coverage at pre-specified times, and 10 centres (71%) provided 24-hour daily coverage.

Outpatient Ambulatory Care. Twenty-five (47%) physicians reported always having the capacity to see an urgent referral within one week. Twenty-two physicians (41%) usually had this capacity (more than 50% of the time), and 4 physicians (8%) reported significant difficulty meeting this need (never or less than 50% of the time). Reported barriers included a lack of

physical space, not having enough clerical staff to make adjustments to the clinic schedule, and not having enough clinical time.

All physician respondents reported accepting referrals for patients who have suspected non-inflammatory joint pain and/or chronic pain, with 81% (n=43) accepting non-inflammatory referrals greater than 50% of the times or always, and 69% (n=37) accepting chronic pain referrals greater than 50% of the times or always. Forty-one of the physician respondents (77%) reported having access to a specific service for these patients, particularly those with chronic musculoskeletal pain, for ongoing follow-up. The most frequently utilized referral services include a chronic pain team, orthopedics, sports medicine, genetics, and physiatry. There was significant variability in the access to these services, with some respondents commenting on long wait lists, services having limited experience with youth and children, and certain services providing initial consultation but no ongoing follow-up care.

Clinic Processes. Fifty-one respondents (68%) engaged in a formal process whereby patients are systematically reviewed in order to prepare for an efficient and complete patient visit (pre-visit planning). Of the providers who endorsed pre-visit planning, 13 (25%) were performed by the physician only, 17 (33%) were performed by the physician and associated clinic nurse, 17 (33%) were performed by a multi-disciplinary team (physician with different AHPs), and 4 (8%) were performed by AHPs only. Most respondents (78%) reviewed all patients who are seen in clinic, while the remaining reviewed only specific patients, often according to disease complexity/severity. Similarly, 52 respondents (68%) engaged in a formal review of patients encounters after the end of a clinic visit (post-visit review).

JIA Tools for Health Outcomes. Over half of respondents reported adherence to tracking patient outcomes using validated instruments, with 45 (59%) recording a disease activity measure and 45 (59%) recording a functional assessment score at every visit all the time or more than 50% of the time. Only 36% (n=27) monitored health-related quality of life at every visit all or more than 50% of the time.

Perceived level of access to Resources. Respondents rated their perceived level of access to rheumatology-care related resources including procedural support, medication infusions, and diagnostic imaging (**Table 4**). Half of the respondents (34, 50%) endorsed timely access to joint injections with sedation support (defined as completion of the joint injection within 2 weeks of the request always or more than 50% of the time). However, if the joint injection was performed by a different service (i.e. Radiology), the majority reported difficulties with timely access. Timely access to medication infusions for patients appeared to be less of a concern, with 86% (n=58) of providers reporting acceptable access more than 50% of the time or always. Timely access to imaging varied across respondents, based on level of clinical acuity and priority.

DISCUSSION

We conducted a nationwide survey to update pediatric rheumatology workforce estimates and summarize the practice patterns employed by pediatric rheumatology health professionals across Canada. Our study attempts to quantify the shortage of rheumatologists across provinces/territories, relative to the pediatric population served. Our study also describes the

variations across the centres as it relates to provision of care, including how providers prioritize and manage referrals, access care resources, and deliver care.

To ensure consistency with other Canadian rheumatology publications, we used an ideal supply and demand ratio of 1 cFTE for 75,000 population served (13, 19, 23); this is the benchmark previously recommended by the CRA and is within similar range of other developed countries (24-26). With this framework, we identified an overall median cFTE of 0.2 per 75,000, and a national deficit of 80 cFTEs. In comparison to other published data, we report the lowest pediatric rheumatologist per capita supply per 75,000 population. For comparison, the American College of Rheumatology reported 287 pediatric rheumatologists per 74 million children in 2015. Their data equated to a comparative median of 0.3 cFTE pediatric rheumatologists per 75,000 population(27). Our reported workforce figure is also slightly lower than the 2010 Canadian pediatric subspecialty workforce study results. This is likely driven by our decision to calculate pediatric rheumatology supply using cFTE data rather than by numbers of academic specialists available (28). When compared to other Canadian pediatric subspecialties, Filler et al. reported that pediatric rheumatology had the third lowest workforce. However, the study does not account for the varying demands for the various subspecialties, which will likely require different workforce targets (28).

Given that the 1:75,000 benchmark is not specific to pediatrics, we performed a sensitivity analysis with the benchmark adjusted to 1:300,000. We justified this lower threshold by estimating prevalence differences between rheumatoid arthritis and JIA (21). However, it is unclear whether this is the correct threshold to use. For instance, the scope of pediatric

rheumatology is rapidly expanding to include the management of complex systemic autoimmune and novel or hereditary autoinflammatory diseases, which may increase the clinical burden and time upon pediatric rheumatologists (29). To our knowledge, there has been no attempt at determining an appropriate pediatric rheumatology-specific per capita benchmark, and future work is needed to determine appropriate recommendations.

Our sensitivity analysis suggests that there may not be a shortage in the number of pediatric rheumatologists relative to demand, but that there is a geographical maldistribution of the workforce (13, 19, 30, 31). This imbalanced distribution of providers has been previously identified in a Canadian rheumatology workforce study by Barber et al (13). Barber et al. mapped the workforce of pediatric and adult rheumatologists combined with a threshold of 1:75,000 and determined that no province/territory achieved this threshold but five provinces (British Columbia, Ontario, Quebec, Prince Edward Island, and Nova Scotia) had 0.7-0.8 clinical FTE per 75,000 population (13). Both our study and Barber et al. reported a significant deficiency in rheumatologists within Northern Canada and relatively improved access in British Columbia and in some of the Maritimes provinces.

With the exception of one centre, all academic institutions provided most recent cFTEs. The divisional director provided the workforce information, and thus, we expect our data to be accurate and reflective of job descriptions. Currently, the provision of pediatric rheumatology care is predominantly provided at academic centres in Canada. This is also reflected in our results by the relatively low percentage of cFTE by community pediatric rheumatologists. Thus, we feel confident in our estimation of our workforce supply.

We acknowledge several limitations to our findings. First, there may be differences in how centres define FTE attributable to clinical care, and although our cFTE is reflective of job descriptions, it may still be discordant with the actual time physicians spend on clinical duties and responsibilities. Second, although our data suggests a geographical imbalance, our data does not provide enough granularity to describe imbalances within specific regions of a province or by rurality. Ease of rheumatology access according to distance from an academic centre deserves further study, given that Canadian provinces are geographically large, the majority of pediatric rheumatologists work in academic centres, and studies have recognized geographic proximity as an important determinant to care access(32-34).

Our results indicate that most pediatric rheumatologists opt to work in multi-disciplinary teams. All academic pediatric rheumatologists work with at least one other AHP, and two thirds have access to a RN, PT, and OT. However, when taking into consideration the actual FTEs dedicated to pediatric rheumatology for each professional group, AHP support may be inadequate at most centres. Other than RN support where the median FTE per centre is 1, the median FTE for remaining professions is considerably less than 1. There is a surprising lack of access to a dedicated pharmacist in most centres despite numerous opportunities for involvement as children with rheumatic disease frequently navigate the process of accessing, adhering to, and tolerating multiple long-term immunosuppressive medications with potential significant drug-drug interactions and side-effects (35).

Our AHP workforce data is reflective of what is available in academic centres. We limited to academic-affiliated AHPs as it would have been challenging to target all AHPs in Canada who occasionally work with pediatric rheumatology patients in a private office. While there are examples within the adult rheumatology context of unique models of care provided by AHPs in the community, these initiatives are not yet common in the Canadian pediatric rheumatology context (36). At present, most pediatric models of care initiatives are coordinated by providers who are affiliated with academic centres, and thus have been captured in our results.

The response rate of AHPs was substantially lower than physicians due to several possible reasons. First, some of the strategies used to maximize responses could not be employed for AHPs. While follow-up reminders were sent, we were unable to provide them with updates of the study through advertisements or meetings. Second, while we attempted to keep the survey applicable to AHPs, some may have found the survey too physician-focused and not applicable. Given the difficulties in capturing the unique perspectives of AHP in multidisciplinary rheumatology care, our future work will use qualitative research methodology to enhance our understanding of AHP roles, responsibilities, and care capacity in the pediatric rheumatology context.

Only half of Canadian rheumatologists reported always having the capacity to accommodate an urgent referral within 1 week, suggesting that there are additional demands on the rheumatology workforce to keep up with clinical demands (37). We attempted to gauge whether this stems from issues such as a high number of non-inflammatory joint pain or chronic pain referrals that may not require involvement of a pediatric rheumatologist. Given that the majority of

respondents accept these referrals, quality improvement measures focusing on improving rheumatic disease recognition by primary care providers may help reduce clinical burden. More research is needed to understand the facilitators and barriers that impact rheumatology care access and care, both from the provider and patient perspective.

In conclusion, our findings summarize the current care resources and processes used by Canadian pediatric rheumatology providers and are a valuable update on the workforce relative to established and estimated benchmarks. The current number of pediatric rheumatologists is inadequate as per currently recommended workforce benchmarks. However, according to our sensitivity analysis, the number of pediatric rheumatologists may be appropriate, but there continues to be geographic disparities. Given the ongoing geographic imbalances, alternative models of care, particularly to provide service to children in provinces/territories without pediatric rheumatology presence, should be explored within the Canadian context. In particular, future evaluation of telemedicine in underserved areas (since its increased acceptability and use during the COVID-19 pandemic) will be important. While a multi-disciplinary team approach is used in nearly all settings, the care capacity by the allied workforce may be limited, given the low median FTEs reported. The AHP role, integration, and responsibilities in pediatric rheumatology multidisciplinary care will need to be explored further in order to improve our understanding of successful models of care that improve care access and quality.

REFERENCES

1. Moorthy LN, Peterson MGE, Hassett AL, Lehman TJA. Burden of childhood-onset arthritis. *Pediatr Rheumatol Online J* 2010;8:20.
2. James SL, Abate D, Abate KH, Abay SM, Abbafati C, Abbasi N, et al. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories: A systematic analysis for the global burden of disease study 2017. *The Lancet* 2018;392:1789-858.
3. Badley EM, Wang PP. The contribution of arthritis and arthritis disability to nonparticipation in the labor force: A canadian example. *J Rheumatol* 2001;28:1077-82.
4. Jetha A, Bowring J, Tucker S, Connelly CE, Martin Ginis KA, Proulx L, et al. Transitions that matter: Life course differences in the employment of adults with arthritis. *Disabil Rehabil* 2018;40:3127-35.
5. Oen K, Guzman J, Dufault B, Tucker LB, Shiff NJ, Duffy KW, et al. Health-related quality of life in an inception cohort of children with juvenile idiopathic arthritis: A longitudinal analysis. *Arthritis Care Res (Hoboken)* 2018;70:134-44.
6. Oen K, Malleson PN, Cabral DA, Rosenberg AM, Petty RE, Cheang M. Disease course and outcome of juvenile rheumatoid arthritis in a multicenter cohort. *J Rheumatol* 2002;29:1989-99.
7. Yazdany J, MacLean CH. Quality of care in the rheumatic diseases: Current status and future directions. *Curr Opin Rheumatol* 2008;20:159-66.
8. McGlynn EA, Asch SM, Adams J, Keesey J, Hicks J, DeCristofaro A, et al. The quality of health care delivered to adults in the united states. *N Engl J Med* 2003;348:2635-45.

9. Passo MH, Taylor J. Quality improvement in pediatric rheumatology: What do we need to do? *Curr Opin Rheumatol* 2008;20:625-30.
10. Lacaille D, Anis AH, Guh DP, Esdaile JM. Gaps in care for rheumatoid arthritis: A population study. *Arthritis Rheum* 2005;53:241-8.
11. Glazier RH, Badley EM, Wright JG, Coyte PC, Williams JI, Harvey B, et al. Patient and provider factors related to comprehensive arthritis care in a community setting in ontario, canada. *J Rheumatol* 2003;30:1846-50.
12. Neogi T, Hunter DJ, Chaisson CE, Allensworth-Davies D, Zhang Y. Frequency and predictors of inappropriate management of recurrent gout attacks in a longitudinal study. *J Rheumatol* 2006;33:104-9.
13. Barber CEH, 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* 2016.
14. Shipton D, Badley EM, Bookman AA, Hawker GA. Barriers to providing adequate rheumatology care: Implications from a survey of rheumatologists in ontario, canada. *J Rheumatol* 2002;29:2420-5.
15. 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.
16. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (redcap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform X* 2009;42:377-81.

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17. Lundon K, Inrig T, Paton M, Shupak R, Kennedy C, McGlynn M, et al. Measuring advanced/extended practice roles in arthritis and musculoskeletal care in canada. *ACR Open Rheumatol* 2020;2:242-50.
 18. Sas university edition, release 3.6 (basic edition). 3.6 ed. Cary, NC, USA: SAS Institute Inc.
 19. Kur Jason KB. Rheumatologist demographics in british columbia: A looming crisis. *B C Med J* 2011;53.
 20. Canada S. Population estimates on july 1st, by age and sex. 2020 [updated 2020; cited 2020]; Available from: <https://www150.statcan.gc.ca/>.
 21. Helmick CG, Felson DT, Lawrence RC, Gabriel S, Hirsch R, Kwoh CK, et al. Estimates of the prevalence of arthritis and other rheumatic conditions in the united states. Part i. *Arthritis Rheum* 2008;58:15-25.
 22. alliance Wt. Wait time benchmarks for arthritis care. 2014 [updated 2014; cited 2020]; Available from: <https://www.waittimealliance.ca/benchmarks/arthritis-care/>.
 23. Brophy J, Marshall DA, Badley EM, Hanly JG, Aaverns H, Ellsworth J, et al. Measuring the rheumatology workforce in canada: A literature review. *J Rheumatol* 2016;43:1121-9.
 24. Badley EM, Davis AM. Meeting the challenge of the ageing of the population: Issues in access to specialist care for arthritis. *Best Pract Res Clin Rheumatol* 2012;26:599-609.
 25. Harrison MJ, Lee S, Deighton C, Symmons DP. Uk rheumatology consultant workforce provision 2007-9: Results from the bsr/arthritis research uk consultant workforce register. *Clin Med (Lond)* 2011;11:119-24.

26. Deal CL, Hooker R, Harrington T, Birnbaum N, Hogan P, Bouchery E, et al. The united states rheumatology workforce: Supply and demand, 2005-2025. *Arthritis Rheum* 2007;56:722-9.
27. Correll CK, Ditmyer MM, Mehta J, Imundo LF, Klein-Gitelman MS, Monrad SU, et al. 2015 american college of rheumatology workforce study and demand projections of pediatric rheumatology workforce, 2015-2030. *Arthritis Care & Research* 2020;n/a.
28. Filler G, Piedboeuf B. Variability of the pediatric subspecialty workforce in canada. *J Pediatr* 2010;157:844-7.e1.
29. Schaller JG. The history of pediatric rheumatology. *Pediatr Res* 2005;58:997-1007.
30. Widdifield J, Bernatsky S, Pope JE, Ahluwalia V, Barber CEH, Eder L, et al. Encounters with rheumatologists in a publicly-funded canadian healthcare system: A population-based study. *J Rheumatol* 2019;jrheum.190034.
31. ACREU. 2007 survey of rheumatologists in ontario. 2007 [updated 2007; cited 2020]; Available from: <http://www.acreu.ca/pdf/pub5/08-03.pdf>.
32. Pang R, Gunz A, Jackson B, Berard R. Geographic distribution of pediatric rheumatology referrals in southwestern ontario: The association of travel distance with visit frequency in juvenile idiopathic arthritis. *J Rheumatol* 2017;44:944.
33. Agarwal M, Freychet C, Jain S, Shivpuri A, Singh A, Dinand V, et al. Factors impacting referral of jia patients to a tertiary level pediatric rheumatology center in north india: A retrospective cohort study. *Pediatr Rheumatol Online J* 2020;18:21.
34. Tzaribachev N, Benseler SM, Tyrrell PN, Meyer A, Kuemmerle-deschner JB. Predictors of delayed referral to a pediatric rheumatology center. *Arthritis Care Res (Hoboken)* 2009;61:1367-72.

35. Gray NJ, Shaw KL, Smith FJ, Burton J, Prescott J, Roberts R, et al. The role of pharmacists in caring for young people with chronic illness. *J Adolesc Health* 2017;60:219-25.
36. 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.
37. Association CR. Wait time benchmarks. 2014 [updated 2014; cited]; Available from: https://www.waittimealliance.ca/wp-content/uploads/2014/05/Arthritis_Care_CRA_Benchmarks.pdf.

FIGURE LEGENDS

Figure 1. Breakdown of the reported total FTE according to four responsibilities: Clinical care, administrative, research, and teaching, visualized by box plot. Median percentage, lower (Q1) and upper quartile (Q3) of the interquartile range (IQR), and outliers are visually represented

Figure 2. Map of Canada depicting the number of cFTE pediatric rheumatologists per 300,000 population ≤ 19 years old, according to census data. cFTE: clinical full-time equivalent, BC: British Columbia, AB: Alberta, SK: Saskatchewan, MB: Manitoba, ON: Ontario, QC: Quebec, NFLD: Newfoundland and Labrador. Northern Territories consist of Yukon, Northwest Territories, and Nunavut. Maritimes consists of Prince Edward Island, New Brunswick, and Nova Scotia.

Table 1. Respondent Characteristics

Characteristic	n (%)
Position	
Rheumatologist	53 (69.7)
Registered Nurse	12 (15.7)
Rehabilitation Therapists ¹	9 (11.8)
Other ²	2 (2.6)
Region of Practice	
Western Canada ³	23 (30.3)
- British Columbia	10 (13.2)
Central Canada ⁴	46 (60.5)
- Quebec	15 (19.7)
- Ontario	31 (40.8)
Atlantic Canada ⁵	7 (9.2)
Northern Canada ⁶	0 (0)

¹ Rehabilitation therapists include physical therapists, occupational therapists and advanced clinical practitioners in arthritis care

² Other: Grouped as cell size too small to report. Includes other allied health professionals not listed.

³ Western Canada: British Columbia, Alberta, Manitoba, Saskatchewan

⁴ Central Canada: Ontario, Quebec

⁵ Atlantic Canada: Nova Scotia, New Brunswick, Prince Edward Island, and Newfoundland and Labrador

⁶ Northern Canada: Yukon, Northwest Territories, Nunavut

Table 2. Pediatric Rheumatologists (Clinical FTE) per Capita Using # per 300,000 benchmark (Estimated Benchmark)

Region	Number of Clinical FTE	2019 Population Estimate (≤ 19 years old)	# per 300,000
Northern Territories ¹	0	36,421	0
British Columbia	4.2	990,700	1.3
Alberta	5.9	1,074,744	1.6
Saskatchewan	0.8	301,858	0.8
Manitoba	0.9	346,946	0.8
Ontario	8.8	3,141,693	0.8
Quebec	4.7	1,763,147	0.8
Maritime Provinces ²	2.4	374,907	1.9
Newfoundland	0.7	98,508	2.1

¹ Northern Territories: Nunavut, Northwest Territories, Yukon

² Maritime Provinces: New Brunswick, Prince Edward Island, Nova Scotia

Table 3. Rheumatology-Affiliated Allied Health Professional (AHP) Workforce

AHP	Number (%) of Centres with AHP (N=15)	Median Number of AHP per centre (IQR)	Median Total FTE of all centres (IQR)¹	Median Total FTE of applicable centres²(IQR)
Nurse ³	100 (100)	2 (1)	0.9 (0.8) ⁴	1.0 (0.8)
Physiotherapists	12 (80)	1 (0.5)	0.3 (0.9)	0.6 (0.7)
Occupational Therapists	9 (60)	1 (1)	0 (0.4)	0.3 (0.5)
Advanced Practice Therapists	- ⁵	-	-	-
Social Workers	12 (80)	1 (0)	0.2 (0.4)	0.25 (0.2)

¹For centres that do not have a particular AHP, the FTE is reported as 0 and is included in the FTE calculations

²Centres that do not have a particular AHP or did not provide any information have been excluded from these calculations

³Nurse: Registered Nurse or Nurse Practitioner

⁴One centre did not elaborate on FTE information

⁵Em dashes (-) indicate a cell size that is too small (n<6)

Table 4. Perceived Level of Access to Rheumatology Care-Related Resources

Perceived Level of Access to Care-Related Resource	Never n (%)	Less than 50% of the time n (%)	More than 50% of the time n (%)	Always n (%)
Procedures				
Joint injection with sedation within 2 weeks of request date	8 (12)	26 (38)	28 (41)	6 (9)
Joint injection by another service within 2 weeks of request date	15 (22)	43 (64)	8 (12)	1 (1)
Medications				
Outpatient medication infusions within 2 weeks of request date	3 (4)	6 (9)	37 (55)	21 (31)
Imaging¹				
Timely access to urgent MRI with sedation	5 (7)	22 (32)	33 (49)	8 (12)
Timely access to urgent MRI without sedation	0 (0)	14 (21)	35 (52)	18 (27)
Timely access to non-urgent MRI with sedation	6 (9)	29 (43)	18 (27)	14 (21)
Timely access to non-urgent MRI without sedation	2 (3)	22 (33)	27 (41)	15 (23)

¹Timely access to MRIs were not explicitly defined by days, given the possible significant variability of potential cases. Timely access was defined as respondent perception.

Figure 1. Breakdown of the reported FTE at Pediatric Rheumatology Academic Centres

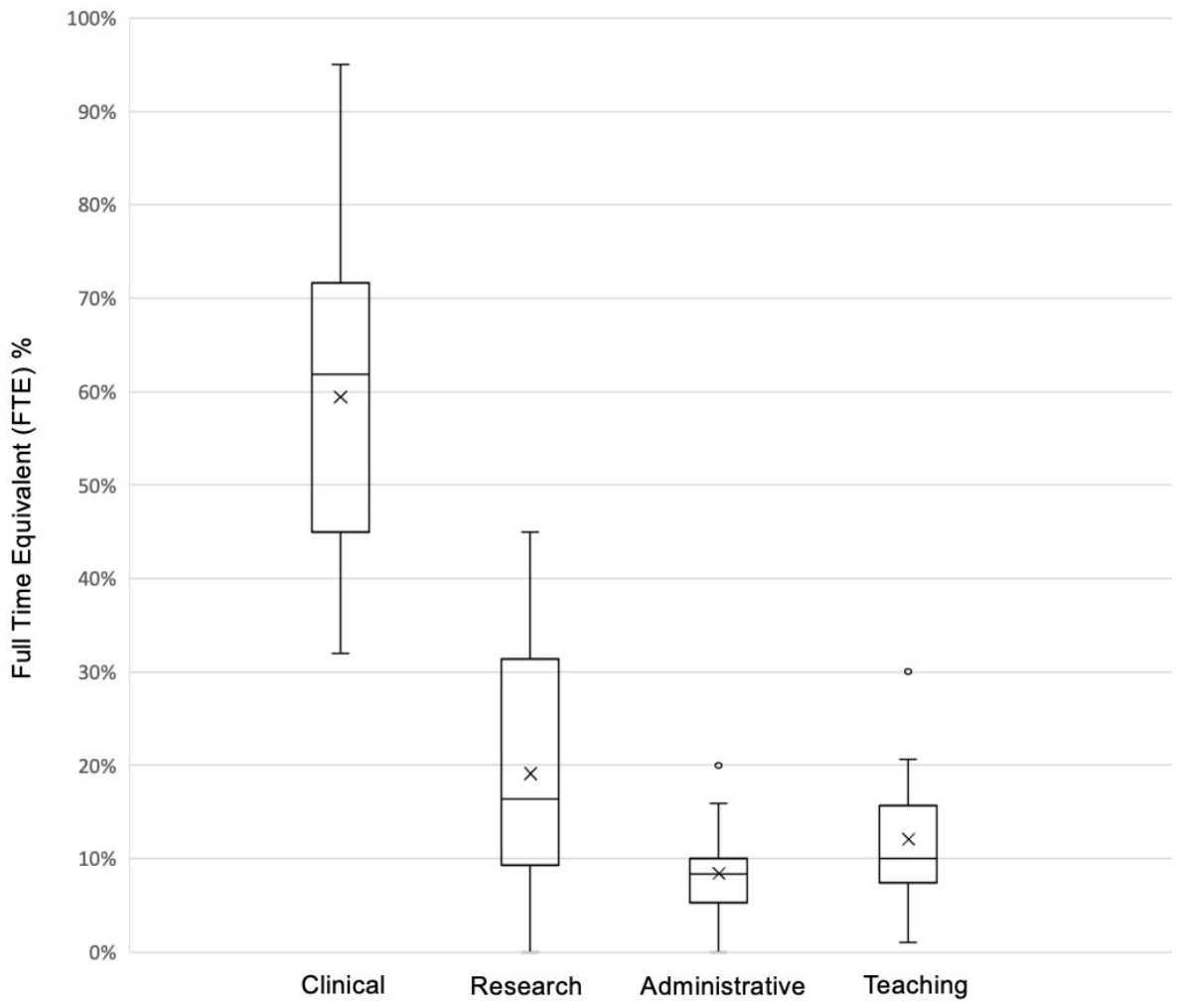


Figure 2. Map of Canada depicting the number of Clinical FTE (cFTE) per 300,000 population (Estimated Benchmark)

