

# Consultation With an Arthritis Specialist for Children With Suspected Juvenile Rheumatoid Arthritis

## *A Population-Based Study*

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**Objectives:** To describe consultation with an arthritis specialist because of suspected new-onset juvenile rheumatoid arthritis (JRA) and to determine factors associated with prompt consultation.

**Design:** Retrospective cohort study.

**Setting:** Physician reimbursement administrative data were obtained for all children aged 16 years or younger in the Province of Québec (Canada).

**Participants:** Suspected new-onset cases of JRA in 2000 were defined by a physician visit because of JRA, providing there had been no such claims in the preceding 3 years.

**Main Exposure:** First JRA diagnosis made by a non-arthritis specialist.

**Main Outcome Measures:** First consultation with an arthritis specialist subsequent to diagnosis by a non-

arthritis specialist and time to first consultation with an arthritis specialist.

**Results:** Of 352 children and adolescents with suspected new-onset JRA identified by non-arthritis specialists, 159 (45.2%) were subsequently seen by an arthritis specialist. Mean (SD) time to consultation for those seen was 115.3 (213.8) days (median, 28 days). Younger children were more likely to obtain care from an arthritis specialist compared with those having JRA first diagnosed by a general practitioner.

**Conclusion:** Most patients with suspected new-onset JRA do not obtain prompt care from an arthritis specialist. Further research and action should focus on this issue so that outcomes may be optimized.

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JUVENILE RHEUMATOID ARTHRITIS (JRA) is one of the most common chronic diseases of childhood. It is often associated with severe joint destruction and disability and frequently extends past adolescence into adulthood.<sup>1-5</sup> More than one-third of patients with JRA develop joint destruction and other complications within 6 years after diagnosis.<sup>4</sup> Most of this damage occurs early in the course of the disease; thus, early aggressive therapy may be especially important. It has also been suggested that, if remission does not occur within 10 years after onset of JRA, the disease will continue to be active.<sup>3</sup>

Management of JRA involves a multidisciplinary approach including pharmacologic treatment, physical therapy, and other aids.<sup>6</sup> New advances in pharmacologic treatments have been promising,<sup>7</sup> and

early intervention with disease-modifying antirheumatic drugs may help minimize joint damage<sup>8,9</sup> and increase remission rates.<sup>10</sup> However, use of such drugs can be complex, particularly insofar as appropriate dosing in children and monitoring for possible adverse effects. In addition, the long-term effects of these medications in children are unknown. Because rheumatologists have the most experience with such agents, early consultation with a rheumatologist or pediatric arthritis specialist is important.

To our knowledge, there have been no population-based studies of consultation with arthritis specialists for children and adolescents with suspected JRA. The objectives of this study were to describe consultation with an arthritis specialist because of suspected JRA and to determine factors associated with prompt consultation.

## DATA SOURCE AND STUDY POPULATION

Data were obtained from a physician claims administrative database including all residents of the Province of Québec (the Régie de l'Assurance Maladie du Québec). We obtained permission from the Access to Information Commission of the Province of Québec before obtaining these data. Our study population consisted of all children and adolescents aged 16 years or younger who had visited a physician in 2000 because of JRA (*International Classification of Diseases, Ninth Revision, Clinical Modification* [ICD-9-CM] code 714). The cutoff of 16 years was selected because this is one of the diagnostic criteria for JRA. Data were available for these children and adolescents for the period between January 1, 1997, and June 30, 2003. Although the terminology has changed in the last decade and JRA is considered a subset of the broader category of juvenile idiopathic arthritis, in this article, we focus on JRA because our population was defined by having a JRA ICD-9-CM code 714 visit in 2000; thus, we did not capture all those children and adolescents having other juvenile idiopathic arthritis diagnoses such as psoriatic arthritis and enthesitis-related arthritis.

There were 842 children and adolescents with at least 1 physician visit diagnostic code for JRA in 2000. We established that 523 of 842 patients (62.1%) had no previous physician visits because of JRA in the preceding 3 years. These 523 children were considered incident cases, or suspected new-onset cases of JRA. Within this group, 352 children (67.3%) had their first JRA visit coded by a non-arthritis specialist. Pediatric arthritis specialists in Quebec bill the government as either internists, pediatricians, immunologists, or rheumatologists. We considered pediatric arthritis specialists to be rheumatologists or other physicians who saw patients in the juvenile arthritis clinic at the various pediatric hospitals in the province. We identified these pediatric arthritis specialists from the physician claims administrative database as one of the following: an internist who saw the patient in the pediatric hospital and assigned the patient a diagnosis of JRA (1 internist worked exclusively in the arthritis clinic at 1 of the pediatric hospitals in Quebec and had more than 10 years of experience in the field of juvenile arthritis); a pediatrician who saw the patient in the pediatric hospital, assigned a diagnosis of JRA, and during the study had recorded more than 70 visits by patients with JRA and, thus, was identified as a pediatrician/arthritis specialist who worked in the arthritis clinic of the pediatric hospital; a pediatric immunologist who saw the patient in the pediatric hospital and assigned the patient a diagnosis of JRA; or a rheumatologist.

For the group of 352 children first diagnosed by a non-arthritis specialist, we calculated the percentage of those who subsequently consulted with an arthritis specialist and investigated factors associated with time to consultation. We assumed that a physician who records a JRA visit believes that the child likely has JRA and, on that basis, may refer the family to an arthritis specialist. Although confirmation of a diagnosis of JRA is not central to our purposes, in secondary analyses we also used the algorithm of MacLean et al<sup>11</sup> for identifying incident cases of rheumatoid arthritis. This algorithm requires 2 visits because of rheumatoid arthritis, at least 2 months apart but within 2 years, after verifying that no previous claim had been made for this condition.

We examined both patient- and physician-related factors potentially associated with consultation to an arthritis specialist. Patient-related factors included sex, age at first JRA visit, socioeconomic status (SES), and proximity to available services. Socioeconomic status was based on a validated indicator that uses postal code to estimate neighborhood SES and provides an eco-

logical index of material and social deprivation.<sup>12</sup> We dichotomized SES at the top 2 quintiles vs the lower 3 quintiles. Proximity to available services was classified according to the density of primary and secondary care facilities and was described as high, moderate, or low, depending on whether both, 1, or no primary and secondary services were available. Physician-related factors assessed included sex,<sup>13</sup> years since graduation, and specialty (pediatrician or other specialist vs general practitioner).

## STATISTICAL ANALYSIS

We described the characteristics of all children and adolescents having a diagnosis of JRA in 2000 and categorized the cases according to physician specialty at the first recorded JRA visit. We then described contact with an arthritis specialist for both incident cases and non-incident cases.

We analyzed the data for those 352 incident cases whose first JRA visit was to a non-arthritis specialist. In initial analyses, we compared those who consulted with an arthritis specialist any time during follow-up with those who did not, using multiple logistic regression. Our primary analyses then focused on factors associated with time to first consultation with an arthritis specialist. The incident JRA visit was defined as "time zero," and the time to the first visit to an arthritis specialist was defined as "event time." Patients who did not consult with an arthritis specialist by the end of follow-up (end of the study [June 30, 2003] or death) were censored at that time. Multivariate Cox proportional hazards regression<sup>14</sup> was used to estimate the independent effects of patient sex, age (dichotomized at the mean), SES, and service availability, and the characteristics of the physician visited at the time of the initial JRA diagnosis (sex, years since graduation, and specialist vs general practitioner). At regression analyses, all hypotheses were tested using the 2-tailed Wald test, with  $P < .05$  considered statistically significant.

## RESULTS

Of the 842 patients with JRA recorded in Quebec in 2000, 557 (66.2%) had contact with an arthritis specialist some time between January 1, 1997, and June 30, 2003. Of these 842 patients, 523 had incident JRA. Their characteristics are given in **Table 1** and compared with those of the 319 patients with nonincident JRA, that is, those who had a JRA visit previous to the first visit in 2000. The mean (SD) age for the entire group was 10.0 (4.4) years.

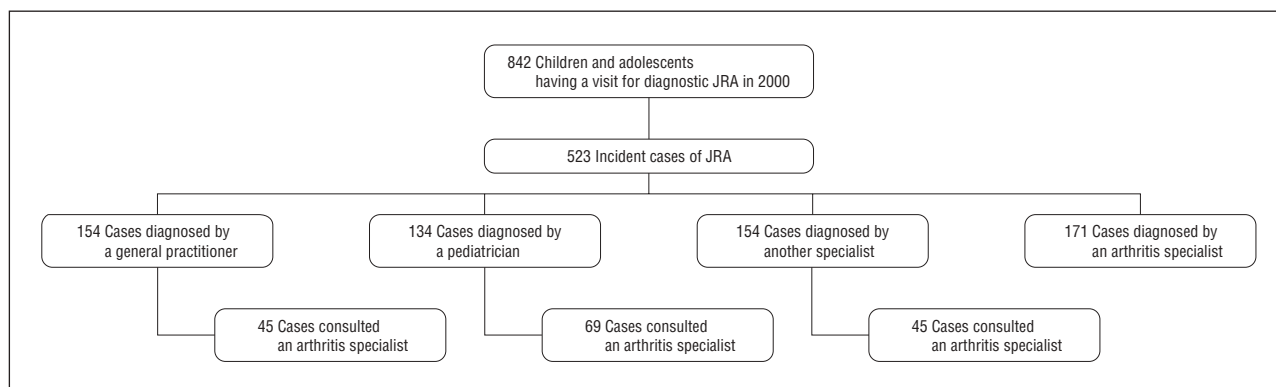
Among the 523 incident cases, 352 were first assigned a JRA diagnosis by a non-arthritis specialist. For the 352 patients, the diagnosis was made by a family physician in 154 cases (43.8%), by a pediatrician in 134 cases (38.1%), and by another specialist in 65 cases (18.2%). Only 159 of these 352 patients with JRA initially diagnosed by a non-arthritis specialist (45.2%) visited an arthritis specialist within the subsequent 3-year follow-up. Of these 159 patients, 22 (13.8%) were diagnosed by the arthritis specialist as having JRA, 36 (22.6%) as having another type of arthritis (ICD-9-CM codes 710-720, excluding code 714 for JRA), and 101 (63.6%) as having a noninflammatory or nonrheumatologic disorder. Consultation patterns are shown in **Figure 1**. In the 159 patients who consulted an arthritis specialist, the mean (SD) time between the first diagnostic visit with the non-arthritis specialist and consultation with the arthritis specialist was 115.3 (213.8) days (median, 28.0 days; interquartile range, 2-105 days). Specifically, of the 159 patients, 71 (44.7%) were seen by the

**Table 1. Comparison of Incident and Nonincident JRA Cases Identified in the Province of Quebec in 2000**

Variable	Incident JRA Cases (n=523)				Nonincident JRA Cases (n=319)
	Physician Who First Coded JRA				
	General Practitioner (n=154)	Pediatrician (n=134)	Arthritis Specialist (n=171)	Other Specialist (n=64)	
Age, mean (SD), y	10.62 (4.54)	8.31 (4.12)	10.27 (4.55)	10.00 (4.35)	10.16 (4.15)
Female sex, %	56.49	61.19	69.59	59.38	73.35
Urban dweller, %	74.68	78.36	87.13	65.63	73.98
High SES, %	34.00	36.43	48.19	44.26	38.72
Comorbidities, mean (SD), No. <sup>a</sup>	0.32 (0.49)	0.42 (0.57)	0.40 (0.57)	0.38 (0.49)	0.29 (0.54)
Availability of services, %					
High	75.97	77.61	88.89	81.25	78.37
Moderate	18.84	14.93	8.19	7.81	14.73
Low	5.19	7.46	2.92	10.94	6.90

Abbreviations: JRA, juvenile rheumatoid arthritis; SES, socioeconomic status.

<sup>a</sup>Number of comorbidities equals the sum of the following: asthma (*International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM] code 493*), cancer (*ICD-9-CM codes 140-172, 174-195, and 200-208*), cystic fibrosis (*ICD-9-CM codes 277*), diabetes mellitus (*ICD-9-CM code 250*), epilepsy (*ICD-9-CM code 345*), and hemophilia (*ICD-9-CM code 286*).



**Figure 1.** Flowchart shows patterns of consultation for 842 children and adolescents with juvenile rheumatoid arthritis (JRA).

**Table 2. Multiple Logistic Regression: Factors Associated With Consultation With an Arthritis Specialist**

Variable	Adjusted OR (95% CI)
Age, y	0.98 (0.92-1.03)
Female vs male sex	1.74 (1.07-2.83) <sup>a</sup>
Higher vs lower SES	1.25 (0.77-2.03)
Availability of services	
High	1 [Reference]
Moderate	0.45 (0.21-0.95) <sup>a</sup>
Low	0.51 (0.20-1.29)
Physician who first diagnosed JRA	
General practitioner	1 [Reference]
Pediatrician	2.39 (1.35-3.94) <sup>a</sup>
Other specialist	5.58 (2.82-11.01) <sup>a</sup>
Female vs male sex	1.24 (0.72-2.13)
Years postgraduation	0.99 (0.97-1.02)

Abbreviations: CI, confidence interval; JRA, juvenile rheumatoid arthritis; OR, odds ratio; SES, socioeconomic status.

<sup>a</sup> $P < .05$ , 2-tailed Wald test.

arthritis specialist in the first 3 months, 132 (83.0%) within the first 6 months, and 149 (93.7%) within 12 months. Because children with musculoskeletal signs or symp-

toms often see orthopedic surgeons because of these problems,<sup>15</sup> we determined that 63 of the 159 children or adolescents who consulted an arthritis specialist (39.6%) saw an orthopedist first.

Using the algorithm of MacLean et al<sup>11</sup> (ie, 2 coded JRA visits by a non–arthritis specialist at least 2 months apart within 2 years), we identified 43 incident JRA cases, 31 of whom (72.1%) were subsequently seen by an arthritis specialist. The median time from the first diagnostic JRA visit to consultation with an arthritis specialist for these 31 children was long: 286 days (interquartile range, 167-394 days).

Univariate analyses revealed that more female patients consulted arthritis specialists ( $P = .02$ ), as did children and adolescents who lived in areas with higher service availability ( $P = .02$ ) and who had their first JRA diagnosis posed by a non–arthritis specialist or a pediatrician as opposed to a general practitioner ( $P < .001$ ).

Results of multivariate logistic regression analysis are given in **Table 2**. Girls and those in whom JRA was first diagnosed by a pediatrician or another specialist as opposed to a general practitioner were more likely to have consulted with an arthritis specialist. Children and adolescents living in areas with medium service availabil-

ity, compared with high service availability, were less likely to consult an arthritis specialist, with a similar trend for those living in areas with low service availability.

**Figure 2** shows Kaplan-Meier curves comparing how the percentage of children and adolescents who have not yet consulted an arthritis specialist changes with time for younger ( $\leq 10$  years) vs older ( $> 10$  years) patients at the first JRA visit. This indicates that younger children tend to consult arthritis specialists sooner than older children do.

The adjusted hazard ratio estimates from the multivariate Cox regression models are given in **Table 3**. These show that younger children had a significantly shorter time to consultation with an arthritis specialist.

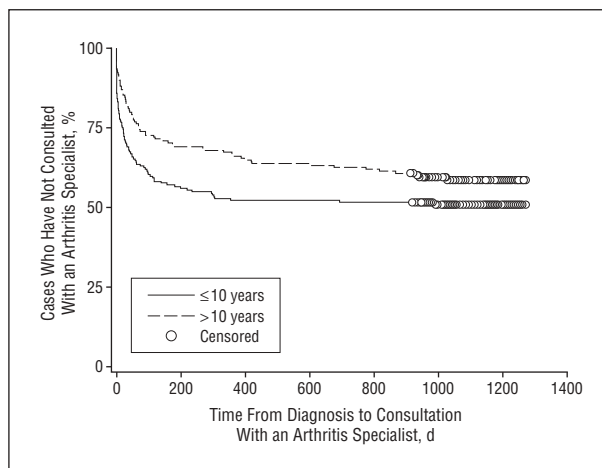
## COMMENT

Our primary analyses indicated that only 45% of children and adolescents with suspected new-onset JRA visited an arthritis specialist during the 3 years after an initial diagnosis made by a non-arthritis specialist. Younger children, female patients, and those first diagnosed by another specialist as opposed to a general practitioner seemed more likely to visit an arthritis specialist.

We found that about 40% of children and youth with incident JRA or suspected JRA (all subtypes) who consulted an arthritis specialist first consulted an orthopedic surgeon. Consultation with a pediatric arthritis specialist is most often because of musculoskeletal pain, which is found to be inflammatory disease in a minority of patients.<sup>16</sup> The effects of first referral to an orthopedic surgeon and possibly overreferral of a child with noninflammatory disease to an arthritis specialist may result in delay in consultation with an arthritis specialist.

Younger children and female patients tend to consult an arthritis specialist sooner. Cuesta et al<sup>15</sup> reported that younger children with pauciarticular JRA who consulted pediatric rheumatologists tend to be referred first to orthopedists. The differential diagnosis of pauciarticular JRA is more likely to include orthopedic problems as opposed to the differential diagnosis of polyarticular or systemic-onset arthritis. Moreover, these authors did not consider all children and adolescents having a diagnosis of JRA but only those who consulted a rheumatologist, and they did not indicate whether the time to consultation was shorter for older children. Physicians may be more likely to refer female patients with suspected JRA because they may be more certain of the diagnosis inasmuch as JRA occurs more frequently in girls.<sup>6</sup>

The finding that patients diagnosed by other specialists were more likely to consult an arthritis specialist may be because specialists are more likely to refer to other specialists when they recognize that a patient's disorder is not within their domain of expertise, whereas a general practitioner may continue to see the patient, order tests, and observe the patient over time.<sup>17</sup> Moreover, this concurs in part with the findings of McGhee et al,<sup>16</sup> who found that orthopedic surgeons are more likely to refer children with JRA to rheumatologists than are primary care physicians and other specialists. Our finding that patients who were first diagnosed by a pediatrician are more likely to consult an arthritis specialist than are those who



**Figure 2.** Time from first diagnosis of juvenile rheumatoid arthritis by a non-arthritis specialist until consultation with an arthritis specialist.

**Table 3. Multivariate Cox Regression Analysis: Factors Associated With Time to Consultation With an Arthritis Specialist**

Variable	Adjusted HR (95% CI)
Age, y	0.95 (0.91-0.99) <sup>a</sup>
Female vs male sex	1.24 (0.86-1.79)
Higher vs lower SES	0.86 (0.61-1.23)
Availability of services	
High	1 [Reference]
Moderate	0.79 (0.39-1.61)
Low	0.59 (0.31-1.11)
Physician who first diagnosed JRA	
General practitioner	1 [Reference]
Pediatrician	1.11 (0.73-1.70)
Other specialist	1.26 (0.79-2.00)
Female vs male sex	1.43 (0.97-2.12)
Years postgraduation	1.00 (0.99-1.02)

Abbreviations: CI, confidence interval; HR, hazard ratio (HR < 1.00 indicates that a given duration was associated with a longer time to consultation, whereas HR > 1.00 indicates a shorter time); JRA, juvenile rheumatoid arthritis; SES, socioeconomic status.

<sup>a</sup>  $P < .05$ , 2-tailed Wald test.

were first diagnosed by a family practitioner agrees with the findings of Freed et al,<sup>18</sup> who reported that 42% of pediatricians and 32% of family practitioners claim to refer all of their patients with JRA.

Unlike findings in adult rheumatoid arthritis,<sup>19</sup> we did not find an association between SES and consultation with an arthritis specialist. This is encouraging, especially in view of recent findings of worse outcomes for patients with JRA with lower SES.<sup>20</sup>

Examination skills of primary care physicians and pediatricians may be lower for the musculoskeletal system than for other body systems.<sup>21,22</sup> Recently, screening tools have been developed that may aid physicians in identifying children with inflammatory arthritis and, subsequently, may aid appropriate rheumatology referral.<sup>23,24</sup>

Studies based on administrative data, such as ours, have inherent limitations including lack of quality-control of diagnostic coding and difficulty in capturing disease severity. Based on our data, there were 193 incident cases

of JRA: 171 first diagnosed by an arthritis specialist and another 22 of the 159 initially diagnosed by a nonspecialist and later confirmed by an arthritis specialist. Based on the Quebec population of approximately 1.5 million persons aged 0 to 16 years, the cumulative incidence for 2000 in our study would be 12.9 per 100 000 persons, which is slightly higher than the 11.7 per 100 000 persons estimated in Rochester, Minnesota,<sup>25</sup> and lower than the 19.5 per 100 000 persons estimated in Finland.<sup>26</sup> In this study, we did not insist on high sensitivity of the diagnosis. If the diagnosing physician coded a diagnosis as JRA, we assumed that he or she believed that the patient had JRA or, perhaps, a related condition. Diagnoses can change with time; for example, it may be reasonable for a physician to observe a patient with suspected post-viral arthritis to determine whether symptoms resolve. Nevertheless, we contend that, if a physician suspected JRA, in view of recommendations for early treatment,<sup>8,9</sup> consultation with an arthritis specialist may be important. When using the more stringent algorithm of MacLean et al,<sup>11</sup> the consultation rate was much higher (72%) but still indicated that more than one-fourth of these children and adolescents did not consult an arthritis specialist because of JRA. Moreover, the time to consultation was long. We could not differentiate types of JRA from the database codes. Disease severity may affect perceived need for consultation because, we presume, more severe disease, such as systemic disease, may be diagnosed sooner and specialized treatment may be considered more urgent.<sup>27</sup> Nevertheless, early treatment of JRA is thought to be beneficial regardless of severity.<sup>8,9</sup>

We did not include in our analysis those patients in whom JRA was initially diagnosed by an arthritis specialist. These patients were most probably referred to an arthritis specialist by another physician at some time. Some of these patients may have had disease that had been in remission for more than 3 years and, therefore, were not incident cases. Others may have been referred with a diagnosis other than JRA. It is impossible to identify a priori all patients having other diagnoses who would possibly be referred to an arthritis specialist, especially inasmuch as they may have been referred but the arthritis specialist may not have confirmed a diagnosis of JRA. Despite these limitations, we believe that our analysis depicts consultation patterns for patients with suspected JRA, defined by a coded JRA visit to a non-arthritis specialist.

Another consideration is that administrative databases describe actual consultations with specialists. We cannot know whether these constitute all referrals because some referrals may not be acted on. In addition, we were unable to address other issues related to accessibility to specialists such as waiting times, transportation difficulties, family problems, or mental health issues. We classified patients as having suspected new-onset JRA if they did not visit a physician because of JRA in the previous 3 years. In some patients, JRA may have been in remission for several years and may have been erroneously included as new-onset JRA. However, one would expect that these patients would have been more, not less, likely to consult an arthritis specialist because they may have done so in the past. Thus, if such patients were included in our incident group, then the rate of

consultation for new-onset JRA may be even lower than what we report.

In conclusion, our data show a low rate of rheumatology consultation because of suspected new-onset JRA. Of possible concern is that this reflects a shortage of pediatric rheumatologists in the Province of Québec, as has been reported in North America in general.<sup>28</sup> This would compound the difficulty primary care physicians have insofar as the diagnosis and treatment of JRA. Potential solutions include both improved medical education and the implementation of good screening techniques to help primary care physicians identify probable JRA. In addition, triaging rheumatology consultations according to the degree of concern on the part of the referring physician may enable patients with inflammatory arthritis to receive prompt, appropriate management and, thus, maximize outcomes for this potentially disabling condition. Also, increasing the number of pediatric rheumatologists may improve the situation.

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**Author Contributions:** Dr Ehrmann Feldman had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. *Study concept and design:* Ehrmann Feldman, Bernatsky, Abrahamowicz, Haggerty, Leffondré, and Tousignant. *Acquisition of data:* Ehrmann Feldman and Haggerty. *Analysis and interpretation of data:* Ehrmann Feldman, Bernatsky, Abrahamowicz, Roy, Xiao, Haggerty, Leffondré, Tousignant, and Duffy. *Drafting of the manuscript:* Ehrmann Feldman and Roy. *Critical revision of the manuscript for important intellectual content:* Ehrmann Feldman, Bernatsky, Abrahamowicz, Xiao, Haggerty, Leffondré, Tousignant, and Duffy. *Statistical analysis:* Ehrmann Feldman, Abrahamowicz, Roy, Xiao, Haggerty, and Leffondré. *Obtained funding:* Ehrmann Feldman, Bernatsky, Abrahamowicz, Haggerty, Leffondré, and Tousignant. *Administrative, technical, and material support:* Roy. *Study supervision:* Ehrmann Feldman and Bernatsky. *Content expertise:* Duffy.

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