# Arthritis in Aboriginal Manitobans: Evidence for a High Burden of Disease

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ABSTRACT. Objective. To evaluate the relative burden of arthritis and patterns of care in Aboriginal Manitobans, using multiple data sets to ensure a representative picture.

> Methods. Arthritis burden and healthcare utilization was ascertained using 3 separate data sources. Physician claims for 3 common ICD-9 musculoskeletal diagnoses were abstracted from the Population Health Research Data Repository for First Nations (FN) Manitobans and compared to all other Manitobans. Self-reported arthritis rates were obtained from the Manitoba First Nations Regional Longitudinal Health Survey (MFN Survey), which surveyed FN persons living on-reserve. Data on ethnicity and diagnoses were abstracted from the Arthritis Centre research database, which contains records of all patients seen at the Arthritis Centre.

> Results. Twice as many FN Manitobans had physician claims for rheumatoid arthritis, degenerative arthritis, and unspecified arthropathy compared to all other Manitobans. MFN Survey data identified a self-reported arthritis rate of 21.0% and a rheumatoid arthritis (RA) rate of 3.0%. Data for 687 Aboriginal patients and 4135 Caucasian patients were abstracted from the Arthritis Centre database. Aboriginal patients seen in the Arthritis Centre were 2 to 4 times more likely to have a diagnosis of inflammatory disease, and less than half as likely to have noninflammatory disease.

> Conclusion. The data highlight the increased burden of arthritis in Aboriginal Manitobans, and draw attention to large gaps in our knowledge of how, why, and when Aboriginals access medical care. (First Release April 15 2008; J Rheumatol 2008;35:1145–50)

Key Indexing Terms:

**ARTHRITIS** NORTH AMERICAN INDIANS INDIGENOUS HEALTH SERVICES

HEALTHCARE DELIVERY REFERRAL DISPARITY

Increasingly, arthritis is recognized to be a major chronic health problem among Canada's Aboriginal people<sup>1-4</sup>. This parallels general recognition of the burden of arthritis in Canada as a whole, with direct and indirect costs of arthritis exceeding \$14 billion annually<sup>5</sup>, and these costs are expected to continue to rise sharply over the next decades. The Canadian Aboriginal population is growing at twice the rate of the general Canadian population<sup>6</sup>, making it even more important to better define arthritis burden, patterns of care, and needs for this population.

In 2002, the Canadian Medical Association recognized that the health status of Aboriginal Canadians was well

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below that of other Canadians, and that especially those residing in northern Canada were underserviced with respect to healthcare<sup>7</sup>. The increasing incidence and prevalence of arthritis was noted, as were multiple barriers to care.

However, available data on arthritis in Aboriginal people are scattered and piecemeal<sup>2,8-10</sup>: arthritis specialists working in areas with large Aboriginal populations report impressions of high frequency of disease with increased severity, with little controlled data to confirm such impressions. Moreover, the wide variation in culture, environment, geography, and genetic ancestry among Canada's Aboriginal people<sup>8</sup> make it inadvisable to generalize findings from one region or Aboriginal population to others. The Aboriginal peoples in Canada are the descendants of the original inhabitants of North America; the term Aboriginal, per the Constitution Act 1982, includes Indians [commonly referred to as First Nations (FN)], Metis, and Inuit. These are 3 distinct peoples with unique heritages, languages, cultural practices, and spiritual beliefs.

Our objective was to evaluate the relative burden of arthritis and patterns of care in Aboriginal Manitobans compared to other Manitobans. The description of arthritis data from multiple data sets ensures a broader, more complete picture and will assist in planning healthcare delivery in the future.

### MATERIALS AND METHODS

Three separate data sources were used to summarize the burden of rheumatic disease in Aboriginal Manitobans.

Population Health Research Data Repository (Research Repository). The province of Manitoba has a universally accessible, government-funded healthcare system, administered by Manitoba Health. This system covers all residents, including FN people, regardless of where care is obtained within Canada. Participation in the plan is virtually complete, numbering about 1.1 million in total, with about 800,000 adults over the age of 18 years. The population enrolled in the plan closely matches the provincial population as determined by the Canadian census. Physicians are paid for their services on the basis of their claims to Manitoba Health specifying the service and the patient's diagnosis. Hospital discharges from inpatient stays and from emergency departments are similarly recorded. All diagnoses are recorded according to the Ninth Revision of the International Classification of Diseases (ICD-9)11. Physician claims and hospital discharges include the patient's Manitoba Health number, date of birth, and gender. As part of the process of registration with Manitoba Health, an attempt is made to verify whether new registrants are registered under the Indian Act. If so, their FN affiliation is recorded. There are no identifiers for the Metis or Inuit population; therefore Research Repository data refer only to FN people. Physician claims include a single ICD code referring to the primary reason for the physician visit, while hospital discharge records include up to 16 diagnoses. Manitoba Health provides copies of computerized healthcare utilization files, with identifiers removed, to the Research Repository. The general reliability and validity of the diagnoses on these records and of the database for epidemiologic studies has been established<sup>12,13</sup>.

Disease coding and case definition. ICD-714 [rheumatoid arthritis and other inflammatory arthropathies (RA)], ICD-715 [degenerative arthritis (OA)], and ICD-716 [unspecified arthropathies (UA)] were used to estimate the burden of arthritis. These are the 3 most common musculoskeletal diagnoses used. Connective tissue diseases, crystal arthropathies, and spondyloarthropathies were not separately evaluated, as separation of individual diseases using 3-digit ICD-9 codes is difficult and beyond the scope of this article. All individuals over the age of 18 years registered with Manitoba Health were included. To estimate the number of individuals attending a physician or admitted to hospital for arthritis in a given year, the proportion of adults within each fiscal year for whom at least one physician claim or hospital discharge diagnosis for RA, OA, or UA was made was calculated. To account for known differences in the population structure, rates of visits for arthritis were age- and sex-standardized to the 1984/85 Manitoba non-Aboriginal population. An age-adjusted rate is a weighted average of the age-specific (crude) rates, where the weights are the proportions of persons in the corresponding age groups of a standard population. Only 19% of the FN population is age 40 years or older, compared with 44% of the non-Aboriginal population. For age 65 years or older, the figures are 3% for Status Indians and 14% for non-Aboriginal people. Standardized comparisons are necessary when comparing populations with such very different age structures to reduce the potential confounding effect of age, and make meaningful comparisons between FN and other populations<sup>14</sup>. The standard used here was the non-Aboriginal Manitoba population for 1984/85, the beginning of the data extraction period.

We did not attempt to establish the diagnostic accuracy of these records, as our aim was to establish the burden of arthritis in general, rather than prevalence rates for specific diseases.

To further examine potential differences in access to or utilization of medical services, overall medical claims data were compared for the FN population and the remainder of the Manitoba population.

Manitoba First Nations Regional Longitudinal Health Survey. In 1997, a joint initiative between the Assembly of Manitoba Chiefs (AMC) and the Centre for Aboriginal Health Research at the University of Manitoba resulted in a survey of 17 randomly selected Manitoba FN communities as part of a national FN and Inuit Health Survey. In 2002, survey participation was increased to 35 out of a possible 62 communities, with a multistage strati-

fied random-sampling approach to select small (population < 500 persons), medium (population 500–999), and large communities (population > 1000) from different Tribal Council regions<sup>15</sup>. The cross-sectional survey, comprising 3 surveys directed at 3 separate age groups representing children, youth, and adults, includes a set of "National Core Questions" and questions specific for the Manitoba FN population. Only adult responses are reported in this article. All respondents provided written consent, and were given the choice of a verbal interview or to perform the survey independently with an interviewer assisting with questions on request. The survey covered a broad range of health related topics, including sociodemographic parameters, health related behaviors, spirituality, mental health, and physical health. The results reported here are from the health condition section of the survey, which included a list of chronic health conditions and asked participants whether they had been diagnosed with the condition by a healthcare professional. If a respondent indicated yes to a condition, they were asked further whether they were undergoing treatment or taking medications for the condition and whether the condition limited their activities. Relevant conditions included here were "arthritis," and "rheumatoid arthritis." Details of treatment and medications were not collected. The adult survey achieved a response rate of 77% (n = 3301 sample; 4330 target sample; N = 26 communities), with 60% of the communities achieving a response rate of over 80%. Slightly more adult females (55%; nf = 1815) as opposed to males (45%; nm = 1485) participated in the survey. The age distribution of the adult sample was 41% for 18 to 34-year-olds, 23% for 35 to 44-yearolds, 14% for 45 to 54-year-olds, and 10% for 65 years and older. The age distribution did not differ by gender.

Arthritis Centre database. A prospective longitudinal database of all outpatients seen at the Arthritis Centre at the Health Sciences Centre in Winnipeg, Manitoba, has been maintained since 1991. Patients provide their demographic information, including self-identification of ethnicity. Multiple definitions for Aboriginal ethnicity have been used over time, leading to difficulties in separating data for FN, Metis, and Inuit patients, such that they are used collectively for calculations at this time. Clinical and diagnostic information is recorded and entered into the database with each visit. American College of Rheumatology (ACR) diagnostic criteria are used where applicable, and overwritten if the diagnosis changes or evolves. Written consent is obtained from each patient prior to inclusion in the database. Efforts are made to ensure completeness and accuracy of each record in a concerted effort between rheumatologists, data clerks, and the authors.

Disclaimer. The results and conclusions are those of the authors and no official endorsement by Manitoba Health or the FN or Metis people of Manitoba was intended or should be implied.

## **RESULTS**

Research Repository data. In the 1995/96 fiscal year, the adult FN population identified in the Research Repository database numbered 34,750, compared to 807,095 adults not identified as FN. The percentage of the population with a minimum of one ambulatory care physician claim (for any diagnosis) was similar for FN and all other Manitobans, at 82% and 83%, respectively. Total ambulatory care visits per 1000 adults were somewhat higher for FN Manitobans, as were visits for arthritis, and visits per user (Table 1).

Twice as many FN Manitobans had physician claims for ICD-714 (RA) for fiscal years 1986/87 to 1995/96, at about 10/1000 adults, compared to 5/1000 adults for all other Manitobans (Figure 1).

Similarly, about twice as many FN Manitobans had annual claims for ICD-715 (OA) and ICD-716 (UA) compared to all other Manitobans (Figures 2 and 3). On average, 58/1000

Table 1. Comparative claims data.

Fiscal Year 1995/96	First Nations, n	All Others, n	Total, n
Population age ≥ 18 yrs	34,750	807,095	841,844
Proportion with $\geq 1$ ambulator	y		
care claim, %	82.1	83.0	83.0
All visits/1000*	6197	4815	4869
All visits/user	7.55	5.80	5.87
Arthritis visits/1000* (ICD 714, 715, 716)	431.1	272.7	278.2

<sup>\*</sup> Standardized to 1984-85 non-Aboriginal population.

FN Manitobans over the age of 18 years were seen annually for a complaint labeled degenerative arthritis, compared to 34/1000 of other Manitobans annually during the same 10-year period. As well, 53/1000 FN Manitoba adults were seen annually for an unspecified arthropathy, compared to 28/1000 for all other Manitobans.

Manitoba First Nations Regional Longitudinal Health Survey. Overall, 54% of FN persons living on-reserve indicated a diagnosis of a chronic health condition 16. Arthritis was the second most commonly reported condition at 21%, surpassed only by diabetes at 24%. Three percent reported a diagnosis of RA. More women than men self-report arthritis and RA in all age groups, with the prevalence increasing with age in both men and women.

Forty percent were not receiving any treatment and/or not using medication for arthritis at the time of the survey. Selfreported activity limitations were high for rheumatic disease and related musculoskeletal disease, with 77% reporting limitations due to RA, and 68% reporting limitations for arthritis.

Arthritis Centre database. Data are available for 5213 patients up to November 30, 2003. Of these, 4135 (79.3%) patients self-identified as Caucasian, and 687 (13.2%) self-identified as Aboriginal, comparable to the 13.6% of the provincial population self-identified as Aboriginal people in the 2001 census<sup>17</sup>.

Rheumatologic diagnosis by ethnic group is provided in Table 2. The inflammatory disorders of RA, juvenile RA, systemic lupus erythematosus, vasculitis, and reactive arthritis were more frequently diagnosed in Aboriginal patients, and comprise 58% of all Aboriginal patients seen at the Arthritis Centre, compared to 35% of Caucasian patients seen. Psoriatic arthritis and polymyalgia rheumatica were diagnosed significantly less often in the Aboriginal population. Noninflammatory conditions including OA, fibromyalgia, and mechanical back pain were also seen less than half as often in Aboriginal patients compared to Caucasian patients. Aboriginal patients followed at the Arthritis Centre are seen less often than Caucasian patients (2.7  $\pm$  2.2 visits/year of followup for Aboriginals, compared to  $3.1 \pm 2.8$ for Caucasians; p = 0.016), in spite of more frequent diagnoses of inflammatory disease.

#### DISCUSSION

We have clearly identified more frequent arthritis-related physician visits in Aboriginal Manitobans compared to all other residents of Manitoba. In addition, the high prevalence

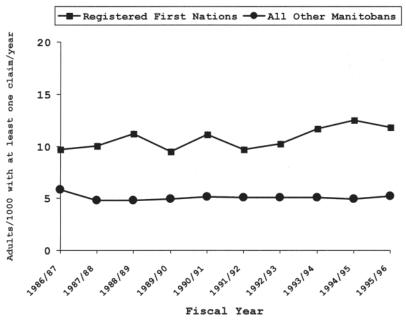


Figure 1. Prevalence of adults within each fiscal year for whom at least one ICD-714 (rheumatoid arthritis) physician claim was made, fiscal years 1986/87-1995/96. Rates are per 1000 population, age and sex standardized to 1984/85 non-First Nations population.

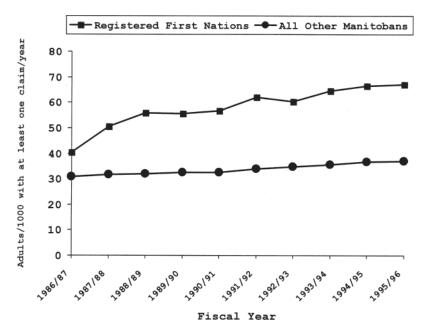


Figure 2. Prevalence of adults within each fiscal year for whom at least one ICD-715 (degenerative arthritis) physician claim was made, fiscal years 1986/87-1995/96. Rates are per 1000 population, age and sex standardized to 1984/85 non-First Nations population.

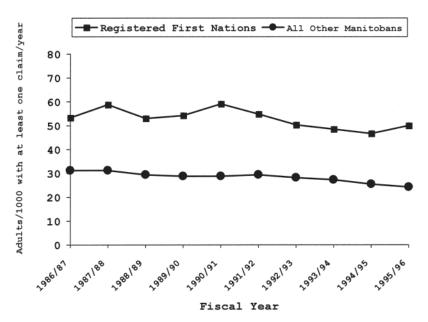


Figure 3. Prevalence of adults within each fiscal year for whom at least one ICD-716 (unspecified arthropathy) physician claim was made, fiscal years 1986/87-1995/96. Rates are per 1000 population, age and sex standardized to 1984/85 non-First Nations population.

of self-identified RA and other forms of arthritis reported by the Manitoban First Nations Health Survey echo the rates described in national surveys, including the Canadian Community Health Survey, compiled by Statistics Canada in the year 2000, which identified arthritis as the most prevalent chronic condition in the Aboriginal population, surpassing hypertension, asthma, and diabetes. Self-reported preva-

1148

lence of arthritis in our study was almost twice as high for Aboriginal persons at 27%, compared to 16% for other Canadians<sup>2</sup>. Similar findings were reported in the 2001 Aboriginal Peoples Survey<sup>18</sup>: across all provinces and territories in Canada, and for all Aboriginal identities including Metis people, arthritis or rheumatism was the most commonly reported chronic condition, at a rate of 19.3%, almost

*Table 2.* Differences in diagnoses seen between Aboriginal and Caucasian Arthritis Centre patients.

Diagnosis	Aboriginal*, n = 687 (%)	Caucasian*, n = 4135 (%)	p
Rheumatoid arthritis	281 (40.9)	1070 (25.9)	0.000
Lupus	51 (7.4)	214 (5.2)	0.017
Juvenile rheumatoid arthritis	31 (4.5)	92 (2.2)	0.000
Vasculitis	22 (3.2)	80 (1.9)	0.033
Reactive arthritis	11 (1.6)	17 (0.4)	0.000
Psoriatic arthritis	13 (1.9)	170 (4.1)	0.005
Crystal arthropathy	3 (0.4)	76 (1.8)	0.007
Polymyalgia rheumatica	1 (0.1)	95 (2.3)	0.000
Osteoarthritis	33 (4.8)	473 (11.4)	0.000
Fibromyalgia	13 (1.9)	200 (4.8)	0.001
Mechanical low back pain	2 (0.3)	49 (1.2)	0.034

 $<sup>^{*}</sup>$  Includes only diagnoses with significant differences in proportions; total numbers do not equal 100%

twice the frequency of 11% reported by the remainder of Canadians. The high frequency of activity limitations in Aboriginals with arthritis reported in the Manitoba First Nations survey is also supported by Health Canada data. In a survey of Aboriginal people across the country, among those who reported having arthritis, Aboriginals also had statistically significantly higher rates of activity limitation, as well as higher rates of disability as measured by the Health Utility Index compared to non-Aboriginals<sup>2</sup>.

The Research Repository data confirm the high rates of arthritis related visits, with twice as many FN people attending physicians for the 3 most common ICD-9 musculoskeletal diagnoses. Moreover, these data underestimate the actual frequency of arthritis-related visits in Aboriginal Manitobans. First, not all FN Manitobans are correctly identified as such in the Research Repository<sup>19</sup>. Only about 70% of the Manitoba FN population registered under the Indian Act is identified as FN in the Research Repository. The 1996 Canadian census data report about 45,000 FN adults in the Province of Manitoba<sup>20</sup>, compared to the 34,740 identified in the Research Repository. Second, Statistics Canada reports 45,360 Metis people living in Manitoba in 1996<sup>20</sup>, growing to 56,860 in 2001<sup>17</sup>. Health Canada survey data suggest similar health profiles among FN and Metis people in contrast to the Metis and Caucasians, including statistically similar rates of self-reported arthritis between Metis and FN people<sup>18</sup>, pointing to a further underestimate of disease burden in Aboriginal Manitobans. Therefore extrapolating these results to the general term Aboriginal, inclusive of both FN and Metis populations, seems reasonable for discussion purposes, although additional research may demonstrate a divergence in arthritis profiles between Metis and FN Canadians. As there are only 285 Inuit people resident in Manitoba according to the 2001 Canadian census, and no separate identifiers for Inuit people in the Research Repository, we are unable to draw conclusions in this article regarding arthritis in Inuit people.

Neither the Manitoba First Nations Health Survey data nor the Research Repository claims-based data include verification of specific arthritis diagnoses, as this is beyond the scope of this article. Therefore, these data should not be used to draw conclusions regarding prevalence rates of individual diseases, causality, appropriate treatment, or outcomes; neither can the Arthritis Centre data be used to infer prevalence rates. Additional limitations of this study include lack of information for the large Manitoba Metis population, nonregistered FN people, and the Inuit. The widely disparate methods of data collection for the 3 datasets also hamper comparability of the data. Nonetheless, collectively, these 3 datasets provide convincing evidence of a high burden of arthritis.

Based on the Research Repository and Manitoba First Nations Health survey data, one might have expected a proportionally increased referral rate to rheumatologists, resulting in a higher proportion of Aboriginal clinic patients than was seen. Instead, while the Arthritis Centre database confirms that Aboriginal patients seen were more frequently diagnosed with serious inflammatory rheumatic diseases compared to Caucasian patients, the proportion of Aboriginal clinic patients was comparable to the population proportion.

Although a direct link between the high Research Repository claims rates for Aboriginals and the proportion of Arthritis Centre Aboriginal patients is not possible, this greater severity raises the possibility that only the most severe patients are being referred to specialists. A similar pattern was seen in a British Columbia study of FN patient referrals to rheumatology, with few referrals for noninflammatory disease compared to inflammatory and autoimmune diseases<sup>21</sup>.

Aboriginal people are unlikely to be disproportionately referred to other provincial rheumatologists. The hospital site has, as part of its mission, provision of care to the province's Aboriginal population. In addition, all rheumatologists in the province practice in Winnipeg, and the majority (4 out of 7) practice at the Arthritis Centre. More Aboriginal patients reside outside Winnipeg (37% of Manitoba's Aboriginal population resides in Winnipeg <sup>14</sup> vs 58% of the total Manitoba population<sup>22</sup>), so required travel may be playing a role. However, detailed analysis of healthcare utilization by FN Manitobans has shown that overall specialist contacts are lowest in some of the southern regions, closest to Winnipeg, compared to more distant regions<sup>23</sup>.

Underutilization of specialists by Aboriginal patients has been clearly documented in Manitoba. A population-based study by the Manitoba Centre for Health Policy demonstrated global decreased contact with specialists for FN patients versus other Manitobans, despite overall worse health indicators<sup>23,24</sup>. Although FN people living in Winnipeg (the province's major urban center) had a higher rate of special-

ist contact than in any other provincial region, this rate is still less than that of all other Winnipeg residents (21.7% vs 32.2%). The study also identified that the area with the poorest health status, located in southwestern Manitoba, had the lowest consultation rates in the province<sup>23,24</sup>.

Travel to urban centers for specialist care is an obvious problem for Aboriginal populations in northern and remote areas, as also noted by others<sup>7,25</sup>; however, disparities in specialist utilization in health regions relatively closer to specialists, reported by the Manitoba Centre for Health Policy<sup>24</sup>, suggest other barriers exist as well. A self-identified lack of access to information on available services, as well as a fear of racism and being uncomfortable in a healthcare setting has been reported<sup>25</sup>. Lack of integration and understanding of Aboriginal culture on the part of caregivers has also been recognized as an obstacle to optimal care, as has the need to understand how Aboriginal people interpret their illness experience and respond to treatment regimens<sup>26</sup>.

In conclusion, these data provide evidence of a high burden of arthritis, but also point to large gaps in our knowledge of how, why, and when Aboriginal Manitobans access arthritis care, and how they experience interaction within the medical system. Given the current emphasis on early diagnosis and timely access to services<sup>27</sup>, future research must address the barriers to care as much as genetic or environmental determinants of disease. These factors must be taken into consideration when planning future service delivery to ensure that all patients receive appropriate and culturally competent healthcare. To better understand the true burden of arthritis that afflicts the Aboriginal population in Manitoba, specifically the incidence and prevalence, it is necessary and critical to improve upon current documentation for all groups, including Metis, Inuit, and First Nations populations. This will certainly increase the possibility that such populations will receive timely specialist care.

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