

# Estimates of the Prevalence of Arthritis and Other Rheumatic Conditions in the United States

## Part I

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**Objective.** To provide a single source for the best available estimates of the US prevalence of and number of individuals affected by arthritis overall, rheumatoid arthritis, juvenile arthritis, the spondylarthritides, systemic lupus erythematosus, systemic sclerosis, and Sjögren's syndrome. A companion article (part II) addresses additional conditions.

**Methods.** The National Arthritis Data Workgroup reviewed published analyses from available national

surveys, such as the National Health and Nutrition Examination Survey and the National Health Interview Survey (NHIS). For analysis of overall arthritis, we used the NHIS. Because data based on national population samples are unavailable for most specific rheumatic conditions, we derived estimates from published studies of smaller, defined populations. For specific conditions, the best available prevalence estimates were applied to the corresponding 2005 US population estimates from the Census Bureau, to estimate the number affected with each condition.

**Results.** More than 21% of US adults (46.4 million persons) were found to have self-reported doctor-diagnosed arthritis. We estimated that rheumatoid arthritis affects 1.3 million adults (down from the estimate of 2.1 million for 1995), juvenile arthritis affects 294,000 children, spondylarthritides affect from 0.6 million to 2.4 million adults, systemic lupus erythematosus affects from 161,000 to 322,000 adults, systemic sclerosis affects 49,000 adults, and primary Sjögren's syndrome affects from 0.4 million to 3.1 million adults.

**Conclusion.** Arthritis and other rheumatic conditions continue to be a large and growing public health problem. Estimates for many specific rheumatic conditions rely on a few, small studies of uncertain generalizability to the US population. This report provides the best available prevalence estimates for the US, but for most specific conditions, more studies generalizable to the US or addressing understudied populations are needed.

In adults, arthritis is the leading cause of disability (1) and is among the leading conditions causing work

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention, the National Institutes of Health, or the Department of Veterans Affairs.

The National Arthritis Data Workgroup is a consortium of experts in epidemiology organized to provide a single source of national data on the prevalence and impact of rheumatic diseases. It is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases, NIH; the National Center for Chronic Disease Prevention and Health Promotion and National Center for Health Statistics, CDC; the American College of Rheumatology; and the Arthritis Foundation.

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Submitted for publication June 7, 2007; accepted in revised form September 14, 2007.

limitations (2). Over the next 25 years the number of people affected and the social impact of doctor-diagnosed arthritis are projected to increase by 40% in the US (3). Estimating the burden in the US population of the various rheumatic conditions that comprise arthritis is important for understanding their current and potential future impact on the health care and public health systems. Equally important is identifying the gaps in our understanding of burden.

This and a companion article (4) update the National Arthritis Data Workgroup (NADW) reports of arthritis prevalence, our measure of burden, from 1989 and 1998 (5,6). Sjögren's syndrome and carpal tunnel syndrome have been included for the first time, and additionally, the common symptoms of neck and back pain are addressed.

## METHODS

The term "prevalence" has been defined and used in conflicting ways. In these 2 articles, we use prevalence to mean "prevalence proportion" (incorrectly called "prevalence rate" at times), meaning the proportion of persons in the population with the condition. We use the phrase "number affected" to refer to the absolute number of people affected in the population.

US estimates of disease prevalence were usually based on data from published national or local population-based studies from the US and, if no accurate US data were available, from international studies. For overall arthritis, the number affected was based on the population sampled in the 2003–2005 National Health Interview Survey (NHIS). For other conditions, the best available prevalence estimates were applied to the corresponding July 1, 2005 population estimates from the Census Bureau (<http://www.census.gov/popest/national/asrh/NC-EST2005-sa.html>) to estimate the number affected. Some of the US population-based studies were special studies in small areas that may not reflect the racial and ethnic profile of the US or of those affected by the illness. Caveats accompany the estimates presented, when there are concerns about generalizability.

Several estimates came from 2 National Center for Health Statistics surveys: the NHIS and the National Health and Nutrition Examination Survey (NHANES). Both use probability samples of the US civilian, noninstitutionalized population to generate national health estimates. The NHANES uses interviews and examinations (e.g., physical examinations, laboratory tests, and radiographs) from ~5,000 respondents annually. The much larger NHIS uses an annual cross-sectional, in-person interview survey of ~106,000 respondents in 43,000 households to collect self-reported health status information. Estimates for overall arthritis obtained using the NHIS were age adjusted to the projected 2000 population age  $\geq 18$  years by 3 age groups (18–44 years, 45–64 years, and  $\geq 65$  years) to allow better comparison of demographic groups (available at <http://www.cdc.gov/nchs/data/>

[statnt/statnt20.pdf](#) [used .530458, .299194, and .170271 from distribution 9, for ages 18–44, 45–64, and  $\geq 65$ , respectively]).

Measuring the prevalence of arthritis poses many challenges. From study to study, the distinction between point prevalence and cumulative (i.e., lifetime) prevalence is not always clear. Prevalence is difficult to determine for conditions that are episodic. Some conditions have no standard case definition, whereas others have competing or evolving case definitions based on different symptoms, signs, radiographic findings, or laboratory data. Estimates vary depending on the inclusion or exclusion of asymptomatic, mild, or early disease and the aggressiveness of case finding. Symptomatic individuals in the community who do not seek treatment may go uncounted. Furthermore, individuals frequently do not know what specific rheumatic disease they have, so self-reported data cannot be used for estimates of specific conditions.

## RESULTS

**Overall arthritis.** The case definition used to identify persons with arthritis has changed since our last report (6). In 1997 the NHIS stopped using condition lists and International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) codes, the basis of our previous method, and instead adopted new surveillance questions. Based on cognitive and validation studies (7,8), "self-reported doctor-diagnosed arthritis" is thought to provide the most credible estimate of overall arthritis prevalence, with acceptable sensitivity and specificity for surveillance purposes. Respondents were defined as having doctor-diagnosed arthritis if they answered "yes" to the question, "Have you EVER been told by a doctor or other health professional that you have some form of arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia?" Among those with doctor-diagnosed arthritis, activity limitation attributable to arthritis was defined by a "yes" answer to the question, "Are you now limited in any way in any of your usual activities because of arthritis or joint symptoms?"

The prevalence of self-reported doctor-diagnosed arthritis among adults age  $\geq 18$  years, estimated using the annual average from the 2003–2005 NHIS surveys, was 21.6%, or 46.4 million (9) (Table 1). Although arthritis prevalence was higher in older age groups, with half of adults age  $\geq 65$  years being affected, nearly two-thirds of the adults reporting doctor-diagnosed arthritis were younger than 65 (Table 1). More than 60% were women. Age-adjusted arthritis prevalence was higher for women than for men (24% versus 18%) but was similar for non-Hispanic whites and African Americans (~22%), whose rates were higher than those for Hispanics (16.5%). The number of persons with doctor-diagnosed arthritis is projected to

**Table 1.** Unadjusted and age-adjusted estimates of the prevalence of and number affected by self-reported doctor-diagnosed arthritis and arthritis-attributable activity limitations among adults age  $\geq 18$  years, by sex, age, and race/ethnicity, National Health Interview Survey, United States, 2003–2005\*

	Population, in 1,000's	Doctor-diagnosed arthritis (46.4 million affected)		Arthritis-attributable activity limitation (18.9 million affected)		Proportion with arthritis- attributable activity limitation among those with doctor- diagnosed arthritis	
		Unadjusted % $\pm$ 95% CI (no. affected)	Age-adjusted % $\pm$ 95% CI†	Unadjusted % $\pm$ 95% CI (no. affected)	Age-adjusted % $\pm$ 95% CI†	Unadjusted % $\pm$ 95% CI	Age-adjusted % $\pm$ 95% CI†
<b>Sex</b>							
Men	103,362	17.6 $\pm$ 0.5 (18.2 million)	18.1 $\pm$ 0.5	6.8 $\pm$ 0.3 (7.0 million)	7.0 $\pm$ 0.3	38.8 $\pm$ 1.4	36.6 $\pm$ 1.8
Women	111,411	25.4 $\pm$ 0.6 (28.3 million)	24.4 $\pm$ 0.5	10.7 $\pm$ 0.3 (11.9 million)	10.3 $\pm$ 0.3	42.3 $\pm$ 0.9	39.0 $\pm$ 1.2
<b>Age, years</b>							
18–44	110,318	7.9 $\pm$ 0.3 (8.7 million)	–	2.7 $\pm$ 0.2 (3.0 million)	–	34.6 $\pm$ 1.9	–
45–64	70,019	29.3 $\pm$ 0.7 (20.5 million)	–	11.8 $\pm$ 0.4 (8.2 million)	–	40.3 $\pm$ 1.2	–
$\geq 65$ †	34,435	50.0 $\pm$ 0.9 (17.2 million)	–	22.4 $\pm$ 0.7 (7.7 million)	–	44.9 $\pm$ 1.3	–
<b>Race/ethnicity</b>							
White, non-Hispanic	153,148	24.3 $\pm$ 0.5 (37.2 million)	22.6 $\pm$ 0.4	9.6 $\pm$ 0.3 (14.7 million)	8.9 $\pm$ 0.3	39.5 $\pm$ 0.9	36.4 $\pm$ 1.2
Black, non-Hispanic	23,775	19.2 $\pm$ 0.9 (4.6 million)	21.4 $\pm$ 0.9	9.2 $\pm$ 0.6 (2.2 million)	10.3 $\pm$ 0.7	47.8 $\pm$ 2.4	44.3 $\pm$ 3.2
Hispanic	26,904	11.4 $\pm$ 0.6 (3.1 million)	16.5 $\pm$ 0.8	5.4 $\pm$ 0.4 (1.5 million)	8.2 $\pm$ 0.6	47.6 $\pm$ 2.6	45.2 $\pm$ 3.2
Other non-Hispanic	10,946	14.7 $\pm$ 1.3 (1.6 million)	17.3 $\pm$ 1.3	6.0 $\pm$ 0.8 (0.66 million)	7.2 $\pm$ 1.0	41.1 $\pm$ 4.8	40.5 $\pm$ 5.4
<b>Total</b>	214,772	21.6 $\pm$ 0.4	21.5 $\pm$ 0.4	8.8 $\pm$ 0.2	8.8 $\pm$ 0.2	40.9 $\pm$ 0.8	38.1 $\pm$ 1.0

\* See ref. 9.

† Adjusted to the projected 2000 population age  $\geq 18$  years by 3 age groups: 18–44 years, 45–64 years, and  $\geq 65$  years (see ref. 88). 95% CI = 95% confidence interval.

increase to nearly 67 million by 2030 (3)—an increase of ~40%.

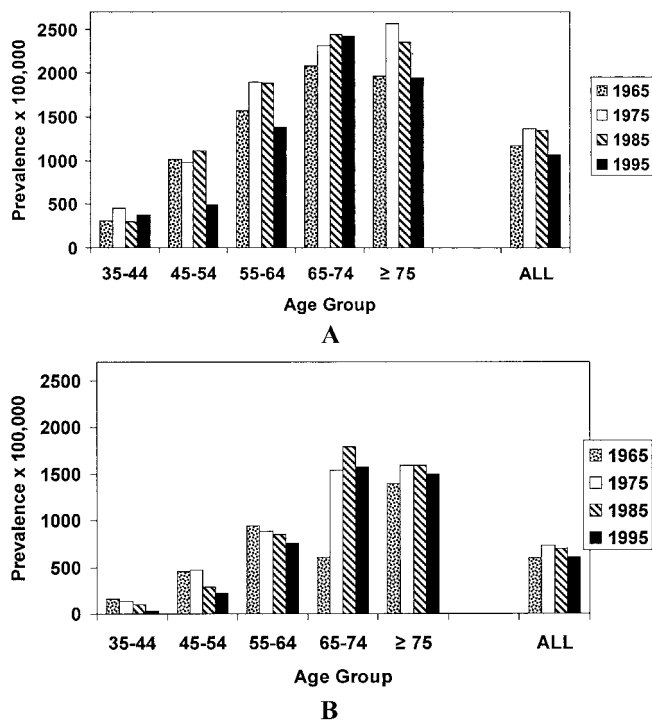
Using the same report as was used to determine prevalence (9), we found that an estimated 8.8% of all US adults, or nearly 19 million persons, had arthritis-attributable activity limitations (Table 1). The prevalence of activity limitations was higher in older age groups (affecting >22% of all adults age  $\geq 65$  years), higher among women, and lower among Hispanics. Arthritis or joint symptoms led to activity limitation in >40% of adults with doctor-diagnosed arthritis. This outcome is projected to increase to 25 million (9.3% of the adult population) by 2030 (3).

The high population prevalence of arthritis and of arthritis-related activity limitations translates into an immense personal and societal burden, often differing by race/ethnicity (10). This situation results in “arthritis and rheumatism” being the leading cause of physical disability in the US (1) and causes affected persons to have a substantially worse health-related quality of life

(11). Among various other impact/burden measures, arthritis and other rheumatic conditions in 1997 were the underlying cause of death in 9,367 persons in the US (12), were present in 300,000 nursing home residents (19%) (13), and resulted in 744,000 hospitalizations (14) and 36.5 million ambulatory care visits (15). Costs of arthritis and other rheumatic conditions in 2003 were \$128 billion (16).

**Rheumatoid arthritis (RA).** RA is a multisystem disorder of unknown etiology, characterized by chronic destructive synovitis. Our previous national prevalence estimates for RA (6) were derived from the NHANES I, which used a case definition based on the clinical diagnosis by the examining physician. Since that time, classification criteria for RA have been revised (17–19).

Several studies have provided estimates of the prevalence of RA in defined populations. Although these studies had a number of methodologic limitations (20), the remarkable finding was the uniformity of prevalence estimates in populations from different de-



**Figure 1.** Prevalence of rheumatoid arthritis (adjusted to the 2000 white US population) among female residents (A) and male residents (B) of Rochester, Minnesota at 4 time points (1965, 1975, 1985, and 1995 [January 1 of each year]), by age group.

veloped countries: ~0.5%–1% of the adult population. However, studies from the Pima Indian population showed significantly higher incidence and prevalence estimates (21).

A study from Rochester, Minnesota showed a prevalence of RA in 1985 of 1.07% (95% confidence interval [95% CI] 0.94–1.20) among adults  $\geq 35$  years of age (22); this fell to 0.85% in 1995 (95% CI 0.75–0.95) (Gabriel S, et al: unpublished data). The prevalence among women in 1995 was approximately double that in men (1.06% versus 0.61%) (Gabriel S, et al: unpublished data).

Trends in RA prevalence in Rochester, Minnesota by age and calendar year show increasing prevalence with older age and decreasing prevalence for most age groups in more recent time periods (Figure 1). These trends, by calendar year, age, and sex, have also been demonstrated in numerous other populations (21–26). In particular, the temporal decline in RA prevalence is consistent with studies showing a progressive decline in RA incidence since the early 1960s (21,27–30). Also, the average age of persons with prevalent RA has increased steadily over time, from 63.3 years in 1965 to

66.8 years in 1995, suggesting that RA is becoming a disease of older adults. This observation, along with the expected rapid growth in the proportion of Americans age  $>60$  years, suggests that RA-associated morbidity, mortality, and disability are likely to increase among older adults.

Using the 1995 Rochester, Minnesota age/sex-specific prevalence and the corresponding 2005 population estimates from the Census Bureau, we estimated that 1,293,000 American adults age  $\geq 18$  years (0.6%) have RA. This is lower than the previous estimate of 2,100,000 (6) because of the decline in RA prevalence. These Rochester estimates are likely to be generalizable to the white US population, but their generalizability to other racial/ethnic populations is uncertain.

**Juvenile arthritis.** The prevalence of chronic, inflammatory arthritis in children is difficult to estimate because of differences in nomenclature (e.g., “juvenile rheumatoid arthritis” [JRA], “juvenile chronic arthritis” [JCA], and most recently “juvenile idiopathic arthritis” [JIA]) and classification criteria (1977 American College of Rheumatology [ACR; formerly, the American Rheumatism Association] [31], 1978 European League Against Rheumatism [32], and 1997 International League of Associations for Rheumatology [33] with a revision published in 2004 [34]), and the heterogeneity of the diseases and their subtypes encompassed under this rubric (35). In addition, variability in disease course among the subtypes of JIA may make it difficult to compare prevalence estimates for this condition across different study settings. In some types of the disease extended remissions occur, so that prevalence estimates include individuals who were ever affected, but are not currently affected.

Prevalence reported in a comprehensive review ranged from 7 to 401 per 100,000 children across a broad diversity of geographic regions (35). Data from Rochester, Minnesota suggested declining prevalence, from 9.43 per 100,000 children in 1980 to 8.61 per 100,000 children in 1990 (36). These prevalences were lower than previous estimates from the same population, owing, in part, to differences in assignment of case definition.

The combined incidence of JRA and juvenile spondylarthritis (“spondylarthritis” being a more contemporary term for what is synonymously referred to in many earlier publications as “spondylarthropathy” [see below]) from other recent US and Canadian studies consistently ranges from 4.1 to 6.1 per 100,000, with the incidence of juvenile spondylarthritis ranging from 1.1 to 2 per 100,000 (37–39). These studies have encompassed



**Table 2.** Prevalence of spondylarthritides, overall and by subtype

Disease subtype	Group	Ref.	Prevalence per 100,000*		
			Male	Female	Total
Ankylosing spondylitis	Nationally representative (age $\geq$ 25 years men, $\geq$ 50 years women)	48	730	300	520
	Whites (age $\geq$ 15 years) men and women	46	200	70	130
	Blacks	47	50–200	NA	NA
	Eskimos (age $\geq$ 20 years)	53, 61	400	400	400
Psoriatic arthritis	Whites (age $\geq$ 20 years)	54			101
Enteropathic					
Peripheral		56, 57			65
Axial		57–59			50–250
Undifferentiated spondylarthritides		60, 61			374†
Overall spondylarthritides					346–1,310‡

\* NA = not applicable.

† The undifferentiated spondylarthritides estimate was derived by multiplying the frequency of the other spondylarthritides by 40% (assuming the maximum estimate for enteropathic arthritis) ( $[520 + 101 + 65 + 250] \times 0.4 = 374$ ).

‡ The low range of overall spondylarthritides was derived by adding the total prevalence estimates for ankylosing spondylitis among whites, psoriatic arthritis, peripheral enteropathic arthritis, and the low estimate for axial enteropathic arthritis ( $130 + 101 + 65 + 50 = 346$ ); undifferentiated spondylarthritides was excluded. The high range was derived by adding the total prevalence estimates for nationally representative ankylosing spondylitis, psoriatic arthritis, peripheral enteropathic arthritis, the high estimate for axial enteropathic arthritis, and undifferentiated spondylarthritides ( $520 + 101 + 65 + 250 + 374 = 1,310$ ).

a number of diverse regions including New England; Manitoba, Canada; and 13 other centers across Canada. The prevalence of JCA from 2 Canadian studies was 3.2 and 4.0 per 100,000 children (40).

The prevalence of JRA in the US in different published reports ranged from 1.6 to 86.1 per 100,000. Data from the NHIS suggested a prevalence of 150 per 100,000 for all types of childhood arthritis, including JRA, juvenile spondylarthritides, Lyme disease, arthritis associated with the less common pediatric connective tissue diseases, and other types of childhood arthritis. The prevalence of JCA (the name for JRA outside the US) found in a population-based study in Australia, in which respondents were surveyed door to door (41), was far higher (400 per 100,000) than has been found in other studies.

In summary, there are very wide variations in the reported prevalences of chronic inflammatory arthritides of childhood, such as JRA and juvenile spondylarthritides. The lack of comparable prevalence estimates across different regions in the US makes it difficult to estimate the total number affected. Perhaps the best prevalence estimates come via a novel approach using data from pediatric ambulatory care visits recorded in the 2001–2004 National Ambulatory and Medical Care Survey and the NADW ICD-9-CM case definition for adults (6) modified to reflect pediatric conditions, by which it was estimated that 294,000 children ages 0–17 years (95% CI 188,000–400,000) were affected by the broadly defined “arthritis or other rheumatic conditions” (42).

**Spondylarthritides.** The spondylarthritides (more contemporary term for what is synonymously referred to in many earlier publications as “spondylarthropathies”) are a family of diseases that includes ankylosing spondylitis (AS), reactive arthritis (formerly known as Reiter’s syndrome), psoriatic arthritis, enteropathic arthritis (associated with ulcerative colitis or Crohn’s disease), juvenile spondylarthritides, and undifferentiated spondylarthritides, which encompasses disorders expressing elements of but failing to fulfill criteria for the above diseases. The prevalence of AS and other spondylarthritides parallels the frequency of the genotype HLA-B27.

*Ankylosing spondylitis.* Among studies of white Europeans and East Asians, the reported prevalence of AS has varied between 30 per 100,000 and 900 per 100,000 (reflecting differences in HLA-B27 frequency and in patient referral and disease ascertainment) (43–45). In the US, a 1979 study from Rochester, Minnesota showed a prevalence of 129 per 100,000 in a Caucasian population (46). Prevalence data suggest that AS occurs less frequently in African Americans than in whites (47).

The overall prevalence of severe or moderate radiographic sacroiliitis on pelvic radiographs in men ages 25–74 years in the NHANES I was 730 per 100,000; among women ages 50–74 years, the prevalence was 300 per 100,000 (48) (Table 2). Of those with moderate to severe radiographic sacroiliitis, only 7.6% were currently experiencing “significant pain in their lower backs on most days for at least one month.” Since questions

regarding inflammatory back pain (49) were not asked in this survey, the prevalence of AS cannot be ascertained.

**Reactive arthritis.** The prevalence of reactive arthritis appears to be decreasing in developed countries (50). One study in Rochester, Minnesota investigated incidence (51), but prevalence in the general US population is unknown. Studies of American Indian groups have shown frequencies of 300 per 100,000 among Navajos (52) and 200–1,000 per 100,000 among Alaskan Yupik and Inupiat Eskimos (53), 2 groups with a high frequency of HLA-B27. Because many persons with reactive arthritis have remissions, prevalence estimates include individuals who were ever affected but are not currently affected.

**Psoriatic arthritis.** In Olmsted County, Minnesota, the prevalence of psoriatic arthritis in 1992 was 101 per 100,000 (95% CI 81–121 per 100,000) (54) (Table 2). There are no published data on its prevalence in African Americans or Hispanics.

**Enteropathic arthritis.** The prevalence of inflammatory bowel disease (IBD) in the US has been estimated to be 500 per 100,000 (55). However, the prevalence of enteropathic arthritis/spondylitis has not been determined. The self-limited and nondestructive nature of peripheral enteropathic arthritis complicates calculations of its prevalence (56), although it has been reported to occur in up to 13% of patients with IBD (57–59). Although inflammatory back pain occurs in up to 50% of patients with IBD (58,59), AS occurs in <10% (57). Applying these percentages (13% for peripheral arthritis and 10–50% for spinal arthritis) to the prevalence of 0.5% for IBD, the estimated US prevalence of enteropathic peripheral arthritis is 65 per 100,000 and that of enteropathic spinal arthritis ranges from 50 to 250 per 100,000 (Table 2).

**Undifferentiated spondylarthritis.** Limited data from Europe (60) and Alaska (61) suggest that ~40% of patients with spondylarthritis have “undifferentiated” spondylarthritis. Better population-based data are needed, especially from the mainland US, where the prevalence of this disorder has not been directly assessed.

**Overall spondylarthritis.** The prevalence of spondylarthritis in the US is unknown. In studies of European whites, the reported prevalence has varied widely, from 470 per 100,000 (60) to 1,900 per 100,000 (44). Higher prevalences in Eskimos from Siberia and Alaska have been reported (53). The prevalence of overall spondylarthritis in the US can be roughly estimated by summing either low or high prevalence estimates of its component subtypes, resulting in a range of 346–1,310

per 100,000 among those age  $\geq 25$  years (Table 2). Using this range of prevalence and the corresponding 2005 population estimates from the Census Bureau, we estimated that between 639,000 and 2,417,000 adults age  $\geq 25$  years have spondylarthritis.

**Systemic lupus erythematosus (SLE).** SLE is a multisystem autoimmune disorder of unknown etiology, with disease manifestations that vary over time. The 1982 ACR criteria for the classification of SLE (62), which are the most widely used, rely on signs and symptoms present at any time during a person's illness. Patients with early or atypical disease often have not accumulated enough manifestations to meet criteria, and may not be counted.

Studies of SLE prevalence have been performed in different regions of the country and have used varying methods of case identification, including screening of inpatient and outpatient records (63,64) and inferring prevalence on the basis of cases identified using multiple outpatient and hospital sources (65). In studies from a San Francisco, California health maintenance organization (HMO) and from Rochester, Minnesota, both involving predominantly white populations, SLE prevalence was estimated to be 44 per 100,000 whites (63) and 40 per 100,000 (mostly whites) (64,66), respectively. In a study from Nogales, Arizona, prevalence in Hispanic women was estimated to be 103 per 100,000 (67). A study from Hawaii showed a prevalence of 50 per 100,000 among whites and persons of Japanese descent, versus 100 per 100,000 among persons of Chinese descent (68). In all of these studies, prevalence estimates of SLE among nonwhites were based on a limited number of cases, resulting in wide confidence intervals and limiting the precision of results.

The estimated prevalence of SLE from the NHANES III was 53.6 per 100,000 among adults age  $\geq 18$  years and 100 per 100,000 among adult women, based on self-reported physician diagnosis and current prescription of medications used for SLE treatment (69).

Among both whites and blacks, the prevalence of SLE is higher in women than in men. Using data from the San Francisco study (63), the prevalences in whites and African Americans among those ages 15–64 years were as follows: 100 per 100,000 white women, 400 per 100,000 black women, 10 per 100,000 white men, and 50 per 100,000 black men.

Findings of one study suggest that the prevalence of suspected SLE is similar to that of definite SLE (66). For estimating SLE prevalence, we used a range that included the number of persons with definite SLE at the

low end and double that number at the high end, to include patients with suspected disease who do not meet strict ACR criteria for disease. Our reason was that the latter patients, like those who do meet the classification criteria, consume health resources and must cope with their illness, and many of them meet criteria later in their disease course (63,64,67–69). Using the San Francisco sex/race prevalence among persons ages 15–64 and the corresponding 2005 population estimates from the Census Bureau, we estimated that as few as 161,000 and as many as 322,000 persons in the US have SLE (161,000 definite SLE [11,000 white men, 80,000 white women, 7,000 African American men, 56,000 African American women, and 7,000 people of other races]; 322,000 definite or suspected SLE), although the generalizability of the San Francisco HMO data to the US population has not been determined.

**Systemic sclerosis (SSc; scleroderma).** There are 2 forms of SSc: a systemic form, which can have limited or diffuse skin involvement, and a localized form, which is confined to the skin and surrounding tissue. This report addresses only the systemic form.

In a population-based study of SSc in southeast Michigan, prevalence was ascertained from multiple sources, including hospital discharge data, outpatient data from 2 academic centers, private-practice rheumatologists, and the local chapter of a scleroderma support group. Cases were defined as persons age  $\geq 18$  years who met the 1980 ACR preliminary criteria for the classification of SSc (70). Persons were also considered to be cases if they had a physician diagnosis and at least 2 of the 5 features of CREST syndrome (calcinosis, Raynaud's phenomenon, esophageal dysmotility, sclerodactyly, telangiectasias) (71). Seven hundred six SSc cases were identified and extrapolated to the US population, yielding a prevalence of 24.2 per 100,000 adults (95% CI 21.3–27.4) (72). Using capture–recapture methods, an estimated number of missing cases was added, yielding a revised prevalence estimate of 27.6 cases per 100,000 US adults (95% CI 24.5–31.0). Women were affected 4.6 times more frequently than men. SSc prevalence had a modestly higher prevalence among African Americans than whites, with an age-adjusted prevalence ratio of 1.15 (95% CI 1.02–1.30). In addition, African Americans were significantly younger than whites at the time of diagnosis (mean  $\pm$  SD 41.0  $\pm$  14.6 years versus 48.1  $\pm$  15.9 years;  $P < 0.001$ ).

The highest reported prevalence of SSc has been in a Choctaw Indian group in Oklahoma (66 cases per 100,000, based on 14 cases) (73). There may be genetic

factors that contribute to increased disease susceptibility in this group (74–76).

A 20-year study of hospital-diagnosed scleroderma cases in Allegheny County, Pennsylvania from 1963 through 1982 suggested that disease incidence doubled over this period (77). However, recent data do not suggest any continued increase in incidence or prevalence (78).

Using the southeast Michigan sex/race prevalence and the corresponding 2005 population estimates from the Census Bureau, we estimated that 49,000 Americans age 18 and older have SSc, although the generalizability of the Michigan data to the US population has not been determined.

**Primary Sjögren's syndrome (SS).** SS may occur alone (primary SS) or with other autoimmune diseases, including RA or SLE (secondary SS). Prevalence estimates reported herein are confined to primary SS because there are insufficient data to evaluate the prevalence of secondary SS.

Primary SS prevalence estimates have ranged from 0.05% to 4.8% across international communities (79–86), but only 3 of these studies (79–81) were population based. More recently reported prevalence rates have generally tended to be lower than those in earlier publications, which could reflect increasing rigor of epidemiologic studies, more restrictive and objective classification criteria, small sample sizes in earlier studies, and selection biases. For example, in 1988, a prevalence of 4.8% (95% CI 3.1–6.5%) was found in an elderly and institutionalized population (84), and in 1989 a prevalence of 2.7% (95% CI 1.0–4.3%) was found in Swedish adults (85). Subsequent studies provided lower SS prevalence estimates in Greek women (0.6% [95% CI 0.19–1.39%]) (81), in residents of Olmsted County, Minnesota (0.32% cumulative incidence [which approximates prevalence]) (80), and in China (0.77% [95% CI 0.62–0.92%]) (79). The prevalence of SS among women from 2 primary care practices in the UK ranged from  $<0.1\%$  to 0.4% (86).

Because no prevalence studies have been performed in the US, we used incidence data from Olmsted County, Minnesota (80) and prevalence data from international studies (79,81) to infer SS prevalence in the US. The population-based study in Olmsted County was based on existing records, reflected physician-diagnosed cases, and included few confirmatory labial salivary gland biopsies. The Chinese study (79) examined a substantial population in clinics that served and were likely to be representative of the general Chinese population. The Greek study included only women (81). The

cumulative incidence data from Olmsted County and the data from China and Greece suggest a similar prevalence estimate for SS of  $\sim 0.6\%$  (600 per 100,000), which may be as low as 0.19% or as high as 1.39% according to the highest and lowest confidence intervals from the international studies.

Using the Olmsted County prevalence estimates and the corresponding 2005 population estimates from the Census Bureau, we estimated that 1.3 million American adults (range 0.4–3.1 million) have primary SS. The Olmsted County estimates are generalizable to the white US population, but their generalizability to other racial/ethnic populations is uncertain, as is the generalizability of the data from the international studies.

## DISCUSSION

The burden of a chronic condition can be measured in various ways. The NADW has chosen to focus on national disease prevalence as an important measure for this report and previous publications (5,6), because prevalence includes people with existing disease as well as those with new disease. Incidence (new cases), a competing measure, can provide a picture of how a disease is newly affecting a population, but is very difficult to measure because it requires a record of the date of disease onset, which is difficult to come by for most of the conditions of interest, especially in the published literature.

The prevalence of overall arthritis in the US has continued to grow since our last estimate (6), which is not surprising given that many of these conditions are age related and the overall population is aging. This increase suggests that overall arthritis will have a growing impact on the health care and public health systems in the future, one that needs to be anticipated in order to provide the early diagnosis and interventions that could help reduce that impact. Of interest is the decline in the prevalence of RA, which is consistent with findings of other studies but has no clear explanation.

We have provided estimates of prevalence and numbers of persons affected for overall arthritis and for selected rheumatic conditions in this and the companion article (4) and given a rough snapshot of current burden. These estimates have been made by recognized disease experts using the best data available, but, as noted in many of the sections, must be interpreted with several limitations in mind.

First, there may be competing case definitions for each disease, which may vary by symptoms, signs, laboratory results, and radiographic and other factors used in

various classification criteria. Second, there may be difficulty in deciding the appropriate measurement interval for a disease (e.g., gout), resulting in compromises such as 1-year prevalence and lifetime prevalence estimates. Third, many of these conditions (e.g., SLE) are difficult to diagnose even by experienced clinicians, especially early in the course of disease, which may necessitate the inclusion of patients with suspected disease as well as those classified as having definite disease, and may result in missed cases. Fourth, some of these conditions may not be chronic in the traditional sense but rather may have extended remissions (e.g., pauciarticular juvenile arthritis, “burnt out” RA) or be episodic by nature (e.g., gout) or because of good treatment (e.g., RA). These potential difficulties must be kept in mind when interpreting prevalence estimates. Fifth, for many conditions the studies of prevalence have been infrequent, leading to wide variation in competing estimates (e.g., 8-fold range in estimates for primary SS and 4-fold range in estimates for overall spondylarthritides), or may be small, leading to wide confidence intervals around the estimate, or may lack specific data (e.g., information on age, sex, and race) to allow extrapolation to larger populations. Sixth, some of the estimates are based on data that are old (e.g., estimates of overall osteoarthritis rely on data from the 1971–1975 NHANES; estimates of SLE rely on San Francisco data from the 1970s), meaning that any changes occurring since those studies were conducted are not taken into account. Seventh, most of the specific conditions have not been studied from a national perspective, necessitating assumptions about the generalizability of available but more localized data in generating national estimates.

Finally, many of the estimates are based on data from a single study site in Rochester (Olmsted County), Minnesota and raise the question of just how representative that site is. The Rochester Epidemiology Project (REP) represents one of the best data sources for estimating the US prevalence of any disease (not just arthritis), and because of its expense is unlikely to be replicated elsewhere. The unique capabilities of the REP allow enumeration of the entire Olmsted County population over many years of followup (typically decades) and provide an accurate account of in- and out-migration as well as deaths. There is no other community in the US where this is feasible. No single community can be fully representative of the US population, but this issue has been examined well in the long-running REP, and the limitations described. Comparisons of these studies with US Census data and other



published literature have shown that, with the exception of a higher proportion of the working population being employed in the health care industry, the demographic characteristics of the Rochester population are similar to those of the majority of the US (i.e., whites) (87). Therefore, while the REP is often the only source of relevant data, these data have uncertain generalizability to nonwhite populations.

We have presented the best available prevalence estimates and tried to identify many of the gaps and limitations in their interpretation. Given the large and growing burden of arthritis and other rheumatic conditions, we hope this work will inspire studies that better address these gaps and limitations and provide a better understanding of the burden of these conditions.

#### AUTHOR CONTRIBUTIONS

Dr. Helmick had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Study design.** Helmick, Felson, Lawrence, Gabriel, Kwoh, Liang, Reveille.

**Acquisition of data.** Helmick, Felson, Maradit Kremers, Liang, Mayes, Merkel Pillemer, Reveille, Stone.

**Analysis and interpretation of data.** Helmick, Felson, Gabriel, Maradit Kremers, Kwoh, Liang, Mayes, Merkel, Pillemer, Reveille, Stone.

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