Arthritis in Kansas

An informational and state capacity planning document for addressing arthritis and related conditions in Kansas

This document was created as a result of collaboration among the Kansas Statewide Arthritis Steering Committee, the Kansas and Greater Kansas City chapters of the Arthritis Foundation, and the Kansas Department of Health and Environment's Bureau of Health Promotion

Fall 2002

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The *Arthritis in Kansas* document is the result of the guidance and collaboration of the Kansas Statewide Arthritis Steering Committee - a committee of people with arthritis, the Kansas and Western Missouri/Greater Kansas City Arthritis Foundation chapters, health professionals, university partners, representatives of the Kansas Departments of Aging and Social and Rehabilitation Services and the KDHE Bureau of Health Promotion. The committee members gave their time and expertise to create a plan that will encourage Kansans with arthritis to find ways to lessen the impact of this disease.

A special thanks is extended to the Kansans with arthritis who participated in the focus groups held across the state during the winter of 2000 - 2001. Their stories and experiences formed the base on which this plan was built. This "blueprint" provides the foundation to continue building partnerships on the local, state, and national level to help Kansans with arthritis manage their condition in the best way possible.

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Kansas Arthritis Facts

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Data from the 1996 Kansas Behavioral Risk Factor Survey (BRFS)** indicate that approximately 23% of the Kansas population between the ages of 45 and 55 reported they had arthritis; 32% of the Kansas population between the ages of 55 and 64 reported they had arthritis; and 46 % of the Kansas population over the age of 65 reported they had arthritis.

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When respondents to the 1996 Kansas BRFS who reported physician-diagnosed arthritis were asked about the type of arthritis they have, 20% reported they have osteoarthritis; 11% reported they have rheumatoid arthritis; 7% reported they have a form of rheumatism; 6% reported they have some other type of arthritis ; 2% reported they had not seen a doctor, and 54% reported they did not know or were not sure about the type of arthritis they have.

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The 1996 BRFS data provide an estimate that 40% of the Kansans who reported physician-diagnosed arthritis have an annual income of $9,999 or less, while 18% reported having an annual household income of $50,000 or more.

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Data from the 1997 KDHE Special Disability Survey indicate that Kansans with an activity limitation appear to be more likely to attribute their activity limitation to arthritis than to other suggested factors.

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Kansans who self-identified themselves as a person with arthritis and who participated in focus groups across the state, identified depression, anger, frustration, anxiety, embarrassment and isolation as psychological factors related to their activity limitations and pain; they identified limited employment, limited dexterity and strength, limited locomotion, and limited recreational activities as factors limiting daily activities.

***Kansas Department of Health & Environment, 2001**

**The BRFS is a state-based telephone survey designed to measure health status and health risks in the population. The BRFS is conducted in every state and several U.S. territories, and now, with more than 200,000 respondents annually, is the world’s largest continuously conducted telephone survey.

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Arthritis in Kansas
Executive Summary

Arthritis is a word used to describe many different conditions related to chronic joint symptoms, connective tissue disorders, and other rheumatic conditions. As a technical term, arthritis is defined as inflammation of the joint or joints. For the purposes of this document, *Arthritis in Kansas*, **arthritis will be operationally defined as chronic joint symptoms and/or doctor-diagnosed arthritis.**

According to the Centers for Disease Control and Prevention (CDC), arthritis is the leading cause of disability and affects an estimated 43 million Americans. The CDC expects that number to rise to 60 million by 2020 as "baby boomers" age. Approximately 285,000 children under the age of 16 have arthritis (American Juvenile Arthritis Association). According to the Arthritis Foundation - Kansas Chapter, approximately 407,000 Kansans have some form of chronic joint disease or rheumatic disease, including osteoarthritis, rheumatoid arthritis, fibromyalgia, juvenile arthritis, lupus, and gout, and other connective tissue diseases.

The Kansas Statewide Arthritis Steering Committee's overarching goal is to improve the quality of life among Kansans with arthritis. This goal was created to encompass the many facets of addressing this chronic disease. Reaching this goal over the next several years will entail the collaboration of state and local partnerships, health care professionals and the general public. With that in mind, the steering committee developed objectives and strategies to begin the process of developing a public and private partnership to address arthritis in Kansas. These objectives and strategies fall into three main categories: 1) Awareness; 2) Community-based Interventions, and 3) Evaluation/Surveillance.

Awareness

The Kansas Statewide Arthritis Steering Committee agreed a greater awareness of arthritis and its impact on those who have it should be increased within the general public. The adaptation of CDC arthritis awareness materials for Kansas should address, committee members agreed, the following areas:
1) The negative physical and psychological impacts of arthritis; 2) the availability of self-management services available to Kansans with arthritis; and 3) the benefits of physical activity to self-manage arthritis.

The committee members also agreed that identifying and documenting evidence-based arthritis interventions is necessary to assess what services currently exist for Kansans with arthritis. With this information in hand, the committee plans to create a resource guide that identifies physical activity and other self-management programs available in the state. The intent is for this guide to be published, made available statewide, and posted on websites of arthritis program partner organizations as well as others identified by the steering committee.

Community-Based Interventions

The advisory committee agreed that programs provided and coalitions created on the community level would have the greatest chance for success. The committee supports the expansion of evidence-based self-management activities (i.e, Arthritis Foundation aquatics program, People with Arthritis Can Exercise, Arthritis Self-Help Course) into Kansas counties that currently do not have these programs. Committee members recommended the creation of two pilot projects, one urban and one rural. These pilots would provide the "testing ground" for getting key stakeholders to begin working together to address arthritis in their community. If these pilots are successful, they will be replicated in other Kansas communities.

Evaluation/Surveillance

Evaluation of efficacy of physical activity programs as they relate to arthritis will continue through partnerships with the state's universities. Researchers from the Kansas State University Department of Kinesiology and Office of Community Health will continue to study the physical, psychological, and social efficacy of physical activity interventions for the self-management of arthritis. In addition, other health professionals will be asked to conduct studies on the economic impact arthritis and related conditions have on the state's economy. This information will be useful to Kansas employers to gain a better understanding of arthritis-related diseases and how they affect productivity.

Arthritis and chronic joint symptom questions were asked during the 1996 and 2000 Kansas BRFSS survey years. The Behavioral Risk Factor Surveillance System (BRFSS) is a state-based telephone survey designed to measure health status and health risks in the population. The BRFSS is conducted in every state and several U.S. territories, and now, with more than 200,000 respondents annually, is the world's largest telephone survey. Committee members agreed that arthritis/chronic joint symptom questions should continue to be asked in future survey years.

Arthritis/Chronic Joint Symptoms and Other Rheumatic Conditions

Although the term arthritis specifically refers to diseases of joints, it has also come to represent a broader array of conditions which affect bone, joint, synovium, cartilage, tendon, fascia, and muscle. These arthritic diseases (also known as rheumatic diseases or connective tissue diseases) have diverse etiologies, symptoms, treatments and outcomes. However, they share in common a propensity to damage the musculoskeletal tissues resulting in two common manifestations - pain and impairment of mobility.

No single classification of arthritic diseases exists. However, most of the diseases will fit into **one or more** of the following classifications:

Classification	Example
Degenerative	**Osteoarthritis**
Crystal	**Gout, Pseudo-gout**
Immune	**Rheumatoid, Lupus**
Spondylitis	**Ankylosing spondylitis, Psoriatic**
Infectious	**Lyme disease, Septic arthritis**
Myopathic	**Dermatomyositis**
Vasculitis	**Polyarteritis nodosa, Giant cell arteritis**
Localized	**Tendonitis, Bursitis, Carpal tunnel**
Primary non-rheumatic disease	**Crohn's disease, Fibromyalgia**

Risk factors are likely different for different arthritic diseases, but for most of these diseases, no modifiable risk factors are known. Three risk factors which may be modifiable are repetitive motion, joint injury, and obesity. These risk factors likely contribute to a large number of individuals having an arthritic disease because they are associated with some of the most common conditions (e.g., carpal tunnel syndrome, tendonitis, osteoarthritis). However, there is no indication that these factors contribute to a large number of different diseases. Diet is a risk factor for gout, and environmental exposures and behaviors are risk factors for some infectious and spondylitis syndromes (Lyme, reactive arthritis).

Because arthritic diseases are diverse, their manifestations are also diverse. Some diseases are typified by acute exacerbations with assymptomatic interim periods (e.g., gout). Some are specific to a single tissue or organ (e.g., osteoarthritis, tendonitis), while others have the potential to affect almost any

tissue in the body (e.g., systemic lupus erythematosis). Some arise without an apparent precipitant (e.g., rheumatoid arthritis); others may follow mechanical injury or repetitive motion (e.g., osteoarthritis, carpal tunnel syndrome), while others may be triggered by infections (lyme disease, Reiter's syndrome). Some affect women more than men (e.g., fibromyalgia) and some affect men more than women (e.g., ankylosing spondylitis). For some pain and immobility are the dominant manifestations (e.g., osteoarthritis), while for others pain and immobility are part of a constellation of symptoms (e.g., lupus). Some are well understood (e.g., gout), while others are poorly understood (e.g., fibromyalgia). Some respond well to treatment (e.g., gout) while others are progressive despite treatment (psoriatic arthritis).

Affecting such a diverse array of conditions in a meaningful way will be difficult; however, pain and immobility represent common paths which lead to much of the disability associated with arthritic diseases. It is the particular interest of this project to prevent or ameliorate the disability and improve the quality of life of affected persons regardless of the specific syndrome.

Common Forms of Arthritis/Chronic Joint Pain and other Rheumatic Conditions

(All of the following definitions were adapted from the National Arthritis Foundation website, www.arthritis.org)

Osteoarthritis (OA) or degenerative joint disease, is the most common type of arthritis. It is characterized by the breakdown of the joint's cartilage. Cartilage is the part of the joint that cushions the ends of bones. Cartilage breakdown causes bones to rub against each other, causing pain and loss of movement. Most commonly affecting middle-aged and older people, OA can range from very mild to very severe. It most commonly affects hands and weight-bearing joints such as knees, hips, feet and the back.

Rheumatoid Arthritis (RA) involves inflammation in the lining of the joints and/or other internal organs. RA typically affects many different joints. It can be chronic, which means it lasts a long time, and can be a disease of flares (active) and remissions (little to no activity or persistent and progressive). RA is a systemic disease that affects the entire body and is one of the most common forms of arthritis. It is characterized by the inflammation of the membrane lining the joint, which causes pain, stiffness, warmth, redness and swelling. The inflamed joint lining, the synovium, can invade and damage bone and cartilage. Inflammatory cells release enzymes that may digest bone and cartilage. The involved joint can lose its shape and alignment, resulting in pain and loss of movement.

Fibromyalgia is a common form of generalized muscular pain and fatigue. The name "fibromyalgia" means pain in the muscles and fibrous connective tissues (ligaments and tendons). This condition is referred to as a "syndrome" because it's a set of signs and symptoms that occur together. Fibromyalgia is especially confusing and often misunderstood because symptoms are common in other conditions. It is a form of soft-tissue or muscular rheumatism rather than arthritis of a joint.

Juvenile Arthritis (JA) is a general term for all types of arthritis and related conditions that occur in children. An estimated 300,000 children under age 17 are affected by juvenile arthritis, and juvenile rheumatoid arthritis (JRA) affects up to 50,000 children. Arthritis affects girls twice as often as boys. Juvenile arthritis can occur anytime from birth until the age of 16 years. Some children's symptoms of juvenile arthritis go into remission -- and others will be affected to some degree throughout their lifetime.

Systemic **Lupus** Erythematosus is a chronic (long-lasting) rheumatic disease which affects joints, muscles and other parts of the body. Lupus involves inflammation (the immune system's response to kill foreign agents, virus, bacteria). Systemic lupus erythematosus involves chronic inflammation that can affect many parts of the body, including the heart, lungs, skin, joints, blood-forming organs, kidneys, and nervous system.

Gout causes sudden, severe attacks of pain and tenderness, redness, warmth, and swelling in some joints. Usually affects one joint at a time -- often the big toe. The metabolism of nucleic acids (e.g. DNA) produces uric acid. In some persons, high blood levels of uric acid cause it to deposit as crystals inside the joint space resulting in inflammation and pain.

History of the Kansas Arthritis Program (KAP)

In October 1999, the Centers for Disease Control and Prevention (CDC) awarded the Kansas Department of Health and Environment a $65,000 grant to establish an arthritis program within the state to reduce the negative impact of arthritis and improve the quality of life of Kansans with arthritis. The initial two-year grant enhanced a partnership with the Arthritis Foundation - Kansas Chapter, Arthritis Foundation - Western Missouri/Greater Kansas City Chapter, and created the Kansas Statewide Arthritis Steering Committee. This committee has provided the advisory structure for the creation of this document, *Arthritis in Kansas*, to guide program planning and decision-making for arthritis-related interventions across the state.

When the KDHE Office of Injury and Disability was awarded the grant, the agency hired a full-time arthritis program coordinator, strengthened the relationship with the Arthritis Foundation, and formed the statewide steering committee. This committee is comprised of people with arthritis, health professionals in the arthritis field, representatives of the disability community, and public health representatives.

The Kansas Statewide Arthritis Steering Committee met for the first time in July 2000 for two main objectives: 1) receive an overview of the grant and what their involvement in the state plan would be; and 2) be apprized of the arthritis-related data obtained from the 1996 Kansas Behavioral Risk Factor Surveillance System and the Arthritis Foundation - Kansas Chapter. The committee agreed that several focus groups needed to be conducted across the state to supplement the existing state data for arthritis.

From November 2000 to February 2001, several focus groups were held across Kansas with people with arthritis (see p.19). The groups were conducted in Wichita, Garden City, Liberal, Osage City, and Mayetta. The individuals who comprised the groups were from various socio-economic and ethnic backgrounds and ranged in age from 25 to 82. The steering committee made recommendations on what kinds of questions to ask the focus group participants, agreeing that the answers would be incorporated into the state capacity planning document's objectives and strategies. Those questions were the following:

< How does arthritis impact your life?
< How do you attempt to cope with your arthritis?
< What are the barriers that you face when trying to cope with your arthritis?
< What is your relationship with your physician?

The advisory committee reconvened in February 2001 to receive the data from the focus groups. That data, the 1996 Kansas BRFSS arthritis data, and the Arthritis Foundation-Kansas Chapter program statistics guided the committee in forming the objectives and strategies for this state capacity planning document.

The focus group data also provided some support for the next grant KDHE received in October 2001. The purpose of the current CDC-funded grant awarded to Kansas is to promote physical activity interventions, create greater public awareness about arthritis and its impact and engage in additional state-based arthritis evaluation and surveillance activities.

Kansas Arthritis State Plan Goals/Objectives/Strategies

<u>Overall Goal</u>:

< **Increased quality of life for Kansans with arthritis.**

AWARENESS

The Centers for Disease Control and Prevention (CDC) estimates that as many as 43 million Americans have some form of arthritis and it is the leading cause of disability in the United States. The Arthritis Foundation - Kansas Chapter estimates that 407,000 Kansans have the disease. The 1997 Kansas Special Disability Survey ranks arthritis as the leading cause of activity limitation among respondents. Despite these figures, the Kansas Statewide Arthritis Steering Committee agreed there remains a low level of awareness about the impact of arthritis and prevention/self-management strategies. To address these concerns, the committee recommended that a state-level campaign be implemented to raise awareness among the general Kansas public. This communications campaign will 1) promote self-management programs, 2) promote the benefits of physical activity for managing symptoms, and 3) provide general information about how arthritis impacts those who have it.

<u>Objectives/Strategies</u>:

VI. Increase overall awareness in Kansas about the prevalence of arthritis, the negative impact of arthritis and prevention strategies by 50 percent by 2010. (Process objective; baseline data needed.)

A. General public

1. Increase the general public's knowledge through a media/public awareness campaign.

a. Develop materials and public service announcements (PSA's) that highlight the partnerships of the statewide steering committee with general information about arthritis and where Kansans with the disease can go for arthritis education and other services.

b. Develop a relationship with the state's health reporters and provide them with news releases and story ideas concerning the prevalence of arthritis, the impact of arthritis, prevention strategies, and the benefits of physical activity.

c. Develop and maintain a Kansas Arthritis Program website with links to the *Arthritis in Kansas* state capacity planning document and all partner agencies and organizations. Information about arthritis and what programs and services that can be accessed will be included on the website.

2. Increase Kansas employers' awareness of arthritis.

   a. Work with the Kansas Chamber of Commerce and Industry to offer newsletter articles and other informational resources about arthritis. Include information about lost days of work and lower productivity.

   b. Provide Kansas insurance companies with state-based information about arthritis.

B. Health professionals

1. Increase arthritis knowledge of primary care physicians and nurse practitioners by providing information about diagnosis and treatment.

   a. Partner with professional health organizations and training institutions to encourage educational opportunities/activities about arthritis.

   b. Send health professionals materials concerning the availability of Arthritis Foundation and other services for their patients with arthritis.

COMMUNITY-BASED INTERVENTIONS

As stated in the National Arthritis Action Plan, (NAAP), "No one organization can effectively address arthritis. Strong partnerships must be built among the medical, voluntary, and public health communities to ensure a coordinated, united effort. Only through the collective energy of an interdisciplinary approach can we truly reduce the arthritis burden." The Kansas Statewide Arthritis Steering Committee agreed that collaborative efforts that build partnerships on the local level is essential.

The statewide steering committee recommended the creation of two pilot projects, one urban and one rural. These pilots would provide the "testing ground" for getting key stakeholders to begin working together to address arthritis in their particular community. If these pilots are successful, they will be replicated in other Kansas communities. In the meantime, the steering committee will continue to work together, making certain the objectives and strategies of the state plan are carried forward and bringing in additional partners to see that arthritis is being addressed with a multi-disciplinary approach.

As part of the pilot projects, local coalitions will be encouraged to address the social isolation and depression associated with arthritis. The NAAP challenges state programs to "define the impact of coping, depression, and other emotional responses to arthritis."

VII. Improve quality of services available for Kansans with arthritis by 50 percent by 2010. (Process objective; baseline data needed.)

A. Implement two pilot projects (one urban; one rural) that create an integrated system of primary, secondary and tertiary prevention services by 2003. Utilize the statewide arthritis steering committee and other related partners to determine which sites will host the pilot projects through a Request for Proposals (RFP) process.

1. Primary prevention

a. Partners in the pilot sites will develop relationships with local schools, recreational programs and related entities to address the prevention of sports injuries and weight control as primary prevention practices.

b. The KDHE arthritis staff will pursue membership on the Kansas Council on Fitness and other related organizations.

2. Secondary prevention

a. Through local awareness campaigns, the early diagnosis and treatment of arthritis will be encouraged.

b. Increase the knowledge of people with arthritis about their condition.

c. Increase the knowledge of people with arthritis about the basic standard of care when visiting their physician.

d. Have the local coalition (pilot site) create or build upon an existing physical activity intervention, specific to that community's needs and resources.

e. Encourage people who have been diagnosed with arthritis to practice weight control and increase physical activity to self-manage their disease.

f. Encourage the proper use of arthritis-related medications.

3. Tertiary prevention

a. Identify and initiate potential partnerships for the implementation of self-management programs.

b. Increase the knowledge and awareness of Arthritis Foundation services (i.e, the aquatics program, People with Arthritis Can Exercise (PACE), Arthritis Self-Help Course) and other self-management programs.

c. Encourage local communities to use their resources in implementing self-management programs specific to their needs.

d. Encourage the proper use of arthritis-related medications.

e. Encourage weight control and physical activity self-management programs.

B. By 2006, develop programs to specifically address coping strategies, social isolation and depression in Kansans with arthritis.

1. The coalition members of the pilot sites are strongly encouraged to develop methods/programs to address social isolation and depression in people with arthritis, specific to their community, by including mental health professionals in the coalition.

VIII. Increase community involvement of Kansans with arthritis and key stakeholders by 50 percent by 2010. (Process objective; baseline data needed.)

A. Involve people with arthritis (and key stakeholders) in the planning, implementing, evaluating, and monitoring of activities that address their condition.

1. Build and maintain a representative coalition that includes key stakeholders in each pilot site to ensure effective community involvement of all members of the coalition.
a. Encourage regular meetings of pilot site coalitions.

2. Maintain the Kansas Statewide Arthritis Steering Committee as an advisory group.
a. Continually seek committee members who represent all facets of the arthritis community.
b. Define members' roles on the committee by having them serve on subcommittees that address the prevalence of arthritis, the negative impact of arthritis, prevention strategies, and physical activity programs. Include the use of bylaws for the operation of the committee and subcommittees.

EVALUATION/SURVEILLANCE

Evaluation of arthritis self-management programs is a vital tool in knowing how well programs and activities are working to improve range-of-motion and increase the ability to perform tasks of daily living. An assessment of as many of the state-based arthritis surveillance sources is also needed. (Surveillance is the public health term for tracking incidence, prevalence, and risk factors associated with a disease or condition over time.) The National Arthritis Action Plan (NAAP) states that surveillance would "facilitate greater understanding of who is affected; who is at greatest risk; what health beliefs and behaviors increase that risk; which occupations and occupational activities increase that risk; and how the disease affects physical health, quality of life, economics, and other areas."

The KDHE Bureau of Health Promotion as well as the KDHE Disability and Health Program have gathered information regarding arthritis in Kansas through the Behavioral Risk Factor Surveillance System (BRFSS) in 1996 and 2000. Kansas BRFSS data gathered in 1996 showed one-third of the Kansans surveyed reported some kind of joint pain during the past 12 months. In addition, a survey using similar methodology was conducted of more than 500 Kansans with disabilities in 1997. This Special Disability Survey targeted adults with a disability and included questions concerning daily activity limitations; the resulting data indicate that Kansans with a disability were more likely to attribute any reported activity limitation to arthritis than any other factor.

IX. Document and evaluate arthritis-related programs in Kansas by 2010 (Process objective; baseline data needed).

A. By 2003, develop a resource guide for arthritis information/services, interventions, and data (hard copy and posted on Kansas Arthritis Program website and partner websites).

1. Utilize expertise of steering committee and other networks to gather the necessary information for the resource guide.

2. Set up a schedule for printing and distribution.

3. Obtain funding if necessary.

B. By 2003, document the implementation of the pilot projects (see Objective II) to replicate on the state level.

1. Have the coalition members document their meetings and have them send in reports that document their progress and the barriers they experienced and how they overcame the barriers.
2. Have the coalition members and steering committee meet together to discuss the successes and challenges of the pilot projects. Have the coalition members recommend how best to replicate the pilot projects on the statewide level.

C. By 2006, evaluate the efficacy of arthritis self-management interventions.

1. Capitalize on the expertise at state universities to conduct evaluation activities and/or support the evaluation activities of state universities.
2. Obtain funding if necessary.

D. By 2006, evaluate the economic impact of arthritis in Kansas.

1. Identify experts who can conduct state-based arthritis economic impact studies.
2. Incorporate this information into materials and other public awareness programs to emphasize the impact arthritis has on the Kansas economy and workforce.
3. Obtain funding if necessary.

E. By 2006, include arthritis questions in the state Behavioral Risk Factor Surveillance System (BRFSS) during two survey years.

1. Work with the KDHE BRFSS staff to determine cost, timelines, etc., of including arthritis questions during two survey years.
2. Work with KDHE BRFSS staff to develop arthritis modules if national BRFSS arthritis questions are not being used.
3. Obtain funding from CDC grant and/or other funding sources for the BRFSS questions.
4. With epidemiological support, analyze arthritis-related BRFSS data, including any additional modules and questions as needed. In addition, seek out alternative sources of analysis if necessary.

EXPECTED OUTCOMES

Several positive outcomes are expected to occur with implementation of the strategies outlined in this document, *Arthritis in Kansas*. The overarching outcome expected will be increased awareness of arthritis: its social and economic impact, prevention strategies, and self-management activities. This increased awareness may be reflected in individuals with arthritis in the following manner:

< Increased physical activity among Kansans with arthritis;

< Increased independence and functioning, reflected in decreased activities of daily living limitations

< Increased social support from family members and friends and the service community;

< Increased physician-patient dialogue; and

< Increased self-management of pain.

Over time, increased arthritis awareness and understanding is expected to translate into well-developed overall self-management skills, higher levels of physical activity, increased levels of functioning
with less activity and/or work limitation, and increased overall quality of life for persons with arthritis in Kansas. The Kansas BRFSS will continue to serve as a vital surveillance tool for arthritis, and these anticipated changes may be captured and monitored through BRFSS data collection and analysis.

The BRFSS allows for the measurement of overall health-related quality of life (HRQOL), which may serve as a significant indicator of change within the population of persons with arthritis in Kansas. While modest gains in self-management may be captured through BRFSS data, such as increases in HRQOL measures and increased physical activity among Kansans with arthritis, it is likely that impact evaluation methodology for each proposed intervention will need to be employed in order to reveal more immediate and personal gains stemming from the objectives presented in *Arthritis in Kansas*.

KANSAS ARTHRITIS DATA

1996 Kansas Behavioral Risk Factor Surveillance System - Arthritis Module Summary

The 1996 Kansas Behavioral Risk Factor Surveillance System (BRFSS)* arthritis module data set contains variables that range from demographics to diagnosis, and include age, gender, education level, household income, population density, type of physician-diagnosed arthritis, and others. The respondents were given the choice of answering "yes", "no", "don't know/not sure", or refused to the following questions: (The exception was #5 in which respondents were given the options of osteoarthritis/degenerative arthritis; rheumatism; rheumatoid arthritis; Lyme disease, other; never saw a doctor; don't know/not sure; refused.)

During the past 12 months, have you had pain, aching, stiffness or swelling in or around a joint?

Were these symptoms present on most days for at least one month?

Are you now limited in any way in any activities because of joint symptoms?

Have you ever been told by a doctor that you have arthritis?

What type of arthritis did the doctor say you have?

Are you currently being treated by a doctor for arthritis?

According to the 1996 Kansas BRFSS report, "the percentage of respondents who had joint symptoms, suffered sustained symptoms, and were limited because of their joint symptoms increased with advancing age, and were most common among Kansans with less than a high school education or household incomes below $20,000." For arthritis-specific data, the 1996 Kansas BRFSS report said, "Over a fifth (21%) of respondents reported that they had been told by a doctor that they had arthritis. The prevalence of arthritis was higher among females (25%) than males(17%). The prevalence of arthritis increased with advancing age and generally decreased with rising household income and greater educational attainment. Among the Kansans with arthritis, 54% of the respondents reported that they did not know what kind of arthritis they had, 20% reported they had osteoarthritis/degenerative arthritis, 7% reported they had rheumatism, 6% reported they had some other type of arthritis and 2% reported they had not seen a doctor. Less than a third (31%) of persons who said they had arthritis reported that they were currently being treated by a doctor for arthritis."

* See Appendix A for full tables

1997 Kansas Special Disability Survey Summary

The purpose of the 1997 Kansas Special Disability Survey** was to determine prevalence of disability in adults residing in Kansas to investigate health-related quality of life, to investigate possible social environment correlations, and to identify health disparities. Adult Kansans were surveyed across the state using BRFSS methodology.

Disability was defined operationally for the purposes of this study as an affirmative answer to one or more of the following screening questions regarding limitations:

Are you limited in any way in any activities because of any impairment or health problem?

Do you currently use any assistive devices such as a wheelchair, cane, braces, or prosthesis?

Does any impairment or health problem now keep you from working at a job or business?

When a musculoskeletal condition was identified, **arthritis or another rheumatic disease** was cited as the **leading cause of disability** among the respondents. Arthritis or another rheumatic disease was also cited as the leading cause of activity limitation among the respondents in this survey

**See Appendix B for full tables.

2000/2001 Kansas Arthritis Focus Groups Summary

From November 2000 to February 2001, six focus groups were held across Kansas with people with arthritis. The groups were conducted in Wichita (two separate groups), Garden City, Liberal, Osage City, and Mayetta. The individuals who comprised the groups were from various socio-economic and ethnic backgrounds and ages ranging from 25 to 82. The Kansas Statewide Arthritis Steering Committee recommended what kinds of questions to ask the focus group participants for the resulting data to later support the objectives and strategies in the *Arthritis in Kansas* state capacity planning document. The questions that were developed were the following:

- How does arthritis impact your life?
- How do you attempt to cope with your arthritis?
- What are the barriers that you face when trying to cope with your arthritis?
- What is your relationship with your physician?

Researchers in the Kansas State University Department of Kinesiology and Office of Community Health provided technical assistance in conducting the focus groups and compiled the responses in a document, "Coping with Arthritis: A Report Prepared for the Kansas Arthritis Steering Committee." In this document, the respondents indicated their arthritis impacts their lives physically, in their activities of daily living, psychologically/emotionally, and socially.

Physical disability, pain, and the location of their arthritis characterized the physical impact responses. The respondents described limited employment, dexterity and strength, locomotion, and limited recreational activities when talking about their limited daily activities. Depression, anger, frustration, general negative emotion, anxiety, and embarrassment characterized how the respondents are impacted psychologically and/or emotionally.
In addition, the respondents indicated isolation as having the most social impact on their lives.

Coping with their arthritis was split into two categories by the focus group respondents - behavioral and cognitive. The behavioral category consisted of using movement and/or exercise, family and/or friend support, medication use, and physical adaptation to cope with their arthritis. The cognitive category consisted of using positive thinking and some kind of distraction to manage the negative impact of arthritis.

The barriers the respondents in the focus groups indicated centered around coping with their arthritis. Five different categories of coping barriers were identified. They consisted of a lack of resources, medication side effects, physical barriers, lack of empathy from others, and treatment inefficacy (the inability of certain treatments to work).

The responses the focus group participants gave about their relationship with their physicians was broken down into six categories. Those categories consisted of a positive relationship with their physician, a negative one, general treatment prescription, effective treatments, ineffective treatments, and services used.

The respondents characterized their positive relationship with their physician as one with good communication as well as empathy. The negative characteristics described by the respondents concerning their relationship with their physician fell into two categories - lack of empathy and lack of time with the patient. A few respondents mentioned their physician did not have specific knowledge about arthritis and for the participants in the Liberal and Garden City groups, not having a rheumatologist in western Kansas was a significant concern.

Exercise, heat therapy, and prescribed medications were cited by the respondents as being effective treatments for their arthritis. Ineffective treatment included an adverse reaction to prescribed medications or the medications were not working and over-the-counter medications were not effective.

While talking about exercise, many of the respondents said the Arthritis Foundation-sponsored water exercise classes were an effective tool in managing their arthritis. They said the warm water in the pools helped their joint mobility and gave them an overall sense of well-being. They said that sense of well-being came from physically feeling better after they were done with the class and the feeling of community and comradery with their fellow classmates.

Rheumatologist Responses to Questionnaire

A questionnaire was sent to a sample of five rheumatologists in Kansas in February 2001(there are 15 Kansas rhematologists listed on the Arthritis Foundation - Kansas Chapter physician referral list); three out of the five responded. They were asked questions concerning issues they hear most from their patients, the type of treatments they prescribe and what challenges they face in treating people with arthritis. The questions and answers are listed as follows:

Q: What is the average number of active patients with osteoporosis, rheumatoid arthritis, or fibromyalgia do you see a month?

< 300 - 400
< 240
< 80-90 patients

Q: Of those patients, how many would you estimate are between the ages of 45 and 65?

< 50 percent
< 30 - 40 percent
< 50 percent

Q: What complaint or issue do you hear the most from your patients about their arthritis-related condition?

< Cost of medications.
< Pain and inability to perform daily activities.
< Medications are expensive, medications take edge off pain, don't control it.

Q: What types of treatments do you prescribe to your patients for pain management?

< Physical therapy, medications, water aerobics.
< Acetominophen, non-steriodal anti-inflammatory drugs and other analgesic drugs.
< Medications, heat/cold applications, topical analgesics, range-of-motion exercises, muscle-strengthening exercises.

Q: Do you provide educational support to your patients such as referrals to Arthritis Foundation information or other educational materials?

< Yes.
< Routinely.
< We have Arthritis Foundation educational materials such as diagnosis and medication pamphlets we give to patients at their visit. We also recommend support groups.

Q: What is your and your colleagues' greatest challenge in treating people with arthritis?

< Treating them early enough in the disease process to keep them functional.
< Prescribing drugs that insurance companies will pay for without requiring a phone call for pre-authorization or letter of medical necessity; evaluating patients in a timely manner, utilizing limited resources.

Q: If the State of Kansas had financial resources and/or the ability to build partnerships to improve arthritis patient care, how best do you think those resources should be spent?

< Program to help individuals without adequate insurance coverage for costs of meds would be important.
< Preventive information for how to keep osteoarthritis from progressing. Fibromyalgia programs; early access of rheumatoid arthritis patients into system.
< Evaluate the State of Missouri Arthritis Chapter Program; consider establishing rheumatologist-directed centers in Kansas City, Wichita, and Topeka. Local hospitals may be willing to cost-shave. Expand public education programs.

Additional Data to be Gathered

The Kansas Statewide Arthritis Steering Committee recommends that several other arthritis data sets should be pursued over the next several years. The information to be gathered would be mainly to establish baseline data for achieving the overall objectives pf improved quality of services for Kansans with arthritis; increase the overall awareness of the prevalence of arthritis, the negative impact of arthritis, and prevention strategies; increase community involvement of Kansans with arthritis and key stakeholders; and evaluate arthritis-related programs in the state.

The steering committee will work with the KDHE Behavioral Risk Factor Surveillance System (BRFSS) staff to establish costs and timelines for including arthritis-related questions in optional state modules (the CDC has put arthritis questions in its core modules for the states to use). Future state-based questions may pertain to the use and effectiveness of medications and/or physician care and services.

At the time this document was printed, data had been gathered from arthritis questions contained in the 2000 Kansas BRFSS core module. However, this data must be analyzed and weighted before it can be released for publication. Once this data is officially published, it will be used to guide future program activities and initiatives.

Kansas Arthritis Data

Common Indicators

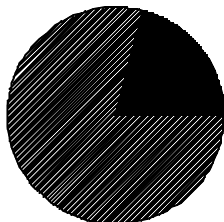
	Joint Pain	Activity	Medication	Physician Access	Doctor diagnosed their arthritis	Not sure of type of arthritis	Depression	Isolation	Lack of resources	Exercise
1996 KDHE BRFSS	X	X			X	X				
1997 KDHE Special Disability Survey	X	X	X				X	X	X	X
2000 Focus Groups	X	X	X	X	X	X	X	X	X	X
Key informant interviews	X	X	X	X					X	X

***Please note that a blank box does not indicate that a data source did not consider a particular issue to be a priority. Different questions were posed to different data sources.

Appendix A:

1996 Kansas Behavioral Risk Factor Surveillance System Survey
Arthritis Data

Arthritis
At Risk 21%



Arthritis: *Respondents who reported that they had ever been told by a doctor that they had arthritis.*
Joint Symptoms: *Respondents who reported that during the past 12 months that they had had pain, aching, stiffness, or swelling in or around a joint.*

Arthritis

Background

Arthritis is a term broadly applied to conditions of joint inflammation. When chronic or persistent it is typically associated with permanent damage to joints, pain, stiffness, and loss of mobility. Although chronic arthritis is usually not preventable and joint damage is not reversible, its huge toll in disability and suffering make it an important public health issue. Joints throughout the body are susceptible to arthritis but different types of arthritis tend to affect different joints. Both the severity of the disease and the specific joints involved determine the nature and extent of disability (e.g., persons with arthritis of the hips may have great difficulty walking but no difficulty eating). Arthritis potentially affects persons of all ages, but because the most common causes are associated with advancing age, it takes its greatest toll among the elderly. Many persons with mild arthritis may have no symptoms and, hence, may be unaware that they have arthritis.

A large number of conditions have been associated with arthritis; however, not all conditions result in chronic arthritic disease or cause permanent joint damage. A few of the more common causes of arthritis include infection (e.g., septic arthritis, Lyme disease), joint damage due to injury or "wear and tear" (e.g., osteoarthritis), autoimmune diseases (e.g. lupus, rheumatoid arthritis), and crystals in joints (e.g., gout). Persons with arthritis may not know the cause of their arthritic condition, sometimes because their joint symptoms have never been clinically evaluated.

Who's At Risk Among Kansans

A third (34%) of respondents reported that they had pain, aching, stiffness, or swelling in or around a joint during the past 12 months. Among persons who suffered joint symptoms during the past 12 months, 56% reported that the symptoms were present on most days for at least one month. Nearly a third (30%) of persons who had joint symptoms reported that they were limited in some way in an activity because of their joint symptoms.

Figure 106

Percentage of Kansans With Joint Symptoms Who Had Joint Symptoms Present for at Least One Month
By Age Group

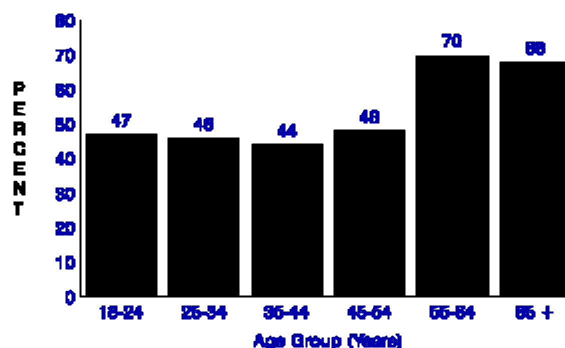


Figure 107

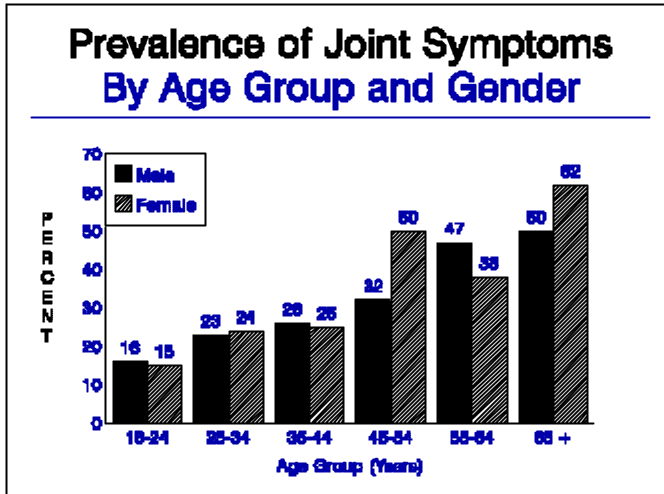


Figure 108

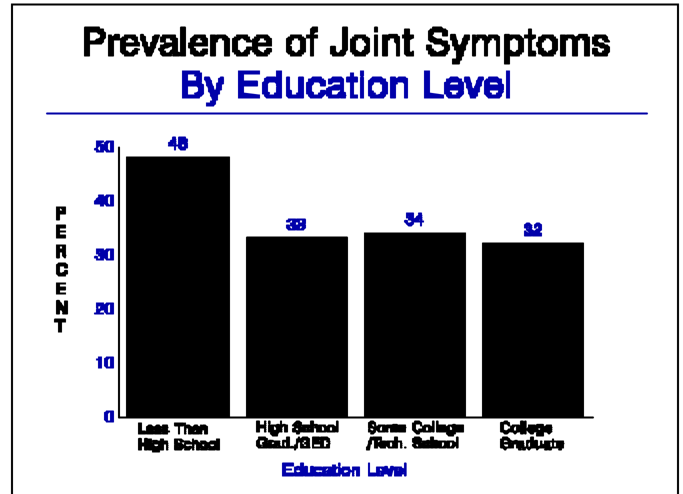


Figure 109

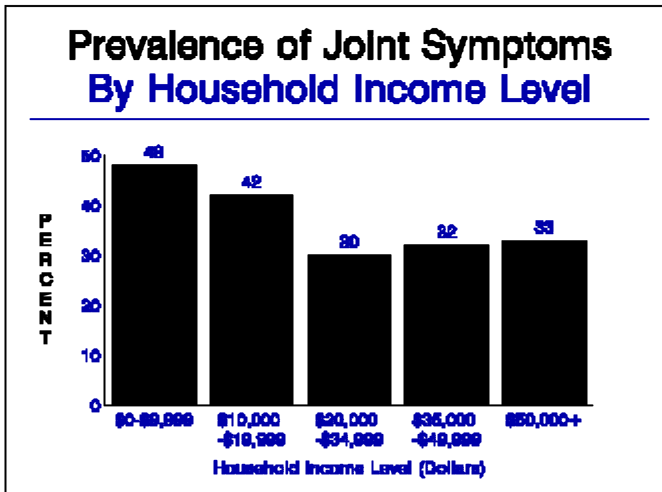
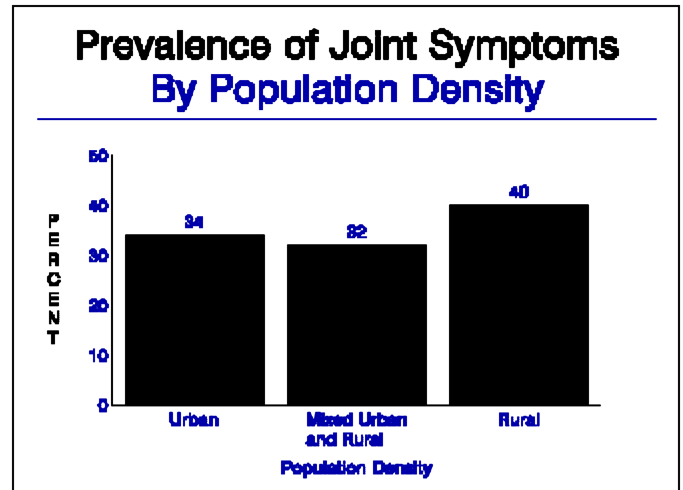
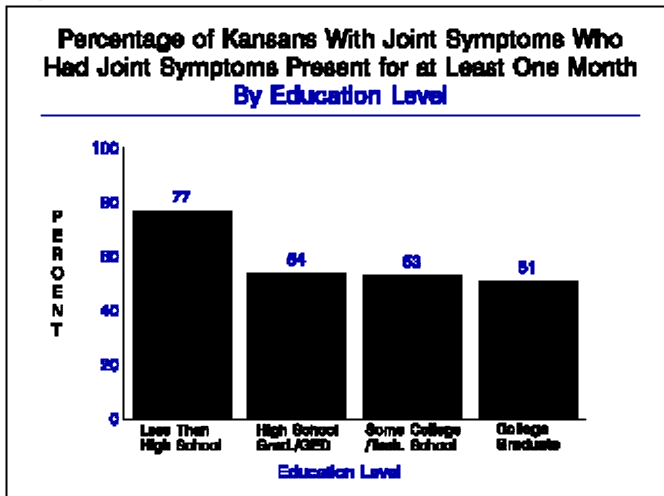


Figure 110



Females were more likely than males to report joint symptoms and to be limited because of joint symptoms, while males were more likely to reported sustained joint symptoms. The percentage of respondents who had joint symptoms, suffered sustained symptoms, and were limited because of their joint symptoms increased with advancing age, and were most common among Kansans with less than a high school education or household incomes below $20,000.

Figure 111



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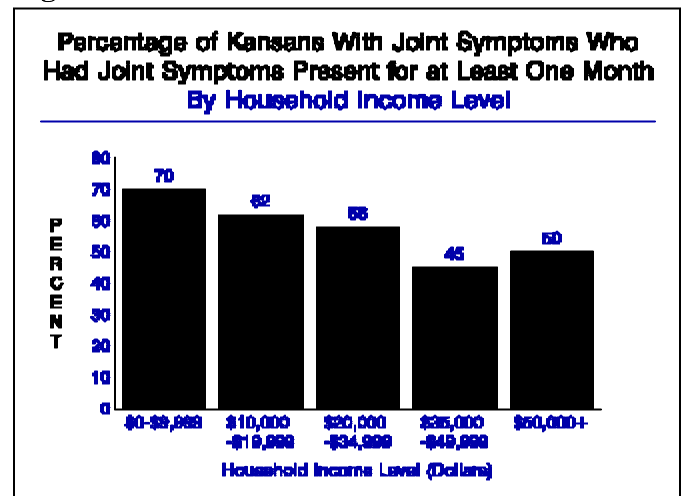
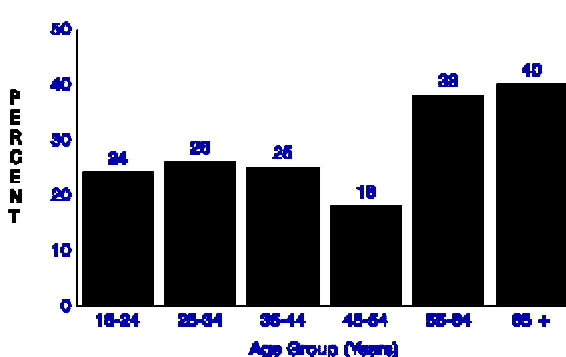


Over a fifth (21%) of respondents reported that they had been told by a doctor that they had arthritis. The prevalence of arthritis was higher among females (25%) than males (17%). The prevalence of arthritis increased with advancing age and generally decreased with rising household income and greater educational attainment. Among Kansans with arthritis, 54% of respondents reported that they did not know what kind of arthritis they had, 20% had osteoarthritis/degenerative arthritis, 11% had rheumatoid arthritis, 7% had rheumatism, 6% had some other type of arthritis, and 2% said they had not seen a doctor. Less than a third (31%) of persons who had arthritis reported that they were currently being treated by a doctor for arthritis.

Figure 113



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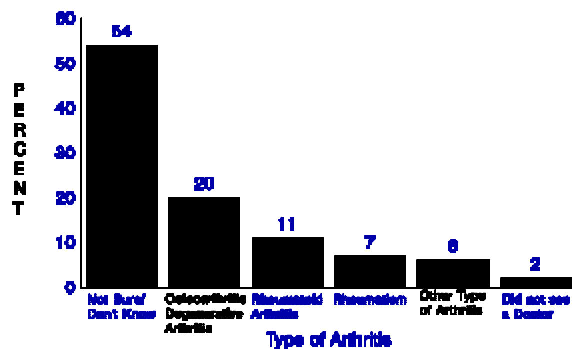

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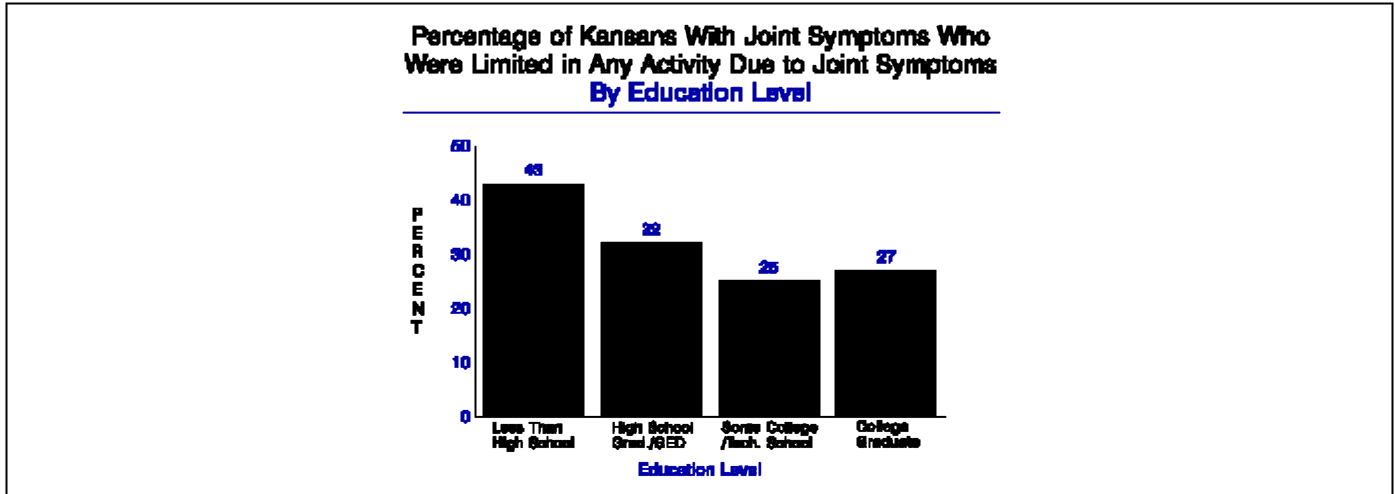

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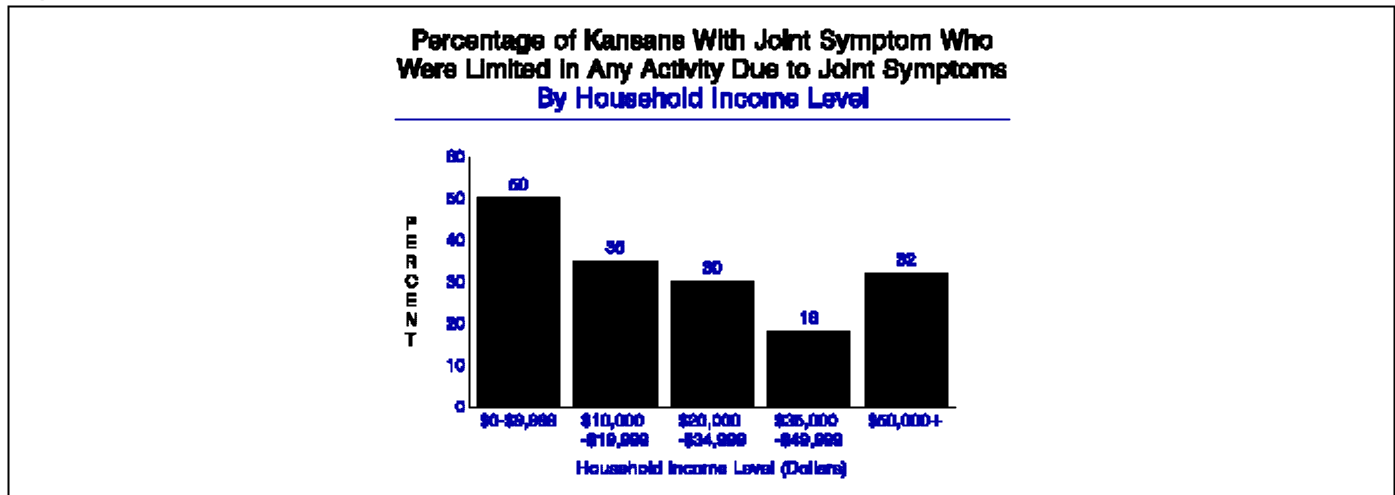

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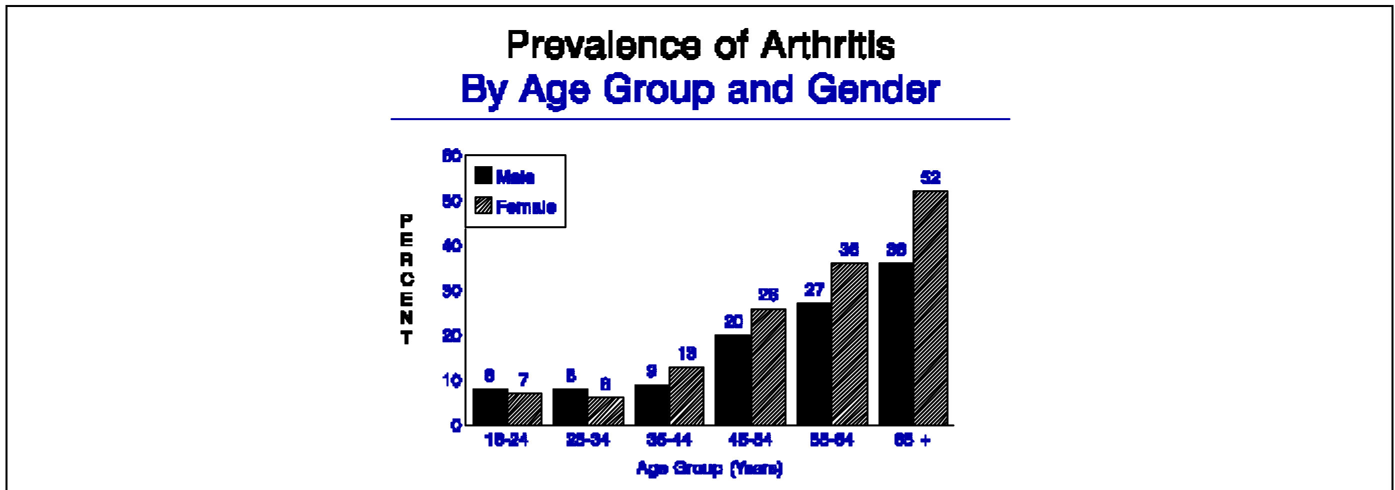


Figure 118

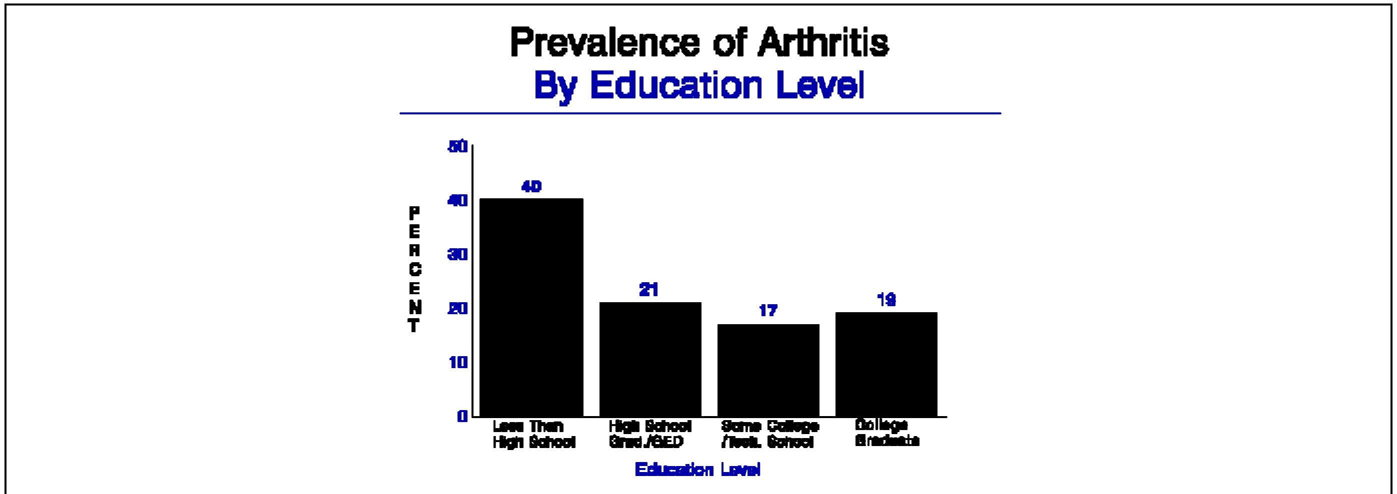


Figure 119

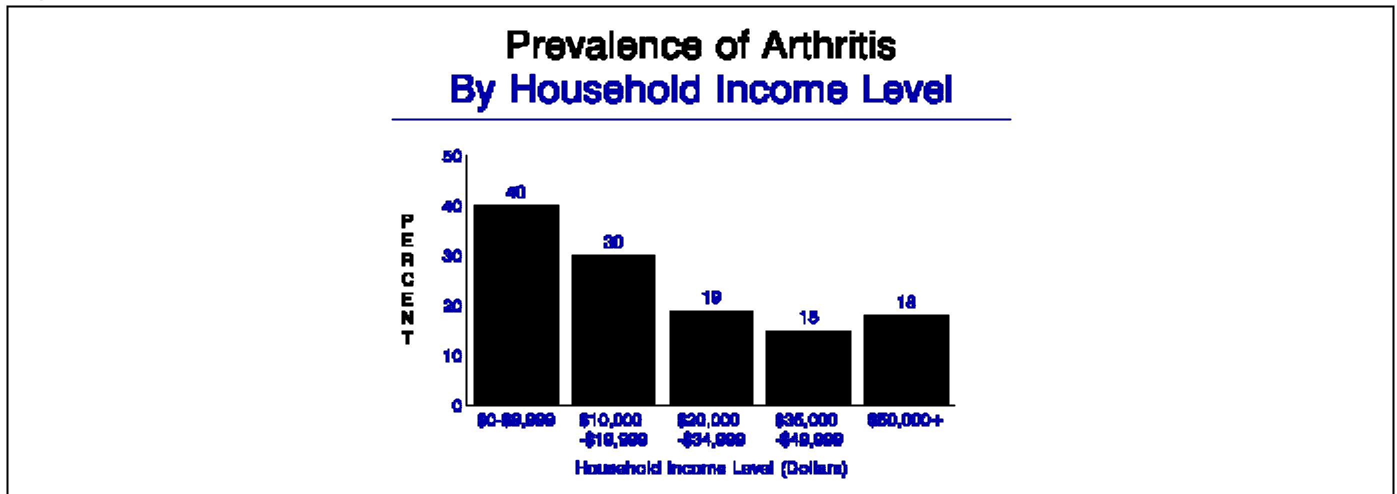
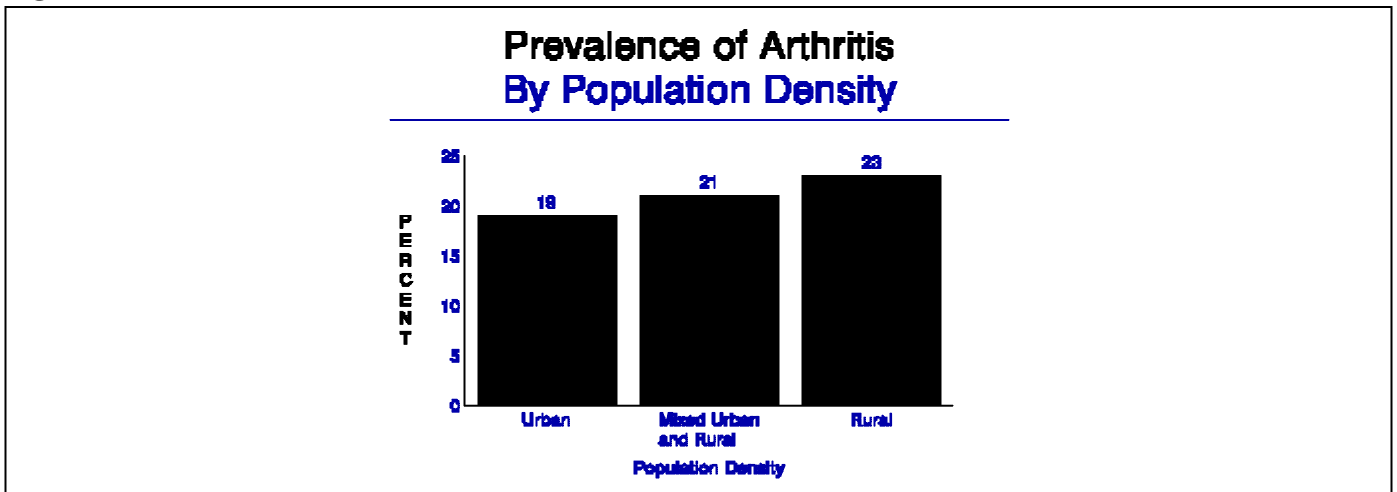


Figure 120



Appendix B:

1997 Kansas Special Disability Survey
Arthritis Data

The purpose of the 1997 Kansas Special Disability Survey was to determine prevalence of disability in adults residing in Kansas to investigate health-related quality of life, to investigate possible social environment correlations, and to identify health disparities. Adult Kansans were surveyed across the state using BRFSS methodology. Disability was defined operationally for the purposes of this study as an affirmative answer to one or more of the following screening questions regarding limitations:

1. Are you limited in any way in any activities because of any impairment or health problem?

2. Do you currently use any assistive devices such as a wheelchair, cane, braces, or prosthesis?

3. Does any impairment or health problem now keep you from working at a job or business?

Table 6.3: Adults with a disability and health conditions that currently affect them

Health Condition	Total Sample Size	Number At Risk	Population At Risk
	N	n	%
Musculo-skeletal			
Arthritis/rheumatism	513	305	59.5
Back or neck injury/pain	517	210	40.6
Spasms/contractions	518	113	21.8
Osteoporosis	514	53	10.3
Fracture/bone/joint injury	516	69	13.3
Impairment			
Hearing loss	517	125	24.2
Eye/vision problems	517	226	43.5
Missing legs,arms,feet	518	14	2.7
Stiffness foot,arm,leg	517	110	21.3
Metabolic or organ			
Diabetic	518	63	12.2
Cirrohsis/hepatitis/liver	518	13	2.5
Kidney disease	518	24	4.6
Reproductive/genital	515	14	2.7
Urinary/bladder problem	518	63	12.2
Bowel problem	518	57	11.0
Skin ulcers/sores	518	27	5.2
Intestinal disease	515	33	6.4
Respiratory			
Lung/breathing problem	517	137	26.5
Severe allergies	515	113	21.9
Nerve or brain			
Brain injury	518	8	1.5
Epilepsy/seizures	518	11	2.1
Cerebral palsy	518	5	1.0
Spinal cord injury	514	26	5.1
Any paralysis	518	17	3.3
Neurologic disorder	514	42	8.1
Migraines	517	97	18.8
Cardiovascular			
Heart disease	517	95	18.4
Stroke	517	23	4.4
Hypertension	517	180	34.8
High cholesterol	504	114	22.6
Cancer			
Any type of cancer	517	40	7.7
Chronic pain/fatigue			
Chronic pain	516	159	30.8
Chronic fatigue	516	122	23.6
Depression			
Depression or anxiety	517	94	18.2

Footnote: Based on the question, "I am going to read a list of various health conditions that you may have experienced. Please answer whether each condition is a current problem, past problem, or never a problem."

Table 6.4: Adults with a disability by type of impairment or health problem that limits activity

Health Condition	Total Sample Size	Number At Risk	Population At Risk
	N	n	%
Musculo-skeletal			
Arthritis/rheumatism	453	79	17.4
Back or neck problem	453	61	13.5
Fracture/bone/joint injury	453	29	6.4
Walking problem	453	42	9.3
Impairment			
Hearing problem	453	9	2.0
Eye/vision problem	453	14	3.1
Metabolic or organ			
Diabetes	453	23	5.1
Respiratory			
Lung/ breathing problem	453	27	6.0
Cardiovascular			
Heart problem	453	41	9.1
Stroke problem	453	9	2.0
Hypertension	453	7	1.5
Cancer			
Any type of cancer	453	18	4.0
Depression/anxiety			
Depression/anxiety	453	5	1.1
Other			
Conditions not specified	453	89	19.6

Footnote: Based on the question, "What is the major impairment or health problem that limits your activities?"

Table 6.5: Adults with a disability who are currently affected by arthritis

Demographic Characteristics	Total Sample Size	Number At Risk	Percent At Risk
	N	n	%
Total	513	305	60
Gender			
Male	181	103	57
Female	332	202	61
Age Group			
18-24	10	1	10
25-34	31	10	31
35-44	66	25	38
45-54	82	44	54
55-64	93	64	69
65+	228	160	70
Don't know/Refused	3	1	-
Education			
< H.S. Grad.	85	57	67
High School Grad.	196	106	54
Some College	132	89	67
College Grad.	97	51	53
Don't Know/Refused	3	2	-
Race/ethnicity			
White, non-Hispanic	459	276	65
African-American	30	16	53
Other	23	13	57
Don't Know/Refused	1	0	-
Marital Status			
Married/Living	254	142	56
Together	91	57	63
Divorced/Separated	130	88	68
Widowed	37	17	46
Never Married	1	1	-
Don't Know/Refused			
Income			
< $10,000	51	34	67
$10,000 < $20,000	108	67	62
$20,000 < $35,000	132	77	58
$ 35,000 < $50,000	64	39	61
$ 50,000 +	63	30	48
Don't Know/Refused	95	58	-
Employment			
Employed for Wages	173	89	51
Out-of-Work	19	10	53
Unable	64	40	63
Retired	217	149	69
Other	39	17	44
Don't Know/Refused	1	0	-

Table 6.6: Adults with a disability who are currently affected by chronic pain or fatigue

Demographic Characteristics	Total Sample Size	Number At Risk	Percent At Risk
	N	n	%
Total	520	199	38
Gender			
Male	184	55	30
Female	336	144	43
Age Group			
18-24	10	4	40
25-34	32	9	28
35-44	66	27	41
45-54	84	41	49
55-64	95	43	45
65+	230	73	32
Don't Know/Refused	3	2	-
Education			
< H.S. Grad.	85	31	37
High School Grad.	200	71	36
Some College	133	54	41
College Grad.	99	42	42
Don't Know/Refused	3	1	-
Race/ethnicity			
White, non-Hispanic	466	179	38
African-American	30	12	40
Other	23	8	35
Don't Know/Refused	1	0	-
Marital Status			
Married/Living Together	258	93	36
Divorced/Separated	92	43	47
Widowed	130	48	37
Never Married	39	15	39
Don't Know/Refused	1	0	-
Income			
< $10,000	52	30	58
$10,000 < $20,000	109	47	43
$20,000 < $35,000	136	56	41
$ 35,000 < $50,000	64	21	33
$ 50,000 +	63	14	22
Don't Know/Refused	96	31	-
Employment			
Employed for Wages	175	64	37
Out-of-Work	19	9	47
Unable	65	40	62
Retired	220	74	34
Other	39	12	31
Don't Know/Refused	2	0	-

Table 6.7: Adults with a disability who are currently affected by depression

Demographic Characteristics	Total Sample Size	Number At Risk	Percent At Risk
	N	n	%
Total	517	94	18
Gender			
Male	184	23	13
Female	333	71	21
Age Group			
18-24	10	3	30
25-34	32	8	25
35-44	65	16	25
45-54	84	26	31
55-64	93	15	16
65+	230	25	11
Don't know/Refused	3	1	-
Education			
< H.S. Grad.	83	20	24
High School Grad.	199	30	15
Some College	133	23	17
College Grad.	99	21	21
Don't Know/Refused	3	0	-
Race/ethnicity			
White, non-Hispanic	463	80	17
African-American	30	9	30
Other	23	5	22
Don't Know/Refused	1	0	-
Marital Status			
Married/Living Together	258	46	18
Divorced/Separated	91	21	23
Widowed	129	17	13
Never Married	38	10	26
Don't Know/Refused	1	0	-
Income			
< $10,000	51	13	26
$10,000 < $20,000	109	24	22
$20,000 < $35,000	135	22	16
$ 35,000 < $50,000	63	14	22
$ 50,000 +	63	5	8
Don't Know/Refused	96	16	-
Employment			
Employed for Wages	173	24	14
Out-of-Work	19	4	21
Unable	65	28	43
Retired	219	26	12
Other	39	10	26
Don't Know/Refused	2	2	-

Table 6.8: Adults with a disability who experience side effects to their medications

Demographic Characteristics	Total Sample Size	Number At Risk	Percent At Risk
	N	n	%
Total	517	84	16
Gender			
Male	184	22	12
Female	333	62	19
Age Group			
18-24	10	1	10
25-34	32	5	16
35-44	66	13	20
45-54	83	23	28
55-64	94	15	16
65+	229	27	12
Don't Know/Refused	3	0	-
Education			
< H.S. Grad.	85	11	13
High School Grad.	199	33	17
Some College	132	26	20
College Grad.	98	14	14
Don't Know/Refused	3	0	-
Race/ethnicity			
White, non-Hispanic	463	68	15
African-American	30	11	37
Other	23	5	22
Don't Know/Refused	1	0	-
Marital Status			
Married/Living Together	257	45	18
Divorced/Separated	92	17	19
Widowed	129	13	10
Never Married	38	9	24
Don't Know/Refused	1	0	-
Income			
< $10,000	51	14	28
$10,000 < $20,000	109	18	17
$20,000 < $35,000	136	22	16
$ 35,000 < $50,000	64	12	19
$ 50,000 +	63	6	10
Don't Know/Refused	94	12	-
Employment			
Employed for Wages	175	30	17
Out-of-Work	19	2	11
Unable	65	22	34
Retired	218	25	12
Other	39	5	13
Don't Know/Refused	1	0	-

Table 6.9: Adults with a disability and medication use

Question Responses	Total Sample Size	Number At Risk	Percent At Risk
	N	n	%
Take/should take daily			
Yes	519	382	74
Meds: frequency used			
All of the time	382	335	88
Most of the time	382	29	8
Some of the time	382	13	3
Rarely	382	3	1
Never	382	2	1
Non-use of medicine due to cost			
Didn't fill first rx.	382	60	16
Didn't fill entire rx.	382	71	19
Didn't refill	381	60	16
Use less frequently	382	62	16
Non-use of medicine Other reasons			
Forget to Use	382	129	34
Side Effects	378	45	12
Cannot Gt to Store	382	35	9
Don't Need	381	45	12
Help with meds			
Need any help	380	28	7
Ordering/Shopping	28	16	57
Reminding/Monitoring	28	20	71
Other Help	28	4	14