

**Data sources for
monitoring arthritis and
musculoskeletal conditions**

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Data sources for monitoring arthritis and musculoskeletal conditions

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National Centre for Monitoring Arthritis and Musculoskeletal Conditions

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AQoL	Assessment of Quality of Life
ARAD	Australian Rheumatology Association Database
ARIA	Accessibility/Remoteness Index for Australia
ASGC	Australian Standard Geographical Classification
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
BEACH	Bettering the Evaluation and Care of Health Survey
BMD	bone mineral density
BMI	body mass index
CATI	computer-assisted telephone interview
DALY	disability-adjusted life year
DMARD	disease modifying anti-rheumatic drug
GP	general practitioner
ICD-10	International Statistical Classification of Diseases and Related Health Problems, tenth revision
ICD-AM	International Statistical Classification of Diseases and Related Health Problems, Australian Modification
ICF	International Classification of Functioning
ICPC-2	International Classification of Primary Care, second edition
MBS	Medicare Benefits Scheme
NAMSCAG	National Arthritis and Musculoskeletal Conditions Advisory Group
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NHPA	National Health Priority Area
NHS	National Health Survey
NSW	New South Wales
NT	Northern Territory
OP	osteoporosis
PBS	Pharmaceutical Benefits Scheme
Qld	Queensland
RPBS	Repatriation Pharmaceutical Benefits Scheme
SA	South Australia
SAMSS	South Australian Monitoring and Surveillance System
SEIFA	Socio-Economic Index for Areas
SERCIS	Social, Environmental and Risk Context Information System
SF	short form

SPANS	(New South Wales) Schools Physical Activity and Nutrition Survey
Vic	Victoria
WA	Western Australia
WHO	World Health Organization
YLD	years of healthy life lost due to disability
YLL	years of healthy life lost due to premature mortality

Summary

In the past there has not been much regular surveillance or monitoring of arthritis and musculoskeletal conditions in Australia. This is probably because these diseases and conditions are largely non-fatal and don't often result in hospitalisation. However, arthritis and musculoskeletal conditions have a high prevalence in Australia, with more than 6.1 million Australians having one or more of these conditions. They also have large impact on health-related quality of life, and cause a large amount of disability. In view of the great burden associated with these conditions it is important that a system be put in place to monitor them.

This report reviews and evaluates data sources for monitoring arthritis and musculoskeletal conditions. It is focused on data sources with data relevant to osteoarthritis, rheumatoid arthritis, juvenile arthritis and osteoporosis but includes information relevant to all musculoskeletal conditions. The data sources are described and evaluated against information requirements to identify limitations. The report also highlights the way forward to improve information on these conditions to develop the monitoring system.

Strengths

There are a large number of national and sub-national data sources that contain information relevant to arthritis and musculoskeletal conditions. This includes various types of data sources such as administrative, surveys and registries. Allowing information to be collected through a number of mechanisms can improve the validity of the data. Some important data sources include the National Health Survey, the Survey of Disability, Ageing and Carers, the Australian Orthopaedic Association National Joint Replacement Registry and the Australian Rheumatology Association Database.

Data are also available to report on the different categories of public health information: population health status, determinants of health, public health interventions, inputs and infrastructure and priority populations. Recently, the National Health Survey has included a module on arthritis and osteoporosis including data on doctors' or nurses' diagnosis of osteoarthritis, rheumatoid arthritis, all types of arthritis and osteoporosis. This is important data to determine the prevalence of these conditions in the Australian population.

Data gaps

A number of gaps in the current data have been identified in this report:

- Self-reported data in surveys need to be validated.
- There are no data on the incidence of these conditions.
- There are no recent national data on biomedical risk factors such as nutrition, measured weight, measured height and bone mineral density scans (used to diagnose osteoporosis).
- There are no data on the incidence of fractures in general. This is because there are no national data on the treatment of fractures in hospital emergency departments or doctors' surgeries.
- There are limited data about visits to specialists and allied health care professionals.

- Also, of particular importance to monitoring rheumatoid arthritis, there is a lack of data on waiting time to see a rheumatologist.
- There is also limited information relating to the effectiveness and uptake of information from health promotion strategies.

Data source limitations

A number of improvements for specific data sources have also been identified:

- Information on specific conditions is lacking in a number of surveys including the Survey of Disability, Ageing and Carers.
- The National Health Survey (NHS) lacks data on quality of life. Information relating to fractures and joint trauma can be improved in the NHS.
- The data are often available from separate data sources that are not linked.
- Information on the use of health services (hospitals and general practitioners) is only episode based. It is not possible to currently determine the number of people using these services.
- The Pharmaceutical Benefits Scheme database needs aggregation to get information about medications used per person.
- Data items also need to be standardised between surveys and between national- and state-based data sources.

In view of these limitations, there is an urgent need to develop a clear strategy for generating information that is suitable for regular monitoring. The National Centre for Monitoring Arthritis and Musculoskeletal Conditions at the Australian Institute of Health and Welfare (AIHW) is undertaking data development projects to improve the data available for a monitoring system.

1 Introduction

Monitoring of arthritis and musculoskeletal conditions is essential to improve Australia's capacity to make decisions for cost-effective allocation of resources, to plan preventive and treatment services, and to target priority population groups. Monitoring is also important to track the impact of risk factors, improved diagnosis, health promotion, and treatment and prevention strategies.

This report describes and evaluates data sources for monitoring arthritis and musculoskeletal conditions in Australia, with an aim to identify gaps and deficiencies in the current information base for regular surveillance and monitoring. The data sources are also evaluated for the quality and usefulness of their contents to contribute to an effective monitoring system.

Arthritis and musculoskeletal conditions have a substantial influence on the health and quality of life of Australians. They also inflict a large cost burden on the health care system, individuals and families. However, because they are largely non-fatal conditions and don't often result in hospitalisation there has not been much regular surveillance or monitoring in the past.

More than 6 million Australians are estimated to have arthritis or other musculoskeletal conditions long-term (ABS 2006a). This number is set to rise with the ageing of the population, as these diseases and conditions are strongly associated with age. Arthritis and musculoskeletal conditions are also a significant cause of disability, with 1.2 million Australians reporting one of them as their main disabling condition (AIHW: Rahman et al. 2005). Health expenditure for arthritis and musculoskeletal conditions is high: \$4.6 billion was spent in the financial year 2000-01, the third largest contributor to direct health expenditure in Australia (AIHW: Penm et al. 2006).

A characteristic feature of arthritis and musculoskeletal conditions is their extensive diversity. There are over 150 different types of arthritis and musculoskeletal conditions (WHO Scientific Group 2003). They vary considerably in the nature of their impact, disease duration, severity of illness, complications and associated disability.

The nature and type of information required to monitor this large group of diseases and conditions is enormous and varied. Not only is information required to describe their occurrence, but regular time series are also needed to track changes in their individual and collective impacts. Information is also required to study outcomes of various public health interventions and treatments. Disability, quality of life, mental health and financial impact associated with various musculoskeletal conditions also need to be monitored regularly.

Information on various aspects of health and wellbeing is available in several administrative and non-administrative databases. However, much of this information is generic in nature and does not pertain to specific diseases and conditions. Also, the nature and type of information available is often inconsistent and lacks detail.

To be able to evaluate the available data sources for monitoring arthritis and musculoskeletal conditions it is important to understand how a disease affects the individual over their lifetime, what types of health care services are needed, and what types of information are required for regular monitoring.

Public health information

To evaluate the data available for monitoring a specific disease, it is important to know what type of information is required for public health action.

Public health as defined by the former National Public Health Partnership is *'The organised response by society to protect and promote health and prevent illness, injury and disability'* (National Public Health Information Working Group & AIHW 1999). The focus is on improving the health of the population or population sub-groups instead of particular individuals, by identifying and attempting to modify various determinants of health. Public health activity involves coordination and cooperation between individuals, carers, government agencies, and private and community-based organisations. The Australian Government Department of Health and Ageing through its Better Arthritis and Osteoporosis Care Program and state and territory governments promote and fund public health activity for arthritis and musculoskeletal conditions. In addition, privately funded and community-based organisations provide services, information and funding; these include Arthritis Australia, Osteoporosis Australia and Carers Australia.

A general model for categorising public health information has been developed by the former National Public Health Partnership. This model describes five categories of public health information that are required to monitor disease in a population (Table 1.1). The categories are population health status, determinants of health, public health interventions, inputs and infrastructure, and priority populations.

Table 1.1: Categories of public health information required for disease monitoring

Population health status	Determinants of health	Public health interventions	Inputs and infrastructure	Priority populations
Morbidity and illness	Biomedical factors	Hospitalisation	Labour force	Groups with equity and access concerns
Disability	Environmental hazards	General practitioner visits	Funding	Aboriginal and Torres Strait Islander peoples
Mortality	Lifestyle factors	Treatments	Training	Residents of rural and remote locations
Quality of life	Age and sex	Allied health care	Research	People with a low socioeconomic status
Injury	Genetics and family history	Public health education	Disability support	Non-English speakers

Source: Modified from National Public Health Information Working Group & AIHW 1999.

This model describes the general types of information needed for monitoring a chronic disease. However, it does not describe the detailed issues that need to be monitored specifically for arthritis and musculoskeletal conditions. To understand these specific issues it is important to examine the impact of arthritis and musculoskeletal conditions on the individual and the health system over the life course. For this reason, a model of the continuum of care has been used in this report to describe interventions required by individuals at each stage of disease, and the health care sectors that are responsible for providing treatment and care in relation to arthritis and musculoskeletal conditions (see Figure 1.1). Together these models have been used to describe what information is needed for an effective monitoring system and to identify areas where there are gaps in the existing data.

The disease continuum for arthritis and musculoskeletal conditions

Arthritis and other musculoskeletal conditions are generally chronic diseases. The information required for monitoring the conditions in each of the categories described above (population health status, determinants of health, public health interventions, inputs and infrastructure, and priority populations) changes over the disease continuum.

The stages of the disease continuum include: the well population, the at-risk/asymptomatic population, the population with a recent diagnosis of disease, the population managing a chronic disease and the population receiving palliative care or those who have died from the condition (Figure 1.1). An example of how the information required for a category can change over the disease continuum is public health education. For the well population or the at-risk population it is important for public health education to promote healthy behaviours such as weight control, preventing joint injury, and promoting other behaviors to improve bone health. However, for those managing chronic disease, public health education needs to promote self-management and optimise treatment.

For each stage of the disease continuum there are a number of interventions that need to be monitored at the population health level for arthritis and musculoskeletal conditions as a whole (Figure 1.1). There are also specific interventions that need to be monitored for specific diseases such as osteoarthritis, rheumatoid arthritis and osteoporosis. Furthermore, data for monitoring need to be collected from the different sectors of the health care and allied health care systems that are involved in the interventions and health promotion at each stage. Public health interventions should aim to prevent people moving through to the subsequent stages of the disease continuum, hence it is important to monitor how many people are at each stage. However, for chronic conditions such as arthritis and musculoskeletal conditions it is not always possible to prevent people moving from disease diagnosis to chronic disease management.

The disease continuum for arthritis and musculoskeletal conditions described in Figure 1.1 specifies important interventions and aspects of disease that need monitoring. These include biological, clinical and social issues. It is not currently possible to monitor many of these aspects. This highlights the need to describe the data that are currently available, and indicate where and how these data can be reported and the gaps and deficiencies they contain.

The monitoring system

Public health information in Australia is collected through a number of mechanisms to make up the monitoring system. Based on the mechanism of data collection, the data sources can be categorised as administrative, surveys, registries, derived and other (described in Chapter 2). The information in these data sources is obtained from individuals, government agencies and private and community-based organisations. A monitoring system includes all of these components (data sources and stakeholders) and it is the connections among the different components that determine how the system functions as a whole.

In the past there has not been much regular surveillance or monitoring of arthritis and musculoskeletal conditions in Australia. This is probably because these diseases and conditions are largely non-fatal and don't often result in hospitalisation. However, arthritis and musculoskeletal conditions have a high prevalence in Australia, a large impact on health-related quality of life, and cause a large amount of disability. In view of the great

Stage of disease continuum	Well population	At-risk or asymptomatic	Diagnosis of disease	Management of chronic disease	Mortality
Level of prevention	Primary prevention	Secondary prevention/ early detection	Disease management, tertiary prevention and rehabilitation		Disease management
Nature of intervention	<ul style="list-style-type: none"> • Promotion of healthy behaviours and environments across the life course - Promote weight control^(a) - Promote joint injury or trauma prevention^{(a) (c)} - Prevent smoking^{(a) (b)} - Promote behaviors to improve bone health including nutrition, exercise and moderate alcohol consumption^(c) • Universal and targeted approaches 	<ul style="list-style-type: none"> • Education programs • Screening <ul style="list-style-type: none"> - Bone mineral density screening^(c) • Case finding • Periodic health examinations <ul style="list-style-type: none"> - Promote weight control and joint injury prevention^(a) • Early intervention <ul style="list-style-type: none"> - Ensure early recognition of symptoms and prompt referral to specialist - Intervene to prevent first fracture • Control risk factors 	<ul style="list-style-type: none"> • Treatment and acute care • Complications management including comorbidity • Preserve function and independence • Promote healthy lifestyle behaviors <ul style="list-style-type: none"> - Initiate disease modifying therapy early^(b) - Support attendance at an educational program^{(b) (c)} - Consider occupational intervention^(b) - Identify people with minimal trauma fracture^(c) - Intervene to prevent further fractures^(c) 	<ul style="list-style-type: none"> • Continuing care • Maintenance <ul style="list-style-type: none"> • Optimise therapy and symptom relief <ul style="list-style-type: none"> - Provide timely access to joint replacement surgery and multidisciplinary care^{(a) (b)} • Disability support and management • Improve functioning (social and physical) • Self-management • Psychosocial support <ul style="list-style-type: none"> - Intervene to prevent further fractures^(c) • Improve health-related quality of life 	<ul style="list-style-type: none"> • Manage pain and discomfort • Improve health-related quality of life
Responsible sectors	<ul style="list-style-type: none"> • Public health initiatives • Primary health care • Other sectors 	<ul style="list-style-type: none"> • Primary health care • Public health initiatives 	<ul style="list-style-type: none"> • Specialist services • Hospital care • Primary health care 	<ul style="list-style-type: none"> • Primary health care • Community care Specialist services 	<ul style="list-style-type: none"> • Hospital care • Primary health care • Community care
<p style="text-align: center;"> Prevent movement to at-risk group ↑ Prevent/delay progression to complications ↑ Prevent progression to established disease ↑ Delay progression of complications ↑ </p>					
<p>(a) Particularly relevant to osteoarthritis. (b) Particularly relevant to rheumatoid arthritis. (c) Particularly relevant to osteoporosis.</p> <p>Source: National Public Health Partnership 2001; DoHA & NAMSCAG 2004.</p>					

Figure 1.1: Public health activities across the disease continuum for arthritis and musculoskeletal conditions

burden associated with these conditions, it is important that a system be put in place to monitor them.

This report describes the national health information available for monitoring arthritis and musculoskeletal conditions. National health information has either national coverage or has relevance nationally. Where no national data are available, state-based and smaller cohort studies may provide data. The data collection does not necessarily have to be a large centralised collection, but it is important to have nation-wide consistency, comparability and relevance.

Benefits of an effective monitoring system

There is considerable potential for health, social and economic gains through effective monitoring of arthritis and musculoskeletal conditions. By measuring achievements and improving care it is possible to gradually improve the outcomes of people with musculoskeletal conditions, thus reducing the burden on both individuals and society.

An integrated monitoring system for arthritis and musculoskeletal conditions is essential to improve Australia's capacity to make decisions for cost-effective allocation of resources, to plan preventive and treatment services, and to target priority population groups. A monitoring system will also track the impact of risk factors and improve diagnosis, health promotion, and treatment and prevention strategies.

Following the declaration of arthritis and musculoskeletal conditions as a National Health Priority Area (NHPA) there is an impetus to report on these conditions. The initial focus is on osteoarthritis, rheumatoid arthritis and osteoporosis, due to their significant disease burden (DoHA & NAMSCAG 2004). Under the 2006 Federal Budget's Better Arthritis and Osteoporosis Care Initiative, an additional focus area is juvenile idiopathic arthritis, also known as juvenile rheumatoid arthritis or juvenile chronic arthritis.

National Action Plan

The National Arthritis and Musculoskeletal Conditions Advisory Group (NAMSCAG) was established along with the announcement of the arthritis and musculoskeletal conditions as a National Health Priority Area (NHPA)¹ to provide the Australian Government with advice on policy and program responses to the challenges. NAMSCAG oversaw the development of the National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis (DoHA & NAMSCAG 2004) and the National Service Improvement Framework for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis, which provides outlines for national efforts to address these conditions.

1 The Australian Government disbanded the National Health Priority Action Council and all NHPA advisory groups (including NAMSCAG) in July 2006, pending a decision about the establishment of new departmental committees for the NHPAs.

National Centre for Monitoring Arthritis and Musculoskeletal Conditions

To develop an effective monitoring system, a dedicated National Centre for Monitoring Arthritis and Musculoskeletal Conditions (the Centre) was established in 2005 at the Australian Institute of Health and Welfare (AIHW). The Centre receives advice from experts, community groups and the government and undertakes national monitoring and surveillance of arthritis and musculoskeletal conditions. A former committee of NAMSCAG, known as the Data Working Group/Steering Committee, currently advises the Centre on strategic directions and proposed activities. The Centre initially focused on osteoarthritis, rheumatoid arthritis and osteoporosis. However, it is now expanding its information base to cover juvenile arthritis.

Report outline

This report aims to outline the data sources for arthritis and musculoskeletal conditions, detailing the information they contain, any gaps and limitations, and potential for development. Sources with data for each category of public health information (Table 1.1) are detailed in this report.

The data sources with information relevant to arthritis and musculoskeletal conditions are reviewed in Chapter 2. In Chapter 3, the data sources are evaluated for their usefulness for reporting on each category of public health information (Table 1.1), in particular for specific issues or interventions for osteoarthritis, rheumatoid arthritis and osteoporosis described in the disease continuum (Figure 1.1). The findings of this review are summarised and future opportunities for data development are outlined in Chapter 4.

2 Overview of data sources

This chapter describes the major Australian data sources available for monitoring arthritis and musculoskeletal conditions. These data sources contain information collected nationally, in a state or territory or regionally when the information included has national relevance or is not contained elsewhere.

Five different types of data sources have been identified including administrative, surveys, registries, derived and other. Unique information can be gained from each type of data source. Access to quality, comparable and consistent data from all types of data sources greatly improves the monitoring system.

The major data sources for monitoring arthritis and musculoskeletal conditions in Australia are listed in Table 2.1. A brief overview of each data source is provided in this chapter. These data sources are then referred to in Chapter 3, which describes how the data can be used to monitor each category of public health information. A comparison of collection methods for each data source and an indication of whether data are available for each category of public health information (as described in Table 1.1) is provided in Appendix A.

Administrative data sources

Administrative data sources contain information about the delivery of services or a record of events, collected for historical or funding purposes. Some Australian examples are death registries, hospital separation records, Medicare payments or prescription pharmaceutical subsidy records. These records are compiled into databases that are managed by various government agencies. The data are often based on use of certain services but do not include data on use of a service by an individual. The data may come from a large range of sources, such as in the AIHW National Hospital Morbidity Database which contains data from the majority of hospitals in Australia. There can be issues with consistency, coverage and scope of the data. However, because the data are often collected for administrative purposes there is a high level of compliance with reporting.

National Hospital Morbidity Database

The AIHW National Hospital Morbidity Database contains data on episodes of care for patients admitted to hospital in Australia. The data are supplied to the AIHW by state and territory health authorities and the Department of Veterans' Affairs using standard definitions contained in the *National Health Data Dictionary*. Since 1996–97 the database includes data from almost all hospitals including public, private, psychiatric hospitals and day hospital facilities. It is not possible to count patients individually as the data are episode-based, and therefore estimates of disease incidence and prevalence cannot be obtained from this data source. The database includes information on sex, age, Aboriginal and Torres Strait Islander status, area of usual residence, diagnoses and procedures (AIHW 2005a). Diagnoses and procedures are coded based on the International Statistical Classification of Diseases and Related Health Problems, Australian Modification (ICD-AM).

Table 2.1: Data sources for arthritis and musculoskeletal conditions

Type of data source	National	State, territory or regional
Administrative	National Hospital Morbidity Database	
	National Mortality Database	
	Medicare Benefits Scheme (MBS)	
	Pharmaceutical Benefits Scheme and Repatriation	
	Pharmaceutical Benefits Scheme (PBS and RPBS)	
Survey	Bettering the Evaluation and Care of Health Survey of General Practice (BEACH)	Children's Health Survey (NSW)
	National Drug Strategy Household Survey	Schools Physical Activity and Nutrition Survey (SPANS) (NSW)
	National Health Survey (NHS)	Victorian Population Health Survey (Vic)
	National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)	Collaborative Health and Wellbeing Survey (WA)
	National Nutrition Survey	Western Australian Aboriginal Child Health Survey (WA)
	National Physical Activity Survey	Western Australian Child and Adolescent Physical Activity and Nutrition Survey (WA)
	Survey of Disability, Ageing and Carers	South Australian Monitoring and Surveillance System (SAMSS) (SA)
	Voice of Arthritis Social Impact Study	Northern Territory Health and Wellbeing Survey (NT)
Registry	Australian Orthopaedic Association National Joint Replacement Registry	
	Australian Rheumatology Association Database (ARAD)	
Derived	Burden of Disease Studies	
	Disease Expenditure Database	
Other	Australian Diabetes, Obesity and Lifestyle Study (AusDiab)	Geelong Osteoporosis Study
		North West Adelaide Health Study
	Australian Longitudinal Study on Women's Health	Australian Longitudinal Studies of Ageing (various)

National Mortality Database

The AIHW National Mortality Database contains information pertaining to deaths registered in Australia. Deaths are registered by the Registrars of Births, Deaths and Marriages in each state and territory. The information is provided to the Australian Bureau of Statistics (ABS) for coding of the cause of death and compilation into aggregate statistics. Information available includes sex, age at death, date of death, area of usual residence, Aboriginal and Torres Strait Islander status, country of birth and cause of death. The cause of death is certified by the medical practitioner or the coroner and coded using the International Classification of Diseases (ICD). Multiple causes of death, including the underlying and all associated causes of death recorded on the death certificate, are available from 1997 onwards.

Medicare Benefits Scheme

The Australian Medicare program provides payment or reimbursement for certain medical services under the Medicare Benefits Scheme (MBS). Aggregate data on Medicare-paid

services are available to the public online on Medicare Australia's website. The online database contains a monthly, yearly, age and state breakdown of the usage and costing of these services from 1994 onwards (Medicare Australia 2005). However, there is limited information about why a service is used. The database includes details of private hospitalisation but not public hospitalisation.

Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme

The Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) are national government-funded schemes that subsidise the cost of a wide range of pharmaceutical medicines to help provide affordable access to medications for Australians. About 80% of all prescription medications available in Australian pharmacies are listed on the PBS or RPBS. However, only medications provided at a reduced cost due to a subsidy are included in the database. This data source contains information about prescription medications, such as details of type, date of prescription and supply, pharmacy postcode, patient details (date of birth, sex, postcode), prescribing doctor type (GP or specialist), cost and type of subsidy (that is general, concession or safety net). Monthly data are available from 1992 onwards, however data are more consistently reliable from 1996 onwards. The database includes details for each script supplied that is subsidised by the PBS or RPBS scheme but it is not possible to get information about scripts filled by an individual unless the data are internally linked.

Survey-based data sources

Survey-based data sources collect health-related information through a population sample. Some of the information collected can overlap with data obtained from administrative data sources, however, survey data include details relating to the experiences of the individual surveyed. The quality of data from these sources is therefore dependent on the response (willingness to participate), recall (ability to remember accurately) and the quality of the questions asked. Survey data can be collected in person or over the phone, for example, using the computer-assisted telephone interview (CATI) methodology. Surveys may also include the collection of biomedical data through medical examinations conducted by medical professionals, which may include collecting blood or urine samples and taking physical measurements.

Australian survey data sources contain large amounts of information relevant to arthritis and musculoskeletal conditions including disease prevalence, risk factors, disability, health service usage, health-related quality of life, mental health and pharmaceutical use.

Bettering the Evaluation and Care of Health Survey of General Practice

The Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice is an ongoing survey looking at the clinical activities of general practitioners (GPs). The survey is conducted by the Australian General Practice Statistics and Classification Centre (an AIHW collaborating unit) at the University of Sydney. BEACH began in April 1998 and involves a random sample of approximately 1,000 GPs per year, collecting information on almost

100,000 GP-patient encounters (AIHW 2005b). Data relevant to arthritis and musculoskeletal conditions include reasons for encounter, problem managed, management techniques, and details of pharmacological and non-pharmacological treatments prescribed.

National Drug Strategy Household Survey

This survey is conducted by the AIHW to collect self-reported information on drug-related attitudes, behaviours, consumption and health. The sample covers non-institutionalised Australians aged 14 years and over (12 years and over from 2004) (AIHW 2005c). Previous surveys were conducted every 2-3 years since 1985. The data relevant to osteoporosis include smoking and alcohol consumption behaviours.

National Health Survey

The National Health Survey (NHS) is designed to obtain national information on the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle (ABS 1995, 2001, 2006b). The survey is currently conducted every three years, having been conducted in 1977, 1983, 1989-90, 1995, 2001 and 2004-05 by the Australian Bureau of Statistics. It does not include information from people living in nursing homes or otherwise institutionalised. Data available from these surveys include self-reports of various forms of arthritis, back pain, osteoporosis and other diseases of the musculoskeletal system and connective tissues. Some information on age at diagnosis, medications used and other actions taken for arthritis and osteoporosis is also available.

National Aboriginal and Torres Strait Islander Health Survey

The National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) is conducted by the ABS, concurrently with the National Health Survey. The survey will be repeated at 6-yearly intervals and the survey was last conducted in 2004-05. Data collected from respondents to the National Health Survey also contribute to data in the NATSIHS. The 2004-05 NATSIHS includes responses from 10,439 Aboriginal and Torres Strait Islander people, and provides information about the health circumstances of people living in remote and non-remote areas.

National Nutrition Survey (1995)

The National Nutrition Survey was conducted between February 1995 and March 1996 by the Australian Bureau of Statistics (ABS & DoHA 1998). The data available from this survey include details of food and beverage intake, usual frequency of intake, food-related habits and attitudes, and physical measurements of people aged 2 years and older. Data relevant to arthritis and osteoporosis include macronutrient and micronutrient (calcium) intake and measured weight and height.

National Physical Activity Survey (1997, 1999 and 2000)

These surveys collected information on the participation of Australian adults (aged 18-75 years) in physical activity for recreation, exercise or transport, and their knowledge of public health messages related to physical activity in Australia (AIHW 2003). The surveys were

conducted in 1997, 1999 and 2000. Data on the level of physical activity are relevant to osteoporosis and osteoarthritis.

Survey of Disability, Ageing and Carers

The Survey of Disability, Ageing and Carers collects national information on persons with disabilities, older persons (aged 60 years or over) and their carers. The survey is conducted every 5 years, having been conducted in 1988, 1993, 1998 and 2003 by the ABS (ABS 2003). It covers people in private and non-private dwellings, including people in cared accommodation establishments, but excluding those in correctional institutions. The survey collects data on disability in relation to impairments, activity limitation, employment or participation restriction and health conditions (osteoporosis and arthritis and related disorders).

Voice of Arthritis Social Impact Study (2004)

The Voice of Arthritis Social Impact Study was conducted in 2004 by Arthritis Australia to investigate the impact of arthritis on sufferers, on their families or carers and on their career. The survey was mailed out to 3,000 persons with arthritis in March 2004, with 1,016 responding (Arthritis Australia: MacDougall et al. 2004). About three-quarters of respondents (76%) were 60 years of age or older, 61% were female and 8% were in full-time employment. The majority of respondents had osteoarthritis (68%) and a smaller proportion had rheumatoid arthritis (28%). The study explored respondents' levels of satisfaction or dissatisfaction with medication, therapy, information available, physical health, economic issues, education, relationships, lifestyle and employment.

State and territory surveys

A number of the states and territories regularly monitor the health of their population by undertaking health surveys. No health surveys are conducted in Queensland, Tasmania or the Australian Capital Territory but some New South Wales health surveys include the Australian Capital Territory.

New South Wales

The New South Wales Department of Health regularly conducts a Population Health Survey and conducted an Older People's Health Survey in 1999. Neither of these surveys contains data on the prevalence of arthritis or osteoporosis (NSW Department of Health: Centre for Epidemiology and Research 2003; NSW Health Department: Public Health Division 2000). However, they do contain some data on the risk factors of falls and self-reports of height and weight. The Department has also conducted surveys on child health and physical activity which contain data on risk factors for arthritis and musculoskeletal conditions.

Children's Health Survey (2001)

This survey was conducted in 2001 to collect information about the health and wellbeing of children in New South Wales. It collected information about 9,425 children aged 0-12 years, including 500 from the Australian Capital Territory (Centre for Epidemiology and Research & NSW Department of Health 2001). Data of relevance to musculoskeletal conditions include physical activity and nutrition.

NSW Schools Physical Activity and Nutrition Survey (SPANS) (2004)

The New South Wales Schools Physical Activity and Nutrition Survey was conducted by the New South Wales Department of Health and the University of Sydney in 2004. It involved 8,000 students aged 5 to 16 years, from about 90 schools in New South Wales (University of Sydney 2006). The study investigated the fitness, physical activity, body measurements and eating habits of the students by paper-based survey and physical examination.

Victoria

Health surveys in Victoria are conducted by the Victorian Government Department of Human Services.

Victorian Population Health Survey (2004)

This survey was conducted using CATI in August–November 2004, and includes information from 4,575 people over the age of 18 years from private dwellings across Victoria (Department of Human Services 2004). Of interest to arthritis and musculoskeletal conditions are data on the prevalence of health conditions (arthritis and osteoporosis), health care utilisation, height and weight, smoking, diet, medication use and quality of life as measured by Short Form (SF)-12.

Western Australia

The Health Department of Western Australia has recently undertaken a number of surveys to investigate child and adult health in Western Australia.

Collaborative Health and Wellbeing Survey (2000)

This survey was conducted using CATI and collected information about the health and wellbeing of the Western Australian population. It was conducted in December 2000 to February 2001 by the Health Department of Western Australia. It included information from 7,506 persons over the age of 18 years in Western Australia (Health Department of Western Australia 2001). The survey was conducted in collaboration with Northern Territory and South Australia. The survey included data on the prevalence of arthritis and osteoporosis,² health care utilisation, height and weight, smoking, diet, medication use and quality of life.

Western Australian Aboriginal Child Health Survey (2000–2002)

This was the first state-wide Aboriginal community child health survey. It was designed to determine the physical and mental health of Western Australian Aboriginal children and young people. The survey was conducted by the Telethon Institute for Child Health Research between May 2000 and June 2002 (Telethon Institute for Child Health Research 2002). Carer reports were obtained for 1,399 children and self-reports from 1,073 children aged 0–17 years. Of relevance to arthritis and musculoskeletal conditions were data on smoking, physical activity levels and remoteness.

2 The Collaborative Health and Wellbeing Survey asked the questions 'Have you ever been told by a doctor that you have arthritis?', 'Have you ever been told by a doctor that you have osteoporosis (not osteoarthritis)?'.

Western Australian Child and Adolescent Physical Activity and Nutrition Survey (2003)

The Western Australian Child and Adolescent Physical Activity and Nutrition Survey was conducted in August to December 2003 by the Telethon Institute for Child Health Research and the University of Notre Dame, with funding from the Government of Western Australia. It included 2,800 students from 32 primary and secondary schools (Government of Western Australia 2005). The study reports on physical activity (measured by survey and a pedometer), nutrition (measured by survey and a food diary) and clinically obtained height and weight measurements.

South Australia

The South Australian Department of Health conducts a number of surveys of the South Australian population. Most of the surveys are variable (Health Omnibus Survey, Health Monitor Survey and the Social, Environmental and Risk Context Information System (SERCIS)) in that it is possible for organisations to purchase questions to be asked as part of the survey and the method of data collection is also variable (South Australian Department of Human Services 2002a, 2002b, 2002e). Of interest to arthritis are the 1997 SERCIS mental health survey and the 1998 SERCIS physical activity survey of people residing in South Australia. The 1997 SERCIS survey used the Short Form (SF)-12 and General Health Questionnaire to assess the impact of arthritis on mental health and the 1998 SERCIS physical activity survey included information about participation in physical activity and physical capabilities of people with arthritis.

South Australian Monitoring and Surveillance System

The South Australian Monitoring and Surveillance System (SAMSS) survey monitors key health and human service issues in South Australia on a regular monthly basis using key indicators (South Australian Department of Human Services 2002d). The survey includes self-reports from people aged 16 years and over, and answers from the most appropriate adult on the person's behalf when the person is less than 16 years of age. The survey is conducted by the South Australian Department of Health and approximately 600 interviews are conducted each month. Information relevant to arthritis and musculoskeletal conditions include data on the prevalence of arthritis and osteoporosis,³ health care utilisation, height and weight, smoking, diet, medication use, sociodemographics and quality of life as measured by SF-36.

Northern Territory

The Northern Territory Government Department of Health and Community Services conducts health surveys in the Northern Territory. The last survey was conducted in 2000.

Northern Territory Health and Wellbeing Survey (2000)

This survey was conducted using CATI and collected information about the physical and mental health of Northern Territorians. It was conducted in November to December 2000 by the Northern Territory Government Department of Health and Community Services. It

3 The SAMSS survey includes the questions 'Have you ever been told by a doctor that you have arthritis?', 'If yes then prompt 'the type of arthritis: osteoarthritis, rheumatoid arthritis, juvenile rheumatoid arthritis or other (which can be specified)' and 'Have you ever been told by a doctor that you have osteoporosis?'

included information from 2,498 persons over the age of 18 years in the Northern Territory (d'Espaignet et al. 2002). The survey was conducted in collaboration with South Australia and Western Australia. The survey included data on the prevalence of arthritis and osteoporosis,⁴ health care utilisation, height and weight, smoking, diet, medication use and quality of life.

Registry data sources

Registries systematically collect detailed information on persons with a certain disease or receiving a particular treatment. The data can be used to determine the incidence of an event or a disease, and the nature of an intervention or procedure. However, the data are specific to these events and do not include information from the general population. Results from registries are therefore not generalisable to the population as a whole. Australian registry data sources contain data on joint replacements primarily for osteoarthritis and outcomes for people with rheumatoid arthritis.

Australian Orthopaedic Association National Joint Replacement Registry

This registry continually monitors all joint replacements (partial and total) that take place in Australian hospitals (both public and private). The registry began in South Australia in September 1999 and became a national database in 2002 (Australian Orthopaedic Association: National Joint Replacement Registry 2005). The registry contains information predominantly on hip and knee replacements, including the age, gender, diagnosis and outcomes (mainly surgery revision) for the patient, and the type of prosthesis and surgical techniques used. The data are validated against the National Hospital Morbidity Database.

Australian Rheumatology Association Database

The Australian Rheumatology Association Database (ARAD) is a national database that was developed to follow patients with arthritis commencing treatment with disease modifying anti-rheumatic drugs (DMARD) following consultation with a rheumatologist. The database was started in 2002 and as of September 2006 there were 1,326 participants (Australian Rheumatology Association 2006). Included in this database at present are patients with rheumatoid arthritis, juvenile idiopathic arthritis, ankylosing spondylitis and psoriatic arthritis who commenced treatment with DMARDs including Enbrel (Etanercept, Wyeth), Remicade (Infliximab, Schering Plough), Humira (Adalimumab, Abbott) or Kineret (Anakinra, Amgen). The database contains information on participants' location, arthritis history, health status (including quality of life and other health conditions), and treatment history (including adverse reactions to medication). For some participants the database also contains information about arthritis status (including tender and swollen joint count) and

4 The Northern Territory Health and Wellbeing Survey asked the questions 'Have you ever been told by a doctor that you have arthritis?', 'Have you ever been told by a doctor that you have osteoporosis (not osteoarthritis)?'.

markers of inflammation (including erythrocyte sedimentation rate and C-reactive protein and rheumatoid factor status).

Derived data sources

Derived data sources use information from other data sources to derive data items. Some examples are to derive summary measures or derive monetary costs of a disease or condition. The accuracy and validity of the data in the derived database are dependent on where the information was derived from, the methods used to calculate the derived data and any assumptions made. Deriving data can be a powerful way of summarising information from a range of sources and can allow comparisons across a range of variables or factors (for example, disease types, risk factors and type of health service). Australian derived data sources contain data on disability adjusted life years and expenditure associated with arthritis and musculoskeletal conditions.

Burden of Disease Studies

The Australian Burden of Disease and Injury Study compiled existing data on the incidence, prevalence, case fatality and severity for diseases and injury to estimate the burden of disease in Australia relating to specific diseases and injury, key risk factors and selected priority population groups. The study was first conducted in 1998 on 1996 data and was repeated in 2005 (AIHW: Mathers et al. 1999). The study reported on disability-adjusted life years (DALYs), which is the sum of years of life lost due to premature mortality and years of life lost due to disability in a population for incident cases of a health condition. The DALY is a summary measure that combines information on fatal and non-fatal health outcomes to represent the cost of disease as a single number. Data relevant to arthritis and osteoporosis in this study include DALYs for falls, musculoskeletal conditions, osteoporosis and the risk factors obesity, inadequate physical activity and inadequate fruit and vegetable consumption.

Disease Expenditure Database

The Disease Expenditure Database contains information about the money spent by both governments and individuals to purchase or provide goods and services for particular diseases. The information is collected from a wide range of sources including the Australian Bureau of Statistics, Australian Government, state and territory health authorities, the Department of Veterans' Affairs, the Private Health Insurance Administration Council, Comcare, and the major workers' compensation and compulsory motor vehicle third-party insurers in each state and territory.

The first detailed Australian study of expenditure across disease and injury groups using the Disease Expenditure Database was published in 1998 and referred to the financial year 1993–94; the latest refers to the financial year 2000–01 (AIHW 2004a). The information from the database is linked to other non-monetary data sources and analyses to provide information specific to diseases, injury groups, age and sex. The database does not include information on other costs incurred by patients (such as the cost of pain and suffering, travel costs, and lost quality and quantity of life) or by their carers and families.

Other data sources

Other data sources include experimental studies that test hypotheses or that collect health-related information on a smaller scale than state-wide and national studies. These experimental studies may be cohort, case control, longitudinal or observational studies.

A cohort is a group of individuals who are followed over a period of time. The cohort usually comprises people with common characteristics such as an exposure or an age group. Because of this defined perspective, cohorts provide useful information about a health-related outcome of interest. In a cohort study, one or more cohorts are followed to measure the occurrence of disease or an outcome. The studies may be either retrospective or prospective in design.

A case control study is similar to a cohort except that instead of following a large cohort to see who develops an outcome, those with a defined outcome are compared to randomly selected controls from the source population. The level of exposure to a certain factor is then compared between the two groups.

A longitudinal study is also like a cohort except the cohort is not followed continuously but is studied multiple times, often many years later following the initial collection of participants.

An observational study simply collects data on the occurrence of exposure or a disease outcome at a particular point of time in a sample population.

Several experimental studies have been undertaken or are currently in progress in Australia to generate information on various aspects of arthritis and musculoskeletal conditions. While some of these studies simply track risk factor information without implying causality, others provide useful information about a range of outcomes in relation to these diseases and conditions.

Australian Diabetes, Obesity and Lifestyle Study (AusDiab) (1999 and 2004)

The AusDiab study was designed to determine the prevalence of diabetes in Australian adults (aged 25 years or over), however, it also includes details of lifestyle and diabetes risk factors. The survey of 11,247 people was conducted in 1999–2000 by the International Diabetes Institute and was partially funded by the then Australian Government Department of Health and Aged Care (Dunstan et al. 2001). A five-year follow-up study of the eligible participants from the initial study was conducted in 2004–05 and included 6,537 participants. Data relevant to arthritis and musculoskeletal conditions from this study include self-reports of physical activity, smoking, alcohol consumption and diet, and measured data on height, weight and waist circumference. Blood and urine samples were also taken, however, no markers relevant to arthritis and musculoskeletal conditions were assessed.

Australian Longitudinal Studies of Ageing (a collection of studies)

There are a number of longitudinal (over time) cohort studies undertaken in Australia including: the Australian Longitudinal Study of Ageing (2,087 participants from South Australia), the 45 and Up Study (250,000 participants from New South Wales), the Dubbo Study of Health of the Elderly (2,805 participants from Dubbo), the Melbourne Longitudinal Studies on Healthy Ageing Program (1,000 participants from Melbourne), the Tasmanian

Older Adult Cohort (1,074 participants from Hobart), the Sydney Older Persons Study (647 participants from Sydney), the Health Retirement Project (590 participants from Victoria), the Stories of Ageing: A Longitudinal Study of Women's Self-Representation (40 Women from Australia), the Canberra Longitudinal Study of Ageing (1,000 participants from Canberra and Queanbeyan) and the Florey Adelaide Male Ageing Study (600 men from Adelaide). These data sources have been extensively reviewed in a previous AIHW publication (AIHW 2004b).

Australian Longitudinal Study on Women's Health

This study aims to examine the health of Australian women in three age groups (originally aged 18–23, 45–50 and 70–75 years) over a 20-year period. The study examines health status, use of health services and lifestyle factors for over 40,000 Australian women. Participants were recruited through a random mail-out using details from the Medicare database. Women in rural and remote areas were sampled at twice the rate of women in urban areas to allow for statistical comparisons between women living in these locations. Each age group is surveyed once every 3 years, via surveys sent in the mail. The study includes data on physical and emotional health, use of health services, risk factors, employment status and sociodemographic factors. Participants are also involved in sub-studies focusing on specific areas of health, for example, a sub-study titled 'A functional model of falls risk' was completed in 2004. Access to the data is restricted to collaborating researchers who have obtained approval from the Publications Analyses and Substudies Committee of the Australian Longitudinal Study on Women's Health. However, reports are regularly published by the study investigators.

Geelong Osteoporosis Study

This study investigates the prevalence of osteoporosis in Australian women using bone mineral density analysis. The sample is representative of the age, sex and socioeconomic distribution of Australia. The Geelong Osteoporosis Study includes 1,494 women aged 20–95 years (Henry et al. 2000).

North West Adelaide Health Study (2001 and 2006)

The North West Adelaide Health Study used an interview, a self-completed questionnaire and clinical measurements to assess the clinical prevalence of chronic diseases (including arthritis and musculoskeletal conditions, diabetes, chronic obstructive pulmonary disease and asthma) and their risk factors. The study was conducted by the North Western Adelaide Health Service, the South Australian Department of Human Services, the University of Adelaide and the University of South Australia. The study was longitudinal with an initial study in 2001 and a second phase in 2006. The clinical component of the second phase of the study included about 3,500 participants aged 20 years or over and collects data relevant to arthritis and musculoskeletal conditions (South Australian Department of Human Services 2002c). Clinical measurements were taken of height, weight, digital photographs of both hands, flexibility of shoulder joints and grip strength. Bone mineral density was also measured in consenting participants over the age of 50 years. Telephone interviews collected data on pain, stiffness and aching in the lower back, hip, knee, feet or shoulder, on hip and knee replacement, on the WOMAC osteoarthritis index, on the AUSCAN osteoarthritis hand

index and on falls. Self-completed questionnaires provided data on minimum trauma fractures, quality of life, demographics and socioeconomics.

3 Evaluation of data sources for monitoring arthritis and musculoskeletal conditions

The data sources described in Chapter 2 can be used to monitor different aspects of the disease continuum for arthritis and musculoskeletal conditions (Figure 1.1). This chapter evaluates the sources for their usefulness for reporting on each category of public health information (Table 1.1), in particular for specific issues or interventions for osteoarthritis, rheumatoid arthritis and osteoporosis described in the disease continuum (Figure 1.1).

Population health status

Measuring the population health status is important to assess the impact of arthritis and musculoskeletal conditions. Measures include morbidity (the level of ill health in a population), mortality (the amount of death in a population), disability, quality of life, pain, days of work lost, psychological distress, comorbid conditions and injury. This section outlines the data available and any gaps and deficiencies for each of these measurements of population health status.

Incidence

The incidence is the number of new cases of a disease or condition in a given year. There are currently no data sources that can be used to reliably determine the incidence of arthritis and other musculoskeletal conditions at a national or state level.

Prevalence

The prevalence of rheumatoid arthritis, osteoarthritis and osteoporosis can be estimated from self-reports of these diseases from national and state-based data sources. Survey questions that include information about a doctor diagnosis of a musculoskeletal condition have been shown to increase the validity of the information. Many of the state-based surveys do not include questions to differentiate between the different types of arthritis.

Self-reports of rheumatoid arthritis give a higher prevalence estimate than registries and clinical examinations, although the pattern of distribution in terms of age and gender is similar (DoHA & NAMSCAG 2004). Conversely self-reports of osteoarthritis have good sensitivity but underestimate prevalence. Osteoporosis is also considerably underestimated as many people do not know or are not told that they have the condition.

Data sources

National Health Survey

The 2001 and 2004–05 surveys record if the respondent has gout, osteoarthritis, rheumatoid arthritis, rheumatism, another type of arthritis, an unknown type of arthritis, osteoporosis or osteopenia, and if the condition is long term (that is, has lasted or is likely to last for 6 months or more). The 2004–05 survey also asks if the respondent was told by a doctor or nurse that they had the condition/s.

Survey of Disability, Ageing and Carers

The Survey of Disability, Ageing and Carers records the condition causing the most disability, and also has an item on whether the respondent has a long-term health condition.

North West Adelaide Health Study

The North West Adelaide Health Study includes clinical measurements, an interview and questionnaire from a cohort of 3,500 people in North West Adelaide aged 20 years or older in 2006. Data include clinical measurement of flexibility of shoulder joints, grip strength and digital photographs of both hands, the WOMAC osteoarthritis index, of the AUSCAN osteoarthritis hand index and history of falls and of minimum trauma fractures.

Gaps and deficiencies

There are several limitations to gaining information about the prevalence of arthritis and musculoskeletal conditions from self-reports. Many people are not aware of which type of arthritis they have, and people still refer to these conditions using the word 'rheumatism' which leads to confusion about rheumatoid arthritis. This is further complicated by the similar names for conditions such as osteoarthritis and osteoporosis. Moreover, people may have probable rheumatoid arthritis or undifferentiated arthritis that is difficult to categorise.

Reporting of health conditions in surveys is generally not based on any clinical diagnosis or objective criteria. The survey may pick up on cases of self-diagnosis but miss out cases where the individual is unaware that they have the condition. This is particularly relevant to osteoporosis, as clinical studies have found that only 40% of women aged 60 years and older were told that they had osteoporosis following a fracture (Eisman et al. 2004). The self-reporting of disease is complex and dynamic and is often influenced by the respondent's knowledge and attitudes, the availability of health services, and information made available through public education and awareness programs.

Questions relating to doctor diagnosis of the condition are thought to give a more reliable estimate of disease prevalence. The addition of these questions to the 2004–05 National Health Survey will greatly improve prevalence estimates. However, this survey does not cover people residing in institutions such as hostels and nursing homes, therefore the estimates of arthritis and osteoporosis prevalence in the population are likely to be underestimated because these conditions commonly affect the aged.

The Survey of Disability, Ageing and Carers cannot be used to determine the prevalence of arthritis and musculoskeletal conditions, because respondents to the survey must be aged 60 years or older or have a disability.

Minimum trauma fractures

Osteoporosis clinically manifests as a skeletal fracture sustained with minimal trauma. Most of the fractures that occur in people over the age of 50 years are caused by osteoporosis. Self-reports of minimal trauma fracture among elderly people are a good estimate for the prevalence of osteoporosis. However, reliability is dependent on the site of the fracture. Agreement between self-report and clinical assessment is highest for non-vertebral fractures (especially in the hip, forearm or wrist) and lowest for vertebral fractures. Hip fractures result in hospitalisation more commonly than other fracture types and are therefore a good indicator of osteoporosis prevalence. The term 'minimal' as part of 'minimal trauma fracture' can be misunderstood, and other ways of phrasing the questions such as 'a fall from a low height' may be used instead.

Data sources

National Health Survey

The National Health Survey includes data on the three most recent injuries sustained within the previous 4 weeks, including low falls that result in a fracture. Information collected includes the location of the fracture, the activity being undertaken at the time of injury, where the injury took place, what kind of treatment was sought and whether the injury resulted in days away from work/study or reduced activities.

National Hospital Morbidity Database

The National Hospital Morbidity Database contains details of episodes of admitted patient care occurring in Australian hospitals. Data include length of stay, age, sex, Aboriginal and Torres Strait Islander status, place of usual residence, diagnoses and procedures performed.

North West Adelaide Health Study

The North West Adelaide Health Study includes self-reports of falls and fractures from a cohort of 3,500 people in North West Adelaide aged 20 years or older in 2006.

Gaps and deficiencies

The available data sources will not capture all fractures. Injuries treated in emergency departments, health clinics or GP surgeries will not be included in the hospital database. The NHS does not include people living in residential or aged-care facilities, or other institutions. As many of the people at risk of osteoporotic fractures may be living in a care facility, fractures occurring among these people will not be captured by the NHS.

It is not currently possible to determine the outcomes from a fracture in a patient (such as a diagnosis of osteoporosis). It is important to note that not all fractures are caused by osteoporosis, even those in people aged over 50 years.

Juvenile arthritis

Juvenile arthritis is emerging as an important condition, but there are little data available on the disease in Australia. The most common type of juvenile arthritis is juvenile idiopathic arthritis, also known as juvenile rheumatoid arthritis and juvenile chronic arthritis.

Data sources

National Health Survey

The National Health Survey includes people of all ages, and responses are given by parents or guardians for people under 18 years of age. The survey includes data on whether the child has arthritis, and what treatment and care they receive (health professional visits, actions taken to improve health, and medication).

BEACH Survey of General Practice

This data source of GP encounters includes information on the reason for the visit, type of management received, concurrent conditions, the type of medication prescribed and referrals to specialists.

National Hospitals Morbidity Database

This database contains details of episodes of admitted patient care occurring in Australian hospitals. Data include length of stay, age, sex, Aboriginal and Torres Strait Islander status, place of usual residence, diagnoses and procedures performed.

Gaps and deficiencies

It is not currently possible to obtain national prevalence data on the most common types of juvenile arthritis. Information on this specific type of arthritis is not collected in the NHS.

Mortality

Death is not commonly caused by arthritis and musculoskeletal conditions. Most arthritis and musculoskeletal conditions cause disability and a loss of quality of life but do not kill directly. Certain types of fractures in people with osteoporosis can increase the risk of death. Non-steroidal anti-inflammatory drugs taken by people with arthritis may also cause premature death due to the perforation of stomach ulcers.

Data sources

National Mortality Database

Multiple causes of death including the underlying and all associated causes of death recorded on the death certificate are available from 1997. Hip fractures as a cause of death can be used as a proxy for death caused by osteoporosis. The National Mortality Database uses the ICD-10 classification system for coding of cause of death (see Appendix B for more information).

Gaps and deficiencies

Accurate mortality data requires recognition and accurate reporting of the contribution of these diseases as an underlying or associated cause of death.

Disability

Arthritis and musculoskeletal conditions are a significant cause of disability. Disability includes limited mobility, difficulty undertaking or participating in recreational, school or work-related activities, needing assistance, needing adjustments to the living environment and needing formal or informal care.

Data sources

Survey of Disability, Ageing and Carers

This survey includes data on whether the respondent has a long-term health condition (arthritis and related disorder and osteoporosis), whether they have a disability, disability type (self-care, mobility, communication, severity) and main disabling condition (the long-term condition that is responsible for the most disability). Details about the main disabling condition include the cause, where and when it happened, types of restrictions or impairments, severity of restrictions, types of core activity limitation, and limitations in activity (schooling, employment and participation).

The survey also includes data on the need for assistance of various types, need for adjustments (use of aids, home modification, occupation modification), informal care (relationship to carer, assistance provided) and the effects on primary carers of their caring role (personal/health effects, effects on relationships, financial effects, effect on work, support of primary carers, unmet needs of primary carers).

Voice of Arthritis Social Impact Study

The survey includes satisfaction or dissatisfaction of people with arthritis in Australia with the physical impact of their condition, the impact on family and carers, social impact and impact on employment/career. The survey also includes details of the way in which arthritis impacts on physical health, carers, social interaction and employment.

Gaps and deficiencies

The Survey of Disability, Ageing and Carers does not differentiate between types of arthritis and therefore it is not possible to determine the disability associated with osteoarthritis or rheumatoid arthritis individually.

Further, information on disability is associated with arthritis or related disorder or osteoporosis when one of these health conditions is reported as the 'main disabling condition'. Therefore the disability may be associated with arthritis or related disorder or osteoporosis but it is not possible to determine if the disability is directly caused by arthritis or related disorder or osteoporosis.

Quality of life

Arthritis and musculoskeletal conditions have a substantial impact on health-related quality of life because of the painful and disabling nature of the diseases. A number of different methods have been developed to assess quality of life in a survey including Short Form (SF)-1, SF-12, SF-36 and Assessment of Quality of Life (AQoL). The SF-12, commonly used in Australian surveys, consists of 12 questions assessing how emotional health, physical health and pain affects ability to accomplish tasks, to do moderate activities and to do social activities. There are also questions on mental health effects and a rating of general health.

Data sources

Survey of Disability, Ageing and Carers

This survey includes the SF-12 questions, along with reports of disabilities and their main cause.

North West Adelaide Health Study

The North West Adelaide Health Study includes quality of life information from a cohort of 3,500 people in North West Adelaide aged 20 years and over in 2006.

SERCIS South Australia

The 1997 SERCIS survey of the South Australian adult population used the SF-12 to assess the impact of arthritis on general health.

Gaps and deficiencies

The Survey of Disability, Ageing and Carers does not differentiate between types of arthritis and therefore it is not possible to determine the individual effects of osteoarthritis or rheumatoid arthritis on quality of life. Further, the survey only covers people with a disability and those over the age of 60 years, so estimates do not relate to the general population of people with arthritis and musculoskeletal conditions.

Pain

Pain is a key symptom for most forms of arthritis and musculoskeletal conditions. The pain can be mild or chronic and may originate from many sources within the joint (DoHA & NAMSCAG 2004). The amount of pain varies between people with osteoporosis, and fractures (particularly vertebral fractures) can even be pain free.

Data sources

Survey of Disability, Ageing and Carers

This survey includes data on chronic or recurrent pain suffered by persons with a disability associated with arthritis and related disorders or osteoporosis.

North West Adelaide Health Study

The North West Adelaide Health Study includes data from a cohort of 3,500 people in North West Adelaide aged 20 years and over in 2006. Data include self-reports of pain, stiffness and aching in the lower back, hip, knee, feet or shoulder, of the WOMAC osteoarthritis index and of the AUSCAN osteoarthritis hand index.

Gaps and deficiencies

The Survey of Disability, Ageing and Carers does not differentiate between types of arthritis and therefore it is not possible to attribute the pain associated with osteoarthritis or rheumatoid arthritis individually.

Days of work lost

The pain, disability and psychological distress associated with arthritis and musculoskeletal conditions may cause people to be unable to attend work. This may have severe economic consequences for the person and their family or dependants.

Data sources

National Health Survey

The National Health Survey includes data on days of work lost in the last 2 weeks due to illness or injury, the amount of time taken and if any other activities were affected. Information on days of school or study lost among people studying is also recorded.

Gaps and deficiencies

Although the number of days of work lost can be compared between those self-reporting a diagnosis of arthritis and musculoskeletal conditions and those not reporting one or more of these conditions, the days missed can not be directly attributed to arthritis or musculoskeletal conditions.

Psychological distress

Psychological distress suffered by people with arthritis and related conditions can include negative emotional states, anxiety, depression and feelings of helplessness. Psychological distress may be measured using specific survey instruments, such as the 10-item Kessler Psychological Distress Scale (see Appendix B for more information).

Data sources

National Health Survey

The 2001 and 2004–05 National Health Surveys included the items of the Kessler Psychological Distress Scale.

Gaps and deficiencies

Any distress identified by the survey can not be directly attributed to arthritis or musculoskeletal conditions.

Comorbid conditions

People with arthritis and musculoskeletal conditions may also have other conditions because of similar underlying disease processes, co-occurrence of age-dependent problems or the presence of common risk factors (such as excess weight or autoimmunity).

Data sources

National Health Survey

The survey includes data on the comorbid conditions that people with arthritis and other musculoskeletal conditions have, including mental health conditions.

Australian Rheumatology Association Database

This national database includes data on health status and other health conditions of people seeing a rheumatologist and commencing treatment with disease modifying anti-rheumatic drugs.

Gaps and deficiencies

It is not possible to distinguish how each of the comorbid conditions may individually contribute to health and functioning. The presence of comorbid conditions may complicate the interpretation of data about non-specific health impacts such as psychological distress and quality of life.

Determinants of health

Determinants of health are otherwise known as risk factors for a disease, where the determinant increases the risk of developing a health disorder or other unwanted condition or event. They can be environmental, chemical, physiological, psychological or genetic factors. Some risk factors may be regarded as causes, others as contributors. Risk factors can be modifiable (such as nutrition and weight) or non-modifiable (such as genetic predisposition). The major modifiable risk factors for some arthritis and musculoskeletal conditions include poor nutrition, weight, smoking, physical inactivity, excessive alcohol consumption, and joint trauma. This section outlines the data available and any gaps and deficiencies for each of these determinants of health.

Nutrition

Consuming certain nutritional factors as part of a person's diet has been shown to prevent the onset of some types of arthritis and the progression of other types. Poor general nutrition is linked to increased body weight, a major risk factor for osteoarthritis.

Insufficient amounts of vitamin D affects bone repair and muscle strength predisposing development of osteoporosis, osteoarthritis in the hip and progression of osteoarthritis in the knee (DoHA & NAMSCAG 2004). Vitamin D can be obtained from the diet but most is synthesised by the body as a result of exposure to ultraviolet light and is therefore difficult to measure in nutritional surveys. Calcium is important for the prevention of osteoporosis as it is an essential bone-forming mineral. A diet including sufficient amounts of vitamin D and calcium can reduce the risk of non-vertebral fractures. Conversely, diets high in sodium increase fracture risk (DoHA & NAMSCAG 2004).

Evidence suggests that having a diet high in omega-3 fatty acids can protect against the development of rheumatoid arthritis (DoHA & NAMSCAG 2004).

Data sources

National Nutrition Survey

The 1995 National Nutrition Survey includes details of macronutrients and micronutrients consumed, calculated from a recall of the food consumed in the 24 hours prior to conducting the survey. This survey can be linked to the 1995 National Health Survey to obtain information on socio-demographics, health conditions and health service use.

Macronutrients include protein, fats (saturated, monounsaturated and polyunsaturated), cholesterol, total carbohydrates (sugars and starch), dietary fibre and alcohol. Micronutrients include vitamins (A, D and C) and minerals (calcium, phosphorus, magnesium, iron, zinc and potassium).

National Health Survey

Concerning specific nutrients, before 2001 this survey did not contain information about the consumption of specific vitamins and minerals. The 2004-05 survey included items on the name and brand of vitamin or herbal supplements or herbal or natural therapies taken to treat arthritis and other musculoskeletal conditions.

Concerning general nutrition, the 1989-90 survey included details about general nutrition including items on change in diet with regard to certain types of food. The 1995 NHS does not include dietary items because it was supplemented by the National Nutrition Survey. In 2001 and 2004-05 items recorded information on type of milk used, servings of fruit and vegetables consumed, and added salt.

Gaps and deficiencies

There are no recent national detailed data on nutrition.

The data from the National Health Survey are not very detailed and contain only basic information about fruit and vegetable consumption. More detailed information about the level of micronutrient intake in the general population is only available from intermittent surveys. Information on the amount of calcium intake in children and young adults is very important because having adequate bone density during this period is very important for the incidence of osteoporosis later in life.

Weight

Obesity is an important risk factor for the development and progression of osteoarthritis in the knee joint and there is some evidence to suggest that it can also predispose to the development of hip osteoarthritis. Weight loss can reduce symptoms in people with knee osteoarthritis by 25-50% (DoHA & NAMSCAG 2004).

For monitoring purposes, the weight of a person is measured in two ways: by calculating body mass index (BMI) from the self-reported or measured height and weight ($\text{height}/\text{weight}^2$) or by measuring waist circumference. BMI is considered a better measure of weight for determining its effect on osteoarthritis because the distribution of the excess weight (for example, whether it is located around the waist or around the hips) does not affect the development of disease.

Being underweight (BMI<20) is associated with lower bone mineral density which is a risk factor for osteoporosis (DoHA & NAMSCAG 2004).

Data sources: measured height and weight

National Nutrition Survey

This survey, conducted in 1995, includes the height, weight and waist circumference of people aged 2 years and older living in private dwellings, as measured by a trained interviewer.

AusDiab

Clinicians measured the height, weight and waist circumference of a national (excluding the Australian Capital Territory), non-remote population sample aged 25 years and over.

North West Adelaide Health Study

Clinicians measured the height and weight of a cohort of 3,500 people aged 20 years and older in North West Adelaide.

SERCIS South Australia

The SERCIS studies in South Australia have collected measured data on height and weight in adults.

Data sources: self-reported height and weight

National Health Survey

The survey provides national population samples including people of all ages and was conducted in 1989–90, 1995, 2001 and 2004–05.

National Physical Activity Surveys

The survey provides national population samples including people aged 18–75 years, and was conducted in 1997, 1999 and 2000.

State-based surveys

Surveys that include self-reports of height and weight in adults have been conducted from 2000 to 2004 in the Northern Territory, Victoria, South Australia, Queensland, New South Wales (older adults from the Australian Capital Territory were included in the New South Wales survey) and Western Australia.

Gaps and deficiencies

Self-reports of height and weight are known to be inaccurate (AIHW: Dixon & Waters 2003). There is no recent national measured data on height and weight in adults.

Obesity in children

Obesity in childhood is a risk factor for being obese during adulthood, and also increases the risk of osteoarthritis. It is not suitable to use adult standards for BMI to determine overweight and obesity in children. Hence, age- and sex-specific BMI values for determining overweight and obesity in children aged 2–17 years have been developed (Cole et al. 2000).

Data sources

National Health Survey

The survey collected national data in 1989–90, 1995, 2001 and 2004–05. The survey includes details of height and weight reported by a parent or guardian for children aged 0–17 years.

SAMSS South Australia

A monthly survey of the South Australian population collects guardian-reported details of height and weight.

SPANS New South Wales

This state-based survey includes data on measured children's height and weight that were collected in a school setting.

Western Australian Child and Adolescent Physical Activity and Nutrition Survey

This state-based survey has data on children's measured height and weight that were collected in a school setting.

Gaps and deficiencies

There is currently no national measured data on overweight and obesity in Australian children. Estimates based on self-reported or parent-reported data often considerably underestimate obesity prevalence.

Smoking

Smoking has many negative health impacts. Smoking is a risk factor for rheumatoid arthritis and is associated with lower bone mineral density, therefore also increasing risk of osteoporosis.

Data sources

National Health Survey

This survey includes details of smoking habits (current or ex-smoker) and the number of people who smoke in the household.

National Drug Strategy Household Survey

This survey contains detailed questions about smoking habits including amount smoked, type of tobacco, strategies employed to quit smoking and reasons for wanting to quit.

AusDiab

This survey provides a national non-remote population sample of people aged 25 years and older, including data on smoking status (current smoker, ex-smoker, or never smoked).

Physical inactivity

Being physically inactive is a risk factor for osteoarthritis and osteoporosis, as well as many other health conditions. The benefits of physical activity on the musculoskeletal system

include improved joint health, increased muscle strength and weight management. Being physically active throughout life reduces the risk of fracture in people with osteoporosis because it increases bone mass and coordination, which decreases the risk of a fall (DoHA & NAMSCAG 2004).

Current Australian and international guidelines recommend that adults do at least 30 minutes of moderate intensity activity (such as brisk walking) on most days of the week to achieve health benefits. In monitoring terms this is generally interpreted to mean that a person reporting less than 150 minutes of at least moderate intensity activity per week (equivalent to 30 minutes per day for 5 days) is not doing enough physical activity for good health.

Data sources

National Health Survey

This national data source includes items on walking, moderate and vigorous exercise, including the frequency and the amount of time spent exercising, for people aged 15 years or over.

National Physical Activity Surveys

This survey was conducted in 1997, 1999 and 2000 and included questions on walking, moderate and vigorous exercise (including frequency and the amount of time spent exercising) for people aged 18–75 years. The survey also included questions on knowledge of public health messages relating to physical activity.

AusDiab

This data source contains national data on the physical activity status of people aged 25 years or over.

Alcohol

Moderate consumption of alcohol has been shown in some studies to protect against rheumatoid arthritis and osteoporosis. However, a high level of alcohol consumption causes bone loss and increases fracture risk, especially in men.

Data sources

National Health Survey

The survey includes details of alcohol consumption including the frequency, quantity and type of alcohol consumed.

National Drug Strategy Household Survey

The survey is conducted every 3 years on average and includes information from people aged 14 years and older. The survey includes detailed questions about alcohol consumption including frequency, quantity, type of alcohol consumed, place of consumption and attempts to quit or reduce consumption.

Gaps and deficiencies

There is a large amount of data on alcohol consumption. However, all the data are based on self-reported consumption and are therefore subject to recall bias.

Joint trauma

Joint trauma and repetitive load-bearing activities (not including running or walking) predispose to osteoarthritis in the knee or hip. Damage or trauma to the joints can occur while taking part in sport, recreational and occupational activities.

While fractures that result from osteoporosis are a type of joint trauma they are addressed as an impact on health and functioning (see 'Minimum trauma fractures' above).

Data sources

National Health Survey

The 2001 NHS contains questions on the three most recent injury events that occurred in the 4 weeks before the survey was conducted. This includes information about the cause, type and site of the injury. Information relating to joint trauma includes fracture, dislocation, sprains, and torn muscles or ligaments, and injury sites of shoulder, arms (including wrists), hands/fingers, trunk (internal organs, groin and buttocks), back/spine, hip, leg, or whole body. The survey also includes details of the type of activity (such as working or recreation activity) undertaken when injury occurred.

Gaps and deficiencies

Data from the NHS are based on self-reports and the respondent may not always know what type of injury they have suffered. There is no national data on hospital emergency visits for joint trauma.

Bone mineral density

Bone mineral density (BMD) can be used to screen for osteoporosis. It can be measured safely and effectively using dual energy X-ray absorptiometry. Measurement of BMD is used to identify people at high risk of fracture or osteoporosis and intervene to prevent first fracture. Low BMD is a risk factor for a fracture. Conversely, high BMD is associated with higher risk of developing osteoarthritis (Felson et al. 2000).

Data sources

Medicare Benefits Schedule

Data on bone mineral density scans are available for cases where the service is rebated by the Medicare Benefits Scheme (which occurs either following a minimum trauma fracture or for monitoring of low bone mineral density proven by previous bone densitometry). The database includes details of cost and number of services provided, by age and sex, from 1994 onwards.

Longitudinal studies of ageing (Dubbo Study of Health of the Elderly and Tasmanian Older Adult Cohort)

The Dubbo Study of Health of the Elderly measured the bone mineral density of 2,805 participants from Dubbo. The Tasmanian Older Adult Cohort measured the bone mineral density of 1,074 participants from Hobart.

Geelong Osteoporosis Study

This study on a regional population measured the bone mineral density of 1,494 women aged 20–94 years in the Barwon statistical division of Victoria.

North West Adelaide Health Study

The North West Adelaide Health Study includes clinical measurements of bone mineral density from a cohort of 3,500 people in North West Adelaide aged 20 years and older in 2006.

Gaps and deficiencies

There is no national data source that includes all BMD tests for detecting, diagnosing and treating osteoporosis. As Medicare rebates are not paid for scans undertaken without a fracture or previous diagnosis, many will not be included in the Medicare database.

The National Action Plan for osteoarthritis, rheumatoid arthritis and osteoporosis includes identifying people at high risk and intervening to prevent first fracture as an opportunity for improvement. Further, a key objective for the 'at-risk' population is to promote appropriate post-fracture assessment to minimise further osteoporotic fractures. Data on BMD scans will help to determine the effectiveness of the programs implemented to address this issue.

Environment

The interaction between the environment and the population can have large impacts on the health of the population. It is the potential hazards in the environment that can impact on health (ENHEALTH & National Public Health Partnership 2001). Hazards may occur in relation to things like the air, the built environment, vector-borne (that is, invertebrate-borne) disease and water. The environment can affect the onset of arthritis and musculoskeletal conditions in a number of ways. The occupational environment may contribute to the development of osteoarthritis. This may occur when working in occupations that require repetitive load-bearing activities that cause joint trauma.

For rheumatoid arthritis, genetic predisposition is not enough to cause the development of disease. Some environmental exposure, such as contact with an infectious agent (virus or bacteria), is thought to trigger the onset of disease. But the disease is not transmissible by contact.

The risk of fracture for people with osteoporosis may be influenced by the home environment, for example, the presence or absence of railings, stairs and slippery surfaces. Many of these hazards are difficult to measure at the population level and many of them are not clearly described.

There are currently no national data to report on this topic.

Public health intervention

Many health practitioners are required to manage the treatment of these diseases including general practitioners, specialists and allied health care professionals. Treatment involves a combination of physical therapy, medication and surgery to limit joint damage, pain and inflammation. Public health intervention can also occur through health promotion and improving health literacy. This section outlines the data available and any gaps and deficiencies for monitoring public health intervention.

Hospitalisation

Only a small percentage of people with rheumatoid arthritis or osteoarthritis are hospitalised. These individuals are hospitalised to undertake a number of surgical and non-surgical procedures, the most common being knee or hip replacement surgery.

Data sources

National Hospital Morbidity Database

This database contains details of episodes of admitted patient care occurring in Australian hospitals. Data include length of stay, age, sex, Aboriginal and Torres Strait Islander status, place of usual residence, diagnoses and procedures performed. Diagnoses and procedures are coded using the ICD-10-AM classification (for more information see Appendix B).

Gaps and deficiencies

The National Hospital Morbidity Database does have reliable data on certain types of fractures (such as leg or hip fracture) that commonly result in hospitalisation. However, osteoporosis is not often recorded as the principal diagnosis and may be under-recorded as an additional diagnosis.

General practitioner visits

A large amount of management of arthritis and musculoskeletal conditions is done through GPs.

Data sources

BEACH Survey of General Practice

This data source contains details of patients treated by a random sample of general practitioners. Data available include the reason(s) for the visit, types of management received, concurrent conditions, the types of medication prescribed, advised or supplied, and details of referrals to specialists. Data from the BEACH Survey of General Practice are coded following the International Classification of Primary Care, second edition (ICPC-2) (see Appendix B for more information).

Gaps and deficiencies

The scripts prescribed by GPs may not be filled by the patient and repeats are not counted by the survey.

The problem management rate cannot be extrapolated to either patient-population prevalence or total population prevalence of disease.

Allied health care

A number of the symptoms of arthritis and musculoskeletal conditions, such as pain and activity limitations, are treated by allied health care practitioners such as physiotherapists and massage therapists. Data on the use of these allied health care services can be obtained from self-reports.

Data sources

National Health Survey

The 2004–05 NHS includes self-reported data on actions taken for the treatment of arthritis and musculoskeletal conditions, including visits to allied health professionals (for example, a physiotherapist, chiropractor or occupational therapist).

Gaps and deficiencies

There are currently no data on the frequency or duration of visits with the allied health professionals mentioned as part of the survey. Further, the type of professional visited is not recorded, so the particular allied health professionals providing services to people with arthritis and musculoskeletal conditions cannot be determined.

Specialists

There is a variety of specialists who may treat people with arthritis and other musculoskeletal conditions, including rheumatologists, endocrinologists, orthopaedic specialists and orthopaedic surgeons. These specialists may also treat people with a variety of other conditions. Rheumatologists are especially important for the diagnosis and treatment of rheumatoid arthritis. There are currently limited data available on visits to these specialists for arthritis and musculoskeletal conditions.

Data sources

National Health Survey

The 2004–05 NHS includes data on the actions taken for the treatment of arthritis and musculoskeletal conditions, including visits to a GP or specialist. However, the particular specialty of the health professional visited (for example, endocrinology or orthopaedics) is not recorded.

Gaps and deficiencies

It is not currently possible to get data on visits to specific specialists for arthritis and musculoskeletal conditions.

Medications

Prescription and over-the-counter medications are the primary mode of treatment for arthritis and musculoskeletal conditions.

Data sources

Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS)

These data sources contain information about prescription medication covered under the Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme. It includes items on prescription type, date of prescription and supply, pharmacy postcode, patient details (date of birth, sex, postcode), prescribing doctor type (GP or specialist) and type of payment (that is, general, concession or safety net).

National Health Survey

The 2004–05 NHS includes data on the name and brand of up to three medications taken for arthritis and musculoskeletal conditions in the previous 2 weeks, and the total number of medications taken. The survey also contains information about the types of mineral/vitamin/herbal/natural supplements taken by people with arthritis and musculoskeletal conditions. This includes the names and brands of vitamin D supplements, calcium supplements, glucosamine, fish oil/omega 3 oils, fish liver oils, chondroitin/shark cartilage, any other vitamin or mineral supplements and any other natural or herbal treatments taken.

BEACH Survey of General Practice

Information available from this source includes patient reasons for encounter, problems managed, management techniques and details of pharmacological and non-pharmacological treatments prescribed or provided.

Australian Rheumatology Association Database

This database contains details of medications taken by people with rheumatoid arthritis, juvenile idiopathic arthritis, ankylosing spondylitis and psoriatic arthritis. The database includes details on any complications from treatment, previous treatments, health status and history of disease.

Voice of Arthritis Social Impact Study

This data source contains information about age, gender, employment status, residential status, arthritis type, arthritis stage and current medications and treatment of people with arthritis in Australia. The survey also includes details of satisfaction or dissatisfaction with the availability of suitable medications, ease of purchasing medication, accessibility of new drugs, cost of medication, side effects and interaction of medication and lifestyle changes required due to medication.

Gaps and deficiencies

Using data from the PBS and RPBS scheme it is not possible to directly link medication use to a patient with a specific disease. However, some medications are only taken to treat specific conditions so the condition can be inferred from the medication prescribed.

Although the BEACH survey of general practice includes scripts prescribed by GPs, these may not actually be filled by the patient.

Surgery

Joint replacement surgery is an effective treatment for osteoarthritis and rheumatoid arthritis when the condition is unresponsive to non-surgical techniques. Partial hip replacement (replacement of the ball of the joint, but not the socket) is also often used for treatment of hip fracture in people with osteoporosis.

Data sources

Australian Orthopaedic Association National Joint Replacement Registry

The registry contains information predominantly on hip and knee replacements, including the age, gender, diagnosis and outcomes (surgery revision) for the patient, and the type of prosthesis and surgical techniques used.

National Hospital Morbidity Database

This database contains details of episodes of admitted patient care occurring in Australian hospitals. Data include length of stay, age, sex, Aboriginal and Torres Strait Islander status, place of usual residence, diagnoses and procedures performed.

Gaps and deficiencies

Data development will need to continue to capture data on new surgical therapies as they become available.

Exercise as therapy

Exercise is often part of a treatment plan for arthritis and musculoskeletal conditions, because exercise can reduce joint pain and stiffness and increase flexibility, muscle strength, balance, cardiac fitness, and endurance. It also helps with weight reduction and contributes to an improved sense of wellbeing.

Data sources

National Health Survey

The 2004–05 National Health Survey includes items on actions taken specifically for the treatment of arthritis, including weight/strength/resistance training and exercising most days. In addition, the survey includes general items about the type, frequency and duration of activities undertaken for sport, exercise or recreation.

Gaps and deficiencies

The data are based on self-reports of arthritis and the respective exercise therapy taken for arthritis.

Health promotion and health literacy

As part of the National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis, the government is introducing a number of health promotion programs to raise awareness and health literacy in relation to these diseases. An example might be a self-management program where individuals gain skills, knowledge and motivation to effectively manage their day-to-day health needs. It is important to monitor the effectiveness of these programs.

Voice of Arthritis Social Impact Study

This survey included questions relating to the information available to people about arthritis, including a satisfaction scale with regard to: access to relevant information about medication and treatment; access to information via the internet; reliability and helpfulness of information available; accuracy of information; courses available; awareness of courses; usefulness of courses; and support and help available.

Gaps and deficiencies

It is difficult to study directly the impact of, level of awareness about or effectiveness of public health interventions. It will be possible to indirectly monitor the impact of public health interventions through the changes observed in other components of the monitoring system.

Inputs and infrastructure

Inputs and infrastructure includes the money spent or expenditure, labour force, training, research and disability support available. While there are national data available for many of these topics it is not specifically relevant to arthritis and musculoskeletal conditions. Only data relating to expenditure detail inputs for arthritis and musculoskeletal conditions.

Expenditure

Direct health expenditure is money spent by the government, health insurers and individuals to pay for treatment, medication and care for arthritis and musculoskeletal conditions.

Data sources

AIHW Health Expenditure Database

This database includes data for individual arthritis and musculoskeletal conditions including osteoarthritis, chronic back pain, slipped disc, rheumatoid arthritis, osteoporosis and other musculoskeletal conditions. For each of these conditions, expenditure relating to the health service areas of hospitals, aged-care homes, pharmaceuticals, over-the-counter medications, out-of-hospital medical services, other professional services, high level residential aged care and research is available. Estimates by sex and age group can be obtained.

Gaps and deficiencies

It is not currently possible to get information on indirect expenditure associated with arthritis and musculoskeletal conditions, such as the cost of days lost from work and money spent travelling to appointments. These indirect costs may contribute substantially to overall expenditure on arthritis and musculoskeletal conditions, particularly to out-of-pocket expenses borne by people with the conditions and their families.

Priority populations

Priority populations are population groups that require special attention because there are equity and access concerns. To investigate how arthritis and musculoskeletal conditions affect special interest groups differently compared to the general population, individuals who are part of these groups need to be identified.

Socioeconomic status

The prevalence of arthritis and musculoskeletal conditions and associated activity limitations are reported to be greater in persons of low socioeconomic status (DoHA & NAMSCAG 2004).

The Index of Disadvantage summarises a number of socioeconomic attributes by location (see Appendix B for more information). The index refers to the area in which a person lives; it does not describe the socioeconomic situation of a particular individual. Survey responses can be matched to a score on the index via the postcode or statistical local area in which the respondent lives.

Data sources

National Health Survey

Responses to the National Health Survey are mapped to deciles (tenths) of scores on the Index of Disadvantage. This data source also includes information on arthritis and musculoskeletal conditions, risk factors, use of services and treatment taken.

Gaps and deficiencies

Individuals are not placed in categories for Socio-Economic Indexes for Areas (SEIFA), geographical locations are. The accuracy of this data relies on the accuracy of the classification. Comparison between areas of different socioeconomic status may underestimate the disparity between persons resident in those areas.

Aboriginal and Torres Strait Islander peoples

There is currently very little information available about arthritis and musculoskeletal conditions in this population. Although rheumatoid arthritis is relatively rare amongst Aboriginal and Torres Strait Islander Australians, other musculoskeletal conditions, such as osteoarthritis, gout and systemic lupus erythematosus are common and may be more prevalent than in the general population, particularly in the younger age groups.

Data sources

National Aboriginal and Torres Strait Islander Health Survey

This 2004–05 survey included items on whether the respondent had arthritis, gout, rheumatism, osteoporosis or an unknown musculoskeletal condition, if they were told by a doctor or nurse that they had arthritis or osteoporosis, and if they had used any medicine or tablets for arthritis or osteoporosis in the last 2 weeks. The survey also included items about risk factors for arthritis and musculoskeletal conditions, including smoking and exercise habits.

National Hospital Morbidity Database

This database contains details of episodes of admitted patient care occurring in Australian hospitals. Data include length of stay, age, sex, Aboriginal and Torres Strait Islander status, place of usual residence, diagnoses and procedures performed.

Western Australian Aboriginal Child Health Survey

This survey contains items on the smoking habits and physical activity levels of Western Australian Aboriginal children aged 0–17 years. It was conducted in 2000–02.

Gaps and deficiencies

Identification of Aboriginal and Torres Strait Islander people is a major limitation of data relating to this population. Aboriginal and Torres Strait Islander status is sometimes not recorded or wrongly recorded in some data sets. While progress is being made, continued effort is needed to improve and maintain Aboriginal and Torres Strait Islander identification in the different data collections.

The calculation of rates of hospitalisations for Aboriginal and Torres Strait Islander people is affected by the under-identification of Aboriginal and Torres Strait Islander people in all states and territories. The data from Queensland, Western Australia, South Australia and the Northern Territory have been considered, as assessed by the relevant jurisdiction, to be sufficient to calculate rates. However, data from these jurisdictions may not be representative of Australia as a whole.

The 2004–05 National Aboriginal and Torres Strait Islander Health Survey for the first time included data on the social and emotional wellbeing of Aboriginal and Torres Strait Islander people. However, there are no national data on the prevalence of arthritis- or osteoporosis-related disability among Aboriginal and Torres Strait Islander Australians.

Ethnicity

Ethnicity can affect propensity to develop disease because of differences in genetic background. Cultural behaviours may affect development of disease, and cultural practices or beliefs may affect the type of care that is sought. Language barriers can also affect the use of health care services and understanding of health messages.

Ethnicity is determined in many survey data sources by the combination of proficiency in English and language spoken at home. Ethnicity can also be determined from country of birth.

Data sources

National Health Survey

The National Health Survey includes items on language usually spoken at home, country of birth and year of arrival in Australia.

National Hospital Morbidity Database

This database includes information on country of birth.

Survey of Disability, Ageing and Carers

This survey recorded the respondent's country of birth.

BEACH Survey of General Practice

This survey includes an item on whether the patient comes from a non-English-speaking background.

Gaps and deficiencies

There are limited data on the ethnicity of people with arthritis and osteoporosis. Country of birth does not always equate with ethnicity. Language spoken at home combined with proficiency in spoken English is a better method for determining the impact of ethnicity on health because inability to speak English may affect access to health services.

Remoteness

In Australia there are many people living in remote or isolated locations. Each area in Australia is classified using the Australian Standard Geographical Classification (ASGC) which is coded from the address, local government area or the Australian Bureau of Statistics classification of statistical local area. The remoteness of each area is then determined using the Accessibility/Remoteness Index for Australia (ARIA) (see Appendix B for more information).

Data sources

National Health Survey

The National Health Survey classifies respondents into major urban, other urban and other areas within each state and territory. Division into capital city or rest of state is also provided. In addition, the respondent's location is classified as major city, inner regional Australia or other areas, based on the ASGC remoteness groupings.

Survey of Disability, Ageing and Carers

This database includes an item on remoteness that classifies the respondent as living in a major city, inner regional or other areas.

National Hospital Morbidity Database

In the National Hospital Morbidity Database, the area of usual residence is used to code a number of geographical data items including Rural, Remote and Metropolitan Areas,

Accessibility/Remoteness Indicator for Australia (not available for some years) and Remoteness Areas (from 2000-01).

BEACH Survey of General Practice

From the BEACH Survey it is not currently possible to describe and compare patients from remote areas because of the small amount of sampling of people living in these locations. The survey does include an item of Rural, Remote and Metropolitan Areas and, using this, people living in small rural areas, large rural areas and metropolitan locations can be compared (AIHW: Britt et al. 2001).

Gap and deficiencies

Many surveys do not include people living in highly remote locations due to the difficulty of obtaining responses from these populations. Although the NHS does classify locations by remoteness, the sample size in outer regional, remote and very remote areas is too small to allow estimates for these areas to be calculated.

Intentional over-sampling of GPs who service people living in remote locations in the BEACH Survey of General Practice will allow this population to be examined.

4 Future opportunities

This report has identified a number of gaps and deficiencies in the currently available information for monitoring arthritis and musculoskeletal conditions. This assists in highlighting opportunities for improvements in data collection and reporting.

Limitations of current data sources relevant to arthritis and musculoskeletal conditions

Although Australia has a number of data sources relevant to the monitoring of arthritis and musculoskeletal conditions, the data need to be integrated effectively and information gaps and deficiencies addressed. On the whole, few data collections use standardised questions or instruments, are nationally representative, have sufficient numbers from priority populations, use physical measurements or undertake routine validation of self-reported data.

Major gaps and deficiencies of the current data are as follows:

- There are limited data on the biomedical risk factors for arthritis and musculoskeletal conditions. Available data are mostly based on self-reports and are not linked or contained in the same data sources as outcome data.
- There are currently no data sources that can be used to determine the incidence of arthritis and other musculoskeletal conditions.
- Current information on prevalence of arthritis and musculoskeletal conditions is based on self-report. These data are improved for the most recent (2004–05) National Health Survey, with self-reports of doctor diagnosis of a condition. However, this survey does not cover people in nursing homes or other institutionalised care.
- There are inconsistencies between national data sources for reporting the type of arthritis and musculoskeletal condition. Furthermore, the accuracy of self-reports of the particular type of condition a person has is uncertain.
- There is limited information about the quality of life of people with certain types of arthritis or musculoskeletal condition.
- Hospital separations data are episode-based rather than person-based, so it is not possible to determine the number of individuals who are admitted for a particular condition, or to identify re-admissions or treatment patterns.
- Care of musculoskeletal conditions requires the use of a variety of health services, but there is no coordinated system to collect data across these various health contact points and so provide a complete picture of service use and treatment provided.
- There are limited data about and difficulties in identifying individuals from population groups of special interest.
- Information on awareness and understanding of and attitudes towards arthritis and musculoskeletal conditions and their treatment in the general population is not available at a national level.

Opportunities for improving the monitoring of arthritis and musculoskeletal conditions

Effective monitoring of arthritis and musculoskeletal conditions will contribute to the government's efforts to relieve some of the burden from sufferers, their carers and the health care system. In view of the gaps and deficiencies in arthritis and musculoskeletal conditions related information identified in this report, the following strategies may provide opportunities to improve national arthritis and musculoskeletal conditions monitoring in Australia.

The data available for monitoring arthritis and musculoskeletal conditions are currently isolated in a large number of sources as detailed in this report. This results in data being reported as stand-alone pieces of information without details of outcomes or associated factors. To help the available sources to function as a monitoring system, the data from different sources could be linked. An example of a linkage project is to link the PBS/RPBS with the MBS to provide information about the outcomes of taking certain pharmaceutical medication.

The monitoring system would also benefit from improved consistency and compatibility of data from different sources. This could be achieved by developing data standards through stakeholder consultation and workshops. This would involve specifying uniform data items and operational definitions that could then be recommended as best practice.

Standardisation is particularly needed for relevant questions asked in the National Health Survey, the National Aboriginal and Torres Strait Islander Health Survey, the Survey of Disability, Ageing and Carers, and state- or territory-based surveys.

It is also important that the data available on many of the risk factors for arthritis and musculoskeletal conditions are updated. By conducting a regular biomedical survey, objectively measured data could be collected on body weight, height, nutrition and bone mineral density. This data would also be important for monitoring a number of other chronic diseases.

The monitoring system could be improved by modifications and enhancements to existing health surveys to cover arthritis and musculoskeletal conditions and related health issues in more detail. In particular, including quality of life questions in the National Health Survey would greatly improve the data available on this topic for arthritis and musculoskeletal conditions. Selecting the most appropriate method for assessing quality of life in the National Health Survey for arthritis and musculoskeletal conditions requires consultation between various stakeholders including the Data Working Group/Steering Committee of the National Centre for Monitoring Arthritis and Musculoskeletal Conditions, the Centre itself and the Australian Bureau of Statistics.

To improve reporting on priority populations there needs to be higher sampling in surveys and improved recording in administrative databases particularly of Aboriginal and Torres Strait Islander status. This would enable useful comparisons to be made and areas of concern to be identified.

The Centre will continue to play an important role in advising on arthritis and musculoskeletal conditions related information that should be collected, and encouraging data collectors to follow consistent data standards. The Centre, with the Data Working Group/Steering Committee, has recently released a set of strategic indicators for arthritis and musculoskeletal conditions (AIHW 2006). Reporting against these indicators will

provide a profile of the current status and trend data for each condition using the most relevant, accurate and consistent data and data sources. The Centre will continue to provide timely, quality and relevant information for national monitoring of arthritis and musculoskeletal conditions, which will contribute to the improvement of policies, practices, services, and quality of life for people with arthritis and musculoskeletal conditions in Australia.

Appendix A: Comparison of data sources

Table A.1: Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available														
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure	
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force
National Hospital Morbidity Database	Financial years ending 30 June	Episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and drug and alcohol treatment centres in Australia	Almost all Australian hospitals (excluding military). Data are collected from patient administrative and clinical record systems	✓	x	x	✓	x	x	x	✓	x	✓	x	x	x	x	x
National Mortality Database	Calendar years ending 31 December	Cause of death information for all deaths registered in Australia from 1965 onwards	All deaths occurring in Australia. Data are collected by the Registrars of Births, Deaths and Marriages	x	x	x	✓	x	x	x	✓	x	x	x	x	x	x	x
Medicare Benefits Scheme (MBS)	Monthly	Tracking provision of MBS-funded services	Data are collected from MBS administrative systems	x	x	x	x	x	x	✓	x	✓	✓	✓	x	x	✓	x

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Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available																
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure			
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding	Training
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS)	Monthly data	Tracking use of PBS- and RPBS-funded prescription medication	Data are collected from PBS and RPBS administrative systems	x	x	x	x	x	x	x	✓	x	x	x	✓	x	x	x	✓	x
BEACH (Bettering the Evaluation and Care of Health) Survey of General Practice	Financial years ending 30 June	A survey of the clinical activities of general practitioners	A random sample of 1,000 GPs record details of 100 doctor–patient encounters	x	x	x	x	✓	x	x	✓	x	x	✓	✓	✓	✓	x	x	x
National Drug Strategy Household Survey	Conducted every 2–3 years since 1985; most recently in 2004	A survey of drug-related attitudes, behaviours, consumption and health	A survey of randomly selected non-institutionalised Australians (aged 12 years +)	x	x	x	x	x	x	✓	✓	x	x	x	x	x	✓	x	x	x
National Health Survey	Conducted 3-yearly; the most recent was collected between August 2004 and July 2005	A survey of health and health-related issues	A survey of people living in private dwellings in urban and rural locations (all ages)	✓	✓	✓	x	✓	x	✓	✓	x	✓	✓	✓	✓	x	x	x	x

(continued)

Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available															
				Population health status				Determinants of health				Public health interventions				Inputs and infrastructure			
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding
National Aboriginal and Torres Strait Islander Health Survey	2004–05 and repeated every 6 years	A population survey to determine the health of Aboriginal and Torres Strait Islander Australians	A survey of 10,439 randomly selected Aboriginal and Torres Strait Islander Australians from private dwellings in remote and non-remote locations	✓	✓	✓	x	✓	x	✓	✓	x	✓	x	x	x	x		
National Nutrition Survey	February 1995 to March 1996	A survey of nutritional intake and food-related attitudes	A survey and physical examination of 13,800 randomly selected persons (aged 2 years +)	x	x	x	x	x	x	✓	✓	x	x	x	x	✓	x	x	x
National Physical Activity Survey	1997, 1999 and 2000	A survey of physical activity levels and attitudes	A survey of randomly selected people living in private dwellings in urban and rural locations (aged 18–75 years)	x	x	x	x	x	x	✓	✓	x	x	x	x	✓	x	x	x

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Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available																
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure			
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding	Training
Survey of Disability, Ageing and Carers	The survey is conducted every 5 years; most recently in 2003	A survey of the characteristics, health and needs of people with a disability, older persons (aged 60 years or over), and their carers	A random sample survey of people living in private and non-private accommodation, excluding those in correctional institutions	✓	✓	✓	x	x	✓	✓	✓	x	✓	✓	✓	x	x	x	x	
Voice of Arthritis Social Impact Study	2004	To determine the impact of arthritis on sufferers, their families and carers	A survey of 1,016 people with arthritis	x	✓	x	x	x	x	✓	✓	x	x	x	✓	x	✓	x	x	x
NSW Child Health Survey	2001	To collect information on the health and wellbeing of children in NSW	A survey of 9,425 randomly selected children (aged 0–12 years)	✓	✓	✓	x	✓	x	✓	✓	x	✓	✓	x	x	✓	x	x	x

(continued)

Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available																
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure			
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding	Training
NSW Schools Physical Activity and Nutrition Survey (SPANS)	2004	To investigate the activities and nutrition of school-aged children in NSW	A paper-based survey and physical examination of 8,000 students aged 5–16 years from 90 schools in NSW	x	x	x	x	x	x	✓	✓	x	x	x	x	x	x	x	x	
Victorian Population Health Survey	2004	To collect information on the health of Victorian adults	A computer-assisted telephone interview of 4,575 people in Vic (aged 18 years +)	✓	x	✓	x	✓	x	✓	✓	x	✓	✓	✓	x	x	x	x	
Collaborative Health and Wellbeing Survey	2000–01	To collect information on the health and wellbeing of Western Australian adults	A computer-assisted telephone interview of 7,508 people in WA (aged 18 years +)	✓	x	✓	x	✓	x	✓	✓	x	✓	✓	x	x	x	x	x	

(continued)

Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available															
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure		
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding
Western Australian Aboriginal Child Health Survey	2000–02	To determine the physical and mental health of Aboriginal children in WA	A questionnaire completed by a carer or the child (aged 0–17 years) from WA, including remote locations	x	x	x	x	✓	x	✓	✓	x	x	x	x	x	x	x	x
Western Australian Child and Adolescent Physical Activity and Nutrition Survey	2003	To investigate the activities and nutrition of school-aged children in WA	A paper-based survey, food diary and physical examination of 2,800 school-aged children from 32 schools in WA	x	x	x	x	✓	x	✓	✓	x	x	x	x	x	x	x	x
South Australian Monitoring and Surveillance System (SAMSS)	Continuous since 2002	To monitor key indicators in the SA population	A survey of approximately 600 people (per month) of all ages	✓	x	✓	x	x	x	✓	✓	x	✓	✓	x	x	x	x	x

(continued)

Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available																
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure			
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding	Training
Northern Territory Health and Wellbeing Survey	November to December 2000	To collect information on the health and wellbeing of Northern Territorian adults	A computer-assisted telephone interview of 2,550 people in NT (aged 18 years +)	✓	x	✓	x	✓	x	✓	✓	x	✓	✓	x	x	x	x	x	
Australian Orthopaedic Association National Joint Replacement Registry	Continuous in some jurisdictions since 1999; national from 2002	To define, improve and maintain the quality of care of individuals receiving joint replacement surgery	Register of all knee and hip joint replacements (partial and total) undertaken in Australian hospitals; details are provided by the treating physician	✓	x	x	x	x	x	x	✓	x	✓	x	✓	x	x	✓	x	x
Australian Rheumatology Association Database	Continuously since 2002	A national database designed to examine health outcomes for people with arthritis taking DMARDs	Participants are recruited through participating rheumatologists. A questionnaire and medical records from people with arthritis taking DMARDs	✓	x	✓	✓	✓	x	x	✓	x	✓	✓	✓	✓	x	x	x	x

(continued)

Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available															
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure		
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding
Burden of Disease Studies	1998 and 2005	Calculation of DALYs, YLD and YLL for certain diseases and risk factors	A compilation of existing health data	✓	✓	✓	✓	x	x	✓	x	x	x	x	x	x	x	x	x
Disease Expenditure Database	Financial years ending 30 June	Expenditure by governments and individuals to purchase or provide goods and services for health	A derived database using data from a wide range of data sources	x	x	x	x	x	x	x	✓	x	x	x	x	x	x	✓	x
Australian Diabetes, Obesity and Lifestyle Study (AusDiab)	1999–2000	A study of diabetes prevalence and risk factors	Survey and clinical measurements of 11,247 people (aged 25 years +)	✓	x	x	x	✓	x	✓	✓	x	x	x	x	x	x	x	x

(continued)

Table A.1 (continued): Comparison of data sources

Data source	Data collection period	Purpose	Scope and collection methodology	Type of information available																
				Population health status				Determinants of health					Public health interventions				Inputs and infrastructure			
				Morbidity and illness	Disability	Quality of life	Mortality	Biomedical factors	Environmental hazards	Lifestyle	Age	Family history	Hospitalisation	GP visits	Treatments	Allied health care	Public health education	Labour force	Funding	Training
Australian Longitudinal Study of Women's Health	1996–2016	A cohort study to assess the health status, health services use and lifestyle factors of Australian women	Surveys of over 40,000 randomly selected women in three age groups, conducted every 3 years	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	x	x	x	
Geelong Osteoporosis Study	1999	A cohort study to determine the prevalence of osteoporosis	Bone mineral density scans were performed on 1,494 women (aged 20–94 years)	✓	x	x	x	✓	x	x	✓	x	x	x	x	x	x	x	x	x
North West Adelaide Health Study	2006	A cohort study into the prevalence of chronic disease and risk factors	Clinical measurements, interviews and questionnaires of 3,500 people.	✓	✓	✓	x	✓	x	✓	✓	x	x	x	x	x	x	x	x	x

Appendix B: Codes and standards

Remoteness

The Accessibility/Remoteness Index of Australia (ARIA) is a measure of remoteness based on access to service centres located along the road network. 'Service centres' are urban centres of sufficient population size (5,000 people or above) to support the provision of services. The more remote the location, the less access there is to service centres. Localities are then categorised as highly accessible, accessible, moderately accessible, remote and very remote.

Socioeconomic status

The Socio-Economic Indexes for Areas (SEIFA) are four indexes that describe socioeconomic aspects of geographic areas. Each index summarises a different aspect of the socioeconomic conditions in an area. The Index of Disadvantage summarises a number of socioeconomic attributes by location, and can be used to monitor the effect of socioeconomic disadvantage and the development of arthritis and musculoskeletal conditions and treatment of these conditions. Attributes included in the index include low income, low educational attainment, high unemployment and jobs in relatively unskilled occupations. The index refers to the area in which a person lives; it does not describe the socioeconomic situation of a particular individual.

Geographical location

Locations are determined by the Australian Standard Geographical Classification which is coded from the address, local government area or the Australian Bureau of Statistics classification of statistical local area.

Disease classification

Australia currently uses the International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10) classification system for coding of cause of death. This classification is used in the AIHW National Mortality Database for deaths registered from 1997 onwards. Before 1997 the data were coded to ICD-9 (International Classification of Diseases, ninth revision).

For the AIHW National Hospital Morbidity Database, diagnoses and procedures are coded using a modified version of the ICD-10 classification. Hospital data before 1998-99 were coded using ICD-9-CM (International Classification of Diseases, ninth revision, Clinical Modifications) and thereafter using ICD-10-AM (International Statistical Classification of Diseases and Related Health Problems, tenth revision, Australian Modification).

Primary care classification

Data from the BEACH Survey of General Practice are coded following the International Classification of Primary Care, second edition (ICPC-2). ICPC-2 has been accepted in the World Health Organization Family of Classifications and has been declared the national

standard in Australia for reporting of health data from general practice and patient self-reported health information.

Table B.1: Coding of arthritis and musculoskeletal conditions

National Mortality Database	
Condition	ICD-10 codes
Diseases of the musculoskeletal system and connective tissue	M00–M99
Rheumatoid arthritis	M05–M06
Osteoarthritis	M15–M19
Osteoporosis	M80–M82
National Hospital Morbidity Database	
Condition	ICD-10-AM codes
Diseases of the musculoskeletal system and connective tissue	M00–M99
Rheumatoid arthritis	M05–M06
Osteoarthritis	M15–M19
Osteoporosis	M80–M82
BEACH Survey of General Practice	
Condition	ICPC-2-PLUS codes
Diseases of the musculoskeletal system and connective tissue	L (all codes)
Rheumatoid arthritis	L88
Osteoarthritis	L83011, L84004, L84009, L84010, L84011, L84012, L89001, L90001, L91001, L91003, L91008, L91015, L92007
Osteoporosis	L95
National Health Survey	
Condition	CURF^(a) codes (derived from ICD-10 codes)
Diseases of the musculoskeletal system and connective tissue	71–80
Rheumatoid arthritis	72
Osteoarthritis	73
Osteoporosis	80
Survey of Disability, Ageing and Carers	
Condition	CURF codes (derived from ICD-10 codes)
Diseases of the musculoskeletal system and connective tissue	1301, 1303, 1304, 1306, 1307, 1399
Arthritis and related disorders	1301
Osteoporosis	1304

(a) CURF - confidentialised unit record file/

Source: AIHW: Rahman et al. 2005.

Quality of life

National information on quality of life can be derived from the quality of life measure in the National Health Survey (2001), known as ‘The Delighted–Terrible Scale’. It is a seven-point scale that provides a general indicator of satisfaction of life. Adult respondents were asked to choose from seven options in response to the question: ‘How do you feel about your life as a whole, taking into account what has happened in the last year, and what you expect to

happen in the future?'. The response options are delighted, pleased, mostly satisfied, mixed, mostly dissatisfied, unhappy or terrible.

Psychological distress

National information on psychological distress is based on the Kessler Psychological Distress Scale-10 (K10), included in the National Health Survey (2001 and 2004–05). The K10 is a 10-item questionnaire, yielding a measure of psychological distress based on questions about negative emotional states experienced in the 4 weeks prior to interview. It contains from low-threshold to high-threshold items. For each item, there is a five-level response scale based on the amount of time that a respondent experienced the particular problem. The response options are none of the time, a little of the time, some of the time, most of the time, and all of the time. Each of the items is scored from 1 (for none of the time) to 5 (for all of the time). Scores for the 10 items are summed, yielding minimum low levels of psychological distress with high scores indicating high levels of psychological distress. The scores are grouped as follows:

- Low (scores of 10–15), indicating little or no psychological distress
- Moderate (scores of 16–21)
- High (scores of 22–29)
- Very high (scores of 30–50), indicating very high levels of psychological distress.

NHS long-term conditions

In the National Health Survey, information on diseases and conditions is based on long-term conditions. These are defined as medical conditions (illness, injury or disability) which were current at the time of the survey and which had lasted at least 6 months, or which the respondent expected to last for 6 months or more, including:

- long-term conditions from which only infrequent attacks may occur
- long-term conditions which may be under control (for example, through the continuing use of medication)
- conditions which, although present, may not be generally considered 'illness' because they are not necessarily debilitating, such as reduced sight
- long-term or permanent impairments or disability (ICD-10 classification of diseases); this is a derived item.

Multiple categories (1–19) are aggregated to obtain the prevalence of a certain long-term condition.

Disability characteristics

The loss of healthy life due to non-fatal conditions can be categorised using a variety of classifications. The International Classification of Functioning (ICF), a core member of the WHO family of health-related classifications, conceptualises disability as multi dimensional, relating to the body functions and structures of people, the activities they do, the life areas in which they participate and the factors in the environment that affect these experiences. The Survey of Disability, Ageing and Carers operationalises these concepts into 17 different types of limitations, restrictions or impairments. These characteristics can be further related to specific diseases and conditions. The extent of disability associated with various diseases and conditions can also be categorised using disability weights, or health state preferences.

However, no Australia-specific disability weights have been generated. The Australian Burden of Disease Study used numerical categorisation of disability based on the years of healthy life lost due to time lived in states other than the reference state of good health. This is referred to as 'years lost due to disability', or YLD. Both disability weights and the YLD categorisation give a broader interpretation of morbidity or ill health, concepts that are not fully picked up by the ABS survey instrument (which focuses more on diagnoses).

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