Australian Government
Australian Institute of Health and Welfare

Data sources for monitoring arthritis and other musculoskeletal conditions

ARTHRITIS SERIES NO. 19

Australian Government
Australian Institute of Health and Welfare

Authoritative information and statistics to promote better health and wellbeing

ARTHRITIS SERIES
Number 19

Data sources for monitoring arthritis and other musculoskeletal conditions

Australian Institute of Health and Welfare
Canberra
Cat. no. PHE 175

The Australian Institute of Health and Welfare is a major national agency which provides reliable, regular and relevant information and statistics on Australia's health and welfare. The Institute's mission is *authoritative information and statistics to promote better health and wellbeing*.

© Australian Institute of Health and Welfare 2014

This product, excluding the AIHW logo, Commonwealth Coat of Arms and any material owned by a third party or protected by a trademark, has been released under a Creative Commons BY 3.0 (CC-BY 3.0) licence. Excluded material owned by third parties may include, for example, design and layout, images obtained under licence from third parties and signatures. We have made all reasonable efforts to identify and label material owned by third parties.

You may distribute, remix and build upon this work. However, you must attribute the AIHW as the copyright holder of the work in compliance with our attribution policy available at <www.aihw.gov.au/copyright/>. The full terms and conditions of this licence are available at <http://creativecommons.org/licenses/by/3.0/au/>.

Enquiries relating to copyright should be addressed to the Head of the Media and Strategic Engagement Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

This publication is part of the Australian Institute of Health and Welfare's Arthritis series. A complete list of the Institute's publications is available from the Institute's website <www.aihw.gov.au>.

ISSN 1833-0991
ISBN 978-1-74249-572-9

Suggested citation
Australian Institute of Health and Welfare 2013. Data sources for monitoring arthritis and other musculoskeletal conditions. Cat. no. PHE 175. Canberra: AIHW.

Australian Institute of Health and Welfare
Board Chair
Dr Andrew Refshauge

Director
David Kalisch

Any enquiries about or comments on this publication should be directed to:
Media and Strategic Engagement Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1032
Email: info@aihw.gov.au

Published by the Australian Institute of Health and Welfare

Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

Acknowledgments ii
Abbreviations iii
Summary vi
1 Introduction 1
1.1 Structure of the report 1
1.2 Why monitor arthritis and other musculoskeletal conditions? 1
1.3 Information needed for monitoring 3
1.4 The disease continuum for arthritis and other musculoskeletal conditions 4
1.5 Priority information areas and key questions 6
1.6 Assessment approach 6
2 Data source descriptions 8
2.1 Types of data sources 8
2.2 In-scope data sources for arthritis and other musculoskeletal monitoring 10
3 To what extent can in-scope data sources answer key questions? 12
3.1 Key question 1—Modifiable risk factors 12
3.2 Key question 2—Prevalence 17
3.3 Key question 3—Prevention, management and treatment 19
3.4 Key question 4—Health related quality of life 24
3.5 Key question 5—Death and disability 26
3.6 Key question 6—Health Expenditure 28
4 Discussion 31
4.1 Comparative assessment 32
4.2 Future opportunities for data development 34
Appendix A: Data sources template 36
Appendix B: Index of in-scope data sources 37
Appendix C: In-scope data sources 38
References 94
List of tables 97
List of figures 98
List of boxes 99
Related publications 100

Acknowledgments

This report was written by Peta Craig, Louise York, Ann Hunt and Alice Crisp from the Australian Institute of Health and Welfare with contributions by Tomoko Sugiura and Naila Rahman and reviewed by Lisa McGlynn and Pamela Kinnear.

The report was prepared under the guidance of the Arthritis and Other Musculoskeletal Conditions Advisory Group whose members are: Lyn March (Chair), Flavia Cicuttini, Robert Cumming, Peter Ebeling, Ann Taylor, Pam Webster, Mellick Chehade, Chris Maher, Paul Hodges and Tania Winzenberg.

The project was funded by the Australian Government Department of Health.

Abbreviations

AATSIHS	Australian Aboriginal and Torres Strait Islander Health Survey
ABS	Australian Bureau of Statistics
AHS	Australian Health Survey
AIHW	Australian Institute of Health and Welfare
ALSA	Australian Longitudinal Study of Ageing
ALSWH	Australian Longitudinal Study on Women's Health
AOA	Australian Orthopaedic Association
ARAD	Australian Rheumatology Association Database
bDMARDs	biological disease modifying anti-rheumatic drugs
BEACH	Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice
BMD	bone mineral density
BMI	body mass index
CHAMP	Concord Health and Ageing in Men Project
COAG	Council of Australian Governments
DALY	Disability-adjusted Life Year
DHS	Department of Human Services
DMARDs	Disease modifying anti-rheumatic drugs
DOES	Dubbo Osteoporosis Epidemiology Study
DVA	Department of Veterans Affairs
FAMAS	Florey Adelaide Male Ageing Study
GOS	Geelong Osteoporosis Study
GP	General Practitioner
HAQ-DI	Health Assessment Questionnaire – Disability Index
ICUROS	International Costs and Utilities Related to Osteoporotic Fractures Study
IHME	Institute for Health Metrics and Evaluation
LSAC	Growing up in Australia: The Longitudinal Study of Australian Children
LSIC	Footprints in time: The Longitudinal Study of Indigenous Children

MATeS	Men in Australia Telephone Survey
MSC	Musculoskeletal coordinator
MBS	Medical Benefit Schedule
MRI	magnetic resonance imaging
NATSIHMS	National Aboriginal and Torres Strait Islander Health Measures Survey
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NATSINPAS	National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey
NHMD	National Hospital Morbidity Database
NHMS	National Health Measures Survey
NHS	National Health Survey
NMD	National Mortality Database
NMDS	national minimum data set specification
NNAPEDCD	National Non-Admitted Patient Emergency Department Care Database
NNPAS	National Nutrition and Physical Activity Survey
NSW	New South Wales
NWAHS	North West Adelaide Health Study
OAHKS	Osteoarthritis Hip and Knee Service
OECD	Organisation for Economic Cooperation and Development
OH&S	Occupational Health and Safety
OPAL	Optimising Patient outcome in Australian rheumatoLogy
PBS	Pharmaceutical Benefits Scheme
QUMI	Quality Use of Medicines Initiative
RA	rheumatoid arthritis
RPBS	Repatriation Pharmaceutical Benefits Scheme
RRMA	Rural, Remote and Metropolitan Areas
SA	South Australia
SAND	Supplementary Analysis of Nominated Data
SDAC	Survey of Disability, Ageing and Carers
SEIFA	Socio-Economic Indexes for Areas

SLA	Statistical Local Area
TASOAC	Tasmanian Older Adult Cohort
WHO	World Health Organization
YLD	years of life lost due to disability
YLL	years of life lost due to premature mortality

Summary

Within the Australian population, arthritis and other musculoskeletal conditions are highly prevalent, associated with significant disability, and generate large costs for the health and welfare systems. It is important to monitor these conditions to describe existing health patterns, populations at risk of illness, current health service use, and future demands on the health and welfare systems.

This report assesses the potential for existing data sources to improve our understanding of arthritis and other musculoskeletal conditions. Although many of the data sources identified were not primarily designed for monitoring these conditions, they do contain relevant data.

A 4-step process is used to assess the utility of different of data sources, including an initial stocktake of data collections, a review of in-scope data collections, an assessment of individual data collections and lastly an overall assessment of data collections collectively. This methodological approach can be used to assess other data sources for different conditions.

This report acknowledges:

- **Data are available for:**
  - risk factors, including some relevant information from longitudinal surveys
  - prevalence, with the exception of rarer conditions.
- **Data are available but require further development for:**
  - prevention, treatment and management, particularly to fill substantial gaps in relation to prevention activity and the use and appropriateness of care provided in primary health-care settings
  - death and disability, noting additional information is expected in late 2015 from new Australian estimates of burden of disease.
- **Data require development for:**
  - quality of life
  - health expenditure.
- **Future opportunities for improving data include:**
  - data linkage to enhance the information that can be gained using existing data
  - enhancing the current lack of primary health-care data
  - improving consistency and comparability of data from different sources by encouraging development and implementation of information standards
  - regular/ongoing collection of data to enable the assessment of change over time.

1 Introduction

The purpose of this report is to assess the potential for existing data sources to improve our understanding of arthritis and other musculoskeletal conditions. It is not intended to make value judgments about the selected data sources per se but to assess their utility to provide relevant information for these conditions.

Many data sources currently exist that potentially could be used to improve our understanding of arthritis and other musculoskeletal conditions. As many of these data sources were not primarily designed for arthritis monitoring, this report examines their utility in providing relevant information on key areas of interest, such as risk factors, prevalence, prevention, management and treatment, impact (quality of life, death and disability) and cost.

1.1 Structure of the report

This chapter outlines the purpose and scope of the report, the key questions relevant for monitoring arthritis and other musculoskeletal conditions, and our assessment approach.

Chapter 2 provides an overview of the types of data sources available for disease monitoring and identifies those data relevant for monitoring arthritis and other musculoskeletal conditions (including a reference table).

Chapter 3 outlines, in detail, the extent to which existing data sources can answer the key questions for monitoring arthritis and other musculoskeletal conditions.

Chapter 4 discusses and summarises the overall findings and suggests future opportunities for data development.

1.2 Why monitor arthritis and other musculoskeletal conditions?

Disease monitoring, in general, is important for keeping a close watch over the public's health and health services. Data collected through disease monitoring can be used to examine existing and emerging health patterns, population groups at risk of ill health, current health service use and future demand on the health system.

Monitoring assists with allocating resources, planning preventive and treatment services and with targeting priority population groups. Monitoring also assists with tracking the impact of risk factors, improvements in diagnosis, health promotion activities, treatment and prevention strategies, and informing development of new policies and programs and evaluating their progress.

Monitoring arthritis and other musculoskeletal conditions is important because of their:

- high prevalence within the population
- significant association with disability across the life course
- impact on the health and quality of life of sufferers
- cost burden to individuals and the health system.

Prevalence

Current estimates show 6.1 million Australians have arthritis or other long-term musculoskeletal conditions (ABS 2012) and this number is expected to rise as the population ages. While these conditions predominantly affect older populations, they are also experienced by those in younger age groups (ABS 2012).

Arthritis affects an estimated 3.3 million people, which includes osteoarthritis (1.8 million), rheumatoid arthritis (0.4 million) and other forms of arthritis (1.1 million). Back pain/disc disorders affects an estimated 2.8 million people and osteoporosis affects 0.7 million people (ABS 2012).

Quality of life, physical functioning and disability

Arthritis and other musculoskeletal conditions have a substantial impact on the health and quality of life of sufferers. While not often a direct cause of death, these conditions make a large contribution to pain, mobility restriction and functional impairment, as well as affecting mental health and overall quality of life (AIHW 2008a). An estimated 1.4 million Australians report arthritis and other musculoskeletal conditions as their main long-term health condition. In terms of the effect on physical functioning, just over half (57%) of these Australians report they have mild or moderate core activity limitation and more than a quarter (28%) report severe or profound core activity limitation (ABS 2013).

In addition, according to the 2010 Global Burden of Disease Study, 'musculoskeletal disorders' were the highest ranking cause of health lost due to disability in Australasia (Australia and New Zealand), contributing just over a quarter (26.4%) of the non-fatal burden (IHME 2013). See Box 1.1 for further details of musculoskeletal disorders.

Cost burden

Arthritis and other musculoskeletal conditions require ongoing treatment and management which, in turn, places a large cost burden on the health-care system, individuals and families. During the 2008– 09 financial year, direct health expenditure for arthritis and other musculoskeletal conditions was $5.7 billion, the fourth-largest contributor to direct health care expenditure in Australia. The two conditions of osteoarthritis and back problems accounted for half of this expenditure. Admitted patient services were the biggest contributor to overall expenditure (AIHW Disease Expenditure Database).

In addition to these estimates of direct health expenditure, various modelled estimates of the broader concept of 'health costs' have been developed. These models include direct non-health-care costs, such as home help and meals on wheels, and indirect costs from production loss. As a consequence these models provide higher estimates of the costs of these conditions (Arthritis and Osteoporosis Victoria 2013; Watts et al. 2013).

Box 1.1: What are musculoskeletal disorders?

Musculoskeletal disorders include the following:

Osteoarthritis: A degenerative joint condition mostly affecting the hands, spine and joints such as the hips, knees and ankles. Its main feature is the breakdown of the cartilage that overlies the ends of the bones in the joints.

Rheumatoid arthritis: A chronic disease marked by inflammation of the joints, most often affecting the hand joints in a symmetrical fashion (that is, both sides of the body are affected at the same time). The immune system attacks tissues lining the joints, causing pain, swelling and stiffness. Over time there is progressive and irreversible joint damage, resulting in deformities and severe disability. The exact cause of rheumatoid arthritis is poorly understood but there is a strong genetic component.

Juvenile arthritis: A common term used to describe arthritis occurring in children under the age of 16. The condition typically has an unpredictable pattern of activity, with periods of being well followed by a resurgence of signs and severe symptoms such as joint swelling, tenderness, heat, stiffness and pain (known as 'flare-ups'). The cause of juvenile arthritis is unknown.

Back pain: Most cases of back pain do not have an identifiable cause, which is frustrating for both patients and care providers. While episodes of back pain may be short-lived, recurrence is common and in some cases the pain can become long-lasting. The occurrence of back problems has traditionally been associated with age, physical fitness, smoking, being overweight and occupation.

Osteoporosis: Thinning and weakening of bones often occurs with age, increasing the risk of fracture. While osteoporosis occurs in both sexes, it is more common in women. Risk factors for osteoporosis include increasing age, female sex, family history of the condition, low vitamin D levels, low intake of calcium, low body weight, smoking, excessive alcohol consumption, physical inactivity, long-term corticosteroid use and reduced oestrogen levels.

Other musculoskeletal conditions include gout, spondylopathies, osteomyelitis, systemic lupus erythematosus, ankylosing spondylitis, tendinitis, carpal tunnel syndrome and fibromyalgia.

Source: AIHW forthcoming.

1.3 Information needed for monitoring

To evaluate the data available for monitoring a specific disease, it is important to know what type of information is required. Various existing frameworks provide a useful guide for the selection of indicators that assist in understanding and evaluating the health of Australians and performance of the health system.

One such model is the National Health Performance Framework created under the auspices of the Australian Health Ministers' Advisory Council (NHISSC 2009). A modified version of this model is depicted in Table 1.1 and describes 5 categories of public health information that are required to monitor disease in a population, namely population health status; determinants of health; public health interventions; inputs and infrastructure, and priority populations. This model was used to help identify the general information areas for monitoring arthritis and other musculoskeletal conditions.

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
Health conditions and injury	Environmental factors	Hospitalisation	Labour force	Aboriginal and Torres Strait Islander peoples
Human functioning and disability	Community and socioeconomic	General practitioner visits	Expenditure, funding and capital infrastructure	Residents of rural and remote locations
Mortality	Health behaviours	Treatments	Training	People with a low socioeconomic status
Quality of life	Biomedical factors (including genetics and family history)	Allied health care	Research	Non-English speakers
		Public health education		People with disability
		Disability and other non-health support services		Homeless people

Source: Modified from AIHW 2012a.

1.4 The disease continuum for arthritis and other musculoskeletal conditions

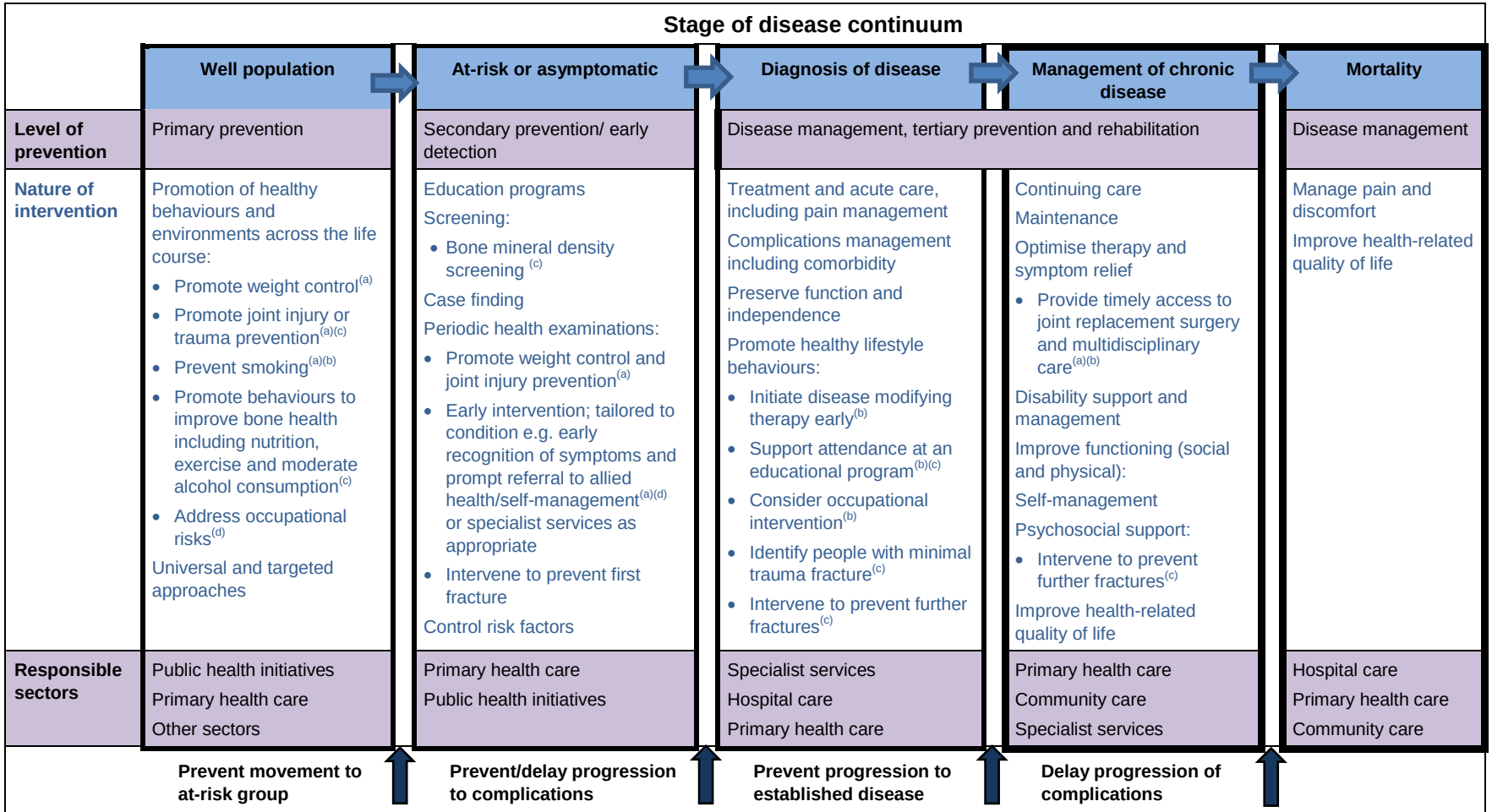
While the model outlined in Table 1.1 describes the general types of information needed for monitoring a chronic disease, it does not describe the detailed issues specific to arthritis and other musculoskeletal conditions that need to be monitored.

A model of the continuum of care for arthritis and other musculoskeletal conditions, based on work by the former Department of Health and Ageing, National Arthritis and Other Musculoskeletal Conditions Advisory Group, and National Public Health Partnership, describes the interventions required by individuals at each stage of the disease, and the health-care sectors responsible for providing treatment and care (Figure 1.1).

As arthritis and other musculoskeletal conditions are generally chronic diseases, information required for monitoring the conditions in each category described in Table 1.1 changes over the disease continuum. The stages of the disease continuum include the well population, at-risk/asymptomatic population, population with a recent disease diagnosis, population managing a chronic disease, and population receiving palliative care or who have died from the condition.

The aim of public health interventions is to prevent people moving to subsequent stages of the disease continuum by ensuring they receive timely and appropriate treatment suitable to their current health status. To evaluate whether this is happening, a comprehensive monitoring system includes information about a range of preventive activities, from health promotion to treatment (for example population-wide, musculoskeletal conditions in general, disease-specific, focused on those with known genetic pre-disposition); from a range of health sectors, and from other sectors such as planning authorities (for example 'Healthy City' planning [WHO 2014]) and professional groups.

Clinical guidelines for managing specific musculoskeletal conditions (for example, RACGP 2009a, 2009b, 2009c, 2010) and models of care for arthritis (Arthritis Australia 2014) are also relevant in considering the types of information needed to monitor progress.



(a) Particularly relevant to osteoarthritis.

(b) Particularly relevant to rheumatoid arthritis.

(c) Particularly relevant to osteoporosis.

(d) Particularly relevant to back problems.

Sources: Modified from DoHA & NAMSCAG 2004; National Public Health Partnership 2001.

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

1.5 Priority information areas and key questions

For this report, the two models presented in Table 1.1 and Figure 1.1 were used to formulate a simplified set of 6 priority information areas for monitoring arthritis and other musculoskeletal conditions. For accurate monitoring, information is required to describe various dimensions of the conditions, including their risk factors, prevalence, how effectively the health system is responding through prevention and treatment, the impact (measured in quality of life, death and disability) and health expenditure. Information is needed to describe the situation at a particular point in time and to track changes over time.These priority information areas translate into the following 6 key questions which are used to guide the remainder of this report (Box 1.2).

Box 1.2: Key questions for monitoring arthritis and other musculoskeletal conditions

1. **Risk factors:** What proportion of the population experience the modifiable risk factors associated with arthritis and other musculoskeletal conditions?
2. **Prevalence:** What is the prevalence of (that is, how common are) arthritis and other musculoskeletal conditions in the population?
3. **Prevention, management and treatment:** What prevention, management and treatment services do the population with arthritis and other musculoskeletal conditions receive?
4. **Quality of life:** How do arthritis and other musculoskeletal conditions affect an individual's quality of life?
5. **Death and disability:** How much death and disability is associated with arthritis and other musculoskeletal conditions?
6. **Health expenditure:** What is known about expenditure on arthritis and other musculoskeletal conditions?

Wherever possible, these questions are examined in relation to arthritis and other musculoskeletal conditions overall, and then for each of the specific conditions (juvenile idiopathic arthritis, rheumatoid arthritis, osteoarthritis, back problems, osteoporosis and 'other' musculoskeletal conditions). The approach taken in this report is to establish the extent to which information is available to answer the key questions in Box 1.2 and refer to examples of more complex follow-up questions in the discussion (Chapter 4).

1.6 Assessment approach

This report describes and assesses data sources for monitoring arthritis and other musculoskeletal conditions in Australia, to identify gaps and deficiencies in the current information base for regular monitoring. Given the population health monitoring focus of this report, data sources that are nationally representative are considered advantageous. The data sources selected for inclusion in this report are not necessarily superior to other collections in general. The authors acknowledge that each data set was established for a particular purpose, not necessarily with musculoskeletal monitoring as its primary purpose.

Depending on the user's information needs, it is possible that many regional or other data collections reviewed will provide some answers to specific questions about arthritis and other musculoskeletal conditions. The AIHW used the 4-step process, outlined in Figure 1.2, to assess the suitability of current data collections in Australia to answer the key questions for monitoring arthritis and other musculoskeletal conditions.

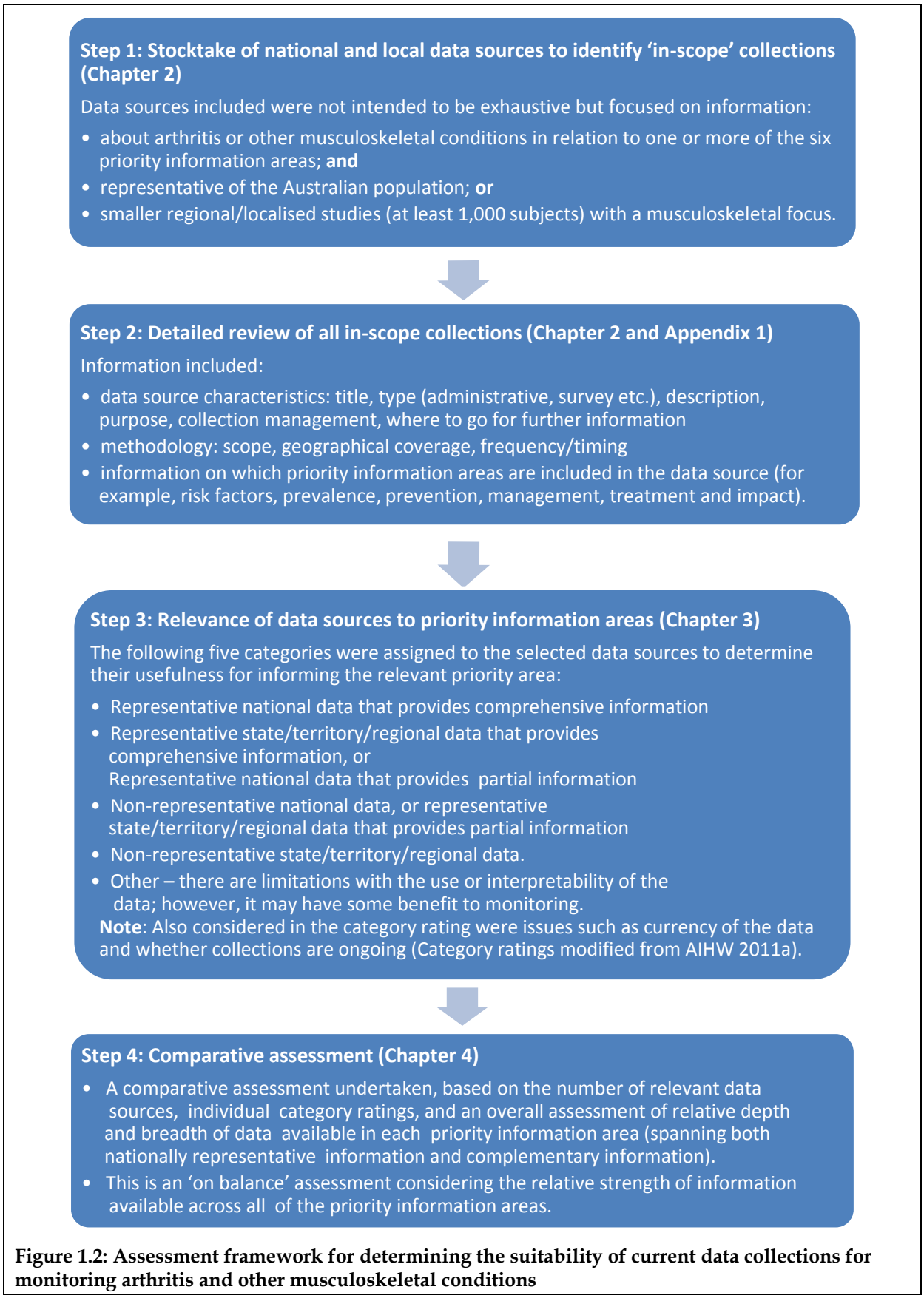


Figure 1.2: Assessment framework for determining the suitability of current data collections for monitoring arthritis and other musculoskeletal conditions

2 Data source descriptions

A number of data sources provide public health information in Australia. Based on the mechanism of data collection, the data sources can be categorised as administrative, survey, registry, derived and longitudinal. The information in these data sources is obtained from individuals, government agencies and private and community organisations and health professionals. A disease monitoring system can include one or more of these data sources to inform the population health issue in question.

Information from these sources may be collected continuously over many years, allowing in-depth analysis of health service use for a given month, year or over time. Surveys may be conducted periodically or 'once-off' and can provide a snapshot at one point in time, including possible comparison with similar cross-sectional data collected at an earlier or later time.

Data may be collected and reported at a national, state/territory or local level. National data sources are beneficial as they provide information at a population level and are often representative; that is, participants closely match the characteristics of the population, which enables the results to be generalised to the whole population.

Public health information obtained at the state and territory level can provide data that complements, or can be used as a substitute for, national data, depending on the collection methods and representativeness.

Regional and local data can also be very useful, particularly in understanding the needs of local communities and the extent to which available services meet these needs. There is growing demand for data at the local level (for example, Medical Locals health needs assessment and planning processes [DoHA 2012]). To meet these local or regional requirements, data are essential to develop an understanding of the population and identify opportunities to improve health; assess existing health-care services to determine what is working, what would be improved and where resources could be used differently; implement initiatives; and monitor performance (DoHA 2012).

Limitations are often associated with using state/territory, regional or local data as they may not be representative or complete. For example, comprehensive, coordinated or standardised primary health care information is not presently collected at the state/territory, regional or local level in Australia.

While recognising the need for information at all of the above levels, the 'representativeness' assessment of data sources undertaken in this review (Step 3) focuses on the national representativeness of each data source.

2.1 Types of data sources

Administrative data sources

Administrative data are collected as a by-product of the delivery of health services. For example, data are recorded during a visit to a general practitioner or hospital admission, or through other processes, such as registrations of births, deaths or marriages.

Administrative data sources can capture information on the majority, if not all, of people receiving a particular service or program. These datasets generally:

- have good coverage of person and service characteristics
- are collected on an ongoing basis and reported frequently
- have sufficient coverage for use at the national, state and territory or regional level.

In addition, where scope, coverage and data quality are consistent over time, administrative datasets provide a valuable source of time series information. There are, however, limitations associated with administrative data sources, because they are:

- by their nature, the by-product information from existing health activities (such as admission to a hospital), therefore limited to specific scope, coverage and data elements available as a cost-effective by-product of that activity
- collected for a particular purpose and then possibly used for a secondary purpose (including aggregate reporting); therefore these sources cannot usually tell us about the non-users of a given program or service type, may not include the depth of information to inform all questions of interest, and may not produce reliable estimates for all regions (depending on coverage)
- limited by the quality and completeness of information provided for each data element.

Survey-based data sources

Survey-based data sources collect health-related information, often by way of a population sample. Survey data include details relating to the experience of the individual surveyed across a range of services and health conditions and can provide a greater depth of information than administrative data. Where question design, sampling and data quality are consistent over time, population health surveys provide a valuable source of time series comparisons.

There are also inherent limitations to this methodology. Respondents may misreport information, either intentionally or unintentionally, which reduces the accuracy of the results. For example, respondents may be unable to recall health events, food intakes, medications or medical advice, particularly over a long time. Additionally, the sampling method for most population surveys is not designed to produce reliable estimates at regional levels nor for small, but important, sub-populations.

Registry data sources

Registries aim to 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 usually do not include information from the general population.

It is difficult to generalise the results from registries to the population as a whole. Further, findings derived from registry data may be limited in instances where full coverage of the relevant disease or treatment population is not obtained. For example, unless registries are supported by business processes, audits, mandatory data entry or by-product information from other technology, their complete coverage cannot be guaranteed.

Derived data sources

Derived data sources use information from other data sources to produce new measures. Some examples are to derive summary measures or monetary costs of a disease or condition. The accuracy and validity of the data are dependent on the quality of the underlying data, the methods used to calculate the derived data and any assumptions made. Derived data can be a powerful way of summarising information from a range of sources and can allow comparisons across variables or factors (for example, disease types, risk factors and type of health service).

Longitudinal data sources

Longitudinal studies involve following a cohort of individuals over time with continuous monitoring of risk factors and/or health outcomes. The length of the study may vary, with some longitudinal studies running for decades. Longitudinal studies are useful as they provide important data about changes experienced by individuals over time and allow for flexibility in the data collected at each time point. However, such studies are time-consuming (which affects participant retention), potentially costly (in order to maintain a committed research team) and not always representative of the general population.

2.2 In-scope data sources for arthritis and other musculoskeletal monitoring

The first step in assessing the suitability of data collections for monitoring musculoskeletal conditions is to identify 'in-scope' data collections (Step 1 of Figure 1.2). The in-scope data sources identified are listed in Table 2.1. The data sources included for assessment are not exhaustive but focus on those that:

- contain some information about arthritis or other musculoskeletal conditions in relation to one or more of the 6 areas of interest; and
- are representative of the Australian population; or
- are smaller regional/localised studies (with at least 1,000 participants) with a musculoskeletal focus.

A detailed review of each source's relevance to the priority information areas is provided at Appendix 1 (Step 2 of Figure 1.2).

Table 2.1: In-scope data sources for arthritis and other musculoskeletal conditions

Type of data source	National	State, territory or regional
Administrative	National Hospital Morbidity Database (NHMD)	
	National Mortality Database	
	Medicare Benefits Scheme (Medicare)	
	Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme (PBS and RPBS)	
	Non-admitted patient care aggregate national minimum data set specification (Non-admitted patient care aggregate NMDS).	
	National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD)	
Survey	Australian Health Survey (AHS) and National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)	
	Bettering the Evaluation and Care of Health Survey of General Practice (BEACH)	
	Survey of Disability, Ageing and Carers (SDAC)	
	Voice of Arthritis Social Impact Study	
	National Drug Strategy Household Survey	
Longitudinal Survey	Australian Longitudinal Study on Women's Health (ALSWH)	The 45 and up study
	The Longitudinal Study of Australian Children (LSAC)	Geelong Osteoporosis Study (GOS)
	The Longitudinal Study of Indigenous Children (LSIC)	North West Adelaide Health Study (NWAHS)
		Australian Longitudinal Study of Aging (ALSA)
		The Tasmanian older adult cohort (TasOAC)
		The Concord Health and Ageing in Men Project (CHAMP)
		Florey Adelaide Male Aging Study (FAMAS)
		Dubbo Osteoporosis Epidemiology Study (DOES)
Registry	Australian Orthopaedic Association National Joint Replacement Registry	
	Australian Rheumatology Association Database (ARAD)	
	Optimising Patient Outcome in Australian Rheumatology (OPAL)	
Derived	Burden of Disease Studies	
	AIHW Disease Expenditure Database	

3 To what extent can in-scope data sources answer key questions?

This section explains Step 3 of Figure 1.2. It identifies the in-scope data sources of most relevance to each priority information area (outlined in Box 1.2) and assesses their representativeness and completeness for this purpose. For each key question, we describe:

- Why collect information in this area?
- What information is available?
- What information is missing?

While there is considerable background information to help set the scene for each information area, this report provides a summary only and directs readers to other information resources as required.

3.1 Key question 1—Modifiable risk factors

Why collect information about modifiable risk factors?

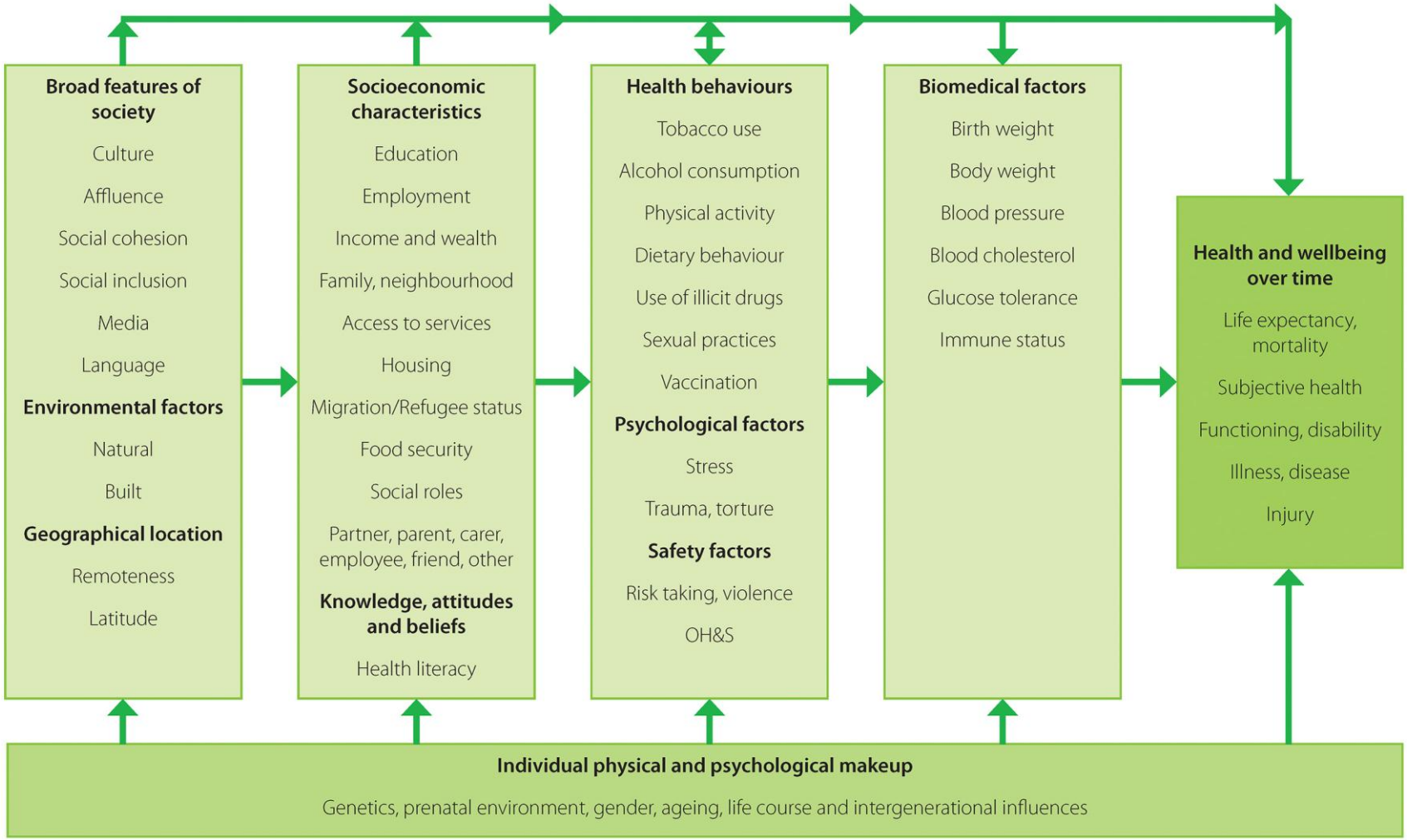
Many factors, often referred to as determinants of health, influence our health and wellbeing (see Figure 3.1). Factors affecting health in a negative way are commonly referred to as risk factors, for example, high blood pressure can increase the likelihood of developing cardiovascular illness. Those affecting health in a positive way are known as protective factors, for example, good nutrition and exercise can help prevent many chronic conditions (AIHW 2012a).

Risk factors can be separated into those that are modifiable and those that are not. Non-modifiable risk factors include age, sex and family history. While these risk factors cannot be modified, information about them can help identify people at high risk of developing a disease so that prevention strategies and relevant medical services can be devised and located to best effect (AIHW 2008a).

In contrast, health behaviours are risk factors that individuals have more power to change and are, therefore, described as modifiable. Biomedical risk factors are bodily states that carry relatively direct and specific risks for health. They are often influenced by health behaviours and are therefore potentially modifiable through self-management, health promotion and other health interventions (AIHW 2012a).

This report focuses on the potentially modifiable risk factors in the framework (Figure 3.1) —health behaviours and biomedical factors. Understanding patterns of health behaviours are important for preventing and managing arthritis and other musculoskeletal conditions. These behaviours include meeting the recommended guidelines for physical activity, body weight, a nutritious diet, alcohol intake, and not smoking (AIHW 2008a).

Maintaining appropriate vitamin D levels may also have a role in preventing osteoporosis, while avoiding or limiting repetitive load-bearing activities and prevention of joint trauma can reduce the risk of developing osteoarthritis (Ebeling et al. 2013). Risk factors for lower back pain/disc problems also include excessive mechanical loading of spine (for example due to incorrect lifting techniques or poor work design), poor psychosocial health/wellbeing and advancing age (Better Health Channel 2013; Hoy et al. 2010).



Source: AIHW 2012c.

Figure 3.1: A conceptual framework for determinants of health

Further information on risk factors for musculoskeletal conditions and the presence of risk factors in those with and without musculoskeletal conditions is available in AIHW and other publications (for example AIHW 2013b, AIHW 2013a, AIHW 2011, AIHW 2008a, National Health Priority Action Council 2006).

In addition, the AIHW publication *Risk factors contributing to chronic disease* (AIHW 2012c) provides a comprehensive picture of risk factor behaviours in Australia, many of which are relevant to arthritis and other musculoskeletal conditions.

What information is available?

The most relevant data sources for monitoring modifiable risk factors are presented in Table 3.1. Our assessment is that the available data sources in this area are 'Very well developed', consisting of several representative, ongoing data collections, spanning both point-in-time collections and longitudinal studies.

The two main data sources, the Australian Health Survey (AHS) and the Australian Longitudinal Study on Women's Health (ALSWH), collect broad lifestyle risk factor data particularly relevant for monitoring arthritis and other musculoskeletal conditions.

The AHS for 2011-13 is particularly useful because, in addition to self-reported data, it collects measured risk factor data, which includes vitamin D levels. Measured data are often more reliable than self-reports from participants (AIHW 2012a).

These data sources are complemented by a number of other national and state-based surveys, some of which are ongoing data collections, including:

- Longitudinal Study of Australian Children
- National Drug Strategy Household Survey
- The 45 and Up Study
- Concord Health and Ageing in Men Project
- Geelong Osteoporosis Study.

For the purposes of monitoring the modifiable risk factors for arthritis and other musculoskeletal conditions , the above 5 data sources are limited in the type of risk factor data available and/or their representativeness of the Australian population. For example, the Longitudinal Study of Australian Children (LSAC) collects data only in relation to Body Mass Index (BMI), exercise and smoking status (for the parents), and the Concord Health and Ageing in Men Project (CHAMP) collects data in relation to smoking, alcohol and physical activity for men aged 70 and over in the inner west area of Sydney. The longitudinal surveys (Longitudinal Study of Australian Children, the 45 and Up, Concord Health and Ageing in Men Project) offer the benefit of tracking participants experiencing arthritis and other musculoskeletal risk factors over time to explore the development of these conditions.

Table 3.1: Assessment of data sources for monitoring modifiable risk factors for arthritis and other musculoskeletal conditions

Key data source	Notes	Monitoring relevance
Australian Health Survey	Collects a range of measured and self-reported risk factor data Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Representative national data providing comprehensive information
Australian Longitudinal Study on Women's Health	Collects a range of risk factor data Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Representative national data providing comprehensive information
Longitudinal Study of Australian Children	Collects a limited range of risk factor data for children and their parents Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Representative national data providing partial information
National Drug Strategy Household Survey	Collects a limited range of risk factor data for Australians aged 12 and above Data relevant for osteoporosis and rheumatoid arthritis Ongoing/regular collection	Representative national data providing partial information
The 45 and Up Study	Collects a range of risk factor data Data relevant across arthritis and other musculoskeletal conditions Ongoing/regular collection	Representative state data providing comprehensive information
Concord Health and Ageing in Men Project	Collects a range of risk factor data Data relevant across arthritis and other musculoskeletal conditions Ongoing/regular collection	Representative regional data providing comprehensive information
Geelong Osteoporosis Study	Collects a range of risk factor data, including prevalence and severity of low bone mineral density Data relevant for arthritis and other musculoskeletal conditions, particularly osteoporosis Ongoing/regular collection	Representative state data providing comprehensive information
Australian Longitudinal Study of Ageing (SA)	Collects a range of risk factor data Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Non-representative state data providing partial information
The Tasmanian Older Adult Cohort	Collects a range of risk factor data Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Non-representative state data providing partial information
Florey Adelaide Male Ageing Study	Collects a range of risk factor data Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Non-representative state data providing partial information
Dubbo Osteoporosis Epidemiology Study	Collects a range of risk factor data Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Non-representative state data providing partial information
The Longitudinal Study of Indigenous Children	Collects a limited range of risk factor data for children and parents Data relevant for arthritis and other musculoskeletal conditions Ongoing/regular collection	Partial information
North West Adelaide Health Study	Collects a limited range of risk factor data Data relevant for arthritis and other musculoskeletal conditions No future data collections	Partial information, non-ongoing
Overall assessment of all available data sources		**Very well developed**

What information is missing?

Whilst robust data exist for lifestyle risk factors implicated in arthritis and other musculoskeletal conditions (for example, physical activity levels), information is less developed in the area of risk factors specifically for back problems (for example, incorrect lifting techniques, and occupational factors).

Currently, there is a lack of nationally representative data on risks for back problems related to occupational or sporting/leisure activities. Many of the population may be considered at risk of developing back problems through their involvement in a sedentary lifestyle, workforce participation or sporting participation. While the Australian Bureau of Statistics (ABS) Census and survey products provide broad estimates of the population participating in various workforce occupations and sporting activities, this is unlikely to be useful for monitoring purposes.

Injury is also recognised as a risk factor for various forms of arthritis and back problems. For example, someone who has injured a joint while playing a sport is more likely to subsequently develop arthritis in that joint (AIHW 2008a).

Examples of injury data that could be used to predict future prevalence of musculoskeletal conditions include:

- The ABS work-related injuries survey, which looks at the causes of the most recent work-related injury/illness. The data provide an indication of injuries that can be implicated in causing back problems, for example, lifting objects, repetitive movement and prolonged standing (ABS 2010). This information is restricted to the most recent injury only, has limited information about whether the back problem existed before injury and the survey is infrequently conducted. It has therefore not been further explored in this report.
- Information about the numbers of people on the Disability Support Pension and related pensions or payments may also provide some information about the outcomes of back-related injury or illness in terms of the numbers of people unable to work due to these conditions and eligible for government income support (for example, FaHCSIA 2012 provides high-level data). The usefulness of these data for this purpose may warrant further exploration.

Workplace compensation data (for example, Safe Work Australia 2013) may also provide high-level information about one particular component of occupational injury relating to back problems (that is, those injuries for which compensation was sought).

A further data limitation is the lack of information about the link between risk factors and the onset of arthritis and other musculoskeletal conditions. This information is largely missing and only available from longitudinal studies, which are not always fully representative.

In addition, the data sources available for monitoring risk factors for arthritis and other musculoskeletal conditions primarily rely on self-reported information from participants, which can be incorrectly recalled and under-reported.

3.2 Key question 2—Prevalence

Why collect information about prevalence?

Prevalence is a measure of the level of a disease or characteristic in a population at a specific time. It is distinct from incidence, which refers to the number of new cases diagnosed in a given period. Prevalence is a direct product of incidence and survival; for example, health conditions with high incidence and high survival tend to have high prevalence, as is the case with arthritis and other musculoskeletal conditions.

It is important to measure the incidence and prevalence of health conditions because knowing how often and how much disease occurs in the population, and in particular population groups, plays an important role in preventing and treating illness. The different measures can inform aspects of health services planning and delivery (AIHW 2012a).

For diseases that are mandatorily reported in Australia, incidence statistics can be readily obtained, for example, health practitioners' reporting to state health authorities on cases of HIV, tuberculosis and swine flu. In addition, comprehensive and reliable figures can be obtained for diseases that have a nationally coordinated and comprehensive register. However, for other conditions including arthritis and other musculoskeletal conditions, incidence data are not readily available (AIHW 2012a) and so for this report, incidence is not discussed further.

What information is available?

The most relevant data sources for monitoring the prevalence of arthritis and other musculoskeletal conditions are presented in Table 3.2. Our assessment is that the available data sources for this information area are 'Very well developed', consisting of several representative, ongoing data collections, spanning both point-in-time collections and longitudinal studies.

The two main data sources, the AHS and the ALSWH, collect comprehensive information on arthritis and other musculoskeletal conditions. This includes professional/doctor-diagnosed representative prevalence information for the Australian population, noting that ALSWH is representative of women only. These data sources collect information on osteoarthritis, rheumatoid arthritis, 'other arthritis', gout, osteoporosis, osteopenia, back pain or back problems and 'other musculoskeletal conditions' and are undertaken on a regular/ongoing basis.

A selection of other state-based data sources provide complementary data, partly due to their narrower focus. For example:

- the 45 and Up Study provides comprehensive information, concentrating on osteoarthritis and osteoporosis
- the Geelong Osteoporosis Study focuses on osteoporosis
- the Australian Longitudinal Study of Ageing includes both osteoporosis and osteopenia
- the North West Adelaide Health Study contains data on a range of doctor-diagnosed arthritis and other musculoskeletal conditions.

Table 3.2: Assessment of data sources for monitoring prevalence of arthritis and other musculoskeletal conditions

Key data source	Notes	Monitoring relevance
Australian Health Survey	Collects prevalence estimates for self-reported doctor diagnosed osteoarthritis, rheumatoid arthritis, gout, osteoporosis, osteopenia and back pain/problems Ongoing/regular collection	Representative national data providing comprehensive information
Australian Longitudinal Study on Women's Health	Collects prevalence estimates for self-reported doctor-diagnosed osteoporosis, rheumatoid arthritis, 'other arthritis', osteoporosis and 'other' as well as self-diagnosed back pain Ongoing/regular collection	Representative national data providing comprehensive information
The 45 and Up Study	Collects data on whether participants have received treatment for osteoarthritis or osteoporosis and whether they have any other important illnesses. Also collects data on doctor-diagnosed prevalence of osteoarthritis Ongoing/regular collection	Representative state data providing comprehensive information
Concord Health and Ageing in Men Project	Collects data on osteoporosis and osteopenia through bone mineral testing of the hip and spine Ongoing/regular collection	Representative regional data providing partial information
Geelong Osteoporosis Study	Collects data on prevalence and severity of low bone mineral density, which indicates the risk of osteoporosis Ongoing/regular collection	Non-representative regional data providing partial information
Australian Longitudinal Study of Ageing (SA)	Collects data on prevalence of osteoporosis and osteopenia measured by bone densitometry Ongoing/regular collection	Non-representative state data providing partial information
The Tasmania Older Adult Cohort	Collects data on doctor-diagnosed osteoporosis and rheumatoid arthritis and some data on osteoporosis and osteopenia Ongoing/regular collection	Non-representative state data providing partial information
Dubbo Osteoporosis Epidemiology Study	Collects data on minimal trauma fractures, which is particularly relevant to osteoporosis Ongoing/regular collection	Non-representative regional data providing partial information
North West Adelaide Health Study	Collected data on self-reported doctor-diagnosed arthritis (osteoarthritis, rheumatoid arthritis, 'other'), musculoskeletal pain and stiffness (e.g. back pain/stiffness, shoulder pain/stiffness) and osteoporosis. Also undertook bone mineral density scans for participants aged 50 and above to measure osteoporosis and osteopenia No future data collections	Non-representative regional data providing partial information
Florey Adelaide Male Ageing Study	Collected data on the prevalence of osteopenia and osteoporosis from bone scans Ongoing/regular collection	Non-representative regional data providing partial information
Overall assessment of all available data sources		**Very well developed**

What information is missing?

Reliance on self-reported cases

The majority of assessed data sources for measuring prevalence are based on doctor-diagnosed cases as self-reported by participants. The validity of self-reported data have previously been questioned because they do not always align with data from clinical examination and diagnosis (AIHW: Rahman et al. 2005). For example, prevalence estimates for osteoporosis are likely to be lower than those based on clinical examination.

In addition, respondents may not be familiar with the medical terminology used in the survey response options, leading to possible classification and counting inconsistencies.

Classification inconsistencies

There may be inconsistencies regarding the classification of the conditions in some surveys, which has an impact on the quality of the outputs. The use of rheumatism, a catch-all term that means different things to different people, may cause confusion and influence participant reporting, particularly affecting estimates of osteoarthritis and rheumatoid arthritis.

In addition, for arthritis and other musculoskeletal conditions, population surveys that provide prevalence data are often reported under the broad category of musculoskeletal conditions, rather than according to the specific conditions.

Prevalence of rare and specific conditions

Due to sample sizes, it is generally not possible to obtain reliable estimates for the prevalence of rare and specific conditions, including juvenile idiopathic arthritis. There are potential gaps in the prevalence data for this disease. In particular, because of its age-limited definition (defined as onset of persistent arthritis before 16 years of age), prevalence estimates for juvenile idiopathic arthritis are often based on the number of children with arthritis in the population despite the fact that many adults continue to have the condition. Prevalence estimates for juvenile idiopathic arthritis are therefore likely to be underestimated (AIHW 2008c).

Coverage

The AHS does not cover *Very remote* areas or non-private dwellings such as hotels, motels, hostels, hospitals, nursing homes and short-stay caravan parks. It is therefore likely to under-represent some groups including those with more severe complications of musculoskeletal conditions, and the elderly.

3.3 Key question 3—Prevention, management and treatment

Why collect information about prevention, management and treatment?

Prevention (of disease or ill health) is described as action to reduce or eliminate the onset, causes, complications or recurrence of disease or ill health (AIHW 2008b). There is an increasing emphasis on prevention in most health systems, including in Australia, in light of the growing burden of chronic diseases, their amenability to preventive health activity and the potential to decrease costs.

A useful framework for understanding prevention, and availability of information about prevention, was published by the AIHW in 2009. This report presented the first systematic approach to monitoring prevention in relation to cardiovascular disease, diabetes and chronic kidney disease, but is relevant across all chronic diseases. It sets out 3 main components of prevention—prevention of risk factors (causes), prevention of disease (onset) and prevention of progression, complications and recurrence in people with the disease—noting that, for each of these 3 components, it is important to monitor the outcomes that are to be prevented and the prevention services being provided (AIHW 2009).

As arthritis and other musculoskeletal conditions cannot generally be cured, management and treatment options focus on alleviating symptoms, maximising function and quality of life and minimising the impact of disability. This is most commonly achieved through medication, in combination with physical and occupational therapy and self-management education. In severe cases surgery may be required, for example joint replacement surgery is needed for some people with osteoarthritis and rheumatoid arthritis to reduce pain, increase joint functionality and improve quality of life (AIHW 2008a).

Information about the full range of services available for and used by people with musculoskeletal conditions would support assessment and evaluation of the quality, effectiveness and outcomes of this care. Such an assessment would ideally be undertaken with reference to clinical guidelines and agreed models of care (for example, RACGP 2009a, 2009b, 2009c, 2010 and Arthritis Australia 2014).

For example, clinical guidelines developed for rheumatoid arthritis, juvenile idiopathic arthritis, osteoarthritis and osteoporosis recognise that the first point of contact for the patient is usually the GP who can refer to, and coordinate care with, specialists and other health professionals (RACGP 2009a, 2009b, 2009c, 2010). Specialists such as rheumatologists and orthopaedic surgeons are important for diagnosing rheumatoid arthritis and surgical treatment of osteoarthritis.

The multidisciplinary nature of musculoskeletal management means that information is needed about activities in primary health care (which includes most services not provided by hospitals and delivered in the community, such as by GPs, pharmacists, community health workers, allied health practitioners and practice nurses) and specialist care and the interactions between these sectors. In particular, given the continuing and predominant role of primary health care (for example, GPs and allied health professionals are generally the first point of contact for identification and management of low back pain [Maher et al. 2011]), information about GP and allied health activity (such as physiotherapists, occupational therapists and podiatrists) is crucial in understanding management of these conditions.

What information is available?

The most relevant data sources for monitoring the prevention, management and treatment of arthritis and other musculoskeletal conditions are presented in Table 3.3. Our assessment of the suitability of available data sources in this area is that it is 'Underdeveloped'. This rating largely reflects the lack of data to describe comprehensively the full range of services currently being accessed by people with musculoskeletal conditions, or to understand the level of unmet demand for such services.

A number of available data sources provide an overview of the management and treatment services received by those with arthritis and other musculoskeletal conditions in specific selected settings. The main 4 sources are the National Hospital Morbidity Database (NHMD), the Australian Health Survey, the Survey of Disability, Ageing and Carers (SDAC) and the Australian Orthopaedic Association National Joint Replacement Registry. These sources collect data at the national level on a regular or continuing basis.

Various data sources can be used to describe the results of serious fractures. For example, data from the NHMD provide ongoing information about fractures requiring hospitalisation or surgery. Hip fracture is a serious and costly osteoporotic fracture suffered by older people. The Australian and New Zealand Hip Fracture Registry is being established to improve outcomes in hip fracture management. In the future, this registry could provide valuable information on the treatment and management of hip fracture (ANZHFR 2014).

A range of other data sources provide complementary data to help complete the picture of some management and treatment aspects of arthritis and other musculoskeletal conditions, including the Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice, the Geelong Osteoporosis Study (GOS) and the Australian Rheumatology Association Database (ARAD). These sources are limited in their ability to provide representative and/or comprehensive data.

The list of data sources reviewed does not include localised management and treatment programs throughout Australia, as they are not readily visible in national information. Although these programs may be a valuable resource to sufferers of arthritis and other musculoskeletal conditions, routine data collection for monitoring may not be undertaken and/or may be difficult to access. An example is the Osteoarthritis Hip and Knee Service (OAHKS) in Victoria established to improve management for people with osteoarthritis of the hip or knee. The OAHKS stemmed from a localised research project and in 2014 was currently operating in 14 hospitals in Victoria. It was also being applied in most other Australian states (Box 3.1).

Box 3.1: The Osteoarthritis Hip and Knee Service

The primary aims for treatment of established osteoarthritis of the hip and knee are to reduce symptoms, prevent disability, maintain or improve quality of life and ensure timely access to joint replacement surgery. Before 2006, Victorian patients experienced long waiting times to see an orthopaedic surgeon in public hospital outpatient clinics after referral by their GP, and even longer waiting times for surgery, if needed. There was also variation in the use of the joint replacement surgery categorisation system by surgeons and minimal management options offered to patients waiting to see the specialist or for surgery.

The OAHKS is a multidisciplinary service in which a musculoskeletal coordinator plays a key role, along with a prioritisation tool (the hip and knee questionnaire). Following a GP referral to an orthopaedic outpatient clinic, a patient completes the prioritisation tool, which is used to manage their position on the waiting list. The tool is completed at approximately 3-monthly intervals during the patient's time in the system.

While waiting, patients visit the osteoarthritis hip and knee clinic where they are seen by the coordinator who assesses the severity of their condition and need for conservative management. The coordinator may also determine if a referral to the surgeon is unnecessary because other management options are available, or if they require an urgent appointment.

Most coordinators are physiotherapists and the multidisciplinary team includes GPs, waiting list managers, other specialists (rehabilitation, mental health, and general medicine), surgeons, allied health and rheumatologists.

A range of benefits have been achieved through system and workforce changes, including:

- more appropriate use of limited specialist orthopaedic services, including deferral of patients not requiring surgery to appropriate conservative management
- early comprehensive assessment resulting in fast-tracking to surgical assessment as appropriate and/or early referral for conservative management
- active management of the elective surgery waiting list, including prioritisation to match patient need, and
- improved patient satisfaction (Victorian Department of Health 2013).

There is, however, limited data on clinical impact and cost-effectiveness.

Table 3.3: Assessment of data sources for monitoring prevention, management and treatment of arthritis and other musculoskeletal conditions

Key data source	Notes	Monitoring relevance
National Hospital Morbidity Database	Collects data on all hospitalisations (including procedures undertaken) related to specific arthritis and other musculoskeletal conditions. Ongoing/regular collection.	Representative national data providing comprehensive information
Australian Health Survey	Collects data on certain management undertaken for arthritis and osteoporosis. Ongoing/regular collection.	Representative national data providing comprehensive information
The Survey of Disability, Ageing and Carers	Collects data on some management aspects for arthritis and related disorders, combined back and neck pain and osteoporosis e.g. use of aids and appliances, disability support. Ongoing/regular collection.	Representative national data providing comprehensive information
Australian Orthopaedic Association National Joint Replacement Registry	Collects data on osteoporotic fracture or severe arthritis (primarily osteoarthritis) requiring joint replacement surgery. Ongoing/regular collection.	Representative national data providing partial information
Australian Longitudinal Study on Women's Health	Collects data on medications for arthritis and backache. Ongoing/regular collection.	Representative national data providing partial information
The Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice	Collects data on a range of treatment and management actions in GP settings related to specific arthritis and other musculoskeletal conditions. Ongoing/regular collection.	Non-representative national data
Geelong Osteoporosis Study	Collects data on use of medications and supplements for those with osteoporosis. Ongoing/regular collection.	Non-representative regional data
Australian Rheumatology Association Database	Collects data on some treatment aspects for inflammatory arthritis. Ongoing/regular collection; has limited coverage of patients.	Limitations with the use or interpretability of the data
Medicare Benefits Scheme	Main source of Australian data on primary care activities; however, cannot be traced to specific health conditions. Ongoing/regular collection.	Limitations with the use or interpretability of the data
Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme	Collects data on medication scripts filled; however, cannot be traced to specific health conditions except in some specific circumstances. Ongoing/regular collection.	Limitations with the use or interpretability of the data
Voice of Arthritis Social Impact Study	Collected data on satisfaction and perceived level of benefit with treatment and management for osteoarthritis and rheumatoid arthritis. No future data collections.	Limitations with the use or interpretability of the data
National Non-Admitted Patient Emergency Department Care Database	Collects data on presentations to emergency departments; however, information is not yet available on the health conditions. Ongoing/regular collection.	Limitations with the use or interpretability of the data
Non-admitted patient care aggregate national minimum data set specification	Collects data on occasions of service provided in selected hospitals and emergency departments by clinic type including orthopaedic outpatient clinics. Ongoing/regular collection.	Limitations with the use or interpretability of the data
Overall assessment of all available data sources		**Underdeveloped**

What information is missing?

Prevention

There is very little or no information about the prevention of arthritis and other musculoskeletal conditions either at the population or individual level. There is also is very little information on primary health care activity of relevance to early detection and ongoing effective management of these conditions, other than data collected through the BEACH Survey.

Management and treatment

While a number of data sources provide an overview of the management and treatment services received by those with arthritis and other musculoskeletal conditions, this information is incomplete and only available in selected settings. Gaps and limitations include:

- **Medicare and the PBS** data provide the main national administrative data collections for primary and specialist health care in the community. These national ongoing datasets provide information about GP, selected allied health care and medical specialist services reimbursed under Medicare, and pharmaceuticals attracting a government subsidy. They do not cover the whole primary health care sector (for example, not all allied health services, specialist services and home modifications and appliances), nor all pharmaceuticals (for example, not over-the-counter medications and supplements commonly used to manage musculoskeletal conditions). In addition to lack of coverage, these data sources cannot generally be used to describe the condition or problem being treated because there is no information about health condition in Medicare or Pharmaceutical Benefits Scheme (PBS) data.
- **BEACH Survey** collects information about reasons for GP visits, problems managed and medications prescribed by GPs. However, the survey has limitations due to its methodology, quality assurance processes and coverage. Consequently, findings with respect to musculoskeletal conditions need to be interpreted with some caution (refer to BEACH Data Quality Statement, AIHW forthcoming).
- **Allied health and self-management information.** There is currently no national data source for the range of allied health care interventions or self-management advice recommended for treating musculoskeletal conditions (for example, physiotherapy, provision of insoles, taping, physical exercise).

The limitations about primary health care information for musculoskeletal conditions are part of a broader concern with the relative lack of primary health care information in Australia. Primary health care has not experienced the same national focus on data capture, collation and reporting as other parts of the health system. As a result, there is:

- little or no information about why someone went to most primary health care professionals, what occurred during the consultation, what actions were recommended and taken and with what outcome and cost
- very limited national data (broad counts of patient contacts only) for ambulance, aero-medical services and allied health services (including those privately insured)
- no national data about state-funded community health activity
- great difficulty in routinely assessing the appropriateness of care with respect to clinical guidelines (see for example, Runciman et al. 2012) or effectiveness of care.

These limitations mean that it is not possible to describe accurately the full range of services currently being accessed by people with musculoskeletal conditions, or to understand the level of unmet demand for such services. Several studies suggest various barriers to the use of services available to treat musculoskeletal conditions (Box 3.1 and 3.2).

Box 3.2: Uptake of services for people with severe osteoarthritis

For people with 'end stage osteoarthritis', the use of conservative treatments is thought to be low. Management by GPs appears to be the most commonly used option, while options such as physiotherapy and rheumatology are used by few people or not at all. Reasons for lack of uptake may include:

- lack of knowledge about other services available by service providers such as GPs
- financial or other access barriers
- insufficient capacity in community health settings to meet demand (Osborne et al. 2006).

3.4 Key question 4—Health related quality of life

Why collect information about quality of life?

A person's health can be viewed as not merely the absence of disease, but as a combination of factors related to their physical, mental and social wellbeing. Quality of life is a broad concept used to summarise the wellbeing of individuals and societies. Understanding the quality of life of people with musculoskeletal conditions can be useful in comparing it with others who do not have these conditions and over time, particularly in relation to how quality of life may improve or deteriorate following health interventions, such as responses to different medications and treatments.

Understanding the quality of life of people with arthritis and other musculoskeletal conditions is particularly relevant given the long-term nature of these conditions, the presence of acute or chronic pain, possible limitations on daily living activities (such as self-care and mobility), work or recreational activities, and the established relationship between these conditions and psychological distress and mental health problems (see AIHW forthcoming).

While there is no universally agreed definition of what constitutes a 'good' quality of life, influences include physical health, psychological wellbeing, levels of independence and functioning, social support networks, material resources and personal beliefs. Broader policies, social inequalities and economic factors can also contribute (AIHW 2012a).

There are many ways to measure quality of life, including simply asking individuals how they feel about their life in general. While such a question is subjective, the answer generally reflects a combination of physical, psychological and cultural factors. For example, in the ABS 2007 National Survey of Mental Health and Wellbeing, respondents were asked how they felt about their life as a whole, taking into account what had happened in the past year and what was expected to happen in the future (AIHW 2012a). Details about a range of other quality of life measures and their complexities are available in the AIHW publication *Australia's health 2012* (AIHW 2012a).

What information is available?

The most relevant data sources for monitoring quality of life among people with arthritis and other musculoskeletal conditions are presented in Table 3.4. We assess data sources in this area as 'Very underdeveloped', mainly due to a lack of nationally representative data across the spectrum of musculoskeletal conditions.

Table 3.4: Assessment of data sources for monitoring quality of life associated with arthritis and other musculoskeletal conditions

Key data source	Notes	Monitoring relevance
Geelong Osteoporosis Study	Collects data on quality of life and mental health in relation to osteoporosis Ongoing/regular collection	Non-representative regional data
Australian Rheumatology Association Database	Collects data on quality of life in relation to inflammatory arthritis Ongoing/regular collection; has limited coverage of patients	Limitations with the use or interpretability of the data
North West Adelaide Health Study	Collects data on general quality of life, pain and ability to participate in work and social activities. No future data collections	Non-representative regional data providing partial information
The Tasmania Older Adult Cohort	Self-assessed quality of life, level of pain by joint/area (not necessarily related to arthritis or musculoskeletal conditions	Non-representative state data providing partial information
Optimising Patient Outcome in Australian Rheumatology	Collects data on quality of life in relation to inflammatory arthritis Ongoing/regular collection; has limited coverage of patients	Limitations with the use or interpretability of the data
Voice of Arthritis Social Impact Study	Non-representative data on impact of arthritis on quality of life, physical health, mental health, burden on family or carers and ability to participate in social events and paid work Data last collected in 2005 and no future data collections planned	Limitations with the use or interpretability of the data
Overall assessment of all available data sources		**Very underdeveloped**

What information is missing?

There are numerous other national data sources asking respondents about their health-related quality of life where these ratings cannot be linked to a specific health condition (for example, the Survey of Disability, Ageing and Carers).

Several emerging studies and methods could provide information on quality of life for specific musculoskeletal conditions. For example, the International Costs and Utilities Related to Osteoporotic Fractures Study (ICUROS) is an international patient-based study investigating the costs and health effects of osteoporotic fractures, including potential differences in quality of life and fracture-related costs. As Australia is one of the participating countries in this study, this may provide information on the costs and quality of life following hip fracture, vertebral fracture and wrist fracture (ICUROS 2011).

Numerous state-level programs are collecting and compiling information on quality of life. For example, the New South Wales Agency for Clinical Innovation is designing and implementing new models of care, such as through the Osteoarthritis Chronic Care Program. As part of this program, data will be collected to assess pain, quality of life, psychological status and disease-specific functional capacity for people with osteoarthritis (ACI 2014).

3.5 Key question 5—Death and disability

Why collect information about death and disability?

Arthritis and other musculoskeletal conditions are generally long-term chronic conditions associated with pain and disability but rarely death. Information about the disabling impact of these conditions is therefore of great interest. Information can be presented either for specific groups of musculoskeletal conditions or in summary measure form, as is done in 'burden of disease' studies.

Burden of disease studies provide a comprehensive summary assessment of the health status of Australians. The studies provide information about the health loss due to mortality and morbidity arising from all diseases and injuries in Australia, including for specific groups of diseases.

One measure of burden of disease is disability-adjusted life years or DALYs, which quantify years of life lost due to premature death, as well as years lived with disability from disease and injury. The DALY allows the effects of different diseases and injuries to be compared on an equal basis and the contribution of various risk factors to be assessed. One DALY is 1 year of life lost due to premature death, prolonged illness or disability, or a combination of these factors.

Further information on DALYs is available from *Australia's health 2012* (AIHW 2012a) and a description of how DALYs are calculated in *Australia's health 2010* (AIHW 2010). Further information on life expectancy and disability is outlined in *Changes in life expectancy and disability in Australia 1998 to 2009* (AIHW 2012b).

What information is available?

The suitability of available data sources for monitoring the extent death and disability are associated with arthritis and other musculoskeletal conditions is rated 'Well developed' (Table 3.5). The main limitation is the difficulty in quantifying accurately disability related to specific musculoskeletal conditions (for example, arthritis compared with other musculoskeletal conditions) or the presence of multiple chronic conditions. The Australian burden of disease information is also dated (2003), with more recent information expected in 2015.

For this aspect of the report the monitoring considers disability, death and burden of disease (as a summary measure of these two factors combined). The three data sources available are the Survey of Disability, Ageing and Carers; the National Mortality Database, and burden of disease studies.

Mortality data are collected by state/territory registrars of births, deaths and marriages and coronial services, coded to the International Classification of Diseases by the ABS, and made available to selected users by the Australian Coordinating Registrar under strict privacy restrictions. These data are ongoing, comprehensive and of high quality.

The Global Burden of Disease Study (2010) is the largest systematic attempt to describe the global distribution and causes of a wide range of major diseases, injuries and health risk factors. This study updates earlier burden of disease information about years of life lost due to premature death and years lived with disability from disease and injury.

The 2010 global study includes estimates for osteoarthritis, rheumatoid arthritis and neck and back pain but not for juvenile arthritis or osteoporosis (which is treated as a risk factor),

and provides information about how this burden varies across major regions of the world. The AIHW is undertaking a project to revise Australia's burden of disease estimates (last produced in 2007 using 2003 data), drawing on the Global Burden of Disease Study methodology, and results are expected in late 2015. The Australian study will include estimates for Indigenous Australians and sub-national estimates where valid, and will provide more detailed information about the burden of selected musculoskeletal conditions in the Australian context.

The Survey of Disability, Ageing and Carers collects data on disability in relation to the health conditions causing disability (main disabling condition), other major health conditions present, impairment level, activity limitations, employment or participation restriction and need for and receipt of assistance. The health conditions covered include osteoporosis, combined back and neck pain and arthritis and related disorders. The latest survey, issued in 2012, is the seventh national survey, following similar surveys in 1981, 1988, 1993, 1998, 2003 and 2009.

Table 3.5: Assessment of data sources for monitoring death and disability associated with arthritis and other musculoskeletal conditions

Key data source	Notes	Monitoring relevance
Survey of Disability, Ageing and Carers	Collects disability data on the level of impairments, activity limitations and participation restrictions for selected musculoskeletal conditions (arthritis and related disorders, combined back and neck pain and osteoporosis) Ongoing/regular collection	Representative national data providing comprehensive information
National Mortality Database	Collects mortality data on arthritis and other musculoskeletal conditions, noting that death is not commonly caused by these conditions. 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 Ongoing/regular collection	Representative national data providing comprehensive information
Burden of disease studies: Australian Burden of Disease Study (2003) and Australian results of Global Burden of Disease Study (2010).	Collects mortality and morbidity data to estimate years of life lost due to premature death and years of life lived with disability from disease and injury Episodic collection	Representative national data providing comprehensive information
Overall assessment of all available data sources		**Well developed**

What information is missing?

The key limitation with the national burden of disease information is that it is now becoming out of date, the latest Australian study being based on 2003 data. An update by AIHW is expected in late 2015. In addition, while information on disability caused by health conditions including arthritis and other musculoskeletal conditions is collected through the Survey of Disability, Ageing and Carers, other long-term chronic conditions experienced by participants may contribute to their assessment, which affects the ability to attribute disability directly to arthritis and other musculoskeletal conditions.

3.6 Key question 6—Health Expenditure

Why collect information about health expenditure?

Measuring health expenditure generally is important to find out:

- who finances the health system and where the funds are directed
- how much, on average, is spent on health for each Australian
- at what rate Australia's health expenditure is growing each year
- how fast health costs are rising and how this compares with general inflation
- how much investment there is in health facilities and equipment.

Health expenditure for sufferers of arthritis and other musculoskeletal conditions is of particular interest because the conditions are highly prevalent, long-term, a significant cause of disability and some treatments are expensive. Direct health expenditure in relation to arthritis and other musculoskeletal conditions relates to the costs incurred for prevention, diagnosis and treatment. Funding for these services comes from government and non-government sources, including from private health insurance and individuals.

Other non-health-care costs and indirect costs also accrue to patients, such as travel costs, social and economic burden on carers and family, and lost wages. Although these costs are not assessed in this report, specific reports do look at these costs, for example, *The rising cost of musculoskeletal conditions in Australia* (Arthritis and Osteoporosis Victoria 2013) and *Osteoporosis costing all Australians: a new burden of disease analysis – 2012 to 2022* (Watts et al. 2013).

What information is available?

The suitability of available data sources for monitoring expenditure associated with arthritis and other musculoskeletal conditions is assessed as 'Very underdeveloped' (Table 3.6), due to the limited and dated information available on the full amount spent on arthritis and other musculoskeletal conditions in Australia.

Table 3.6: Assessment of data sources for monitoring health expenditure associated with arthritis and other musculoskeletal conditions

Key data source	Notes	Monitoring relevance
The AIHW Disease Expenditure Database	Collects data on expenditure for admitted patient hospital services, out-of-hospital medical services and prescription pharmaceuticals for the umbrella term 'musculoskeletal disease' and broken down by categories (osteoarthritis, rheumatoid arthritis, back problems, osteoprosis and 'other') Limitations due to reliance on a range of data sources, particularly BEACH Survey data for modelling expenditure on out-of-hospital medical services and prescription pharmaceuticals for musculoskeletal conditions On-going/regular collection	Representative national data providing partial information
Medicare Benefits Scheme	Main source of Australian data on health expenditure but cannot be traced to specific health conditions (input to the AIHW Disease Expenditure Database) Ongoing/regular collection	Limitations with the use or interpretability of the data
Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme	Collects data on expenditure by the government on medication scripts filled, noting reason for use must be implied (input to the AIHW Disease Expenditure Database) Ongoing/regular collection	Limitations with the use or interpretability of the data
Voice of Arthritis Social Impact Study	Collects data on impact of osteoporosis and rheumatoid arthritis on financial position and impact of factors such as medication costs or effect of lost wages No future data collections	Limitations with the use or interpretability of the data
Overall assessment of all available data sources		**Very underdeveloped**

What information is missing?

The AIHW Disease Expenditure Database contains estimates of expenditure by disease category, age group and sex for admitted patient hospital services, out-of-hospital medical expenses, prescription pharmaceuticals, optometry and dental services, community mental health services and public health cancer screening. This source provides data in relation to musculoskeletal disease as an umbrella term and broken down by categories (osteoarthritis, rheumatoid arthritis, back problems, osteoprosis and 'other').

While this data source provides a broad picture of the use of health system resources classified by disease group, and is a reference source for planners and researchers interested in costs and use patterns for particular disease groups, it has several gaps and limitations. In particular, it does not cover expenditure on the full range of services used by people with musculoskeletal conditions. It does not include expenditure information about out-of-hospital services (such as publicly and privately funded allied health, community health services, and hospital outpatient services) or expenditure on non-prescription pharmaceuticals and supplements commonly used by people with these conditions.

Because there is no appropriate administrative data source, BEACH Survey data (based on a sample of GPs and their encounters with patients) are used in conjunction with other data sources (including Medicare and PBS data) to produce proxy estimates for out-of-hospital medical services and prescription pharmaceutical expenditure. In addition to reliance on survey data to apportion known expenditure, inferences from the AIHW Disease Expenditure Database are affected by other limitations, including a lack of information about most allied health expenditure and use of non-prescription pharmaceuticals. The overall expenditure estimates are therefore affected by these methodological constraints.

For these reasons, some caution is required in estimating the direct health expenditure on musculoskeletal conditions (in dollar terms), although the distribution of health expenditure across the above components (hospital, out-of-hospital and prescription pharmaceuticals) is generally regarded as useful information. Similarly, while the methodologies used to estimate expenditures for out-of-hospital medical expenses and prescription pharmaceuticals have remained unchanged, the current methodology means that time series comparisons for expenditure on musculoskeletal conditions should be made with caution.

Further data collection is also not guaranteed and relies on funding and the availability and quality of data sources. For further information about these limitations refer to *Health expenditure for arthritis and other musculoskeletal conditions* (AIHW 2014 forthcoming).

While studies are commissioned periodically to examine the broader costs to the individual or health system (beyond direct health expenditure) (for example Arthritis and Osteoporosis Victoria 2013 and Watts et al. 2013), there is no comprehensive, ongoing or nationally accepted methodology or data source for this information.

4 Discussion

The purpose of this report is to assess the potential for existing data sources to improve our understanding of arthritis and other musculoskeletal conditions. It is not intended to make value judgments about the selected data sources per se but to assess their utility to provide relevant information for these conditions. The methodological approach presented here can potentially be used to assess other data sources for different conditions and diseases.

For monitoring arthritis and other musculoskeletal conditions, 6 priority information areas are identified. This report identifies and assesses the current in-scope data sources available to help answer key questions in relation to these 6 priority information areas. Although many of the data sources identified were not developed specifically for the purpose of musculoskeletal monitoring, the report examines whether the existing data collected (and already resourced) could be used for this purpose.

The key questions for monitoring are:

1. **Risk factors:** What proportion of the population experience the modifiable risk factors associated with arthritis and other musculoskeletal conditions?
2. **Prevalence:** What is the prevalence of arthritis and other musculoskeletal conditions in the population?
3. **Prevention, management and treatment:** What prevention, management and treatment services do the population with arthritis and other musculoskeletal conditions receive?
4. **Quality of life:** How do arthritis and other musculoskeletal conditions affect an individual's quality of life?
5. **Death and disability:** How much death and disability is associated with arthritis and other musculoskeletal conditions?
6. **Health expenditure:** What is known about expenditure on arthritis and other musculoskeletal conditions?

To determine the suitability of current data collections in Australia, the following steps were undertaken:

Step 1: A stocktake of national and local data sources to identify 'in-scope' collections (Chapter 2).

Step 2: A detailed review of all in-scope collections (Chapter 2 and Appendix 1).

Step 3: An assessment of data sources to determine their relevance to each priority information area and their representativeness and completeness for this purpose (See Chapter 3).

Step 4: A comparative assessment of the overall strength of data for each priority information area.

This discussion summarises the outcomes of this comparative assessment (Step 4) in terms of the relative strength of available data in each of the 6 areas and outlines several opportunities for data development.

This comparative assessment is based on the number of relevant data sources, their individual ratings, and an overall assessment of the relative depth and breadth of data

available in each priority information area (spanning both nationally representative information and complementary information). To some extent this is an 'on balance' assessment, which takes into consideration the relative strength of information available across all of the priority information areas.

4.1 Comparative assessment

Priority information areas with the most developed data

Risk factors

Based on assessment of the identified in-scope data collections, Australia has very well developed data on most modifiable risk factors, particularly the broad lifestyle risk factors implicated for arthritis and other musculoskeletal conditions (for example, physical activity levels). However, data are less developed on risk factors for back problems (for example, psychosocial health, occupational risks associated with lifting, and other forms of injury). In addition, few nationally representative data sources follow populations over time to support examination of the link between risk factors and health. Most data sources rely on self-reported information, which can be biased or under- or over-reported. Overall, these limitations do not lessen the collective value of the data available on risk factors which is rated 'well developed'.

Overall rating: Very well developed for risk factor data

The assessment of risk factors information focuses only on factors that are modifiable. Non-modifiable risk factors, such as family history, age and sex, can help identify people at high risk of developing a disease so that prevention strategies and relevant medical services can be planned and located to best effect. However, because modifiable risk factors are amenable to change in the population, these were selected as the focus for this report.

Prevalence

There is also well developed data to monitor the prevalence of arthritis and other musculoskeletal conditions, with the exception of rarer conditions (for example juvenile idiopathic arthritis). As with information about risk factors, there are some limitations in that many of the key data sources rely on self-reported cases.

Overall rating: Very well developed for prevalence data

Many other questions related to prevalence may be answered through access to high-quality data. These include how the prevalence of arthritis and other musculoskeletal conditions varies according to the living conditions of the population (for example socioeconomic status and geographic remoteness), Indigenous status or country of birth, as well as how prevalence is changing over time. While not addressed in detail here, as the data tables in Appendix A demonstrate, for conditions where prevalence estimates are available it is also generally possible to undertake such analysis.

There are other questions about how many new cases of arthritis or musculoskeletal conditions are diagnosed each year (incidence) and at which stage of the disease progression they were diagnosed. This type of information is important to assess the effectiveness of

preventive health activity (early detection, intervention and early treatment) but is not currently available.

Priority information areas where data requires development

Death and disability

Data sources are well developed for producing information about disability associated with broad categories of musculoskeletal conditions. The main limitation is the difficulty in accurately quantifying disability related to specific musculoskeletal conditions (for example, arthritis compared with other musculoskeletal conditions) or where people have multiple chronic conditions. Methodology and data are also well developed about burden of disease estimates for selected musculoskeletal conditions. However, these are infrequently updated and often based on older data at time of release. Therefore, the data in this area are considered to be only moderately well developed.

Overall rating: Well developed for death and disability data

Prevention, management and treatment

Data sources to describe prevention, management and treatment are considered to be underdeveloped, particularly in relation to prevention activity and the use and appropriateness of care provided in primary health care settings. More information is available on the type of care provided to admitted hospital patients. However, most of the care for arthritis and other musculoskeletal conditions is delivered in GP, community and other primary health care settings for which no systematic data is available.

Identifying and managing the needs of at-risk or asymptomatic people is an important aspect of the continuum of care model presented in Figure 1.1 which includes the early recognition of symptoms and prompt referral to allied health professionals, specialists and education programs. Currently available information does not adequately support the development, implementation and evaluation of policies and interventions, in particular about early diagnosis and appropriate management.

This is a problem at various levels of the health system, including nationally, at the state/territory level and regionally. For example, Medicare Locals have been asked to see and remedy gaps in the needs of their community with respect to primary health care. Medicare Locals are a national network of 61 independent primary health care organisations working with local primary health care providers to plan health systems at the regional level.

Overall rating: Underdeveloped for prevention, management and treatment data

Information on who receives care is part of a broader set of questions about who needs, benefits from and demands care versus those who receive it. In asking questions about what services a population group receives with respect to musculoskeletal conditions, we are interested in what services they need, what services they pursue (demand) and the gap between these factors and what they receive. These questions cannot be adequately answered using available data. Similarly, it is not possible at present to use routinely available data to describe the effectiveness and appropriateness of care for people with musculoskeletal conditions.

Priority information areas where data are lacking

Quality of life and health expenditure

The data sources relating to the impact of arthritis and other musculoskeletal conditions on quality of life and health expenditure are very underdeveloped. While many sources consider quality of life in general, they are not specific about the impact of arthritis and other musculoskeletal conditions.

Only broad information is available on direct expenditure on arthritis and other musculoskeletal conditions, and estimating expenditure on primary health care and prescription pharmaceutical is limited by the lack of an appropriate administrative data source. In addition, the continuation of reporting on expenditure is not guaranteed.

Overall rating: Very underdeveloped for quality of life and health expenditure data

Information about health expenditure is one component of a broader set of questions about direct and indirect costs, costs to consumers versus costs to government, and health costs versus broader social costs. These aspects have not been investigated in this report.

Summary of findings

This report has shown that the data for monitoring arthritis and other musculoskeletal conditions in Australia are strongest in the areas of modifiable risk factors and prevalence; data are available but require development in the areas of prevention, management and treatment and death and disability; and there is a lack of data on quality of life and health expenditure (Table 4.1).

Table 4.1: Assessed data sources: overall rating with respect to each priority information area

Information area	Rating
Risk factors (modifiable)	Very well developed
Prevalence	Very well developed
Death and disability	Well developed
Prevention, management and treatment	Underdeveloped
Quality of life	Very underdeveloped
Health expenditure	Very underdeveloped

4.2 Future opportunities for data development

Effective monitoring of arthritis and other musculoskeletal conditions can contribute to efforts to relieve some of the burden of sufferers, their carers and the health care system. In view of the deficiencies in information about arthritis and other musculoskeletal conditions identified in this report, the following section suggests opportunities to improve national arthritis and other musculoskeletal conditions monitoring in Australia.

Data integration and linkage

By integrating existing data sources, for example through data linkage, it may be possible to provide a more complete picture of arthritis and other musculoskeletal conditions. Well-developed methods exist, with appropriate protections, that help maximise the utility

of existing data, allowing data collected once to be used multiple times. For example, the AIHW is one of only two accredited Commonwealth Integrating Authorities. This allows the AIHW to undertake data linkage work involving Commonwealth data under enhanced security processes and protocols. An example of such linkage could be linking PBS/RPBS data to other treatment and management information, which may provide insights into the results of taking certain pharmaceutical medication. At present such data are available only from a number of longitudinal studies, which are not always fully representative.

Improvements in primary health care data

Considerable limitations apply to primary health care data and information. This is particularly relevant because arthritis and other musculoskeletal conditions are predominantly managed in the primary health care setting. Improvements in this area are part of a broader need for information on primary health care utilisation and outcomes (see for example *Australia's health 2014*, AIHW forthcoming).

Data standards

Monitoring would be enhanced by improved consistency and comparability of data from different sources. This could be achieved (as has been done in relation to other conditions, for example, cancer) by developing data standards through stakeholder consultation. Such standards would include uniform data items, operational definitions and methods of reporting to be used as best practice. For example, standardisation is particularly needed in surveys that cover prevalence of arthritis and other musculoskeletal conditions.

Implementation of standard definitions for musculoskeletal conditions would also vastly improve the quality of information available (for example, about GP consultations and visits to allied health professionals).

Ongoing nature of collections

The high rating of data availability achieved for some priority information areas (for example, risk factors and prevalence) is due to the comprehensive information available from large, nationally representative surveys such as the Australian Health Survey and Australian Longitudinal Study on Women's Health. It is important that these data continue to be collected regularly in a comparable way to assess change over time.

While the AIHW Disease Expenditure Database offers some insight into the estimated cost of arthritis and other musculoskeletal conditions, the continuation of this data collection is not guaranteed.

Appendix A: Data sources template

The 27 data sources outlined in the Index are described using the following template.

Full name of the survey or data collection		
Type of data source		For example: survey type (registry or administrative) and scope (national, state or regional).
Brief description		Brief outline of data source and information relevant for monitoring musculoskeletal conditions.
Purpose(s)		Main stated purpose or purposes of the data source.
Collection methodology		Key features of the collection methodology (administrative or survey) and data collection method (computer-assisted telephone interview, self-completion, administrative).
Scope (theoretical coverage of relevant population)		Population that is potentially covered.
Coverage (actual)		Actual population covered (response rate).
Geographic coverage		National, state or other.
Frequency/timing		Year(s) in which data have been collected.
Basic collection count		For example: treatment episodes, separations, etc.
Size		Sample size or number of records in most recent reference period.
Collection management organisation		The organisation chiefly responsible for collecting and managing the data.
Further information		A web link with further information.
Priority information areas	Risk factors	Modifiable and not.
	Prevalence and incidence	Prevalence and incidence, injury (osteoporotic fracture) and severity.
	Prevention, treatment and management	Prevention, treatment and management (in General Practice, other primary health care, specialist and hospital settings and medication use).
	Quality of life	Includes pain, disability, functioning, problems at school, work disability, loss of productivity, social participation, and mental health, carer impacts.
	Death and disability	Disability, death and burden of disease (as a summary measure of these two factors combined).
	Expenditure, costs	To the individual, family members or carers and the health system.
	Population demographics	For example: age, sex, location (remoteness and socioeconomic status can be generated from location in some cases), Indigenous status, marital status.

Appendix B: Index of in-scope data sources

1. AIHW Disease Expenditure Database 41
2. Australian Health Survey (AHS), 2011–13 43
3. Australian Longitudinal Study of Ageing (ALSA) (SA) 46
4. The Australian Longitudinal Study on Women's Health (ALSWH) 48
5. Australian Orthopaedic Association National Joint Replacement Registry 50
6. Australian Rheumatology Association Database (ARAD) 52
7. The Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice 54
8. Burden of disease studies 56
9. The Concord Health and Ageing in Men Project (CHAMP) 58
10. Dubbo Osteoporosis Epidemiology Study (DOES) 60
11. Florey Adelaide Male Ageing Study (FAMAS) 62
12. Footprints in time: The Longitudinal Study of Indigenous Children (LSIC) 64
13. Geelong Osteoporosis Study (GOS) 66
14. Growing up in Australia: The Longitudinal Study of Australian Children (LSAC) 68
15. Medicare Benefits Scheme (Medicare) data 70
16. National Drug Strategy Household Survey 72
17. National Hospital Morbidity Database (NHMD) 74
18. National Mortality Database (NMD) 76
19. National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD) 78
20. Non-admitted patient care aggregate national minimum data set specification (NMDS) 80
21. North West Adelaide Health Study (NWAHS) 82
22. Optimising Patient outcome in Australian rheumatoLogy (OPAL) – Quality Use of Medicines Initiative (QUMI). 84
23. Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) data 86
24. The Survey of Disability, Ageing and Carers (SDAC) 88
25. The Tasmanian Older Adult Cohort (TASOAC) 91
26. Voice of Arthritis Social Impact Study 93
27. The 45 and Up Study 95

Appendix C: In-scope data sources

1. AIHW Disease Expenditure Database	
Type of data source	Derived (national).
Brief description	The AIHW Disease Expenditure Database contains estimates of expenditure by disease category for: admitted patient hospital services; out-of-hospital medical services; prescription pharmaceuticals; optometry and dental services; community mental health services, and public health cancer screening. The method used to estimate direct health expenditure is generally a 'top–down' approach (except for hospital admitted patient services data) where total expenditure across the health system is estimated and then allocated to the relevant conditions. This method yields consistency, good coverage, and totals that add up to known expenditures, but it is not as sensitive or accurate for any specific disease as a detailed 'bottom–up' analysis of actual costs incurred by patients with that disease may provide. A 'bottom-up' approach in allocating disease expenditure faces several practical difficulties. For example, expenditure such as capital expenses or expenses for general aids and medical appliances cannot be attributed to specific conditions. There is also a lack of available data to link the broad expenditure costs of a particular disease to items such as over-the-counter pharmaceuticals and non-admitted patient services. The Disease Expenditure Database contains a conservative estimate of total expenditure and equates to around 70% of total recurrent health expenditure.
Purpose	A useful source for planners and researchers interested in the costs for particular disease groups.
Collection methodology	Estimates are derived from combining information from the NHMD, the National Public Hospitals Establishments Database, the Health Expenditure Database, the National Hospital Cost Data Collection and the BEACH survey.
Scope (theoretical coverage of relevant population)	Includes admitted patient hospital services; out-of-hospital medical services; prescription pharmaceuticals; optometrical and dental services; community mental health services; and public health cancer screening.

1. AIHW Disease Expenditure Database (Cont.)		
Scope (theoretical coverage of relevant population) (Cont.)		It is not possible to allocate all expenditure on health goods and services by disease. Expenditure not allocated by disease includes: capital expenditure; non-admitted patient hospital services; over-the-counter drugs; other health practitioner services (except optometry); community health services expenditure (except community mental health); expenditure on public health programs (except cancer screening programs); health administration; health aids and appliances; and patient transport (ambulance).
Coverage (actual)		Approximately 70% of total recurrent health expenditure.
Geographic coverage		All states and territories, Australia.
Frequency/timing		2008-09, 2004-05, 2000-01. Future releases are dependent on the availability of data and funding.
Basic collection count		Expenditure (Australian dollars).
Size		Not applicable.
Collection management organisation		AIHW.
Further information		<http://meteor.aihw.gov.au/content/index.phtml/itemId/512599>.
Priority information areas	Risk factors	No data.
	Prevalence and incidence	No data.
	Prevention, treatment and management	No data.
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	Estimates are available for the following areas of expenditure: admitted patient hospital services, out-of-hospital medical services, prescription pharmaceuticals. This source provides data in relation to musculoskeletal disease as an umbrella term and broken down by categories (osteoarthritis, rheumatoid arthritis, back problems, osteoprosis and 'other').
	Population demographics	Age and sex.

2. Australian Health Survey (AHS), 2011–13	
Type of data source	Survey (national).
Brief description	The AHS 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. The AHS has several components: the National Health Survey (NHS) together with two new elements - a National Nutrition and Physical Activity Survey (NNPAS) and a National Health Measures Survey (NHMS). It was not possible for a person to be selected in both the NHS and NNPAS. The NHS collected information about doctor-diagnosed osteoarthritis, rheumatoid arthritis, other arthritis, gout, osteoporosis, osteopenia, back pain or back problems and other musculoskeletal conditions. Information was gathered about whether the condition was current, and whether it had lasted or was likely to last for 6 months or more. The NNPAS collected information on nutrition and physical activity. Following completion of the NHS or NNPAS, respondents were invited to participate in the voluntary NHMS. Blood and urine samples were collected from people aged 12 and over, and for children aged 5-11 urine samples only were requested. Relevant to research on musculoskeletal conditions, the blood samples were tested for Vitamin D levels. The 2011-12 AHS Core comprises a combined data file of both the NHS and NNPAS, containing data items that are common to both surveys. Information on selected long-term health conditions including cardiovascular disease, diabetes and kidney disease was collected from both surveys. However, information on musculoskeletal conditions was not collected from NNPAS. Also part of the AHS, the Australian Aboriginal and Torres Strait Islander Health Survey (AATSIHS) includes an additional representative sample of about 13,000 Aboriginal and Torres Strait Islander people. This is a separate collection for Aboriginal and Torres Strait Islander people living in remote and non-remote areas, including discrete communities. The AATSIHS comprises the 2012-13 National Australian Aboriginal and Torres Strait Islander Health Survey (NATSIHS), the 2012-13 National Aboriginal and Torres Strait Islander Nutrition and Physical Activity Survey (NATSINPAS) and the National Aboriginal and Torres Strait Islander Health Measures Survey (NATSIHMS). Similar to the 2011-12 AHS Core, the AATSIHS Core comprises a combined sample from the NATSIHS and NATSINPAS.
Purpose	To collect information about the health status of Australians, their use of health services and health risk factors.

2. Australian Health Survey (AHS), 2011–13 (Cont.)	
Collection methodology	Information was collected by trained ABS interviewers, through computer-assisted personal interview, computer-assisted telephone interview and biomedical testing at a pathology collection centre.
Scope (theoretical coverage of relevant population)	A representative sample of Australians. For the 2011-13 AHS, persons in scope of the survey were those identified by an adult within each sampled private dwelling as a usual resident of that dwelling. Private dwellings are houses, flats, home units, caravans, garages, tents and other structures being used as a place of residence at the time of the survey. For the NHS and NNPAS, *Very remote* areas were not covered, nor were non-private dwellings such as hotels, motels, hostels, hospitals, nursing homes and short-stay caravan parks. The survey scope does not cover hospitals, nursing homes or similar accommodation and so it is likely to under-represent those with more severe complications of musculoskeletal conditions, and the elderly. The NATSIHS was conducted in more than 5,000 private dwellings selected in remote and non-remote areas throughout Australia, including discrete communities. The sample was designed to provide reliable Aboriginal and Torres Strait Islander estimates for the whole of Australia, for states and territories, for the Torres Strait, and remote and non-remote areas to a similar level of accuracy to NATSIHS 2004-05.
Coverage (actual)	The sample was designed so that within each state or territory, each person had an equal chance of selection and reliable estimates could be produced for each state and territory.
Geographic coverage	All states and territories, Australia. *Very remote* areas were not included in the NHS and NNPAS surveys.
Frequency/timing	The AHS was collected between 2011 and 2013 with results to be released progressively from 2012 to 2014. The NHS was conducted in 1989–90, 1995, 2001, 2004–05 and 2007–08; the NATSIHS survey was conducted in 2004-05 and 2007-08, and the National Nutrition Survey was conducted in 1995.
Basic collection count	Persons in households.
Size	The NHS sample comprised 20,426 persons. The NNPAS sample comprised 12,153 persons. The AHS Core has a combined sample of 25,080 households and 31,837 respondents aged 2 and over. The NATSIHS sample comprised 9,317 persons. The AATSIHS sample size has not yet been released but a total sample of 13,000 is expected.
Collection organisation	ABS.
Further information	<http://www.abs.gov.au/ausstats/abs@.nsf/PrimaryMainFeatures/4363.0.55.001?OpenDocument>.

2. Australian Health Survey (AHS), 2011–13 (Cont.)		
Priority information areas	Risk factors	Smoking, alcohol use, physical activity (including data from a pedometer), long-term health conditions, diet (including consumption of milk), BMI, measured Vitamin D levels.
	Prevalence and incidence	Prevalence estimates for doctor-diagnosed osteoarthritis, rheumatoid arthritis, gout, osteoporosis, osteopenia, and back pain or back problems.
	Prevention, treatment and management	If participants answered 'yes' to being diagnosed with arthritis, osteoporosis or osteopenia, they were asked if they took a range of actions for their condition in the last 2 weeks e.g. weight/strength/resistance training. Information on medications was also collected. Participants with osteoporosis/osteopenia were asked whether they had had their bone mineral density tested and if 'yes', whether this was performed in the last 2 years.
	Quality of life	Participants aged 15 and over in the AHS were asked whether in general they felt their health was: excellent, very good, good, fair, poor. Data was also collected on psychological distress, bodily pain and disability status. Note these questions were not asked specifically in relation to a musculoskeletal condition. Participants were asked about their days away from work or study/school due to ill health and restriction in everyday activities in relation to their musculoskeletal condition.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Age, sex, Indigenous status, place of usual residence, country of birth of respondent and year of arrival in Australia, country of birth of parents, main language spoken at home, proficiency in spoken English, educational qualification, occupation, marital status, household composition.

3. Australian Longitudinal Study of Ageing (ALSA) (SA)	
Type of data source	Longitudinal (state).
Brief description	The ALSA is a cohort study investigating chronic disease, health and wellbeing. The study gathers both self-reported and bio-medically measured information on people living in South Australia. The study includes questions on history of low-trauma fractures. Bone densitometry scans were carried out in 1992, 1994 and 2008 in ancillary clinical studies. The study gathers information on the following conditions (not only doctor-diagnosed): arthritis, osteoporosis, spinal problem, slipped/ruptured disc, gout, broken or fractured hip, other musculoskeletal problem.
Purpose(s)	The general purpose of the study is to gain an understanding of how social, biomedical and environmental factors are associated with age-related changes in health and well-being of people aged 70 and over.
Collection methodology	At baseline (1992), a comprehensive personal interview and assessment of neuropsychological and physiological functions was undertaken at each person's home, supplemented by questionnaires, biochemistry, and additional clinical studies of physical function. Since then a further 11 waves have been completed (some consisting of short telephone interviews). Data was linked from the Health Insurance Commission on Medicare Benefits Scheme and Pharmaceutical Benefits Scheme resource use and expenditure data for 439 participants for the period 2001-2004.
Scope (theoretical coverage of relevant population)	The sample was drawn from the South Australian Electoral roll. In scope were individuals born before 30 June 1922, and their spouses (aged 65 or over in 1992) or co-residents (aged 70 or over in 1992).
Coverage (actual)	2,705 individuals drawn from the electoral roll were eligible for inclusion, and 1,477 were recruited (55%). For the recruited individuals, there were 879 eligible spouses and 24 eligible household members, of whom 597 spouses and 13 household members were recruited (68%). In full, 2,087 individuals were recruited. By 2005 there were 349 participants (85.1% of surviving participants.)
Geographic coverage	South Australia.
Frequency/timing	Began in 1992 and followed up in 1993, 1994, 1995, 1996, 2000, 2003, 2005, 2008, 2009, and 2010. The study is continuing through a new project titled *Resilient ageing and the oldest-old in the Australian Longitudinal Study of Ageing*.

3. Australian Longitudinal Study of Ageing (ALSA) (SA) (Cont.)		
Collection management organisation		The Centre for Ageing Studies, Flinders University.
Further information		<http://www.flinders.edu.au/sabs/fcas/alsa/>.
Basic collection count		Persons.
Priority information areas	Risk factors	Comorbidity, diet, body mass index, waist circumference, smoking, alcohol, exercise, vitamin D in blood sample.
	Prevalence and incidence	Prevalence of osteoporosis and osteopenia measured by bone densitometry, history of low-trauma fractures.
	Prevention, treatment and management	Overnight hospital stay by condition.
	Quality of life	Self-rated health, self-rated quality of life, assistance with daily tasks, mobility, psychological - attitudes and views (control, morale, self-esteem, metamemory), emotional health.
	Death and disability	No data.
	Expenditure, costs	Limited information.
	Population demographics	Age, sex, area of residence, education level, employment, retirement, Indigenous status, nationality, language spoken at home, living arrangements.

4. The Australian Longitudinal Study on Women's Health (ALSWH)	
Type of data source	Longitudinal survey (national)
Brief description	The ALSWH assesses women's physical and mental health, as well as psychosocial aspects of health (such as socio-demographic and lifestyle factors) and their use of health services.
Purpose(s)	To provide data about the health of women across the lifespan, in order to inform federal and state government health policy.
Collection methodology	In April 1996, women in three age groups - 18-23 (born 1973-78), 45-50 (born 1946-51), and 70-75 (born 1921-26) were selected from the Medicare database, which contains the name and address details of all Australian citizens and permanent residents. These women were invited to participate and more than 40,000 agreed to take part in the project for at least 20 years. From 1996 to 2011, each age cohort was surveyed about once every three years by postal surveys. In 2011, the 1921-26 cohort began receiving a shortened survey every six months. From 2012 onwards the 1973-78 and 1946-51 cohorts have been offered the choice of completing the survey online. In 2012-13 the ALSWH has recruited a new cohort of young women, born 1989-94 (aged 18-23 at the time of completing the survey), who will be surveyed annually using an online survey. Data from sub-studies on the ALSWH women include women with arthritis and other musculoskeletal conditions. These sub-study data include additional questionnaires and assess extra variables. Sub-study data are archived by the ALSWH and may be made available to external investigators with the permission of the original researchers. The ALSWH has approval to access a number of national and state-based external data sets: • Medical Benefit Schedule (MBS) • Pharmaceutical Benefits Scheme (PBS) • National Death Index • Perinatal data collections • Cancer registries • Admitted patients data collections. De-identified data can be linked with the ALSWH data to improve researchers' ability to investigate the health of Australian women. Sampling from the population was random within each age group. Women from rural and remote areas were sampled at twice the rate of women in urban areas so that the numbers of women living outside major urban areas were large enough to allow statistical comparisons with women living in major urban areas.

4. The Australian Longitudinal Study on Women's Health (ALSWH) (Cont.)		
Scope (theoretical coverage of relevant population)		Australian women on Medicare database aged 18-23, 45-50, 70-75 in 1996, and from 2013, women aged 18-23 in 1989-94.
Coverage (actual)		40,394 women in the original sample in 1996, which is broadly representative of the Australian female population. A new cohort of at least 14,000 women aged 18-23 is being recruited in 2012 and 2013.
Geographic coverage		Australia.
Frequency/timing		Began in 1996 and to continue until at least 2016.
Basic collection count		Persons.
Size		The most recent (6th) surveys had the following survey sizes: 1973-78 cohort in 2012: 8,008; 1946-51 cohort in 2010: 10,011; 1921-26 cohort in 2011: 4,055. Since the 1921-26 cohort has undergone 6-month surveys at least 3830 participants have responded at least once.
Collection management organisation		The University of Newcastle and the University of Queensland, funded by the Department of Health.
Further information		<http://www.alswh.org.au/about/about-the-study>.
Priority information areas	Risk factors	Age, diet, leisure time, physical activity, sitting time, smoking, alcohol, other drugs, comorbidities, menopausal status.
	Prevalence and incidence	Self-reported doctor-diagnosed prevalence of osteoarthritis, rheumatoid arthritis, 'other arthritis', osteoporosis and 'other'. Self-diagnosed back pain. Major diagnoses and symptoms (of particular relevance is frequency of joint pain and stiffness). Fractures in the elderly (likely to be osteoporotic fractures).
	Prevention, treatment and management	Visits to GPs, specialists, hospital and other health services. The accessibility and level of satisfaction with health services. Medications for arthritis and backache. Linked data from the PBS and Medicare databases.
	Quality of life	Self-reported wellbeing using the Short-Form 36 (SF-36).
	Death and disability	Linked data from National Death Index. Linked data from Admitted Patients Data Collections and cancer registries.
	Expenditure, costs	Linked data from the Medicare (MBS and PBS) databases.
	Population demographics	Sociodemographic factors (location, country of birth, education, employment, family composition, income, how women manage on their available income), time use (including paid and unpaid work and family roles) and life stages and key events (such as childbirth, divorce, death of a spouse). Linked data from the perinatal data collections.

5. Australian Orthopaedic Association National Joint Replacement Registry	
Type of data source	Registry (national).
Brief description	Information on primary and revision joint replacement surgery is collected from all hospitals in Australia. The information covers patient characteristics, prosthesis type and features, method of prosthesis fixation, surgical technique used and the reason for joint replacement. Revision procedures are matched to primary procedures held by the registry. Combined with a careful analysis of the timing, type and reasons for revision this is an accurate measure of the success or otherwise of a procedure. The impact of patient, surgeon and device factors can be determined. The registry also monitors mortality rates. This information is then used to inform surgeons, other health-care professionals, governments, orthopaedic companies and the community.
Purpose(s)	The purpose of the registry is to improve and maintain the quality of care for individuals receiving joint replacement surgery.
Collection methodology	Hospitals provide data on specific registry forms. The paper forms are completed in theatre at the time of surgery and are returned to the registry each month. The registry has extensive internal and external validation checks. External validation for data collected from individual hospitals is undertaken by comparing it with data provided by state and territory health departments.
Scope (theoretical coverage of relevant population)	All cases of hip, knee, shoulder, elbow, wrist and ankle replacement surgery in Australian hospitals.
Coverage (actual)	Close to complete. Patients can opt out by contacting the registry co-ordinator.
Geographic coverage	All states and territories, Australia.
Frequency/timing	The ongoing registry was established in 1999 and became fully national in mid-2002.
Basic collection count	Procedure.
Size	More than 90,000 people have joint replacement surgery each year.
Collection management organisation	Australian Orthopaedic Association and the Data Management & Analysis Centre University of Adelaide which is subcontracted by AOA to manage and analyse data.
Further information	<http://www.aoa.org.au/>.

5. Australian Orthopaedic Association National Joint Replacement Registry (Cont.)		
Priority information areas	Risk factors	No data.
	Prevalence and incidence	Diagnosis – subcaptial fractured neck of femur, major joint disease including severe osteoarthritis, rheumatoid arthritis, other inflammatory arthritis, osteonecrosis and other joint pathology requiring joint replacement surgery.
	Prevention, treatment and management	Joint replacement surgery. Reason for both primary and revision joint replacement is captured. Through procedure linkage the registry is able to identify both best and worst practice.
	Quality of life	Some data.
	Death and disability	No data.
	Expenditure, costs	Prosthesis cost per procedure.
	Population demographics	Age, gender, laterality, location - detailed address enabling SEIFA analysis.

6. Australian Rheumatology Association Database (ARAD)	
Type of data source	Registry (national).
Brief description	The Australian Rheumatology Association Database (ARAD) is a national database developed to follow patients with inflammatory arthritis commencing treatment with biological disease modifying anti-rheumatic drugs (bDMARDs) following consultation with a rheumatologist. Included in the database are patients with rheumatoid arthritis, juvenile idiopathic arthritis, ankylosing spondylitis and psoriatic arthritis who started treatment with bDMARDs. 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 markers of inflammation (including erythrocyte sedimentation rate and C-reactive protein and rheumatoid factor status).
Purpose(s)	The aim of the ARAD is to determine effectiveness and safety of new biological drugs used to treat inflammatory arthritis.
Collection methodology	The ARAD collects information from patients every 6 months by questionnaires. Permission is sought to collect information from state and national registries.
Scope (theoretical coverage of relevant population)	Patients of participating rheumatologists. The study focuses on patients with inflammatory arthritis commencing treatment with bDMARDs, but also includes patients with inflammatory arthritis not taking this class of drugs, included as a control group.
Coverage (actual)	As at December 2013, 3,170 participants had completed questionnaires and a further 2,112 had agreed to allow information to be gathered from state and national registries. Out of 342 registered rheumatologists in Australia, 268 are participating in ARAD.
Geographic coverage	Australia.
Frequency/timing	The database was started in 2002.
Basic collection count	Person.
Size	As at July 2013, there were more than 5,000 participants and more than 30,000 completed questionnaires.
Collection management organisation	Australian Rheumatology Association, with support from Monash University and Cabrini Health.
Further information	<http://www.arad.org.au/Public/Home.aspx>.

6. Australian Rheumatology Association Database (ARAD) (Cont.)		
Priority information areas	Risk factors	Some information on comorbid conditions.
	Prevalence and incidence	No data.
	Prevention, treatment and management	Some information on treatment history, including medication use, hospitalisation and adverse drug reactions.
	Quality of life	Self-assessed quality of life.
	Death and disability	Some data on disability burden via self-assessed quality of life tools.
	Expenditure, costs	Some data on over the counter and complementary medicine use. It's also possible to link to the Pharmaceutical Benefits Scheme regarding drug utilisation, and to the Medicare Benefits Schedule regarding health services utilisation.
	Population demographics	Patient location.

7. The Bettering the Evaluation and Care of Health (BEACH) Survey of General Practice	
Type of data source	Survey (national).
Brief description	The BEACH Survey of General Practice is an ongoing survey of the clinical activities of GPs. BEACH involves collecting details from about 100,000 GP-patient encounters per year, from an ever-changing random sample of 1,000 GPs. The survey collects data relevant to arthritis and other musculoskeletal conditions including the patients' reasons for encounter, problem managed and management actions applied to the problems, including pharmacological and non-pharmacological treatments prescribed. It includes a component where additional questions are asked of patients in subsamples of encounters, called the Supplementary Analysis of Nominated Data (SAND). Different questions are asked in each 5-week recording block. The SAND component asks more detailed questions for people with specific conditions, in some cases musculoskeletal conditions.
Purpose(s)	The BEACH Program continuously collects information about the clinical activities in general practice in Australia including: • characteristics of GPs • characteristics of patients at encounters • reasons people seek medical care • problems managed. For each problem managed the following information is gathered: • medications prescribed, advised, provided • clinical treatments and procedures provided • referrals to specialists and allied health services • test orders including pathology and imaging.
Collection methodology	Collection is continuous with 20 GPs responding per week. Each GP reports on 100 consecutive consultations. All consultations are recorded if they result in a management action e.g. prescription, referral, etc., including indirect consultations such as those by telephone. A paper-based data collection system is used. Encounters are weighted according to each GP participant's Medicare claims activity for the year. Information is available in annual publications, or in detail through data request submissions.
Scope (theoretical coverage of relevant population)	Random sample of 1,000 GPs annually across Australia, selected from Medicare records collecting information on almost 100,000 GP patient encounters. In 2009 in Australia, there were 25,707 practising primary care practitioners (vocationally recognised GPs and other medical practitioners).

7. The BEACH Survey of General Practice (Cont.)		
Coverage (actual)		There is an incentive for GPs to fill in the survey. Participating GPs earn clinical audit points towards their Quality Improvement and Continuing Professional Development requirements through the Royal Australian College of General Practitioners and/or the Australian College of Rural and Remote Medicine. From April 2011 to March 2012 inclusive, 984 practising GPs responded, of 3,644 GPs initially contacted.
Geographic coverage		All states and territories, Australia.
Frequency/timing		The BEACH survey began in 1998 and is undertaken continuously with results released annually.
Basic collection count		GP encounters.
Size		From April 2011 to March 2012 inclusive, 984 practising GPs responded, of 3,644 GPs initially contacted. Each collects data from 100 consecutive consultations.
Collection management organisation		The Family Medicine Research Centre, University of Sydney.
Further information		<http://sydney.edu.au/medicine/fmrc/beach/>.
Priority information areas	Risk factors	For about 33,000 patients a year, the following measures are recorded: height and weight (giving BMI), smoking status, and alcohol consumption. For about 3,000 children aged 2–17 height and weight (giving BMI) are recorded. These risk behaviours can be analysed specifically for patients for whom arthritis and/or other musculoskeletal problems were managed.
	Prevalence and incidence	Estimates of prevalence for all chronic conditions are made on the basis of the SAND substudies, sampling usually 8,000—12,000 in a single year, providing prevalence in patients attending a GP, among all patients who attended a GP at least once that year, and in the population at large.
	Prevention, treatment and management	Treatment and management provided by a GP, including medications prescribed, advised, provided; clinical treatments and procedures provided; referrals to specialists and allied health services, and test orders including pathology and imaging.
	Quality of life	No data.
	Death and disability	No data.
	Expenditure	No data.
	Population demographics	Age, sex, Indigenous status, non-English-speaking background (language other than English spoken at home).

8. Burden of disease studies: the Australian Burden of Disease Study (2007 – using 2003 data) and the Australian results of the Global Burden of Disease Study (2010)	
Type of data source	Derived (national).
Brief description	Burden of disease studies provide a comprehensive assessment of the health of Australians. The studies provide information about health loss due to mortality and health loss due to disability. Burden of disease studies use a metric called the disability-adjusted life year or DALY to quantify years of life lost due to premature death, as well as years of life lived with disability from disease and injury. Burden of disease analysis provides detailed estimates of the burden of mortality and disability for each disease and injury category by sex and age. It also assesses the burden attributable to major risk factors.
Purpose(s)	To assess and compare the relative impact of different diseases and injuries on populations.
Collection methodology	Prevalence, incidence, duration and severity by disease or injury are estimated based on any available information, such as survey, registry and administrative data. Mortality data are drawn from vital registrations. Disease weights in the 2010 Global Burden of Disease Study were derived from large-scale household surveys across 5 countries and an internet survey. Disease weights used in the 1990 global and 2003 Australian studies were assigned based on advice from focus groups of health experts. (Disease weights are used in the calculation of YLD. They quantify social preferences for different states of health). This information was brought together to calculate YLL, YLD and DALY measures.
Scope (theoretical coverage of relevant population)	All Australians (including an Indigenous analysis in the Australian Burden of Disease Study).
Coverage (actual)	Gaps in the data mean that the coverage is not complete.
Geographic coverage	Australia.
Frequency/timing	The Australian study was published in 1999 and 2007. The next study is expected to be published in late 2015. The global study was published in 1990, 2000-02, 2004, 2010 and most recently in 2012-13.
Basic collection count	DALYs, YLLs, YLDs.
Size	Not applicable.

8. Burden of disease studies (Cont.)		
Collection management organisation		Australian Burden of Disease Study, next issue: AIHW; 2007 issue: School of Population Health, University of Queensland and AIHW. Global Burden of Disease Study: 2010 (Institute for Health Metrics and Evaluation). 1990 WHO (World Health Organization).
Further information		Australian Burden of Disease Study, next issue: <http://www.aihw.gov.au/burden-of-disease/>. Global Burden of Disease Study: <http://www.healthmetricsandevaluation.org/>.
Priority information areas	Risk factors	The 2010 Global Burden of Disease Study contains information on occupational risks in relation to arthritis and other musculoskeletal conditions.
	Prevalence and incidence	No data.
	Prevention, treatment and management	No data.
	Quality of life	No data.
	Death and disability	Years of life lost due to premature death, as well as years of life lived with disability from disease and injury. Specifically includes burden of disease data for arthritis and other musculoskeletal conditions (not osteoporosis or juvenile arthritis).
	Expenditure, costs	No data.
	Population demographics	2007 Australian Burden of Disease Study: Results presented by age, sex, socioeconomic status, remoteness, state or territory of residence, Indigenous status. 2010 Global Burden of Disease Study: results presented by age, sex, time (time series available to 1990).

9. The Concord Health and Ageing in Men Project (CHAMP)	
Type of data source	Longitudinal (regional).
Brief description	The CHAMP is a longitudinal study of ageing in men. Doctor-diagnosed osteoporosis is one of the focuses, as is the measurement of bone mineral density (BMD). The researchers note that men in this study are representative of the age and ethnicity of men in the area (inner west Sydney) and have similar health characteristics to older men in the nationally representative MATeS study. Nevertheless, it is likely that frailer men in poor health are less likely to have participated in the study, resulting in an underestimation of the prevalence of fractures and of low BMD.
Purpose(s)	To examine chronic disease and ageing among older males, focusing on cognitive impairment and dementia; falls, fractures and osteoporosis; and urinary problems.
Collection methodology	Names were selected from the NSW electoral roll. Men living in residential aged care facilities were excluded. Self-completed questionnaire and clinical assessments were made of physical performance measures, neuropsychological testing and medication inventory. Following initial baseline assessment, the men were contacted by telephone at 4-monthly intervals to update data on falls, fractures hospitalisation and institutionalisation.
Scope (theoretical coverage of relevant population)	Men aged 70 or over living in three local government areas (Burwood, Canada Bay and Strathfield) in inner west Sydney.
Coverage (actual)	Contact was made with 2,815 eligible men, and 1,511 participated in the study (54%). An additional 194 eligible men volunteered to take part. In total, 1,705 men were recruited in the first stage of the study.
Geographic coverage	Three local government areas in inner west Sydney: Burwood, Canada Bay and Strathfield.
Frequency/timing	Recruitment and clinical assessments between 2005 and 2007 with follow-up phone interviews every four months. Five-year follow-up examinations were completed in 2013. Funding for a 7-year follow-up has been obtained.
Basic collection count	Persons.
Size	1,705 men recruited in the first stage, with data for 1,367 and 955 men at the 2- and 5-year follow-ups respectively.
Collection management organisation	Concord Clinical School, the University of Sydney.
Further information	<http://sydney.edu.au/research/opportunities/opportunities/48>.

9. The Concord Health and Ageing in Men Project (CHAMP) (Cont.)		
Priority information areas	Risk factors	Smoking, alcohol consumption, physical activity, comorbidity, medication use (all prescription and non-prescription medications).
	Prevalence and incidence	Prevalence of osteoporosis and osteopenia based on BMD of the hip and spine, measured by dual X-ray absorptiometry, self-reported minimal trauma fractures over the previous 10 years. New fractures are identified during 4-monthly phone calls.
	Prevention, treatment and management	Every 4 months a phone interview collected information on falls, fractures (fracture site, date, place of treatment) and hospitalisations (reason for admission, date and place of admission). Community service use in the past 12 months, not specific to the musculoskeletal condition (spending at least 1 day in an aged care day centre, being visited by Home Care to help with personal or household duties, using services of the Community and Aged Care packages, or any service to deliver or prepare meals at home.)
	Quality of life	Self-rated health status. Ability to undertake everyday activities. Presence of chronic pain (not specific to a musculoskeletal condition) and about knee, hip and back pain.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Age, marital status, living arrangements, country of birth, age at leaving school, main lifetime occupation (managers and professionals versus other), source of income (government pension only versus other) and house ownership.

10. Dubbo Osteoporosis Epidemiology Study (DOES)	
Type of data source	Longitudinal (regional).
Brief description	The DOES tracks low- trauma fractures and mortality. Participants receive bone density scans, and efforts are made to capture all minimal-trauma fractures in the study population.
Purpose(s)	To investigate the progression of osteoporosis in the study population. A key focus is the prediction of fractures and re-fractures.
Collection methodology	At 2-year intervals, study participants answer questionnaires administered by a nurse and clinical measurements are taken including bone mineral density. For all members of the target population, fractures and mortality are monitored. Clinical fractures are ascertained by reviewing all radiography reports from the local radiology services, ensuring complete ascertainment of all clinical osteoporotic fractures (confirmed by personal interview). Mortality among residents of Dubbo is monitored, based on death certificates.
Scope (theoretical coverage of relevant population)	The target population included people aged 60 and over, living in the Dubbo Local Government Area. The Dubbo population is 98.6% Caucasian.
Coverage (actual)	2,413 women and 1,898 men were in scope, and fracture and mortality data were gathered for these people. 1,358 women and 854 men participated in the study, providing additional information (51%).
Geographic coverage	The Dubbo Local Government Area.
Frequency/timing	Continuous collection of fracture and death data from July 1989. Questionnaires and clinical measurements at staggered 2-year intervals.
Basic collection count	Persons.
Size	Fracture and mortality data for 4,311 people, and within this group, questionnaire and clinical measurement data for 2,212 people.
Collection management organisation	Garvan Institute of Medical Research.
Further information	The DOES (presentation slides): <http://dubbostudy.org/wp-content/uploads/2012/04/Eisman-DOES-30-3-12.pdf>.

10. Dubbo Osteoporosis Epidemiology Study (DOES) (Cont.)		
Priority information areas	Risk factors	Smoking, alcohol consumption, body mass index, previous fractures and falls, physical activity, calcium intake, medication use, postural instability, muscle strength, bone density.
	Prevalence and incidence	Minimal-trauma fractures.
	Prevention, treatment and management	No data.
	Quality of life	No data.
	Death and disability	Mortality data.
	Expenditure, costs	No data.
	Population demographics	Age, sex, reproductive history.

11. Florey Adelaide Male Ageing Study (FAMAS)	
Type of data source	Longitudinal (regional).
Brief description	The FAMAS is a longitudinal study of men aged 35-80 living in the north-west regions of Adelaide. The survey gathers information about doctor-diagnosed osteoarthritis, rheumatoid arthritis and bone fractures using whole body and lumbar spine bone mineral density dual X-ray absorptiometry scans (90% of participants agreed to the scan). One substudy relates to osteoarthritis, with investigations into the bone microenvironment, serum markers of bone turnover, joint pain and development of osteoarthritis (2005–continuing). Comparisons with Census 2001 data showed that participants matched the population for most key demographics, although younger groups and never married men were under-represented and elderly participants were over-represented.
Purpose(s)	To examine the reproductive, physical and psychological health, and health service utilisation of the ageing male Australian population.
Collection methodology	A self-administered questionnaire and a clinical assessment measuring a variety of biomedical factors. Baseline clinic visits occurred between 2002 and 2005, with follow-up clinics from 2007 to 2010. Funding is being sought for a third wave of clinic visits. Follow-up self-administered questionnaires are completed annually. Permission was gathered to link with Medicare Benefits Scheme (Medicare) and Pharmaceutical Benefits Scheme (PBS) data. Participants were also invited to participate in substudies with selected collaborators.
Scope (theoretical coverage of relevant population)	Men aged 35-80 at the time of recruitment, living in western and northern Adelaide. Participants were selected at random from residential properties listed in the Electronic White Pages. Men living in institutions were not in scope.
Coverage (actual)	There were 2,650 eligible subjects and 1,195 participated in baseline clinic visits (45.1%). At follow-up, 82.3% of men participated in clinic visits, with a further 6.8% responding by questionnaire only. As of December 2013, the annual loss to follow-up rate is 1.6%.
Geographic coverage	Western Adelaide and northern Adelaide.
Frequency/timing	Baseline clinic visits occurred between 2002 and 2005, with follow-up clinics from 2007 to 2010. Funding is being sought for a third wave of clinic visits. Follow-up questionnaires are completed annually.
Basic collection count	Persons.

11. Florey Adelaide Male Ageing Study (FAMAS) (Cont.)		
Size		1,195 original participants [967 active participants at January 2014].
Collection management organisation		University of Adelaide.
Further information		<http://www.adelaide.edu.au/mailes/>.
Priority information areas	Risk factors	Smoking, physical activity, diet, body mass index, waist and hip measurement.
	Prevalence and incidence	Self-report of physician-diagnosed osteoarthritis and rheumatoid arthritis. Information about prevalence of osteopenia and osteoporosis among men in the study region from bone scans.
	Prevention, treatment and management	Link with Medicare, PBS.
	Quality of life	SF-36.
	Death and disability	Link with National Death Index.
	Expenditure, costs	Link with Medicare, PBS.
	Population demographics	Age, country of birth, income, education level, work status, household composition, marital status, residence location.

12. Footprints in time: The Longitudinal Study of Indigenous Children (LSIC)	
Type of data source	Longitudinal survey (national).
Brief description	The LSIC generates quantitative and qualitative data that can be used to provide a better insight into how children's early years affect their development. Information can be gathered about children with musculoskeletal conditions (such as juvenile arthritis), risk factors for musculoskeletal conditions among children, and parents or carers with musculoskeletal conditions.
Purpose(s)	The study aims to improve the understanding of, and policy response to, the diverse circumstances faced by Aboriginal and Torres Strait Islander children, their families and communities.
Collection methodology	The study focuses on 11 sites chosen to cover the range of socioeconomic and community environments where Aboriginal and Torres Strait Islander children live. Agreement and approval to participate in the study was sought from communities and Elders in these sites before research within the communities began. Most families in the study were recruited using addresses provided by Centrelink and Medicare Australia. Other informal means of contact such as word of mouth, local knowledge and study promotion were also used to supplement the number of children in the study. The LSIC surveyed cohorts of Indigenous children aged from 6 months to 2 years (Baby cohort, or B cohort) and from 3 years 6 months to 5 years (Child cohort, or K cohort) in Wave 1. The design allows data covering the first 9 or 10 years of Aboriginal and Torres Strait Islander children's lives to be collected in 6 years. Children, parents and carers were surveyed using face-to-face interviews. Additionally, physical measurements were taken of the children. Child care workers and teachers were surveyed using self-completed questionnaires.
Scope (theoretical coverage of relevant population)	The LSIC was designed to sample approximately 150 children in each of the 11 sites, providing a sample of up to 1,650 children. The study selected Indigenous children born between December 2003 and November 2004 (K cohort) or between December 2006 and November 2007 (B cohort).
Coverage (actual)	There were 1,677 children included in Wave 1, with an additional 88 children across the sites added for the second wave (non-representative). In practice, the K cohort consists of children born in 2003, 2004 and 2005 and the B cohort consists of children born in 2006, 2007 and 2008.

12. Footprints in time: The Longitudinal Study of Indigenous Children (LSIC) (Cont.)		
Geographic coverage		Eleven sites in Australia. No study sites were located in the ACT or Tasmania. The LSIC sample is not nationally representative; however, it sufficiently reflects the distribution of Aboriginal and Torres Strait Islander children aged between 0 and 5 years in the states and territories and among urban, regional and remote areas.
Frequency/timing		The survey began in 2008; surveys are carried out each year.
Basic collection count		Person.
Size		In Wave 5, 1,258 children were included.
Collection management organisation		Australian Government Department of Social Services.
Further information		<www.dss.gov.au/lsic>.
Priority information areas	Risk factors	BMI, diet, comorbidity, smoking status of parents.
	Prevalence and incidence	Major health conditions for children, parents or carers. Some activity restriction data are available.
	Prevention, treatment and management	Hospital visits.
	Quality of life	Social and emotional status of children. Information from child care workers and teachers will shed light on a child's ability to participate in schooling and other activities.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Sex, age, Indigenous status, language and cultural practice, family structure, housing type, and specifically for adult family members: education level and income.

13. Geelong Osteoporosis Study (GOS)	
Type of data source	Longitudinal survey (regional).
Brief description	The GOS is a prospective cohort study designed to describe the health burden of osteoporosis and identify risk factors for fragility fracture. The study is set in the Barwon Statistical Division, a region in South-Eastern Australia. Biomedical measurements including bone mineral density measurements are taken from study participants. This allows the estimation of the underlying rates of osteoporosis and osteopenia in the sample population. The study includes a fracture register for the study region. The GOS Fracture Grid is an ongoing, comprehensive repository documenting incident fractures that have occurred in the Barwon Statistical Division.
Purpose(s)	To describe the burden of osteoporosis in the study population and to identify risk factors for fracture.
Collection methodology	Paper-based surveys and clinical assessments including bone mineral density analysis. Dual-energy X-ray absorptiometry provided measures of bone mineral content. Calcaneus ultrasound. Blood and urine tests, DNA samples taken.
Scope (theoretical coverage of relevant population)	The study region is described by the ABS as the Barwon Statistical Division, situated in South-Eastern Australia. Participants were selected from the electoral roll. Persons resident for <6 months and those unable to provide written informed consent were excluded from the study.
Coverage (actual)	2,390 women were invited to participate in the female baseline study run from 1993 to 1997 and 1,494 accepted. 83% of eligible women returned for the 10-year assessment commencing in 2004. 3,273 men were invited to participate in the male baseline study run from 2001 to 2006 and 1,540 accepted. 81% of eligible men returned for the 5-year assessment commencing in 2006. No Indigenous Australians participated.
Geographic coverage	The Barwon Statistical Division, a region in South-Eastern Australia.
Frequency/timing	Baseline measurements for women began from 1993 and 1997 and for men between 2001 and 2006. Female participants were assessed at the following intervals: 2-year, 4-year, 6-year, 7-year, 8-year and 10-year follow-up assessments commencing in 1995, 1998, 2000, 2001, 2002 and 2004 respectively. A further 246 women aged 20-29 were recruited 2006-8. A 15-year follow-up for women, which began in 2011, is soon to be completed. Male participants were assessed at a 5-year and 6-year interval, commencing in 2006 and 2007 respectively.

13. Geelong Osteoporosis Study (GOS) (Cont.)		
Basic collection count		Persons.
Size		881 women returned for the 10-year assessment commencing in 2004. 978 men retuned for the 5-year assessment commencing in 2006.
Collection management organisation		Epidemiology Unit for Healthy Ageing, part of the IMPACT Strategic Research Centre (Deakin University).
Further information		<http://www.barwonhealth.org.au/epidemiology-unit-for-musculoskeletal-and-metabolic-disorders-epi-ummd>. <http://www.deakin.edu.au/research/documents/pasco.pdf> <http://www.deakin.edu.au/research/src/impact/>.
Priority information areas	Risk factors	BMI, sun exposure, comorbidities, medication use, physical activity, alcohol and tobacco use, family history of fractures, diet. Prevalence and severity of low bone mineral density among study participants.
	Prevalence and incidence	Prevalence and severity of osteoporosis and osteopenia based on measured bone mineral density among study participants. Fracture occurrence.
	Prevention, treatment and management	Use of medications and supplements.
	Quality of life	Self-reported quality of life, mobility, use of walking aid, mental health, pain.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Age, sex, socioeconomic status of area of residence, education, marital status, occupation, employment status, country of birth, ethnicity.

14. Growing up in Australia: The Longitudinal Study of Australian Children (LSAC)	
Type of data source	Longitudinal survey (national).
Brief description	The LSAC is a longitudinal survey investigating the contribution of children's social, economic and cultural environments to their adjustment and wellbeing. Information can be gathered about children with musculoskeletal conditions (such as juvenile arthritis), risk factors for musculoskeletal conditions among children, and parents or carers with musculoskeletal conditions.
Purpose(s)	To identify policy opportunities for improving support for children and their families and for early intervention and prevention strategies.
Collection methodology	The study began in 2004 with two cohorts - families with 4-5 year old children and families with 0-1 year old infants. Children, parents, carers, child care workers and teachers were surveyed. A range of survey methods were used, such as face-to-face interviews, self-completed questionnaires, physical measurements of children, audio computer-assisted self interviews and computer-assisted telephone interviews. The sample was selected from Medicare Australia's enrolment database.
Scope (theoretical coverage of relevant population)	Families of 18,800 selected children received letters of invitation to take part in the study.
Coverage (actual)	The final response to the recruitment of children was 54% of those families who were sent the initial letter (10,090 children), with participants representative of Australia's children population.
Geographic coverage	Australia.
Frequency/timing	From 2004, the recruited families have been interviewed every 2 years. In addition, mail-out questionnaires were sent to families in 2005, 2007 and 2009.
Basic collection count	Persons.
Size	The 2010 wave collected data on 8,405 children.
Collection management organisation	The LSAC is conducted by the Australian Government Department of Social Services, the Australian Institute of Family Studies and the Australian Bureau of Statistics. The Wave 1 data collection was undertaken by Colmar-Brunton Social Research and I-view/NCS Pearson, private social research companies. Data collection for waves 2, 3 and 4 was undertaken by the Australian Bureau of Statistics.
Further information	<http://www.growingupinaustralia.gov.au/index.html>.

14. Growing up in Australia: The Longitudinal Study of Australian Children (LSAC) (Cont.)		
Priority information areas	Risk factors	BMI, exercise, smoking status of parents.
	Prevalence and incidence	Diagnosed conditions lasting 6 months or more for children or parents. The following information is gathered about the severity of health limitations, which is relevant when a musculoskeletal condition is present: • limited use of arms or fingers • difficulty gripping • limited use of legs and feet • restrictions in everyday activities • chronic pain.
	Prevention, treatment and management	Hospital stays.
	Quality of life	Social and emotional status of children. Time use data and information from child care workers and teachers will shed light on a child's ability to participate in schooling and other activities.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Age, sex, country of birth, ethnicity, language spoken at home, Indigenous status, family structure, housing type, and specifically for parents and carers: education level and income.

15. Medicare Benefits Scheme (Medicare) data	
Type of data source	Administrative (national).
Brief description	Medicare is Australia's universal health insurance scheme. Medicare provides access to: • free treatment as a public patient in a public hospital • free or subsidised treatment by practitioners such as doctors, including specialists, participating optometrists or dentists (specified services only). All Australian residents and overseas visitors covered by a reciprocal health-care agreement requiring immediate medical attention are eligible for subsided treatment under Medicare. The associated Medicare data set comprises information on all medical services claimed through Medicare. These services include visits to a GP, certain specialists and allied health professionals and hospital visits by a private patient in a public or private hospital. There is limited information about why a service was used. Medicare records include only services that are claimed for Medicare benefits and for which claims have been processed (they do not include services provided under the Department of Veterans Affairs National Treatment Account). Medicare data excludes: • services that have been provided in public hospitals to public patients • services provided in outpatient or emergency departments of public hospitals. These are covered in separate hospitals data.
Purpose(s)	The purpose of Medicare is to provide people with subsidised medical services. Medicare data provides broad information on the type of services used and the benefit paid by Medicare for the service.
Collection methodology	Providers or patients submit claims for payment reflecting Medicare activity.
Scope (theoretical coverage of relevant population)	All Australian residents and eligible overseas visitors.
Coverage (actual)	Information will be missing if individuals or doctors fail to lodge claim information. This should be a rare occurrence, as there is a financial incentive to do so.
Geographic coverage	All states and territories, Australia.
Frequency/timing	Ongoing.
Basic collection count	Number of subsidised medical services.
Size	Not applicable.

15. Medicare Benefits Scheme (Medicare) data (Cont.)		
Collection management organisation		Medicare is managed by the Department of Health and administered by the Department of Human Services.
Further information		<http://www.medicareaustralia.gov.au/provider/medicare/index.jsp>.
Priority information areas	Risk factors	No data.
	Prevalence and incidence	No data.
	Prevention, treatment and management	Management by GPs, private hospitals and some allied health professionals (although information on why the service was used is limited). Location of practice.
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	Expenditure by Medicare on services provided by GPs, private hospitals and some allied health professionals and cost of services.
	Population demographics	Sex, age, usual residence of patient (various levels such as SLA, RRMA). Indigenous status.

16. National Drug Strategy Household Survey	
Type of data source	Survey (National).
Brief description	The National Drug Strategy Household Survey provides representative cross-sectional data on alcohol, tobacco and other drug use in Australia. The data relevant to musculoskeletal conditions include smoking and alcohol consumption behaviours. The survey gathers information about health conditions, but does not include any specific questions about the presence of musculoskeletal conditions (respondents may write it in 'other').
Purpose(s)	This survey is designed to collect self-reported information on drug-related attitudes, behaviours, consumption and health.
Collection methodology	Self-completion paper-based survey. Interviewers make contact with a household, carry out a respondent selection procedure, leave the survey form to be completed and then return to collect it at an agreed time. Before the 2010 survey there was an additional computer-assisted telephone interview component and from 1985-2001 face to face interviews were conducted.
Scope (theoretical coverage of relevant population)	From 2004 the sample has covered Australians aged 12 and over (prior to then it captured age 14 and over). The design of the survey excludes those who live in non-private dwellings, are homeless or live in institutions or on military bases.
Coverage (actual)	For the 2010 survey, contact was made with 52,690 in-scope households, of which 26,648 questionnaires were categorised as being complete and useable, representing a response rate of 50.6%.
Geographic coverage	Australia.
Frequency/timing	Results from the 2013 survey will be released in mid- to late 2014. Previous surveys were conducted in 1985, 1988, 1991, 1993, 1995, 1998, 2001, 2004, 2007 and 2010.
Basic collection count	Persons.
Size	In 2010, 26,648 respondents.
Collection management organisation	AIHW.
Further information	<http://www.aihw.gov.au/national-drugs-strategy-household-surveys/>.

16. National Drug Strategy Household Survey (Cont.)		
Priority information areas	Risk factors	Smoking and alcohol consumption.
	Prevalence and incidence	Limited data, not suitable for musculoskeletal monitoring.
	Prevention, treatment and management	No data.
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Age, sex, location (remoteness and SEIFA), Indigenous status, marital status, education, household composition, employment status.

17. National Hospital Morbidity Database (NHMD)	
Type of data source	Administrative (national).
Brief description	The NHMD is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals.
Purpose(s)	To provide information on admitted patient care, such as demographic, administrative and length of stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning.
Collection methodology	The data supplied are based on the National Minimum Data Set for admitted patient care. Data are supplied to the AIHW by state and territory health authorities under the terms of the National Health Information Agreement.
Scope (theoretical coverage of relevant population)	The NHMD is a comprehensive data set that has records for all episodes of admitted patient care from essentially all public and private hospitals in Australia.
Coverage (actual)	For 2011–12, almost all public hospitals provided data for the NHMD.
Geographic coverage	All states and territories, Australia.
Frequency/timing	Annually from 1993-94.
Basic collection count	Number of separations. A separation is an episode of care, which can be a total hospital stay (from admission to discharge, transfer or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation).
Size	There were 9.3 million separations recorded in the NHMD in 2011-12.
Collection management organisation	The NHMD is compiled by the AIHW from data supplied by the state and territory health authorities under the terms of the National Health Information Agreement.
Further information	<http://meteor.aihw.gov.au/content/index.phtml/itemId/529483>.

17. National Hospital Morbidity Database (NHMD) (Cont.)		
Priority information areas	Risk factors	Smoking rates are recorded for people who are hospitalised. Additional diagnoses are recorded, if the condition or complaint could potentially affect patient management.
	Prevalence and incidence	Fracture data are available; however, although the external cause code provides some information about factors contributing to the injury, it is not always possible to distinguish between low-trauma (osteoporotic) and high-trauma fractures.
	Prevention, treatment and management	Hospital treatment and procedures, area of hospital (statistical local area (SLA) level).
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Sex, age, Indigenous status, area of usual residence (SLA level).

18. National Mortality Database (NMD)	
Type of data source	Administrative (national).
Brief description	The NMD contains information pertaining to deaths registered in Australia since 1964. Information is provided on the underlying cause of death (the disease or condition leading directly to death). From 1997 data are available on the associated causes of death (diseases or conditions other than the underlying cause that contributed to the death).
Purpose(s)	The NMD is used by the AIHW to produce population-level analyses for: monitoring and surveillance of mortality due to specific chronic diseases (or all causes combined); burden of disease research; and to inform Closing the Gap and other COAG indicators. It is also used to fulfil data requests for external researchers.
Collection methodology	Deaths are registered by the registrars of Births, Deaths and Marriages in each state and territory. Death registration is compulsory. The cause of death is certified by the medical practitioner or the coroner and coded using the International Classification of Diseases. Demographic and administrative information about the deceased is collected on the Death Information Form, filled out by the deceased's next of kin in conjunction with the funeral director.
Scope (theoretical coverage of relevant population)	The Australian Bureau of Statistics (ABS) Death Registrations collection includes all deaths that occurred and were registered in Australia, including deaths of persons whose place of usual residence was overseas. Deaths of Australian residents that occurred outside Australia may be registered by individual registrars, but are not included in ABS death statistics.
Coverage (actual)	While all deaths are legally required to be registered some cases may not be registered for an extended time, if at all.
Geographic coverage	Australia.
Frequency/timing	The ABS issues summaries of cause of death annually and the AIHW updates the NMD once these data become available.
Basic collection count	Number of deaths.
Size	There were 137,854 deaths registered in 2007.
Collection management organisation	The information is provided to the ABS for coding the cause of death and compiling into aggregate statistics. The AIHW manages the NMD.
Further information	Quality declaration: <http://www.abs.gov.au/Ausstats/abs@.nsf/0/D4A300EE1E04AA43CA2576E800156A24?OpenDocument>.

18. National Mortality Database (NMD) (Cont.)		
Priority information areas	Risk factors	For people who die with a musculoskeletal condition as the underlying or associated cause of death, information is provided on other contributing factors in the death.
	Prevalence and incidence	No data.
	Prevention, treatment and management	No data.
	Quality of life	No data.
	Death and disability	Mortality burden.
	Expenditure, costs	No data.
	Population demographics	Sex, age at death, area of usual residence (SLA level), remoteness of usual residence, Indigenous status, country of birth.

19. National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD)	
Type of data source	Administrative (national).
Brief description	The NNAPEDCD is a compilation of episode-level data for emergency department presentations in selected public hospitals.
Purpose(s)	To provide information on patient care for emergency department presentations in public hospitals.
Collection methodology	State and territory health authorities provide the data to the AIHW for national collation, on a quarterly basis within 1 month of the end of a reporting period and an annual basis within 3 months of the reporting period.
Scope (theoretical coverage of relevant population)	The scope of the NNAPEDCD is non-admitted patients registered for care in emergency departments in selected public hospitals that are classified as either peer group A or B in the Australian hospital statistics publication from the preceding financial year (principal referral and specialist women's and children's hospitals and large hospitals). Some states and territories also provide data for public hospitals that were classified in peer groups other than A or B (see Australian Hospital Statistics 2011-12 for more information). Before 1 January 2012, the data collection did not include care provided to admit patients in emergency departments. From 1 January 2012, all care provided to patients treated in emergency departments is in scope for this collection. Care is included until the patient is recorded as having physically departed the emergency department, regardless of whether they have been admitted. However, care provided to patients admitted to 'short stay units' is not included.
Coverage (actual)	For 2012-13 the proportion of occasions of service in emergency departments reported to the NNAPEDCD was estimated to account for 84% of all emergency occasions of service in public hospitals.
Geographic coverage	National.
Frequency/timing	Financial year, from 2003-04 onwards.
Basic collection count	Episodes of care.
Size	Not applicable.
Collection management organisation	The database was assembled by the AIHW from data supplied by the state and territory health authorities.
Further information	<http://meteor.aihw.gov.au/content/index.phtml/itemId/546749>.

19. National Non-Admitted Patient Emergency Department Care Database (Cont.)		
Priority information areas	Risk factors	No data.
	Prevalence and incidence	Some information on diagnosis will be available from 2013-14 onwards.
	Prevention, treatment and management	When diagnosis information becomes available, this database may provide information on episodes of care for musculoskeletal conditions provided in emergency departments.
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	Age, sex, Indigenous status, area of usual residence. The quality of the data reported for Indigenous status has not been formally assessed; therefore, caution should be exercised when interpreting these data.

20. Non-admitted patient care aggregate national minimum data set specification (NMD)	
Type of data source	Administrative (national).
Brief description	The non-admitted patient care aggregate NMD contains data on non-admitted patient service events involving non-admitted patients in activity-based funded hospitals. The NMD scope includes all arrangements made to deliver non-admitted patient service events to non-admitted patients: • irrespective of location (includes on- and off-campus) • whose treatment has been funded through the hospital, regardless of the funding source. In particular, Department of Veterans' Affairs, compensable and other patients funded through the hospital (including Medicare ineligible patients) are included • regardless of setting or mode. Excluded from the NMDS scope are all services covered by: • the Admitted patient care NMDS • the Admitted patient mental health care NMDS, • the Non-admitted patient emergency department care NMDS, e.g. all non-admitted services provided to admitted patients are excluded • service events which deliver non-clinical care, e.g. activities such as home cleaning, meals on wheels or home maintenance. Information on diagnosis isn't available in this data set.
Purpose(s)	The non-admitted patient care aggregate NMDS captures instances of service provision from the patient's point of view.
Collection methodology	Hospital records are generated when non-admitted patients receive outpatient services.
Scope (theoretical coverage of relevant population)	All arrangements made to deliver non-admitted patient service events to non-admitted patients.
Coverage (actual)	Yet to be determined. Data for the first year not yet finalised.
Geographic coverage	National.
Frequency/timing	2013-14 onwards. Replaces the Outpatient care NMDS covering 2007-08 to 2012-13.
Basic collection count	Non-admitted patient service event.
Size	Yet to be determined. Data for the first year not yet finalised.
Collection management organisation	The database is being assembled by the AIHW from data supplied by the state and territory health authorities.
Further information	<http://meteor.aihw.gov.au/content/index.phtml/itemId/508306>.

20. Non-admitted patient care aggregate national minimum data set specification (NMDS) (Cont.)		
Priority information areas	Risk factors	No data.
	Prevalence and incidence	No data.
	Prevention, treatment and management	Hospital outpatient services such as orthopaedic services, but these services are not specific to musculoskeletal conditions.
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	No data.
	Population demographics	No data.

21. North West Adelaide Health Study (NWAHS)	
Type of data source	Longitudinal survey (regional).
Brief description	The NWAHS is a longitudinal cohort study investigating chronic disease and health-related risk factors, from both self-reported and biomedically measured information for people living in the north-western region of Adelaide. Information about the prevalence of arthritis (osteoarthritis, rheumatoid arthritis or other arthritis), osteoporosis and musculoskeletal pain and stiffness was gathered in the second and third stages of the study. Information about prevalence of gout was gathered in the third stage of the study. In the second stage of the study, participants aged 50 and over were offered a dual-energy X-ray absorptiometry scan to measure their bone density.
Purpose(s)	To make a comprehensive health assessment of the community of north-west Adelaide in order to inform health policy.
Collection methodology	Telephone and self-complete questionnaires and biomedical measurements. Consent was obtained from participants to link to Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Scheme (PBS) records.
Scope (theoretical coverage of relevant population)	Households in north-west Adelaide were chosen at random from the electronic White Pages. One member of each household over the age of 18 was chosen at random.
Coverage (actual)	4,056 adults attended the Stage 1 clinic visit, between November 1999 and July 2003; 3206 of the cohort returned for the Stage 2 clinic visit between May 2004 and February 2006, and 2,487 of the cohort returned for the Stage 3 clinic visit between June 2008 and August 2010.
Geographic coverage	The north-western region of Adelaide, stretching from the suburbs Glenelg to Gawler.
Frequency/timing	Stage 1 was run between 1999 and 2003, Stage 2 between 2004 and 2006 and Stage 3 between 2008 and 2010. Additional telephone surveys were run in 2002 and 2007.
Basic collection count	Persons.
Size	The original cohort was 4,056 people; 2,487 of these participated in the most recent clinic visit, between June 2008 and August 2010.
Collection management organisation	The NWAHS is led by the University of Adelaide, in collaboration with the University of South Australia, SA Health, the Institute of Medical and Veterinary Science, The Queen Elizabeth Hospital and the Lyell McEwin Hospital.
Further information	<http://www.nwadelaidehealthstudy.org/project_overview.asp>. <http://health.adelaide.edu.au/pros/data/nwahs/>.

21. North West Adelaide Health Study (NWAHS) (Cont.)		
Priority information areas	Risk factors	Smoking, alcohol consumption, obesity (BMI, waist and hip measurements), comorbidity, diet, physical activity, family history of osteoporosis, sun exposure (relevant for vitamin D).
	Prevalence and incidence	Prevalence of self-reported doctor-diagnosed arthritis, osteoporosis and gout. Prevalence of self-reported musculoskeletal pain and stiffness. Self-reported occurrence of minimal trauma fracture. Prevalence of osteoporosis and osteopenia, derived from bone density measurements for participants aged over 50. Measures of severity: grip strength, level of pain, level of stiffness and ache in joints, level of activity limitation due to joint problems.
	Prevention, treatment and management	Hip and knee replacement. Use of health services and prescription medication from the linked MBS and PBS databases.
	Quality of life	General quality of life, perception of general health, physical functioning, bodily pain, ability to participate in work and social activities (SF-36).
	Death and disability	No data.
	Expenditure, costs	MBS and PBS costs.
	Population demographics	Age, sex, postcode, country of birth, Indigenous status, living arrangement, marital status, number of children, occupation, income, education level

22. Optimising Patient outcome in Australian rheumatoLogy (OPAL) – Quality Use of Medicines Initiative (QUMI).	
Type of data source	The OPAL registry is a multi-centre, cross-sectional, retrospective, non-interventional study.
Brief description	In 2009, in consultation with Australian rheumatologists, Roche established a point-of-care disease management and audit software package, initially specific to rheumatoid arthritis (RA), with the intent of addressing unanswered relevant research questions in collaboration with a Steering Committee of 9 Australian rheumatologists.
Purpose(s)	The OPAL–QUMI is designed to both conduct large multi-centre research projects to answer research questions, and directly improve clinical practice in rheumatology. The OPAL–QUMI will enhance the quality use of medicines and / or development of medical knowledge. Initial OPAL–QUMI research has focussed on RA but the group plans to develop modules and undertake research for other diseases in the future.
Collection methodology	Participating OPAL–QUMI clinics will use the audit software to capture data as part of their routine clinical practice. Pre-specified data points (de-identified by patient, clinic and clinician) can be extracted, according to an approved ethics protocol, and aggregated to answer Australian rheumatology research questions.
Scope (theoretical coverage of relevant population)	All patients seeing a rheumatologist in Australia.
Coverage (actual)	All patients from 58 of approximately 300 Australian rheumatologists (~20%).
Geographic coverage	Australia.
Frequency/timing	2009-ongoing.
Basic collection count	Patient encounters in the rheumatology clinic, rheumatological diseases seen, observations relevant to disease (e.g. disease activity in RA), pharmacological treatments, comorbidities.
Size	>10,000 RA patients.
Collection management organisation	S4S, who produce the Audit4 software used by OPAL–QUMI rheumatologists, are responsible for collecting de-identified data, following consent from the participating clinicians. S4S aggregate the de-identified data and provide this to an independent statistician contracted by Roche. OPAL-QUMI Project management is undertaken by Jennifer Young, Medical Manager, Roche.
Further information	Contact Associate Professor Geoffrey Littlejohn at <geoff.littlejohn@monash.edu.au >.

22. Optimising Patient outcome in Australian rheumatoLogy (OPAL) (Cont.)		
Priority information areas	Risk factors	Predictors of disease – demographics, lifestyle factors – smoking, alcohol, immunological factors – e.g. rheumatoid factor, anti-CCP antibody, etc.
	Prevalence and incidence	Incidence and prevalence of rheumatological disease with focus particularly on rheumatoid arthritis; longitudinal study of measures of disease severity in rheumatoid arthritis; also capture all incident events including comorbidities and operations.
	Prevention, treatment and management	The OPAL – QUMI focuses on patterns of treatment (pharmacological therapies) in specialist clinical practice to determine which patterns lead to the most favourable outcomes.
	Quality of life	Disease-specific scales - e.g. modified Health Assessment Questionnaire – Disability Index (HAQ-DI) to measure functional capacity; Visual Analogue Scales for joint symptoms and pain as assessed by patient and clinician.
	Death and disability	Priority information area is disability as measured by HAQ-DI.
	Expenditure, costs	No data.
	Population demographics	Age, gender, ethnicity; postcode to determine socioeconomic status.

23. Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) data	
Type of data source	Administrative (national).
Brief description	The PBS and RPBS are national government-funded schemes designed to subsidise the cost of pharmaceutical medicines. About 80% of all prescription medications available for marketing in Australia are listed on the PBS or RPBS. All Australian residents and overseas visitors covered by a reciprocal health-care agreement requiring immediate medical attention are eligible for subsided medicines under the PBS. Eligible veterans, war widows/widowers and their dependants can get PBS medicines and some other medicines at a lower cost under the RPBS. The PBS and RPBS data sets contain information on the prescribing and dispensing of medicines outlined within the Schedule of Pharmaceutical Benefits. From 1 April 2012, data are collected for all listed pharmaceuticals purchased, not just the listed pharmaceuticals that receive a subsidy. The subsidy received depends on a person's concession status. The PBS and RPBS data do not generally include the reason a medicine has been prescribed and dispensed unless the medicine requires an Authority approval (that is, prior approval from the Department of Human Services or the Department of Veterans' Affairs). 'Restricted Benefit' PBS items also are limited to a stated condition, but do not require authority approval. Medicines that are prescribed for musculoskeletal conditions that do not require an Authority approval will not be identifiable for monitoring purposes. **Note:** Medicines labelled 'Authority required' can be prescribed only for the conditions stated in the PBS for that medicine.
Purpose(s)	The PBS and RPBS were established to provide subsidised medicines for Australians. PBS and RPBS data provide information on the type of medicine, the cost of medicine and the volume of scripts purchased.
Collection methodology	The PBS and RPBS data sources collect information of each event when a person has been supplied with a PBS or RPBS listed pharmaceutical benefit.
Scope (theoretical coverage of relevant population)	All Australian residents, certain Australians posted overseas and eligible overseas visitors.
Coverage (actual)	Information will be missing if pharmacies do not lodge claim information.

23. Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) data (Cont.)		
Geographic coverage		All states and territories, Australia and some overseas postings.
Frequency/timing		Ongoing.
Basic collection count		Number of PBS/RPBS scripts.
Size		Not applicable
Collection management organisation		The PBS is managed by the Department of Health and the RPBS is managed by the Department of Veterans' Affairs. The PBS and the RPBS are administered by the Department of Human Services.
Further information		<http://www.pbs.gov.au/info/browse/statistics>.
Priority information areas	Risk factors	No data.
	Prevalence and incidence	No data.
	Prevention, treatment and management	Pharmaceutical use (where the pharmaceutical is listed on the PBS or RPBS and specific for a musculoskeletal condition), approximate location of pharmacy (postcode).
	Quality of life	No data.
	Death and disability	No data.
	Expenditure, costs	Expenditure by the government and individuals on PBS/RPBS listed pharmaceuticals.
	Population demographics	Age, sex, self-identified Indigenous status, approximate address (postcode).

24. The Survey of Disability, Ageing and Carers (SDAC)	
Type of data source	Survey (national).
Brief description	The SDAC is the most detailed and comprehensive source of Australian population disability data. The survey collects national information on people with disabilities, older people (aged 65 or over) and their carers. In 2012, the definition of an older person changed to 65 years and over (from 60 and over in the previous survey). The SDAC collects data on prevalence of disability, long-term health conditions, main disabling conditions (the conditions causing the most problems), type of impairments and activity limitations, participation restrictions in schooling and employment, level of participation in social and community activities, need for and receipt of assistance, and the need for and use of aids and equipment due to disability. The related information on long-term health conditions includes: osteoporosis, combined back and neck pain and arthritis and related disorders. In the SDAC, disability is defined as any limitation, restriction or impairment that restricts everyday activities and has lasted or is likely to last for at least 6 months.
Purpose(s)	To measure the prevalence of disability in the Australian population and the need for support of older people and people with disability. To describe a demographic and social-economic profile of the population with disability, older people and people providing care for them.
Collection methodology	Multi-stage sampling techniques are used to select the sample for the survey. The SDAC is conducted in two separate parts--the household component and the cared-accommodation component--using different data collection methods. Data for the household component are collected by trained interviewers who conduct computer-assisted personal interviews. A series of screening questions are asked of a responsible adult in the selected household about whether the household includes people with a disability, people aged 65 or older, and potential primary carers (and primary carers were also identified through information provided by recipients of care during their interview). Where possible, personal interviews are then conducted with people identified in any of the above populations. Personal interviews are also conducted with people identified as primary carers of people with a disability.

24. The Survey of Disability, Ageing and Carers (SDAC) (Cont.)	
Collection methodology (Cont.)	Proxy interviews are conducted for people with a disability that prevented them from having a personal interview, children aged under 15, and those aged 15–17 whose parents do not permit them to be personally interviewed. Data for the cared-accommodation component are collected using a mail-based methodology directed to administrators of the selected establishments. This collection identifies disability status and assistance needs. The questions asked are similar to those included in the household component of the survey but the range of data collected in the cared accommodation is smaller than in the household component, as some topics are not suitable for completion by the administrator (e.g. responses based on self-perception) or are not relevant to people living in cared accommodation.
Scope (theoretical coverage of relevant population)	The survey covers people in private and non-private dwellings, including people in cared accommodation establishments. The scope excludes: people living in *Very remote* areas, discrete Indigenous communities, people whose usual residence is outside Australia, non-Australian diplomatic personnel and members of non-Australian defence forces (and their dependents) stationed in Australia. Population groups that are not enumerated for operational reasons include people in: boarding schools, and gaols or correctional institutions.
Coverage (actual)	The sample for the 2012 SDAC consisted of approximately 27,400 private dwellings and 500 other non-private dwellings, and 1,100 establishments (cared accommodation).
Geographic coverage	All states and territories, Australia. Excludes *Very remote* areas.
Frequency/timing	The survey has been conducted 7 times: in 1981, 1988, 1993, 1998, 2003, 2009 and 2012.
Basic collection count	Households, family, income unit, person, long-term health condition, specific activities, restrictions, providers of assistance, recipients of assistance.
Size	The final sample size of the 2012 SDAC comprised 68,802 persons for the household component and 10,362 persons for the cared accommodation component.
Collection management organisation	ABS.
Further information	<http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0 >.

24. The Survey of Disability, Ageing and Carers (SDAC) (Cont.)		
Priority information areas	Risk factors	Information on comorbidity (other long-term health conditions).
	Prevalence and incidence	Prevalence of arthritis and other musculoskeletal conditions among people with disability.
	Prevention, treatment and management	Aids used, assistance received, unmet needs for aids or assistance. The 2012 SDAC collected information about the use of health services among people with disability.
	Quality of life	Self-perception of health and wellbeing, ability to participate in social and community activities. Limitations imposed on mobility and self-care, requirement for assistance, employment limitations. Information is also provided on the impact of the caring role on carers, including carers' self-perception of health and wellbeing.
	Death and disability	The SDAC data are one of the sources for the Australian Burden of Disease study.
	Expenditure, costs	No data on direct costs or expenditure related to disability or caring for people with disability are collected in the SDAC. Information is provided about employment restrictions of people with disability and carers along with the main effect of the caring role on carers' financial situation.
	Population demographics	Age, sex, Indigenous status, country of birth, year of arrival in Australia, main language spoken at home, proficiency in spoken English, broad location of respondent (capital city or rest of state), household and family structure, income, educational attendance and attainment, housing tenure type, living arrangements, marital status.

25. The Tasmanian Older Adult Cohort (TASOAC)	
Type of data source	Longitudinal (regional).
Brief description	The TASOAC study is a longitudinal study set in southern Tasmania examining the determinants of osteoarthritis and osteoporosis in community dwelling older adults.
Purpose(s)	To identify the environmental, genetic, and biochemical factors associated with the development and progression of osteoporosis and osteoarthritis at multiple sites (hand, knee, hip, and spine).
Collection methodology	Self-completed interview, physical measurements, use of a pedometer, blood samples, magnetic resonance imaging (MRI) scans, bone densitometry (DXA), radiography.
Scope (theoretical coverage of relevant population)	Men and women aged 50 to 80 randomly sampled from the electoral roll in southern Tasmania, stratified by sex. Institutionalised persons were excluded.
Coverage (actual)	1,099 attended a baseline clinic between March 2002 and September 2004 (a response rate of 57%). At the phase 2 follow-up, 1,000 were eligible for follow-up and data was collected for 875 participants. Phase 3 follow-up data was collected for 769 participants.
Geographic coverage	Southern Tasmania
Frequency/timing	2002 onwards. Enrolment and a baseline clinic occurred between March 2002 and September 2004. Phase 2 follow-up occurred about 2.7 years later. Phase 3 follow-up occurred about 5 years later. A 10-year follow-up of this cohort is under way (June 2013 onwards).
Basic collection count	Persons.
Size	769 participants in the phase 3 follow-up.
Collection management organisation	Menzies Research Institute Tasmania, University of Tasmania
Further information	<http://www.menzies.utas.edu.au/information.php?Doo=ViewData&type=Project&ID=21>.

25. The Tasmanian Older Adult Cohort (TASOAC) (Cont.)		
Priority information areas	Risk factors	Body mass index, smoking, alcohol consumption, dietary calcium, physical activity, medications--glucocorticoids and hormone therapy (females only)--Vitamin D from blood samples, sunlight exposure, falls risk determined using the short form Physiological Profile Assessment.
	Prevalence and incidence	Doctor-diagnosed osteoarthritis and rheumatoid arthritis. Osteoporosis and osteopenia prevalence from bone mineral density measured using dual-energy X-ray absorptiometry (knee, hip). Knee and hip radiographic osteoarthritis assessed using radiography and the Altman atlas, and MRI to assess cartilage defects. Osteoarthritis severity (pain, stiffness and functional ability) was assessed using the Western Ontario and McMaster Universities Osteoarthritis Index. Self-reported level of pain by joint/area (neck, shoulders, back, hips, hands, knees and feet).
	Prevention, treatment and management	Medication use, joint replacement surgery.
	Quality of life	Self-assessed quality of life, level of pain by joint/area (not necessarily related to arthritis or musculoskeletal conditions).
	Death and disability	Deaths.
	Expenditure, costs	No data.
	Population demographics	Age, sex, residential address, SEIFA.

26. Voice of Arthritis Social Impact Study	
Type of data source	Survey (national).
Brief description	This research study, carried out in March 2004, explored how arthritis (osteoarthritis and rheumatoid arthritis) affects the individual, their family or carer and their workplace. Information is gathered relating to respondents' satisfaction with health services, the support they receive from family or carers, and their ability to participate in work and other activities.
Purpose(s)	To establish and confirm Arthritis Australia's understanding of all aspects of arthritis and how it affects sufferers, their families/carers and their workplaces, enabling Arthritis Australia to prioritise effort and investment in raising awareness of arthritis throughout Australia.
Collection methodology	The survey was a paper based self-completion questionnaire mailed in March 2004 to 3000 people with arthritis by each State Arthritis office from their database.
Scope (theoretical coverage of relevant population)	3000 people on State Arthritis foundation databases.
Coverage (actual)	A response of 1,016 was received before the survey's closing date, representing a response rate of 34%.
Geographic coverage	Australia.
Frequency/timing	March 2004.
Basic collection count	Persons.
Size	1,016 responses.
Collection management organisation	The study was conducted by The Leadership Factor, an international research agency, on behalf of Arthritis Australia.
Further information	<http://www.arthritisaustralia.com.au/images/stories/documents/reports/2011_updates/the%20voice%20of%20arthritis%202004.pdf>.

26. Voice of Arthritis Social Impact Study (Cont.)		
Priority information areas	Risk factors	No data.
	Prevalence and incidence	No data.
	Prevention, treatment and management	Satisfaction and perceived level of benefit with treatment and management such as medication and surgery.
	Quality of life	Impact of arthritis on quality of life, physical health, mental health, burden on family or carers and ability to participate in social events and paid work.
	Death and disability	No data.
	Expenditure, costs	Respondents rated the level of impact of their arthritis on their financial position, and rated the impact of factors such as medication costs and the effect of lost wages.
	Population demographics	Age, sex.

27. The 45 and Up Study	
Type of data source	Longitudinal survey (state).
Brief description	The 45 and Up Study is a longitudinal study of people from NSW. It follows the health of participants to examine which factors are associated with good or poor health as people age. Survey responses are linked to other health databases, allowing a broad view of health service use and outcomes. The study collects information about osteoarthritis and osteoporosis. Participants are able to nominate other important illnesses, so other musculoskeletal conditions will be noted.
Purpose(s)	To develop a research resource to boost understanding of how Australians are ageing. This will answer important health and quality-of-life questions and help manage and prevent illness through improved knowledge of health.
Collection methodology	Potential participants were randomly sampled from the Medicare Australia database and mailed a study questionnaire and information leaflet. Individuals from rural areas and those aged 80 and over were oversampled. Participants joined the study by completing the questionnaire and providing signed consent for follow-up and linkage to a range of health databases. Information available through data linkage includes: health service use from the Medicare Benefits Scheme (Medicare) and Pharmaceutical Benefits Scheme (PBS) databases, hospitalisation data from the National Hospital Mortality Database (NHMD) (with details of patterns of care), aged care and mortality data.
Scope (theoretical coverage of relevant population)	The NSW population, with a higher likelihood of selection for those in rural areas and those aged 80 and over.
Coverage (actual)	The study has recruited more than 250,000 men and women from the NSW general population. The response rate to the study is approximately 18%.
Geographic coverage	NSW.
Frequency/timing	2006-2009 for the first survey, and 2012-15 for the second, with more surveys to be run in the future. Data linkage began in 2008.
Basic collection count	Persons.
Size	More than 250,000 people.
Collection management organisation	The Sax Institute
Further information	<https://www.saxinstitute.org.au/our-work/45-up-study/>.

27. The 45 and Up Study (Cont.)		
Priority information areas	Risk factors	Physical activity, smoking, alcohol consumption, comorbidities, BMI, hours spent outdoors (relevant for vitamin D).
	Prevalence and incidence	The first-round survey asks whether participants have been treated for osteoarthritis or osteoporosis and their age at first treatment, whether they have any other important illness and how they are treated. The second survey also asks whether respondents have been diagnosed with osteoarthritis by a doctor, and age at diagnosis. Fracture data available from the survey and the hospitals database. The survey collects data on general health limitations.
	Prevention, treatment and management	Primary health service use from the Medicare database (reason for treatment may not be available). Medication use, both self-reported and from the PBS database (reason for prescription of the medication may not be available). Longitudinal hospitalisation data from the NHMD. Outcomes such as surgical revisions, mortality.
	Quality of life	Self-rated quality of life, functional capacity, level of psychological distress.
	Death and disability	No data.
	Expenditure, costs	Costs data from the linked data sources: Medicare, PBS, NHMD.
	Population demographics	Age, postcode, education level, ethnicity, country of birth, year of arrival in Australia, language spoken at home, Indigenous status, housing type, relationship status, household income.

References

ABS (Australian Bureau of Statistics) 2010. Work-related injuries, Australia, 2009–10. Cat. no. 6324.0. Canberra: ABS.

ABS 2012. Australian Health Survey: First Results, 2011–12. Cat. no. 4364.0.55.001. Canberra: ABS.

ABS 2013. Disability, Ageing and Carers, Australia: Summary of Findings, 2012. Cat. no. 4430.0. Canberra: ABS.

ACI (Agency for Clinical Innovation) 2014. Osteoarthritis Chronic Care Program Model of Care. Viewed 12 March 2014, <http://www.aci.health.nsw.gov.au/models-of-care/musculoskeletal/osteoarthritis-chronic-care-program>.

AIHW (Australian Institute of Health and Welfare) 2008a. Arthritis and osteoporosis in Australia 2008. Arthritis series no. 8. Cat. no. PHE 106. Canberra: AIHW.

AIHW 2008b. Australia's health 2008. Australia's health no. 11. Cat. no. AUS 99. Canberra: AIHW.

AIHW 2008c. Juvenile arthritis in Australia. Arthritis series no. 7. Cat. no. PHE 101. Canberra: AIHW.

AIHW 2009. Prevention of cardiovascular disease, diabetes and chronic kidney disease: targeting risk factors. Cat. no. PHE 118. Canberra: AIHW.

AIHW 2010. Australia's health 2010. Australia's health no. 12. Cat. no. AUS 122. Canberra: AIHW.

AIHW 2011. A snapshot of osteoporosis in Australia 2011. Arthritis series no. 15. Cat. no. PHE 137. Canberra: AIHW.

AIHW 2012a. Australia's health 2012. Australia's health no. 13. Cat. no. AUS 156. Canberra: AIHW.

AIHW 2012b. Changes in life expectancy and disability in Australia 1998 to 2009. Bulletin no. 111. Cat. no. AUS 166. Canberra: AIHW.

AIHW 2012c. Risk factors contributing to chronic disease. Cat. no. PHE 157. Canberra: AIHW.

AIHW 2013a. A snapshot of juvenile arthritis. AIHW bulletin no. 113. Cat. no. AUS 168. Canberra: AIHW.

AIHW 2013b. A snapshot of rheumatoid arthritis. AIHW bulletin no. 116. Cat. no. AUS 171. Canberra: AIHW.

AIHW, forthcoming. Arthritis and other musculoskeletal conditions across the life stages.

AIHW: Rahman N, Penm E & Bhatia K 2005. Arthritis and musculoskeletal conditions in Australia 2005: with a focus on osteoarthritis, rheumatoid arthritis and osteoporosis. Arthritis series no. 1. Cat. no. PHE 67. Canberra: AIHW.

ANZHFR (Australian and New Zealand Hip Fracture Registry) 2014. Viewed 14 March 2014, <http://anzhfr.org/>.

Arthritis and Osteoporosis Victoria 2013. A problem worth solving. Elsternwick: Arthritis and Osteoporisis Victoria.

Arthritis Australia 2014. Time to Move: arthritis, a national strategy to reduce a costly burden. Viewed 24 March 2014, <http://www.arthritisaustralia.com.au/index.php/news.html>.

Better Health Channel 2013. Back pain - disc problems. Melbourne: State Government of Victoria. Viewed 19 December 2013, <http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Back_pain_disc_problems>.

DoHA (Department of Health and Ageing) 2012. Background paper: Medicare Locals health needs assessment and planning. Canberra: DoHA.

DoHA & NAMSCAG (National Arthritis and Musculoskeletal Conditions Advisory Group) 2004. Evidence to support the National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis. Canberra: DoHA.

Ebeling PR, Daly RM, Kerr DA & Kimlin MG 2013. Building healthy bones throughout life: an evidence-informed strategy to prevent osteoporosis in Australia. Medical Journal of Australia Open 2:1.

FaHCSIA (Department of Families, Housing, Community Services and Indigenous Affairs) 2012. Income support customers: a statistical overview 2011. Canberra: FaHCSIA.

Hoy D, Brooks P, Blyth F & Buchbinder R 2010. The Epidemiology of low back pain. Best Practice & Research Clinical Rheumatology. 24:769-81.

ICUROS (International Costs and Utilities Related to Osteoporotic Fractures Study) 2011. The International Costs and Utilities Related to Osteoporotic Fractures Study. Viewed 12 March 2014, <http://www.icuros.org/>.

IHME (Institute for Health Metrics and Evaluation) 2013. GBD Compare. Washington: Institute for Health Metrics and Evaluation. Viewed 12 December 2013, <http://viz.healthmetricsandevaluation.org/gbd-compare/>.

Maher CG, Williams C, Lin C & Latimer J 2011. Managing low back pain in primary care. Australian Prescriber 34.

National Health Priority Action Council 2006. National service improvement framework for osteoarthritis, rheumatoid arthritis and osteoporosis. Canberra: Australian Government Department of Health and Ageing.

National Public Health Partnership 2001. Preventing chronic disease: a strategic framework. Melbourne: National Public Health Partnership.

NHISSC (National Health Information Standards and Statistics Committee) 2009. The National Health Performance Framework. 2nd edn. Canberra. Viewed 11 March 2014, <http://meteor.aihw.gov.au/content/index.phtml/itemId/435314>.

Osborne R, Haynes K, Jones C, Chubb P, Robbins D & Graves S 2006. Orthopaedic Waiting List Project (OWL), Phase 1, Final report. Victoria: The University of Melbourne and Melbourne Health.

RACGP (Royal Australian College of General Practitioners) 2009a. Clinical guideline for the diagnosis and management of early rheumatoid arthritis. South Melbourne: RACGP.

RACGP 2009b. Clinical guideline for the diagnosis and management of juvenile idiopathic arthritis. South Melbourne: RACGP.

RACGP 2009c. Guideline for the non-surgical management of hip and knee osteoarthritis. South Melbourne: RACGP.

RACGP 2010. Clinical guideline for the prevention and treatment of osteoporosis in post menopausal women and older men. South Melbourne: RACGP.

Runciman WB, Coiera EW, Day RO, Hannaford NA, Hibbert PD, Hunt TD et al. 2012. Towards the delivery of appropriate health care in Australia. Medical Journal of Australia 197:78-81.

Safe Work Australia 2013. Compendium of workers' compensation statistics Australia 2010–11. Canberra: Safe Work Australia.

Victorian Department of Health 2013. Osteoarthritis (OA) Hip & Knee Service. Melbourne: Victorian Department of Health. Viewed 3 September 2013, <http://www.health.vic.gov.au/oahks/>.

Watts JJ, Abimanyi-Ochom J & Sanders KM 2013. Osteoporosis costing all Australians: a new burden of disease analysis – 2012 to 2022. Melbourne: Osteoporosis Australia.

WHO (World Health Organization) 2014. Healthy Settings. Viewed 24 March 2014, <http://www.who.int/healthy_settings/types/cities/en/>.

List of tables

Table 1.1: Categories of public health information required for disease monitoring 4
Table 2.1: In-scope data sources for arthritis and other musculoskeletal conditions 11
Table 3.1: Assessment of data sources for monitoring modifiable risk factors for arthritis and other musculoskeletal conditions 15
Table 3.2: Assessment of data sources for monitoring prevalence of arthritis and other musculoskeletal conditions 18
Table 3.3: Assessment of data sources for monitoring prevention, management and treatment of arthritis and other musculoskeletal conditions 22
Table 3.4: Assessment of data sources for monitoring quality of life associated with arthritis and other musculoskeletal conditions 25
Table 3.5: Assessment of data sources for monitoring death and disability associated with arthritis and other musculoskeletal conditions 27
Table 3.6: Assessment of data sources for monitoring health expenditure associated with arthritis and other musculoskeletal conditions 29
Table 4.1: Assessed data sources: overall rating with respect to each priority information area....34

List of figures

Figure 1.1: Public health activities across the disease continuum for arthritis and other musculoskeletal conditions. 5

Figure 1.2: Assessment framework for determining the suitability of current data collections for monitoring arthritis and other musculoskeletal conditions 7

Figure 3.1: A conceptual framework for determinants of health 13

List of boxes

Box 1.1: What are musculoskeletal disorders? 3
Box 1.2: Key questions for monitoring arthritis and other musculoskeletal conditions 6
Box 3.1: The Osteoarthritis Hip and Knee Service 21
Box 3.2: Uptake of services for people with severe osteoarthritis 24

Related publications

AIHW (Australian Institute of Health and Welfare) 2013. A snapshot of rheumatoid arthritis. Bulletin no. 116. Cat. no. AUS 171. Canberra: AIHW.

AIHW 2013. A snapshot of juvenile arthritis. Bulletin no. 113. Cat. no. AUS 168. Canberra: AIHW.

AIHW 2012. Risk factors contributing to chronic disease. Cat. no. PHE 157. Canberra: AIHW.

AIHW 2011. A snapshot of osteoporosis in Australia 2011. Arthritis series no. 15. Cat. no. PHE 137. Canberra: AIHW.

AIHW 2011. Population differences in health-care use for arthritis and osteoporosis in Australia. Cat. no. PHE 147. Canberra: AIHW.

AIHW 2010. Health system expenditure on disease and injury in Australia, 2004–05. Cat. no. HSE 87. Canberra: AIHW.

AIHW 2010. A snapshot of arthritis in Australia 2010. Cat. no. PHE 126. Canberra: AIHW.

AIHW 2010. Use of health services for arthritis and osteoporosis. Cat. no. PHE 130. Canberra: AIHW.

AIHW 2009. Health expenditure for arthritis and other musculoskeletal conditions, 2004–05. Cat. no. PHE 115. Canberra: AIHW.

AIHW 2009. A picture of rheumatoid arthritis in Australia. Cat. no. PHE 110. Canberra: AIHW.

AIHW 2008. Arthritis and osteoporosis in Australia 2008. Arthritis series no. 8. Cat. no. PHE 106. Canberra: AIHW.

AIHW 2008. Juvenile arthritis in Australia. Cat. no. PHE 101. Canberra: AIHW.

AIHW: Rahman N, Penm E & Bhatia K 2005. Arthritis and other musculoskeletal conditions in Australia 2005: with a focus on osteoarthritis, rheumatoid arthritis and osteoporosis. Arthritis series no. 1. Cat. no. PHE 67. Canberra: AIHW.

This report assesses the potential for existing data sources to improve our understanding of arthritis and other musculoskeletal conditions and highlights future opportunities for improving data for monitoring these conditions. A 4-step process is used to assess the utility of different data sources to provide relevant information on the 6 priority information areas required for monitoring these conditions. This methodological approach may also be useful for monitoring a range of other health conditions.