

8 > Surveillance and monitoring

KEY POINTS

- The national surveillance and monitoring of arthritis and musculoskeletal conditions in Australia is virtually at an incipient stage.
- Many reasons can be advanced for this low priority, but the largely non-fatal nature of the diseases and conditions may have reduced the emphasis.
- The focus in surveillance and monitoring of arthritis and musculoskeletal conditions is on morbidity and functionality. Information on mortality and other severe health outcomes is mostly based on attributable fractions.
- A variety of national and jurisdictional data sources, both administrative and non-administrative, contain information about arthritis and other musculoskeletal conditions; however, this information is generally patchy and non-standard.
- Most of the population data on arthritis and musculoskeletal conditions are based on self-reports, but the information is not backed by radiological or other more objective evidence. The quality and reliability of the available information is also poor.
- Systematic data development through consistent use of defined data items and indicators is required. This is important in view of the aetiological diversity of arthritis and musculoskeletal conditions and the large proportion of the population they affect.

The nature and type of information required for effective surveillance and monitoring of arthritis and musculoskeletal conditions differ both in emphasis and content from that required for other National Health Priority Areas (NHPAs). The National Mortality Database—one of the best sources of information for disease monitoring—is of limited use in monitoring arthritis and musculoskeletal conditions. Similarly, hospital separations constitute only a small proportion of the health service use for these diseases and conditions. Persons with arthritis and musculoskeletal conditions usually seek medical help in primary care settings. Activity limitations associated with these conditions are also varied and considerable.

In view of this restricted range of health outcomes and health service use, much of the information needed for the surveillance and monitoring of arthritis and musculoskeletal conditions is currently obtained through population-based surveys. At a national level, ABS surveys such as the National Health Survey (NHS) and the Survey of Disability, Ageing and Carers (SDAC) have provided some insights into the perceived health status, health behaviours and risks, and use of health services in relation to arthritis and musculoskeletal conditions (ABS 2004a). Some of the state-based surveys have also generated information on the prevalence of arthritis and their impact upon the quality of life at jurisdictional level (Hill et al. 1999). However, the low prevalence of most of the musculoskeletal conditions means that the sampling strategies used for conducting these surveys may not have sufficient power to generate reliable regional estimates. The surveillance and monitoring of arthritis and musculoskeletal conditions in Australia has therefore evolved slowly, and is virtually at an incipient stage.

A variety of reasons may be advanced for the lack of effort in this direction. The largely non-fatal nature of arthritis and musculoskeletal conditions may have reduced their recognition, and therefore priority. The low severity of most of these diseases and conditions may have also reduced the emphasis. The focus in the surveillance and monitoring of arthritis and musculoskeletal conditions is essentially on morbidity and functionality. However, their input to premature mortality and poor quality of life needs to be determined.

For effective surveillance and monitoring, a theoretical framework is required that takes into consideration the development of various diseases and conditions as well as their adverse health outcomes, including activity limitations and functional impairments. The framework can be used to identify relevant datasets and as well as gaps and deficiencies in existing datasets.

This chapter provides a brief overview of data requirements for effective surveillance and monitoring of arthritis and musculoskeletal conditions in Australia. In addition to describing the currently available information, it also identifies data gaps and deficiencies in the existing information base. The process for developing indicators for regular monitoring of arthritis and musculoskeletal conditions as an NHPA is also described.

Surveillance and monitoring issues

Key terms such as pain, stiffness, swelling, deformity, instability, weakness, fracture, functional loss and altered sensibility are often used to describe arthritis and musculoskeletal conditions. The operationalisation of these key terms into an effective measuring system is complicated, however, because of the diversity of arthritis and musculoskeletal conditions and the large range of functional restrictions associated with them. Prominent issues for coverage are listed in Box 8.1.

Box 8.1: Prominent issues for the surveillance and monitoring of arthritis and musculoskeletal conditions

1. Natural history

- causes
- classification
- disease severity and complications
- co-morbidity

2. Risk factors

- late diagnosis
- aging
- immunogenetics
- metabolic disorders
- health behaviours
- biomechanical factors

3. Prevalence and incidence

- new episodes
- recurrence
- exacerbation
- life-time prevalence (chronicity)

4. Service use

- GP consultations
- hospitalisation
- other therapies
- diagnostics and referrals
- health system costs
- formal and informal care

5. Effectiveness and cost-effectiveness of treatment

- early diagnosis
- medicine use
- efficacy of primary care
- physical therapies including surgery
- models of care and their consequences
- carer's health

6. Measuring outcomes

- work loss
- disability: impairment, activity limitation, participation restriction
- pain and discomfort
- quality of life
- premature mortality

A theoretical framework

A major feature of arthritis and musculoskeletal conditions is that they are the cause of difficulty in a wide range of tasks compared with most other conditions that appear to have a more specific relationship with certain types of health outcomes. Despite treatment, most arthritis and musculoskeletal conditions result in significant physical disability for many people. This primarily results from persistent pain, although symptoms such as fatigue and depression are also relevant. In view of these diverse outcomes, it is important to take an integrated approach to health outcome issues for arthritis and musculoskeletal conditions.

The International Classification of Functioning, Disability and Health (ICF) Framework, developed by the World Health Organization (WHO), provides a general framework for human functioning and is suitable for arthritis monitoring.

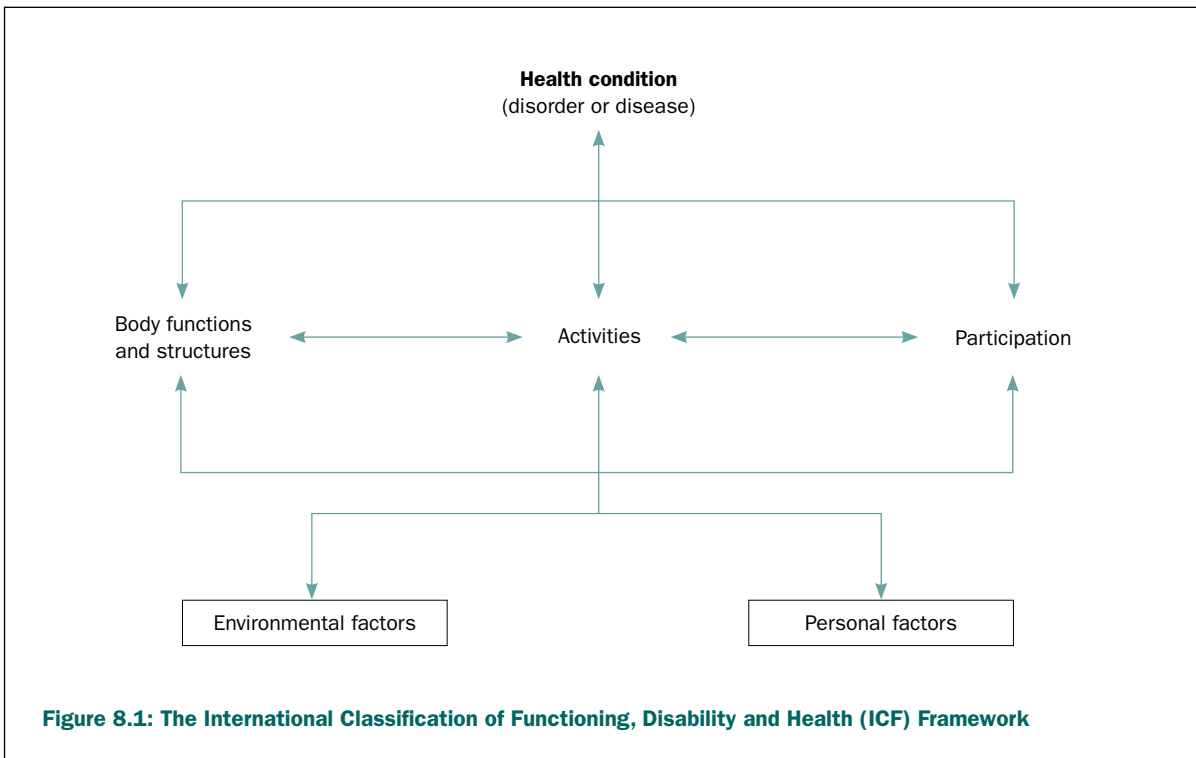
The National Health Performance Framework (NHPC Framework), developed by the National Health Performance Committee (NHPC), is useful to guide the selection of various measures and indicators (AIHW 2004). In itself, the NHPC framework has limited applicability to arthritis and musculoskeletal conditions. However, in combination with the ICF Framework, it can help to identify relevant issues as well as data items for the surveillance and monitoring of arthritis and musculoskeletal conditions.

The International Classification of Functioning, Disability and Health Framework

The ICF Framework (Figure 8.1) defines functioning and disability as multi-dimensional concepts relating to:

- the body functions and structures of people
- the activities people do and the life areas in which they participate, and
- the factors in their environment that affect these experiences.

In ICF, functioning and disability are not merely seen as a consequence of the health condition but as associated with it as well as with personal and environmental factors that contribute to it. The ICF also uses a globally accepted language to communicate about functioning at body, person and societal levels. The relationship between disease and disability is influenced by several non-disease factors.



The various components of the ICF Framework are detailed in Box 8.2.

Box 8.2: Components of the International Classification of Functioning, Disability and Health (ICF) Framework

- **Body Functions:** the physiological functions of body systems (including psychological functions)
- **Body structures:** anatomical parts of the body, such as organs, limbs and their components
- **Impairments:** problems in body function and structure, such as significant deviation or loss
- **Activity:** the execution of a task or action by an individual
- **Participation:** involvement in a life situation
- **Activity limitations:** difficulties an individual may have in executing activities
- **Participation restrictions:** problems an individual may experience in involvement in life situations
- **Environmental factors:** the physical, social and attitudinal environment in which people live and conduct their lives.

Source: WHO 2001.

Identification of datasets

A most important application of ICF in surveillance and monitoring is the identification of relevant data categories (and issues) in various settings, i.e. in the community, in acute hospital settings, in aged care homes and other living arrangements (Cieza et al. 2004a, b; Dreinhofer et al. 2004; Stoll et al. 2005). The ICF contains a hierarchy of classifications and codes for each of its main components:

- Body functions
- Body structures
- Activities, and
- Participation.

A systematic application of the ICF reveals that persons with arthritis and musculoskeletal conditions have a large range of impairments in Body functions and Body structure. The Activities and Participation components also have strong representation. However, the relatively high importance of Environmental factors, in particular those referring to products and technologies, underscores the need for effective management of arthritis and musculoskeletal conditions in many different settings.

'Core sets' have been developed, which can serve as the minimum standard requirements for monitoring arthritis and musculoskeletal conditions. The ICF core sets have already been developed for osteoarthritis and osteoporosis in community settings (Cieza et al. 2004a, b). A core set for patients with musculoskeletal conditions in the acute hospital has also been recently developed (Stoll et al. 2005).

National Health Performance Framework

The NHPC Framework (Table 8.1) is a multi-dimensional framework. It was developed in 2001 to report on the performance of the Australian health system, and provides a structured approach to system appraisal (AIHW 2004). The Framework can also be adapted to identify indicators for public health surveillance and disease monitoring.

The NHPC framework has three tiers, namely

- Health status and outcomes
- Determinants of health, and
- Health system performance.

Although the three tiers of the framework are not hierarchical, the underlying relationships between the tiers and their various dimensions are well recognised.

The NHPC Framework acknowledges that influences in population health emanate from interventions and determinants both within and outside the health system. It therefore helps to monitor all health system interventions, including acute care, community health and public health sectors. The Framework can be applied at all levels and in all sectors of the health system, including at the individual program level and for particular regions.

The NHPC Framework can also be applied to keep indicators for the surveillance and monitoring of individual diseases in line with current thinking about the general health system and health status of Australians. While this approach has the benefit of enabling movement between sets of indicators and disease inter-comparisons, there are limitations because of the more generalised appeal of the NHPC Framework.

Table 8.1: The NHPC Framework

Health status and outcomes				
How healthy are Australians? Is it the same for everyone? Where is the most opportunity for improvement?				
Health conditions	Human function	Life expectancy and wellbeing	Deaths	
Prevalence of disease, disorder, injury or trauma or other health-related states.	Alterations to body, structure or function (impairment), activities (activity limitation) and participation (restrictions in participation).	Broad measures of physical, mental and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).	Age and/or condition-specific death rates.	
Determinants of health				
Are the factors determining health changing for the better? Is it the same for everyone? Where and for whom are they changing?				
Environmental factors	Socioeconomic factors	Community capacity	Health behaviours	Person-related factors
Physical, chemical and biological factors such as air, water, food and soil quality resulting from chemical pollution and waste disposal.	Socioeconomic factors such as education, employment, per capita expenditure on health, and average weekly earnings.	Characteristics of communities and families such as population density, age distribution, health, literacy, housing, community support services and transport	Attitudes, beliefs knowledge and behaviours, e.g. patterns of eating, physical activity, excess alcohol consumption and smoking.	Genetic-related susceptibility to disease and other factors such as blood pressure, cholesterol levels and body weight.
Health system performance				
How well is the health system performing in delivering quality health actions to improve the health of all Australians? Is it the same for everyone?				
Effective		Appropriate		Efficient
Care, intervention or action achieves desired outcome.		Care/intervention/action provided is relevant to the client's needs and based on established standards.		Achieving results with most cost-effective use of resources.
Responsive		Accessible		Safe
Service provides respect for people; is client orientated; and includes respect for dignity, confidentiality, participation in choices, promptness, quality of amenities, access to social support networks, and choice of provider.		Ability of people to obtain health care at the right place and right time irrespective of income, physical location and cultural background.		The avoidance of or reduction to acceptable limits of actual or potential harm from health care management or the environment in which health care is delivered.
Continuous		Capable		Sustainable
Ability to provide uninterrupted, coordinated care or service across programs, practitioners, organisations and levels over time.		An individual's or service's capacity to provide a health service based on skills and knowledge.		System or organisation's capacity to provide infrastructure such as workforce, facilities and equipment, and to be innovative and respond to emerging needs (research, monitoring).

Data classification

Issues to do with data definition and classification are central to effective surveillance and monitoring. A variety of classifications are used to organise the diversity of diseases and conditions and their outcomes. In the case of arthritis and musculoskeletal conditions, a highly diverse group, the use of classifications in categorising various aspects of outcomes and their overlap is important for effective surveillance and monitoring.

The International Classification of Diseases, version 10 (ICD-10), classifies diseases of the musculoskeletal system and connective tissue into six major blocks, namely arthropathies, systemic connective tissue disorders, dorsopathies, soft tissue disorders, osteopathies and chondropathies, and other disorders of the musculoskeletal system and connective tissue (Table 8.2). These blocks of diseases and conditions are further categorised into major disease/condition groups.

Table 8.2: ICD-10 classification of diseases of the musculoskeletal system and connective tissues (Chapter XIII)

Block/Disease group	Codes	Example(s)
Arthropathies (M00–M25)		
Infectious arthropathies	M00–M03	Reactive arthropathies
Inflammatory polyarthropathies	M05–M14	Rheumatoid arthritis
Arthrosis	M15–M19	Osteoarthritis
Other joint disorders	M20–M25	Acquired deformities
Systemic connective tissue disorders (M30–M45)		Systemic lupus erythematosus
Dorsopathies (M40–M54)		
Deforming dorsopathies	M40–M43	Kyphosis
Spondylopathies	M45–M49	Ankylosing spondylitis
Other dorsopathies	M50–M54	Inter-vertebral disc disorders
Soft tissue disorders (M60–M79)		
Disorders of muscles	M60–M63	Myositis
Disorders of synovium and tendon	M65–M68	Synovitis
Other soft tissue disorders	M70–M79	Bursitis
Osteopathies and chondropathies (M80–M94)		
Disorders of bone density and structure	M80–M85	Osteoporosis
Other osteopathies	M86–M90	Osteomyelitis
Chondropathies	M91–M94	Chondromalacia
Other disorders of the musculoskeletal system and connective tissues (M95–M99)		Acquired deformity of pelvis

Mortality classifications

Australia uses the International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD-10) for coding causes of death. In this report, deaths data before 1997 have been coded to ICD-9 (International Classification of Diseases, Ninth Revision) and thereafter to ICD-10. The introduction of ICD-10 and the move from manual coding to automated cause of death coding has resulted in a break in the time series. To overcome this difficulty the ABS coded the 1997 deaths data using both ICD-9 (manual coding) and ICD-10 (automatic coding), which allowed comparability factors between ICD-9 and ICD-10 to be derived.

Most of the mortality-related information is based on the underlying cause of death. The underlying cause is the disease or injury that initiated the sequence of events leading directly to death, or the circumstances of the violence or accident that produced the fatal injury (WHO 1948). Since 1997, information on additional causes of death has also been made available by the ABS (Gaminiratne 2001). This additional information is useful in the context of diseases such as rheumatoid arthritis and osteoporosis, which are not immediately life-threatening or fatal but may contribute directly or indirectly to various processes leading up to death.

Morbidity classifications

For hospital diagnoses and procedures, the international classifications (ICD-9 and ICD-10) have been modified for Australia. The hospital data before 1998–99 were coded using ICD-9-CM (International Classification of Diseases, ninth revision, Clinical Modification) and thereafter using ICD-10-AM (International Statistical Classification of Diseases and Related Health Problems, tenth revision, Australian Modification).

Most of the information related to hospital separations is based on first-listed or principal diagnosis. This is the condition established to be chiefly responsible for the admission to hospital. The principal diagnosis is not necessarily the underlying cause of disease; it may be only a manifestation of the disease (AIHW 2005b). Information on additional diagnoses, whether contributing to the reason of principal diagnosis or not, is also listed and is useful for seeking insight into the contribution of the various conditions to illness and morbidity.

The general practice (GP) data follow the International Classification of Primary Care, second edition (ICPC-2). The ICPC classification has a bi-axial structure, with 17 chapters based on body systems along one axis and seven components covering signs, symptoms, process of care and diagnoses along the other (WICC 1997). The processes of care, including referrals, non-pharmacological treatments and orders (pathology and imaging), were classified by the process components of the ICPC-2 (AIHW: Britt et al. 2004).

Disability characterisation

The loss of healthy life due to non-fatal conditions can be categorised using a variety of classifications. The International Classification of Functioning, Disability and Health (ICF) conceptualises disability as multi-dimensional, relating to the body functions and structures of people, the activities they do, the life areas in which they participate and the factors in the environment that affect these experiences (Figure 8.1).

The ABS Survey of Disability, Ageing and Carers operationalises these concepts into 17 different types of limitations, restrictions or impairments, which can be further related to specific diseases and conditions. Questions on difficulty with activities and assistance needed provide further components of the disability picture.

The extent of disability associated with various diseases and conditions can also be categorised using disability weights, or 'health state' preferences (Murray & Lopez 1996). However, no Australia-specific disability weights have been generated. Another numerical categorisation of disability is based on the years of healthy life lost due to time lived in states other than the reference state of good health, or YLD (AIHW: Mathers et al. 1999). Both disability weights and the YLD categorisation give a broader interpretation of morbidity or ill health.

A national surveillance and monitoring system

No prototype currently exists for national surveillance and monitoring of arthritis and musculoskeletal conditions. Describing the status of a particular disease in the population at regular intervals is not a good enough basis for assessing population health care needs. Information needs to be put together from a variety of data sources to generate disease-specific profiles which, in addition to information on incidence, prevalence, mortality and potential years of life lost, also includes a range of evaluative components.

Broadly, a disease-specific surveillance and monitoring system should have three major components, namely:

- an unambiguous conceptualisation of surveillance and monitoring issues and objectives
- a well-developed database and other sources of relevant information, and
- a fully established plan for data analysis and regular information dissemination.

Objectives

The major objectives in surveillance and monitoring of arthritis and musculoskeletal conditions need to be set out clearly by extensive consultation with experts in the field and other stakeholders. Since the focus of arthritis and musculoskeletal conditions as an NHPA is on osteoarthritis, rheumatoid arthritis and osteoporosis, the system should concentrate on these three topics initially.

Databases and other sources of information

A variety of administrative databases and survey datasets contain useful information about arthritis and other musculoskeletal conditions in Australia. National databases on ambulatory and managed care, such as disease registers, hospital separations, GP encounters, nursing homes, etc., may be a useful source of information.

Health surveys, including the national and state health surveys, and Disability, Ageing and Carers' Survey could provide useful insights into the prevalence and impact of arthritis. Pharmacy data, available through the Pharmaceutical Benefits Scheme (PBS) and BEACH (Bettering the Evaluation and Care of Health) Surveys, should be useful sources of information about the use of medicines for arthritis.

Assessment and validation of various datasets are central to establishing a disease-specific surveillance and monitoring system. Some obvious gaps remain within this mix, with lack of information on risk factors being the most glaring. An information system is required that would link outpatient data with GP referral, specialist's diagnosis and management plan. This, in turn, could be linked to accident and emergency visits, radiology, physiotherapy, day care admissions and inpatient care data.

A systematic approach is also required to assess the quality of the existing information. A well-established plan should enhance the value and quality of existing and continuing collections for arthritis and musculoskeletal conditions monitoring. A more prudent approach would be to develop a set of indicators and pursue data requirements for that particular set only.

Analysis and reporting

A range of analyses are required to get a clear understanding of the underlying patterns. However, most of the analysis should be guided by issues and objectives of the system. Some of the analysis required is as follows:

Trends and differentials

- underlying trends
- small area variation
- health differentials

Disease attribution

- disease attribution
- disease progression and outcomes
- complications
- acute episodes
- community health
- risk factors

Dissemination of information will also need to be organised through a variety of mechanisms, including:

- indicator-based time series in e-format
- state of arthritis reports
- topical surveillance summaries, and
- Australia's Health.

Major activities

Three major activities of such a system would be:

- generation of baseline information
- indicator and data development, and
- integrated monitoring and reporting.

Generation of baseline information

Since there has been no systematic national reporting of this important set of diseases and conditions, an immediate task is to generate baseline information on arthritis and musculoskeletal conditions in Australia. The baselines should not only cover health outcomes (disease severity, pain, disability, mental health, medicine use etc.) but also include health care information—extracted from hospital separations, GP visits and other related data—and health system costs. This report fulfils that requirement to a certain extent.

The extraction of baseline information for this report has provided an excellent opportunity to explore the potential of various data sources, including administrative collections, for the surveillance and monitoring of arthritis and musculoskeletal conditions. The approach has provided insights into who is affected, who is at

increased risk of developing the disease, and how arthritis and musculoskeletal conditions affect physical health, quality of life, economics and other areas. The information so generated should form the basis for initiating time series for regular surveillance and monitoring.

Indicator and data development

National surveillance and monitoring of arthritis and musculoskeletal conditions should be undertaken by using a defined set of indicators. Indicator-based reporting has been the cornerstone of NHPA monitoring and reporting and has proved extremely useful (Appendix F).

Indicator development is a tedious process that requires careful work in consultation with a variety of stakeholders. The task entails not only the design and validation of suitable indicators across the continuum of care—using a well-defined reporting framework, e.g. National Health Performance Framework—but also includes development of appropriate operational definitions and suitable data development.

An indicator development process for arthritis and musculoskeletal conditions is currently underway. A workshop was organised in 2004 to shortlist a set of indicators for further discussion. Consultations regarding the design and use of these indicators, and their data requirements, were occurring at the time of the publication of this report.

Integrated monitoring and reporting

The approaches described above outline both immediate and short-term surveillance and monitoring of arthritis and musculoskeletal conditions in Australia. To achieve an integrated and more complete surveillance and monitoring, a variety of other issues also needs to be addressed. In addition to disease outcomes and risk factors information, there needs to be good data on the quality of life, coping, attitude and behaviours, pain and paths to functional limitation, and effect of arthritis and musculoskeletal conditions on healthy ageing. No population-based data currently exist to help determine how arthritis and musculoskeletal conditions are currently treated in Australia. Efforts would be required to increase understanding of current and future prevention and clinical treatments for arthritis and musculoskeletal conditions.

In addition to standard epidemiological measures for the whole population, differentials between various sub-groups also need to be analysed, especially for rural and remote populations, Indigenous Australians, and various socioeconomic groups. Small area analysis, multivariate analysis and the estimation of attributable fractions are other important approaches to delineate the impact of these diseases on individuals and communities. The possibility of record linkage between data sets may also enhance the analytical capability of the system. These and other related monitoring issues need to be addressed systematically.

Dissemination of suitable information through published reports and the Internet would be central to any strategy aimed at the surveillance and monitoring of arthritis and musculoskeletal conditions. It will be useful to follow this baseline report with special reports on osteoarthritis, rheumatoid arthritis and osteoporosis. Provision of this information and relevant datasets on a dedicated website should be considered. Indicator-based time series should be posted on the website and regularly updated.

Current data sources

The data sources interrogated for the preparation of this baseline report include population surveys, administrative collections, registries and epidemiological studies. The major emphasis was on national collections but, where necessary, quasi-national collections were also used. All these collections are described below in brief.

The following section has been structured in terms of impact components of arthritis and musculoskeletal conditions and their management, specifically the data sources used for morbidity (incidence/prevalence, professional encounters), health-related quality of life, disability, health service use and mortality statistics.

National Health Survey

The NHS is designed to collect information on the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle through self-reports. Historical information is available from four NHS surveys, conducted in 1977, 1983, 1989–90 and 1995. The latest NHS was conducted in 2001, covering a sample of 26,900 people from February to November 2001.

This ABS survey collects information about various forms of arthritis as well as back pain, osteoporosis and other diseases of the musculoskeletal system and connective tissues. The symptoms covered include some type of swelling in the joints, limitations in motion, pain when moving. The reports are not necessarily based on clinical diagnoses (ABS 2002).

Although the NHS allows differentiation between major forms of arthritis, e.g. osteoarthritis and rheumatoid arthritis, the quality and validity of this information is uncertain. The information on osteoporosis is also unreliable as most of the respondents probably heard of the diagnosis only after having had a fracture.

It may also be noted that the NHS is a community-based survey. Since arthritis and musculoskeletal conditions are much more prevalent in older age groups, absence of information on persons in the institutions tend to underestimate the extent of the problem.

The NHS data do not allow health status or health utilisation information to be attributed to arthritis or other musculoskeletal conditions. For example, even if an individual reports the presence of both arthritis and long-term disability, it cannot be ascertained whether the long-term disability is a direct result of the arthritis.

Disability surveys

The disability-related information and information on health-related quality of life was extracted from the Surveys of Disability, Ageing and Carers (SDAC), also conducted by the ABS. The SDAC collects national information on disability levels of Australians, their current and future care needs, and the role of carers. The last survey collected information from a sample of 41,200 people over a six-month period in 2003.

In addition to information on the extent of activity limitations and participation restriction, the disability survey also collects information about the role of various diseases and health conditions as disabling conditions. Multiple conditions are listed. A disease condition may be defined as the main disabling condition—a long-term condition identified by a person as the one causing the most problems—or as another disabling condition (ABS 2004b).

Other population surveys

A variety of population health surveys in Australia generate information on arthritis and musculoskeletal conditions at both national and regional levels. This includes not only information on the presence of the disease/condition but also associated functional limitations. All this information is virtually based on self-reports as no Australian survey has included the objective measures of using x-ray changes (conducted for example, through the National Health and Nutrition Examination survey, or NHANES, in the United States).

Professional encounters

General practitioners (GPs) are usually the first point of call for medical services in Australia. Information on GP–patient encounters is collected through the Bettering the Evaluation and Care of Health (BEACH) Survey, an ongoing national data collection looking at the clinical activities of general practitioners (AIHW: Britt et al. 2001). The General Practice Statistics and Classification Unit (an AIHW collaborating unit within the Family Medicine Research Centre, University of Sydney) conducts the survey.

BEACH began in April 1998 and involves a random sample of approximately 1,000 GPs per year, each collecting data on 100 consecutive patient encounters. The information available includes problems managed, medications, referrals, tests and investigations, and patients reasons for professional encounters.

Morbidity data

Most morbidity data refer to those who seek medical help in primary care setting and hospitals. However, in the absence of any systematic data collection in primary care settings, in Australia, this information is generated using population-based surveys.

Individuals are a major source of data on incidence/prevalence, risk factors, functional limitations and use of health care services for arthritis and musculoskeletal conditions through surveys.

Information on the extent of illness and morbidity was derived from a variety of data sources. The capacity to gather together various, sometimes disparate, pieces of information is limited by a general lack of incidence/prevalence data, incomplete case ascertainment and limited identification of the clinical stage of the diseases and conditions. Information on the duration of illness or morbidity is also sketchy.

Hospital separations

The National Hospital Morbidity Database, maintained at the AIHW, contains demographic, diagnostic, procedural and duration of stay information on episodes of care for patients admitted to hospital (AIHW 2000b). The data items are supplied to the AIHW by the state and territory health authorities, and by the Department of Veterans' Affairs.

In this report, disease data relate to the principal diagnosis for hospitalisation. Data on procedures are also reported for each condition. The data can be used to provide an indication of morbidity levels in the population, as long as it is noted that admission rates are affected by differing admission practices, multiple admissions for chronic diseases and differing access to services.

Mortality data

The cause of death statistics were extracted from the National Mortality Database, maintained at the AIHW. The database contains information on the cause of death supplied by the medical practitioner certifying the death or by a coroner.

Registration of deaths is the responsibility of the state and territory Registrars of Births, Deaths and Marriages. The registrars provide the information to the ABS for coding the cause of death. The AIHW maintains these data without unique identifiers in a national database, updated annually.

On 1 January 1997, the ABS introduced new, automatic coding software that identifies multiple causes of death. This information is useful for monitoring co-morbid conditions and complications. Data for both the underlying cause of death and the additional causes of death have been used in this report.

Health expenditure data

Information on the economic impact of arthritis and musculoskeletal conditions is derived from the AIHW Health Expenditure Database, which contains information on direct health expenditure for about 200 different disease and injury categories. Estimates are available by age group, sex and area of expenditure—hospitals, high-level residential aged care, medical services, other professional services, pharmaceuticals and research. Capital expenditures, expenditure on community health (except community mental health), public health programs (except cancer screening), health administration and health aids and appliances, however, are not allocated by disease group.

The AIHW Health Expenditure Database is a secondary collection, based on analysis of data derived from a range of sources. The analytical techniques used and the assumptions made in arriving at these estimates are described in AIHW (2005b).

Data gaps and deficiencies

Several gaps were identified in the currently available data for arthritis and musculoskeletal conditions. Enhancement of existing and continuing collections through improved comparability and coordination should increase their usefulness for monitoring and surveillance of arthritis and musculoskeletal conditions in Australia.

- Health surveys, based on self-reports, are major sources of national and regional prevalence data in Australia. These surveys provide information on sociodemographic characteristics, medical conditions and health status, although there are questions surrounding the validity of this approach.
 - There are no national data, based on radiological or immunological information, to support self-reports.
 - The current surveys do not enable one to critically differentiate between the many types of arthritis, e.g. osteoarthritis and rheumatoid arthritis.
 - The survey data do not allow health status or health utilisation to be attributed to a specific disease.
- A major gap is the lack of detailed information on the use of health care services by people with arthritis and musculoskeletal conditions. Most of the care for these diseases and conditions, including specialist care, is delivered in community settings for which there are currently no systematic data available.
 - Data are available on surgery and hospitalisation, but only a small proportion of those people who have arthritis and musculoskeletal conditions undergo these interventions.
 - More information is needed about the factors associated with use of care by patients for their arthritis.
 - Information about the use of medical specialists, particularly rheumatologists, by persons with arthritis and musculoskeletal conditions is lacking.

- There are no systematic data available on the prescribing of medications; the use of rehabilitation services, such as physical and occupational therapy; or on access to other services, such as helpful devices, therapeutic exercise programs, community support and self-management.
 - The need for data on the use of prescription medication is of increasing importance in light of current advances in the development of anti-inflammatory drugs (e.g. Cox-2 inhibitors) and effective, but expensive, drugs for the treatment of rheumatoid arthritis.
 - There is a deficit of information on the efficacy and use of alternative health care services and herbal medications. People with arthritis and musculoskeletal conditions are major users of these services and medications.
 - Rehabilitation therapy and community support services are a vast but largely uncharted territory in relation to arthritis and musculoskeletal conditions. There are few data about them and, in the case of community services, very little documentation about what services are available and how they are used.
- Some glaring gaps remain in information on risk factors for arthritis and musculoskeletal conditions.

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