National indicators for monitoring osteoarthritis, rheumatoid arthritis and osteoporosis

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National indicators for monitoring osteoarthritis, rheumatoid arthritis and osteoporosis

National Centre for Monitoring Arthritis and Musculoskeletal Conditions

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Contents

List of figures and tables

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
AQoL	Assessment of Quality of Life instrument: a psychometric measure of health-related quality of life
BEACH	Bettering the Evaluation and Care of Health
BMD	bone mineral density
CATI	computer-assisted telephone interview
EuroQoL	an internationally validated survey on quality of life
GP	general practitioner
HRQoL	health related quality of life
ICF	International Classification of Functioning, Disability and Health
ICD-10	International Classification of Diseases and health-related problems, 10th revision (used in Australia for mortality data)
ICD-10-AM	International Classification of Diseases and health-related problems, 10th revision, Australian Modification (used in Australia for hospital morbidity data)
K10	Kessler 10 Psychological Distress Scale
MTF	minimum trauma fracture
NAMSCAG	National Arthritis and Musculoskeletal Conditions Advisory Group
NHMD	National Hospital Morbidity Database
NHPA	National Health Priority Area
NHS	National Health Survey
OA	osteoarthritis
OP	osteoporosis
RA	rheumatoid arthritis
SDAC	Survey of Disability, Ageing and Carers
SES	socioeconomic status
SF-12	12 item short form questionnaire
SF-8	8 item short form questionnaire

Summary

The use of indicators has been central to the monitoring of Australia's National Health Priority Areas. Sets of 15–20 indicators have been developed to monitor the priority areas of cardiovascular health, cancer control, injury prevention and control, mental health, diabetes mellitus and asthma. This report describes a set of indicators for monitoring arthritis and musculoskeletal conditions in Australia.

Australian Health Ministers declared arthritis and musculoskeletal conditions as the seventh National Health Priority Area in 2002. This priority attention is due to the substantial burden imposed by these conditions on the Australian community. The initial focus of national action was to be on osteoarthritis, rheumatoid arthritis and osteoporosis. These three conditions are among the most common long-term arthritis and musculoskeletal conditions affecting Australians, and result in a significant disease burden.

This report documents the indicator development process, summarising the outcomes of a national expert workshop and views expressed at stakeholder consultation meetings held in six jurisdictions. Operational definitions for the indicators, including methodology and recommended data sources, are included and future data development and evaluation needs identified. The indicators were developed by the Australian Institute of Health and Welfare and the Data Working Group of the National Arthritis and Musculoskeletal Conditions Advisory Group (NAMSCAG), in consultation with various experts and stakeholders.

A set of 16 key indicators has been constructed. The set covers the continuum of care, including indicators relating to risk factors, disease prevalence, quality of life, health service use and mortality.

The indicators covering risk factors for arthritis and osteoporosis are limited to those pertaining to physical activity and excess weight. Physical activity is central to maintaining musculoskeletal health. The lack of physical activity also contributes to overweight and obesity. Excess weight as a risk factor for osteoarthritis is important to monitor both in adults and children. Several risk factors have been identified for the development of osteoporosis but could not be operationalised at this stage because of the lack of suitable national data.

The extent of the problem in Australia will be monitored using the measure of prevalence. Four different indicators, including one on the prevalence of arthritis among Aboriginal and Torres Strait Islander peoples, have been agreed to. In the absence of much objective national data, these indicators will be operationalised using self-reports.

Three indicators have been selected for monitoring the quality of life in relation to arthritis and osteoporosis. A variety of instruments are available to measure quality of life in the general population as well as among people with arthritis and osteoporosis.

The health service use for arthritis and osteoporosis is mostly in primary care settings. However, in the absence of good quality data, the focus of the selected indicators in the recommended set is on knee and hip replacements and hospitalisation for hip fractures. The recognition of the need to diagnose and treat rheumatoid arthritis as early as possible has also been covered by focusing on waiting time to see a rheumatologist. These process indicators should not only provide useful insights into the serious effects of arthritis and osteoporosis but also help monitor the processes underway to manage these problems.

Arthritis and osteoporosis are not generally fatal conditions. Hence the focus on mortality is limited to rheumatoid arthritis. A systemic disease, rheumatoid arthritis is responsible for and contributes to mortality in a number of ways.

The quality and range of national data available for monitoring arthritis and osteoporosis is limited. The consultation process undertaken to develop these indicators has not only identified gaps and deficiencies in the information but also emphasised the need to monitor these largely non-fatal conditions in a systematic fashion. The composition of the indicator set has been inevitably influenced by these data gaps and deficiencies. Nonetheless, regular monitoring and reporting using these indicators should inform decision making, assist evaluation of public health strategies, and contribute to a better evidence base on which to build future strategies and policies for arthritis and musculoskeletal conditions in Australia.

1 Introduction

Arthritis and musculoskeletal conditions are the world's most common cause of severe long-term pain and physical disability (Murray & Lopez 1996). In Australia, these conditions contribute significantly to pain and disability, with more than one in three Australians with a disability having arthritis or a musculoskeletal condition as their main disabling condition (AIHW: Rahman et al. 2005). Arthritis and musculoskeletal conditions are also highly prevalent: an estimated 31% of Australians (6.1 million people) has one or more of these conditions (ABS 2006a), and this number is likely to increase with the ageing of the population. Although arthritis and musculoskeletal conditions are not commonly a direct cause of death, they do affect quality of life and in some cases reduce life expectancy, and are a major reason for health service use and health expenditure. It is therefore important to track changes in the prevalence and effects of these conditions in the population, and monitor the related use of and need for health services.

A national health priority

Arthritis and musculoskeletal conditions were declared a National Health Priority Area (NHPA) by Australian Health Ministers in 2002, the seventh set of diseases and conditions so named. Selection as an NHPA highlights the importance of these conditions, and provides a framework for intervention to improve the health of Australians with or at risk of developing arthritis and musculoskeletal conditions. It also provides impetus for national monitoring, to report regularly on the impact of these conditions.

The NHPA initiative is a collaborative effort involving the federal, state and territory governments, with input from a range of non-government, clinical and consumer groups. It seeks to focus public attention and health policy on areas that contribute significantly to the burden of illness and injury in Australia, but in which there is potential for reduction in this burden and gains in the health of Australians. Common risk factors and health inequalities relating to the chosen focus areas are also important. The initiative recognises that strategies for reducing the burden of disease should work across the continuum of care, from prevention through to treatment and management.

Monitoring the National Health Priority Areas

Sets of key indicators are used for monitoring NHPA diseases and conditions. Monitoring and reporting against these indicators over time allows for evaluation, tracking and prediction of relevant health outcomes. The indicators provide a profile of the current status of each condition, as well as providing historical data from which future trends might be inferred. The indicators are developed using a defined set of criteria, including the availability of or a commitment to collect relevant data. Existing NHPA indicators were developed with input from a wide range of stakeholders, ensuring their relevance, validity and acceptability across the board.

The Australian Institute of Health and Welfare (AIHW) and its collaborating units have been instrumental in developing indicators for various NHPAs. The AIHW and the National Arthritis and Musculoskeletal Conditions Advisory Group (NAMSCAG) Data Working

Group (see Appendix 1) were charged with driving the process of developing indicators for the NHPA of arthritis and musculoskeletal conditions.

Purpose and structure of this report

This report outlines the development of the indicators, summarising feedback received from the expert workshop and stakeholder consultation meetings held in various jurisdictions, and provides operational definitions for the final set of indicators recommended for monitoring arthritis and musculoskeletal conditions in Australia.

Chapter 2 provides an overview of the indicator development process, and summarises the outcomes of a national expert workshop convened to discuss the issues and recommend a short list of indicators for further development. Chapter 3 presents a summary of the views expressed at stakeholder consultations held in six jurisdictions. Operational definitions for the indicators recommended for national monitoring of arthritis and musculoskeletal conditions are presented in Chapter 4. The report concludes in Chapter 5 with a discussion of future indicator and data development work required for effective national monitoring of arthritis and musculoskeletal conditions.

2 Indicator development

Indicator development is an iterative process (Figure 1). The first step in developing national indicators for arthritis and osteoporosis was for the Data Working Group to identify a list of potential indicators. Through an expert workshop and stakeholder consultations, this list was narrowed down and refined further to achieve a final cohesive and parsimonious set. In the future these indicators will be reported against, evaluated and, if necessary, refined to meet future information needs and priorities.

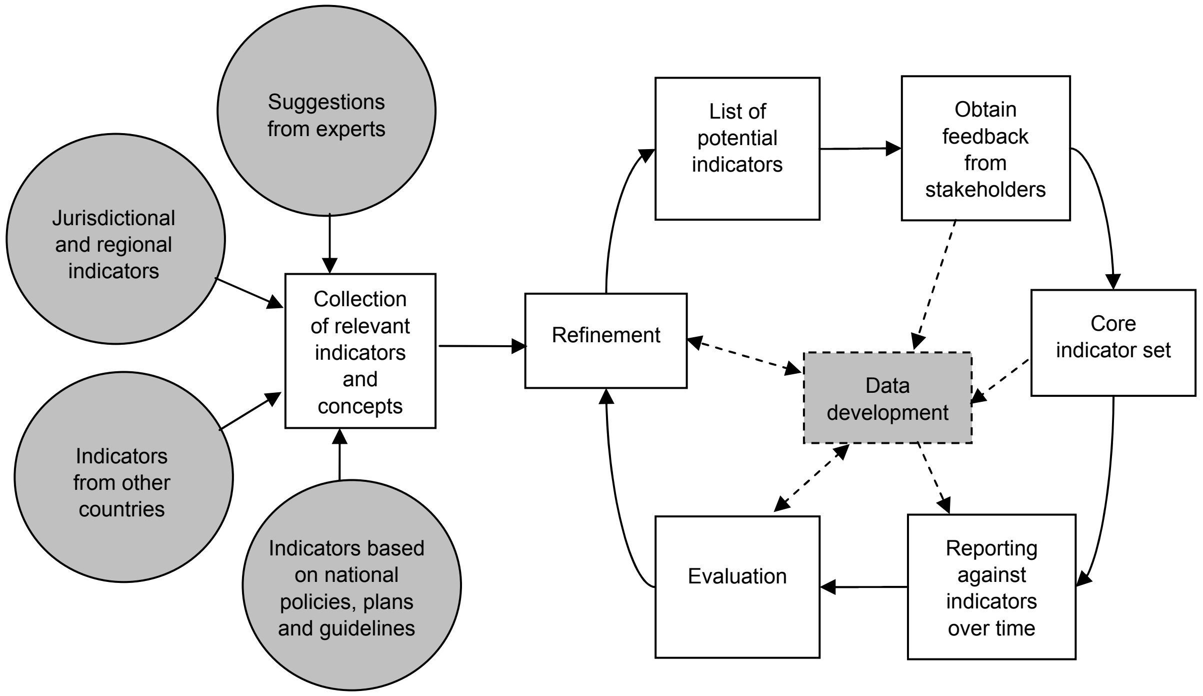

Figure 1: Framework for indicator development

The process undertaken by AIHW and the Data Working Group was as follows:

1. Relevant indicators were identified from a variety of sources, including advice from NAMSCAG's osteoporosis, osteoarthritis and rheumatoid arthritis working groups, the draft National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis, and indicators used in the United Kingdom, the United States and Canada, and by the World Health Organization.
2. The selected indicators were then assessed and refined using the National Health Performance Framework criteria for indicator development (Box 1). This resulted in a list of 50 potential indicators, organised within the dimensions and tiers of the National Health Performance Framework (National Health Performance Committee 2001).
3. These 50 indicators were mapped to each of the three focus areas (osteoporosis, osteoarthritis and rheumatoid arthritis) and common indicators flagged.
4. Feedback on this list of potential indicators was sought from NAMSCAG and its working groups, and through a workshop of national experts. This feedback was considered in drawing up a short list of indicators.

5. Operational definitions were drafted by AIHW for each of the short-listed indicators, and feedback was sought from stakeholders through a series of consultation meetings.
6. The AIHW and the Data Working Group considered all feedback and finalised the composition of the core indicator set and related operational definitions.

Box 1: Selection criteria for developing indicators

Indicators should meet some or all of the following criteria:

1. *Be worth measuring*
2. *Be measurable for diverse populations*
3. *Be understood by people who need to act*
4. *Galvanise action*
5. *Be relevant to policy and practice*
6. *Reflect results of actions when measured over time*
7. *Be feasible to collect and report*
8. *Comply with national processes of data definitions.*

Source: *National Health Performance Committee 2001.*

Indicator development workshop

For national indicators to be widely accepted, agreement on both the nature and form of the indicators is required from many different parties and stakeholders. It was therefore considered appropriate that these parties were involved early in the indicator development process, in order for the process to benefit from their wide-ranging expertise and views and that they in turn could claim ownership of the indicator set. For this reason, once potential indicators or indicator concepts had been identified, a national workshop of experts was convened to discuss the composition of the indicator set, identify relevant data issues, and recommend a short list of indicators for further development.

The indicator workshop was held in Canberra in July 2004. Participants included representatives from around the country with a range of interests, including clinicians, health practitioners with specialised knowledge of osteoarthritis, rheumatoid arthritis and osteoporosis, health information specialists, health administrators and decision makers.

The aims and objectives of the workshop were to:

- recommend on the size and composition of the indicator set
- short-list a set of indicators from the 'potentials' lists
- consider the design of the indicators in the set.

Participants were provided with sets of potential indicators for each condition and a separate set of potential indicators common to two or all three of the conditions. These indicators had been developed by the NAMSCAG Data Working Group, with input from members of NAMSCAG, using the National Health Performance Framework. Some of the indicators included in the list were already being monitored and reported for other NHPAs, under injury prevention and control and NHPA-wide risk factors. In all, the workshop participants considered a total of 50 potential indicators.

The initial discussions aimed at achieving consensus on indicators that were common across two or all three of the focus areas. The discussions revealed the difficulty in drawing these different conditions together under a common set of indicators. While agreement was reached for a small number of indicators, the composition of the set was not fully agreed.

Major issues

Major issues raised at the July 2004 workshop were:

- *What is to be measured, what is actually being measured, and its relevance*

  In some cases this conceptual issue related to the basic need for the development of information. In other cases it was more a matter of understanding the nature and context of data already being collected. Two examples were cost/expenditure and health promotion activities, where it was generally felt that these could be useful measures but at present the data on both lacked sufficient specificity to produce valid national indicators.

- *Appropriateness of the data*

  This issue related to the need for the data to reflect actual changes. For example, do changes in the number of self-reported cases or hospital separations indicate a real change in incidence, or are they a result of changed diagnostic procedures or community awareness campaigns? The need to establish a causal relationship was seen as desirable.

- *Data development*

  This phrase covered activities ranging from conceptual development of data items and indicators to the development and collection of nationally consistent data. In many cases it was felt that available information could not validly be used. There were many examples of agreement about a suitable indicator for which there was currently a lack of data, either because the data were not currently being collected or a particular data item was not uniformly collected. Several data items which required further conceptual work were also identified, such as a meaningful measure of environmental factors in determining health, and how to gauge the impact of a health promotion or community education program.

- *Data availability*

  This was identified as a critical element; the availability of good quality, reliable, appropriate data is central to indicator-based monitoring. To enable useful monitoring, the data also need to be available on a regular basis.

- *Source, regularity and periodicity of data*

  The source of data was considered important in assessing the quality, frequency and reliability of the indicator. For example, information compiled from administrative data sets is likely to be available more frequently than that based on surveys. Surveys may be prone to budget constraints that may result in cessation, a reduced number of questions or reduced frequency of collection. This could affect the quality or availability of data for particular indicators.

- *The need for an ongoing refinement/development process*

  It was recognised that there is a strong case for continuing development and refinement by regular reviews of the indicators and their underpinning data. This would ensure that the indicators remain relevant and valid.

- *Degree of commonality/overlap with other measures*

  Some issues may be described using existing or other measures as a surrogate. The differentiation between issues may not be sufficient to warrant separate indicators, for example, activity limitation and social engagement and participation can be seen as subsets of health-related quality of life.

- *Combining indicators for different conditions*

  Although osteoarthritis, rheumatoid arthritis and osteoporosis are different conditions, they have been put together as the core of the NHPA of arthritis and musculoskeletal conditions. The 'focus' in this particular case is not a single entity but a number of different conditions. While this was seen by some participants as a problem, it is not unusual in the context of NHPA initiatives; injury prevention and control, cardiovascular health, cancer control and mental health all cover groups of conditions. Also, the indicators would not be providing a precise quantitative measure for clinical intervention or for research purposes. Rather, they should provide a broad national picture of the condition, the underlying trend (whether the condition is getting better or worse) and its impact on the Australian community.

Outcomes

Table 1 summarises the workshop outcomes and their rationale. Outcomes have also been provided in relation to a number of the proposed indicators that were common to at least two of the focus areas, some of which were not fully resolved at the workshop. In those cases where a final decision was not arrived at, other sources such as presentations and supporting papers were drawn on to derive a conclusion.

The outcomes were essentially 'accept' or 'reject', although in some cases the need for related development was noted. 'Development' generally refers to data characteristics, such as reliability, consistency, validity, regularity of collection and national consistency. In a few cases, development of the concept underlying the indicator was seen as necessary, for example, environmental factors and health promotion activities.

There were three main grounds for rejecting some of the indicators:

- a lack of clarity or specificity
- the need for long-term information development
- rolling together of some indicators, particularly where there was lack of clarity in some measures.

Table 1: Outcomes of workshop discussions regarding potential indicators for arthritis and musculoskeletal conditions

Dimension	No.	Indicator/concept	OA	RA	OP	Outcome	Rationale
Health status and outcomes							
Health conditions	1	Prevalence (stratified by age, sex, location, and as diagnosed by health professional)	✓	✓ (ASAP)	✓	Accept	Data available.
	2	Prevalence of measured low bone mineral density (BMD)	—	—	✓	Reject	Only covers OP, limited data availability.
	3	Incidence and prevalence of minimal trauma fractures (MTF)	—	—	✓	Reject	Lacks specificity.
Human function	4	Pain (part of HRQoL)	✓	X	X	Reject	Best used as part of HRQoL.
	5	Disability days (part of HRQoL)	—	X	✓	Reject	Best used as part of HRQoL.
	6	Activity limitation (self-care, ambulation, physical, work-related) (part of HRQoL)	Roll into #7	✓ (ASAP)	✓	Reject	Best used as part of HRQoL.
Life expectancy and wellbeing	7	Health-related quality of life (HRQoL) (including pain, mental health, emotional function, self-image, fatigue, sexuality, anxiety, depression)	✓	✓	✓	Accept	Includes human function dimension, but needs to be focused on arthritis impact.
	8	Disability-adjusted life years	X	✓	X	Accept	Data available from Burden of Disease Study.
Deaths	9	Mortality rate	—	✓	X	Reject	Lacks clarity of purpose.
	10	Mortality attributable to falls	—	—	X	Accept	Already reported in injury NHPA.
	11	Mortality attributable to hip fractures (within 6 months post-op)	—	—	✓	Reject	Not appropriate as lacks clarity of purpose.
Determinants of health							
Environmental factors	12	High priority area for indicator development	—	—	—	Accept	Recognised as important factors that should be monitored.
Socioeconomic factors	13	Lost productivity/exit from workforce	✓	✓	X	Reject	Lacks clarity of purpose. Incorporate into HRQoL.

(continued)

Table 1 (continued): Outcomes of workshop discussions regarding potential indicators for arthritis and musculoskeletal conditions

Dimension	No.	Indicator/concept	OA	RA	OP	Outcome	Rationale
Community capacity	14	Carer burden	—	—	—	Reject	Definition and form to be developed. Not supported by currently available data.
	15	Social engagement	Roll into #7	—	—	Reject	Lacks clarity of purpose.
	16	Proportion of children who have experienced a 'bone health' program	—	—	✓	Reject	Lacks clarity of purpose.
	17	Community awareness regarding prevention of falls	—	—	X	Reject	Lacks clarity of purpose.
	18	Health promotion activities *Important issue but desired measurable outcomes need to be agreed and specified*	—	—	—	Accept	Priority for development but need agreed outcomes to monitor effectiveness of health promotion activity.
	19	People with condition who are confident/able to effectively self-manage	✓	—	—	Reject	Lacks clarity of purpose.
	20	Health literacy	—	—	—	Reject	Lacks clarity of purpose.
Health behaviours	21	Level of physical activity	✓	—	✓	Accept	Already reported in NHPA risk factors.
	22	History of joint trauma/injury (sport, recreational, occupational)	✓	—	—	Accept	Important risk factor for the young, but need to develop an appropriate measure.
	23	Dietary intake (of specific nutrients)	X	—	✓	Reject	Lacks clarity of purpose.
	24	Health information-seeking behaviour	—	—	—	Reject	Lacks clarity of purpose.
Person–related factors	25	Prevalence of overweight and obesity	✓	—	—	Accept	Already reported in NHPA risk factors.
Health system performance							
Effective	26	Increased knowledge of self-management strategies by people with the condition	—	—	—	Reject	Lacks clarity of purpose. Roll into #19.
Appropriate	27	Up-to-date evidence-based guidelines exist and are implemented	—	—	—	Reject	Lacks clarity of purpose.
	28	Surgery rate (total joint replacement) per 100, 000 (stratified according to SES, state, age)	✓	✓	—	Accept	Available and appropriate treatment indicator.

(continued)

Table 1 (continued): Outcomes of workshop discussions regarding potential indicators for arthritis and musculoskeletal conditions

Dimension	No.	Indicator/concept	OA	RA	OP	Outcome	Rationale
Appropriate	29	Proportion of 'at risk' population undergoing BMD testing	—	—	✓	Reject	Lacks appropriate statistical basis.
	30	Proportion of 'at risk' population assessed and treated	—	X	✓	Reject	No screening programs in place.
	31	Referral to rehabilitation program	—	X	—	Reject	Lacks clarity of purpose.
Efficient	32	Proportion of expenditure on primary prevention interventions for OA, RA, OP	—	—	—	Reject	Lacks clarity of purpose.
	33	Number and cost of joint replacements, by centre and prosthetic type	X	X	—	Reject	Not an NHPA priority.
	34	Use, cost and type of prescription and non-prescription medications	X	Potential	—	Reject	Lacks clarity of purpose.
Responsive	35	Waiting times to see appropriate specialist	—	✓	X	Accept	Data are available and could provide a useful performance indicator.
	36	Evidence-based information available to consumers	✓	✓	✓	Reject	Lacks clarity of purpose.
	37	Satisfaction with management	✓	✓	✓	Reject	Not appropriate as an NPHA indicator.
	38	Time to total joint replacement (waiting list data)	✓	✓	—	Reject	To be rolled into #35.
	39	Barriers to receiving health care services/factors affecting access to health services	✓	✓	X	Reject	Lacks clarity of purpose.
	40	Risk reduction programs provided for groups at risk	✓	—	X	Reject	Lacks clarity of purpose.
	41	Mechanism in place to fast-track urgent referral	✓	✓	X	Reject	Lacks clarity of purpose.
	42	Consultations with health professionals (e.g. physiotherapist, occupational therapist, nutritionist)	✓	✓	X	Reject	Lacks clarity of purpose.
Safe	43	Mortality associated with joint replacement surgery (primary and revision)	X	X	—	Reject	Reported elsewhere.
	44	Morbidity from treatments (e.g. from post-operative adverse events, medication)	X	✓	X	Reject	Reported elsewhere.

(continued)

Table 1 (continued): Outcomes of workshop discussions regarding potential indicators for arthritis and musculoskeletal conditions

Dimension	No.	Indicator/concept	OA	RA	OP	Outcome	Rationale
Continuous	45	Multidisciplinary/sector approach to care (e.g. appropriate model of care)	✓	✓	X	Reject	Lacks clarity of purpose.
	46	Continuity of care	✓	✓	✓	Reject	Lacks clarity of purpose.
	47	People with condition are educated and confident/able to effectively self-manage	✓	✓	✓	Reject	Lacks clarity of purpose. Roll #19, #26 and #47 together for future development.
Sustainable	48	Appropriate labour force (skilled, knowledgable and adequate) by distribution and numbers	✓	✓	✓	Accept	Data available or can be developed.
	49	Expenditure on education, research and service delivery, relative to burden of disease	✓	✓	✓	Accept	Data are available but may require development and interpretation.
	50	Implementation of National Action Plan strategies by all sectors (national, state, non-government organisations)	✓	✓	✓	Reject	Not appropriate.

Short-listed indicators

Following the workshop, the NAMSCAG Data Working Group and AIHW considered the outcomes and made some additional recommendations. This resulted in a short list of indicators, and related data developments, to be further defined and prioritised (Table 2).

The major criteria used to short-list the indicators were:

- the relevance of the proposed indicator to national monitoring of arthritis and osteoporosis
- the existence of a clear, specific association or relationship
- existing, proposed or easily obtainable data
- clarity of meaning.

In total, 21 indicators/concepts considered at the workshop were retained (Table 2) for further discussion at state and territory consultations. Three other indicators were recommended for background information.

The workshop considered that further development of the indicators would benefit from a staged approach.

Stage 1 would consist of endorsing and publishing a small set of core indicators that had a high degree of acceptance, for which data are readily available and that could be set up within 12–18 months. Designing, developing and reporting against these indicators would provide exposure, allow feedback and provide an opportunity for developing an expanded set of indicators. This stage should not be seen as a trial or pilot study but rather the first step in a process of development and refinement of an authoritative set of national indicators.

A critical element of Stage 1 was considered to be the timely identification of areas requiring data development and having these included in appropriate data development processes. In many cases this would be one of the national information or data development processes. Major players in these processes are state and territory health authorities, and therefore early consultation with those authorities would be important.

Stage 2 would consist of bringing together those indicators that were identified as requiring either conceptual or data development work and those that were incorporated previously. Stage 2 was seen as having a medium- to long-term horizon concerned with building up the number of indicators and enhancing existing indicators. It was thought that the desirability of having long-lived and robust indicators should be a consideration during this stage, and participation in national health information and data development should be continued.

The indicators were therefore divided into three categories:

1. **Category 1** Indicator accepted; to be implemented, collected and reported as soon as practicable (but within 18 months)—by mid 2006
2. **Category 2** (i) *High priority*: commence development process for the indicators, including conceptual and data development—by end 2005
   (ii) *Priority*: commence development of indicators—by end 2006
3. **Background information**—summary indicators that are useful for providing context but have limited value for regular monitoring.

Of the 21 indicators/concepts, seven were classed as category 1. These were regarded as high priority in terms of implementation and reporting. Data are currently available for all of these indicators, two of which are already reported as part of the NHPA risk factor indicator set. The remaining 14 indicators/concepts were categorised as category 2. These indicators were considered to require various levels of developmental work: four were scheduled as high priority, requiring early commencement of the development process (Category 2(i)), and the remaining ten indicators were seen as a priority (Category 2(ii)). The staged approach outline above suggested that indicators in categories 1 and 2(i) would be progressed immediately, whereas those in category 2(ii), which required considerable development, would be revisited at a later stage of the process.

Stakeholder consultations

Stage 1 of the indicator development process included consultation with stakeholders in the various jurisdictions. A series of consultation meetings were organised in Adelaide, Sydney, Brisbane, Perth, Canberra and Melbourne during the second half of 2005 and early 2006 to progress the indicator development. Representatives from the Northern Territory were invited to attend the Brisbane meeting, while Tasmanian stakeholders were invited to attend in Melbourne. Invitees included representatives of the state and territory health departments, clinicians, relevant data experts, allied health professionals and representatives of various consumer and professional organisations (see Appendix 2).

Participants at each meeting were supplied in advance with background material, including a summary of the workshop aims and outcomes, and the short-listed category 1 and 2(i) indicators. A presentation detailing the indicator development process and the ideal attributes of indicators was given at the beginning of each meeting. The indicators were then presented and discussed in turn. Draft operational definitions (including a description, rationale for inclusion, suggested numerator and denominator, and potential data sources) were developed for each of the short-listed indicators, in order to promote discussion of their form, relevance, appropriateness and related data issues. Participants were also asked to suggest other possible indicators not already considered, and to inform the group of any potential data sources existing at the jurisdictional, regional or local level.

Table 2: Short-listed indicators for arthritis and musculoskeletal conditions

Dimension	Indicator/concept	Data source	OA	RA	OP	Common	Priority	Comments
Health status and outcomes								
Health conditions	Prevalence (stratified by age, sex, location, and as diagnosed by health professional)	National Health Survey; BEACH	✓	✓	✓	✓	Category 1	Data available with potential for refinement over time.
	No. of hospital separations for minimal trauma fractures (MTF)	National Hospital Morbidity Database			✓		Category 1	Data readily available.
Life expectancy & wellbeing	Health-related quality of life (including pain, mental health, emotional function, self-image, fatigue, sexuality, anxiety, depression)—include lost productivity	National Health Survey	✓	✓	✓	✓	Category 2(i)	High priority area for development.
Determinants of health								
Environmental factors	An important dimension that requires monitoring [refer to ICF definition of environmental factors]					✓	Category 2(i)	High priority area for development.
Community capacity	Health promotion activities—requires indicators to monitor outcomes, for example: Proportion of children who have experienced a 'bone health' program Community awareness regarding prevention of falls					✓	Category 2(ii)	Long-term development, need measurable outcomes to be agreed and specified.
	Knowledgeable, effective self-management Health literacy Health information-seeking behaviour					✓	Category 2(ii)	Requires significant development.
Health behaviours	Level of physical activity	Risk factor NHPA	✓		✓	✓	Category 1	Already reported in NHPA risk factors.
	History of joint trauma/injury	National Hospital Morbidity Database; BEACH	✓			✓	Category 2(i)	Needs development; important risk factor for the young.
	Disease preventive behaviour Dietary intake					✓	Category 2(ii)	Needs development.

(continued)

Table 2 (continued): Short-listed indicators for arthritis and musculoskeletal conditions

Dimension	Indicator/concept	Data source	OA	RA	OP	Common	Priority	Comments
Person-related factors	Prevalence of overweight and obesity	Risk factor NHPA	✓			✓	Category 1	Already reported in NHPA risk factors.
Health system performance								
Appropriate	Appropriate quality of care, including rehabilitation: existence and implementation of up-to-date evidence-based guidelines						Background	Present as background information.
	Surgery rate (total joint replacement) per 100,000 (stratified according to SES, state and age; both primary and revision rates)	National Hospital Morbidity Database and Joint Replacement Registry	✓	✓		✓	Category 1	Data available; an appropriate treatment indicator.
	Proportion of 'at risk' population assessed & treated					✓	Category 2(ii)	Needs development.
Responsive	Waiting times to see appropriate specialist—including fast-track urgent referral for RA	Medicare database?		✓		✓	Category 2(i)	Data available; requires moderate level of development.
	Barriers to access for health care and services						Background	Present as background information.
	Consultations with health professionals						Category 2(ii)	Needs development.
Safe	Mortality associated with joint replacement surgery	Joint Replacement Registry				✓	Category 1	Data available with potential for refinement over time.
Sustainable	Appropriate labour force (skilled, knowledgable and adequate) by distribution and size	AIHW Labour Force Database			✓	✓	Category 1	Data available on medical specialists and some health professionals.
	Implementation of National Action Plan strategies by all sectors					✓	Background	Present as background information.

3 Results of consultations

The stakeholder consultations focused around those indicators classed as category 1 or 2(i), that is, those that were high priority and for which data were available or required minimal development. Creating relevant indicators for osteoarthritis, osteoporosis and rheumatoid arthritis resulted in a total of 17 indicators, as listed below.

Table 3: Indicators discussed at stakeholder consultations

Id No.	Indicator
Risk factors	
1	Level of physical activity
2	Self-reported prevalence of overweight and obesity
Joint replacement	
3	Total joint replacement surgery in arthritis
4	Mortality associated with joint replacement surgery
Labour force	
5	Appropriate labour force for treating arthritis
6	Appropriate labour force for treating osteoporosis and osteoporotic fractures
Osteoarthritis	
7	Self-reported prevalence of osteoarthritis
8	Health-related quality of life for people with osteoarthritis
9	History of joint trauma or injury (osteoarthritis)
10	Waiting times to see appropriate specialist for osteoarthritis
Rheumatoid arthritis	
11	Self-reported prevalence of rheumatoid arthritis
12	Health-related quality of life of persons with rheumatoid arthritis
13	Waiting times to see appropriate specialist, including fast-track urgent referral, for rheumatoid arthritis
Osteoporosis	
14	Self-reported prevalence of osteoporosis
15	Health-related quality of life for people with osteoporosis
16	Hospital separations for minimal trauma fractures
17	Waiting times to see appropriate specialist for osteoporosis

Major issues raised during the consultations

Various issues were raised by participants at the consultation meetings. Although the focus of the discussions varied depending on the composition of each particular group, common threads emerged across most of the meetings. At each meeting the same set of draft operational definitions for the short-listed indicators was presented, without making alterations to the set following advice given at previous meetings. This ensured that development of the indicators was based on views from all stakeholders.

The advice received from the stakeholder consultation meetings is summarised below. Similar issues were raised for basic indicators dealing with all three of the focus areas (prevalence, quality of life, and waiting times) so these are covered together.

Level of physical activity

Indicator discussed: Proportion of adults not engaged in sufficient physical activity (at least 150 minutes, accrued over at least 5 sessions per week) to confer a health benefit.

It was generally agreed that, although it was based around cardiovascular health, the existing NHPA risk factor indicator for physical activity was good enough for use in arthritis and musculoskeletal conditions monitoring, since it would be cumbersome to have specific physical activity definitions for each of the focus areas. Maintaining standard risk factor indicators across the NHPAs was thought highly desirable.

The Active Australia Survey (AIHW 2003) was considered the best data collection tool, however the infrequent use of this survey at a national level was seen as a barrier to its use for indicator reporting. The survey is used regularly in several of the jurisdictions so it may be possible to combine the data to produce a national estimate. Otherwise, the National Health Survey was thought to be the next best data source due to its regularity, national coverage and similarity to the Active Australia Survey.

Information on physical activity in the elderly (aged 75 years and over) was considered useful but more relevant to prevention of disability and maintaining mobility and independence than to reducing the risk of arthritis and musculoskeletal conditions. Data for children were also seen as desirable but possibly difficult to obtain.

Although it was agreed that information on weight-bearing exercise and muscle-strengthening activities would be useful, it was acknowledged that this information would be difficult to collect, and also that the specific types and amounts of activities that were most important was still unclear.

There was concern in one jurisdiction that since amounts and types of activity vary greatly across the life course, a single summary measure across age groups may not be appropriate. It was suggested that the indicator could be focused on a specific high-risk group (such as young women 12–35 years) and a specific type of activity (such as walking).

Self-reported prevalence of overweight and obesity

Indicator discussed: Proportion of adults who are overweight or obese (body mass index ≥ 25).

This was considered a useful indicator. Both overweight and obesity were seen as indicating increased risk (of osteoarthritis), with body mass index (BMI) agreed to be the best measure.

Central obesity was not considered as relevant to arthritis risk. Although it was acknowledged that waist circumference may provide some indication of metabolic risk, this information is unlikely to be collectable by self-report.

Underweight was considered important as a risk factor for osteoporosis.

It was considered essential to also include data on overweight and obesity in children. Two different indicators (children and adults) may be required.

Experience from one jurisdictional survey has shown that a large proportion of adults can not accurately self-report their height and weight. There was also a concern about the accuracy of parental reports of height and weight in children.

Generally it was agreed that measured data would be preferable to self-reported if it was available, but that the infrequency of measured data collection meant that the National Health Survey (self-reported data) was probably the best data source at present.

Total joint replacement surgery in arthritis

Indicator discussed: Number of total joint replacement procedures with arthritis as the principal diagnosis.

The interpretation of this indicator was seen as problematic. For example, would a decrease in surgery rates indicate reduced need or reduced provision (without reduced need)? What if surgery rates were stable but the average age at surgery increased—this might indicate better management of the condition at the earlier stages leading to a delay in the need for surgery. It was suggested that an additional indicator based on the median age at surgery may be helpful for interpreting changes.

Questions were also raised about the purpose of this indicator: would it be used as a surrogate for need? In this case a measure of the number of people referred to a surgeon would be more informative. An indicator of need or demand for surgery would be useful for planning purposes. Indicators based on waiting time for surgery and waiting time from referral to being seen by an orthopaedic surgeon may also be useful.

It was agreed that the focus should be on hip and knee surgery (excluding other joints) and that these should be reported separately. The majority considered that only primary procedures (as opposed to revisions) should be counted.

The indicator should be focused on 'elective' surgery for arthritis. When counting procedures, those with a principal diagnosis of hip fracture or injury should be excluded. However, there was a concern that hip fractures in the elderly may not always be coded as the principal diagnosis due to the presence of comorbidities and need for complex care. This should be investigated.

It was suggested that partial hip replacement could be a useful indicator for osteoporosis. Partial replacements were thought to be used infrequently for arthritis.

Knee replacements were seen as treatment for osteoarthritis while hip replacements were seen as treatment for osteoporosis.

A lower age limit of 30 years was considered appropriate by most, with no upper age limit. However there was a suggestion that monitoring of younger people may be important for capturing trends in joint replacements needed for sporting injuries.

There was a suggestion that other or earlier types of intervention, such as osteotomy, arthroscopy and steroid injections, should be covered as well as or instead of total joint replacement. However, the use of steroid injections would be difficult to track accurately. Also, as there are several different clinical indications for both osteotomy and arthroscopy (including sports injury, osteoarthritis and exploratory surgery), it was not considered that these procedures would be able to be directly linked to the focus areas.

It was seen as important to present the total number of procedures as well as an age-standardised rate, to indicate the actual burden on the health system in terms of costs and service utilisation.

There was disagreement over the appropriate denominator for rates. Although most participants felt the total population should be used, some felt it should be the number eligible for the procedure. However, estimating the number eligible would be problematic and may add additional complexity to the interpretation of trends.

Both the AIHW National Hospital Morbidity Database (NHMD) (AIHW 2005) and the Australian Orthopaedic Association National Joint Replacement Registry (Australian Orthopaedic Association National Joint Replacement Registry 2004) were seen as appropriate sources of data. The Registry can provide information on the number of people undergoing joint replacement while the NHMD can only provide information on the number of procedures performed. However, a simple count of procedures was considered sufficient for the purpose of this indicator. The Registry has national coverage from 2002, therefore the long-term trend information would need to be sourced from the hospital data.

Mortality associated with joint replacement surgery

Indicator discussed: Proportion of joint replacement surgeries that result in death within 12 months.

In general this was not seen as an appropriate indicator. Post-operative mortality was considered to be a 'quality of care' indicator, reflecting the health of the individual and the generic risks associated with surgery, and not specifically related to the diagnosis. The interpretation of changes would also be difficult as it could indicate changes in casemix (the range and types of patients treated) rather than changes in absolute outcomes.

There were varying opinions regarding the appropriate follow-up period. In general, 4 weeks was seen as providing the most accurate data, but some participants preferred a 12-month follow-up. However, many felt that 12 months was too long a time to be able to attribute cause of death with any certainty.

It was felt that early mortality was likely to be due to comorbidities or the risks attached to any major procedure (anaesthesia, infections, etc.). These were not considered to indicate success/failure of the procedure itself nor to be amenable to intervention. A better indicator of 'success' of surgery would be the revision rate, time to revision or median age at revision (compared to median age at primary procedure). However these types of indicators are more relevant to a clinical indicator set rather than a national set such as this one. Quality of life or functional limitations post-surgery may be good indicators of 'success' of surgery.

If a mortality indicator were desired, hip fracture mortality or mortality associated with rheumatoid arthritis would be more appropriate.

There is an existing indicator in one jurisdiction of 'readmission within 28 days' relating to adverse outcomes, however this requires data linkage so is probably not currently possible to operationalise at the national level. Standard surgical reports do have information on adverse outcomes, so this is probably not needed here as well.

Data from the Joint Replacement Registry are linked to the National Death Index and information on post-operative mortality is available from 2004 (Australian Orthopaedic Association National Joint Replacement Registry 2004).

Appropriate labour force for treating arthritis

Indicator discussed: Number of rheumatologists and orthopaedic specialists per 100,000 population.

Although the labour force issue was seen as important, it was generally considered that the relevant workforce was very broad, including GPs, specialist nurses and allied health professionals as well as the identified specialists. Community programs also provided assistance. This was seen as particularly relevant for rural areas where specialist services are not usually available, and for persons with acute need. A multidisciplinary team is required for optimal care, and the health professional seen would depend on need and the severity of the disease. There was also a perception that many people with osteoarthritis were treated by their GP and never in fact visited a specialist.

Conversely, the identified specialists do not only treat people with arthritis and musculoskeletal conditions so the indicator would not provide an accurate picture of the available workforce. Some measure of the work time assigned to arthritis would be required, however this may be difficult and expensive to collect. It may be more practical to focus the indicator on rheumatologists as the labour force for treatment of rheumatoid arthritis.

In order to be able to interpret the indicator, there needs to be some idea of the optimal number of specialists required. There was also a concern that it may be difficult to interpret changes in the workforce numbers.

It was considered important to have some measure of location in order to identify areas that might be under-serviced. However this information may not be reliable for health professionals who provide travelling services.

Appropriate labour force for treating osteoporosis and osteoporotic fractures

Indicator discussed: Number of endocrinologists and orthopaedic surgeons per 100,000 population.

Similar issues as for the previous indicator were raised here. It was suggested that these two indicators could be combined as ‘number of health professionals available for treating arthritis and musculoskeletal conditions’. The distribution of these services was considered important. In general there seemed to be a belief that both these indicators, though they were dealing with important issues, required much more thought.

Self-reported prevalence

Indicators discussed: Proportion of the population that reports having osteoarthritis/ rheumatoid arthritis/osteoporosis.

Similar issues were raised for each of the three focus conditions (OA, OP and RA). These issues related generally to data collection methods, identification of specific conditions, and relevant age ranges, as discussed below.

Data collection

Although self-reported information was considered sufficient by most participants, it should be based on a ‘doctor diagnosis’ of the condition. Surveys of osteoarthritis have found good sensitivity (that is, most people who report they have osteoarthritis do actually have the condition) but an underestimate of true prevalence. Conversely, rheumatoid arthritis tends to be over-reported as ‘rheumatism’, and other inflammatory conditions may be included.

There was a concern in one jurisdiction that people experiencing mild joint pain may be told they have ‘a touch of arthritis’ without the practitioner actually making a formal diagnosis. It was suggested that information about arthritis for which the patient was receiving treatment (medication, surgery or therapy) may provide a better indication of prevalence.

Osteoporosis is believed to be considerably underestimated as people do not know or are not told that they have it. Some participants thought that self-reported data on osteoporosis was of no use, and reported minimal trauma fractures would provide more reliable information. However, the word ‘minimal’ would need to be used carefully as it could easily be misunderstood. The National Health Survey may provide some information about low falls.

It was suggested that the various regional studies of osteoporosis (for example, the Geelong Osteoporosis Study (Henry et al. 2000)) may be able to be used in place of national data. There was also a suggestion that it may be possible to collate the results of bone mineral density testing obtained from the various providers, however this could be costly and difficult to manage.

It was strongly recommended that the National Health Survey item be altered to collect doctor-diagnosed information; the jurisdictional CATI survey questions are already phrased in this manner. (In fact the 2004–05 National Health Survey, the results of which had not been released at the time of the consultations, did include new items asking about a doctor’s diagnosis of arthritis or osteoporosis.)

Several participants suggested collecting symptom-based information in addition to or instead of diagnostic information.

Type of condition

There is considerable confusion in the community about the definitions of arthritis, and therefore the type of arthritis may not be accurately reported. However, there was a feeling that combining all types into one question would be a step backwards in terms of raising community awareness. It was generally believed that self-reported ‘arthritis’ would probably be osteoarthritis.

Joint-specific information may be useful in determining type, and there may be ways of collecting this. Arthritis at the knee or hip may be a good indicator for osteoarthritis.

Medications used may also be a way of determining the type of arthritis, however a number of drugs are used for several different forms and others may not be specific to a particular type of arthritis.

Age ranges

For osteoarthritis, limiting the indicator to persons aged 25 years and over was considered appropriate; osteoarthritis is uncommon at younger ages, and this age range would be comparable with international data. For rheumatoid arthritis, limiting to ages 18 years and over was considered appropriate by most participants. Osteoporosis data were considered relevant for 'post-menopausal' ages but there was not consensus on the lower age limit, which varied from 40 to 55 years.

Health-related quality of life

Indicators discussed: Health-related quality of life of persons with osteoarthritis/rheumatoid arthritis/osteoporosis.

The issues raised for the three health-related quality of life indicators were very similar across the conditions. Two views emerged:

- measurement of quality of life as a construct using one or more validated instruments
- a specific focus on disability and activity limitations rather than 'quality of life' as a whole.

For both these issues it was considered important to include data on children; stratification by age and time since diagnosis was also thought useful.

Issues relating to quality of life as a construct

There was considerable discussion about whether to use a generic or a specific instrument (or both) to measure quality of life. It was agreed that any instrument chosen would need to be internationally validated. Some participants believed that a specific instrument such as EuroQoL (The EuroQol Group 1990) may be better as it generates subsets of information relevant to arthritis and musculoskeletal conditions. The Assessment of Quality of Life (AQoL) instrument (Hawthorne et al. 1999) is also often used in arthritis research. A generic instrument may be highly influenced by comorbidities and the results difficult to relate to a specific condition.

The National Health Survey and some jurisdictional surveys currently include the Kessler 10 Psychological Distress Scale (K10) (Kessler et al. 2002). The K10 was also included in the 1997 National Survey of the Mental Health and Wellbeing of Adults (ABS 1998). However, many participants felt that this scale was too specifically targeted towards mental distress, and that a more general measure of quality of life as a whole was preferable.

The SF-12 instrument (Ware et al. 1996) is used in the ABS Survey of Disability, Ageing and Carers (ABS 2004). Only one jurisdiction now uses the SF-12 instrument in its regular surveys; one other uses the shorter SF-8. No jurisdictions are currently using the AQoL instrument. Participants considered it important that a generic instrument such as the SF-12 or AQoL be included in the National Health Survey, as quality of life is an issue relevant to all chronic diseases and inclusion in this survey would enable comparisons between various conditions.

The interpretation of differences or changes in quality of life was seen by some as a problem, as it may be affected by life events or personal circumstances not related to health. Further, people may adapt to their condition over time. People's perception of their own quality of life may also be affected by the perceived quality of life of their peers or social companions and may alter over time without actual change in their own health.

Issues relating to disability and activity limitations

A number of participants felt that issues relating to disability and restriction of activities would be more important to individuals than overall quality of life, and would also be useful for highlighting needs for assistance.

Data on several relevant issues are available from the Survey of Disability, Ageing and Carers; this survey also has some information on comorbidities and depression which may be useful. However, the survey does not currently distinguish between osteoarthritis and rheumatoid arthritis; the ABS representative offered to investigate the feasibility of doing so in future surveys.

Lost productivity was suggested as an important factor, however there was a concern that this could disadvantage arthritis and musculoskeletal conditions in comparison to other NHPAs. Reduction in work hours or abilities was also suggested, but many people with arthritis are past retirement age and so this is not relevant to them. 'Role limitations' may be a more useful indicator. For children, days of school missed or days of work lost by parents/carers could be used.

One participant suggested that height loss in people with osteoporosis was an important issue that affected self-esteem.

Waiting times to see appropriate specialist

Indicators discussed: Number of persons with osteoarthritis/rheumatoid arthritis/ osteoporotic fractures waiting to see a specialist for more than 8 weeks.

Although this was originally seen as a common indicator, separate and quite different issues emerged for each of the three focus areas.

Osteoarthritis

The indicator was not considered useful in its current form, as most people with osteoarthritis would not need to see a specialist at the time of diagnosis. The purpose of the indicator was not clear, and the definition of an 'appropriate' specialist would be difficult. Waiting time to see an orthopaedic surgeon or time on the joint replacement waiting list were seen as more appropriate indicators. However, official waiting list times were perceived as 'rubbery', and may be affected by more than just caseload, for example delaying surgery in order to achieve weight reduction. It was considered important that indicators based on waiting time related to patients in the public system only.

Rheumatoid arthritis

This was considered clinically valuable information, but the indicator specification required further thought. The optimal waiting time suggested by participants varied from 2 to 8 weeks, with more aggressive forms requiring urgent referral. It was suggested that if no Australian guidelines for optimal waiting times existed, the Australian Rheumatology Association should be asked to make a recommendation; otherwise those used in the United Kingdom may be appropriate.

Reporting median waiting time was considered by many to be more appropriate than defining a cut-off value. Again, the waiting time should be measured for patients in the public system.

In rural and remote locations access to rheumatologists is a problem. Many rural patients are adequately treated by their GP and never referred to a specialist. In areas where a rheumatologist visits at intervals, the waiting time may be up to 1 year.

Sourcing data for this indicator may be problematic, particularly for private practices. Patient-reported waiting times may be inflated as they could include the time between the patient experiencing symptoms and first seeking medical assistance.

Osteoporosis

This was not considered an appropriate indicator, as the diagnosis of osteoporosis often occurs after a fracture and the patient is not referred to a specialist. Generally management (if any) is through GPs. A more useful indicator may relate to the provision of management following orthopaedic surgery, but this may be difficult to operationalise.

History of joint trauma or injury

Indicator discussed: Proportion of persons with osteoarthritis who have had a past joint trauma or injury.

Although information on joint trauma was thought to be useful, this was not considered to be a good indicator in its current form. Joint trauma was seen as a risk factor indicator and therefore it would be more relevant to present this information prospectively, as an indication of those at risk of future osteoarthritis. The denominator in this case should be the general population. For attribution of current osteoarthritis to past injury, the focus would be on athletes and information of interest would be the level of participation (recreational, competition or elite) and the type of sport. Occupational causes of injury would also be of interest.

It was acknowledged that it may be difficult to collect information on joint trauma. Some regional data on joint trauma are available, and workforce surveys may also have some information. A possible question for future surveys could be 'have you ever had an injury to your knee or hip?'; a time frame may need to be included. It may be more appropriate to ask about recurrent injury.

If current osteoarthritis was to be related to previous joint trauma the sites of both would need to be identified. Osteoarthritis would be unlikely to be recorded as a sequelae of joint trauma in medical records.

Hospital separations for minimal trauma fractures

Indicator discussed: Hospital separations for minimal trauma fractures attributable to osteoporosis (population rate).

This indicator was seen as a good 'window' on osteoporosis and could be a useful proxy for prevalence. Although ideally all osteoporotic fractures should be included, in reality many (particularly wrist and vertebral fractures) would be treated in emergency departments and clinics so it would be difficult to capture these adequately. The indicator should be focused on hip fractures as these would almost all result in admission to hospital.

All minimal trauma fractures in those aged approximately 55 years and over could be assumed to be osteoporotic, unless proven otherwise. Therefore all fractures in this age range could be counted, after excluding those with an external cause of major trauma (such as car accidents or high falls). It was suggested that the age limit for this indicator should match that chosen for the other osteoporosis indicators.

It was suggested that information on second and subsequent fractures would be valuable, as would be information on risk factors for falls and fractures (such as use of certain medications), however it was acknowledged that this information could be very difficult to capture.

Other suggested indicators

A number of other indicators and concepts were suggested by participants in the consultation meetings. These were not fully discussed during the meetings, but were considered by the AIHW and the NAMSCAG Data Working Group when finalising the indicator set. Suggestions ranged across the continuum of care, and included:

- The proportion of nursing home residents with adequate levels of vitamin D.
- Looking at calcium in the elderly as a possible risk factor indicator for osteoporosis. Perhaps something around the provision of calcium supplements.
- Smoking as a risk factor for musculoskeletal conditions.
- The incidence of work-related joint injury.
- Bone mineral density testing for osteoporosis.
- The proportion of people who know what osteoporosis is.
- The proportion of people at risk of osteoporosis who have had a bone scan.
- Prevalence of osteoarthritis in Indigenous Australians.
- Prevalence of osteoarthritis in socioeconomically disadvantaged people.
- Including more health promotion or health behaviour indicators, for example numbers 18 (health promotion activities), 20 (health literacy) and 26 (increased knowledge of self-management strategies) of Table 1 (p. 7).
- Disability could be examined separately from health-related quality of life, for example using the Health Assessment Questionnaire or the ABS Survey of Disability, Ageing and Carers.
- Need for assistance with core activities.
- Looking at the usage of community care (including self-management and practice nurses) as there is a current trend to decrease the pressure on medical specialists.
- Access to community programs, for example physical activity, rehabilitation, education. These are particularly important in rural areas where specialist care is limited.
- Waiting time to get joint replacement surgery.
- Partial hip replacement (the ball of the joint, but not the socket) should be considered as an indicator for osteoporosis.
- A post-operative rehabilitation indicator for each focus area.
- Ongoing management after orthopaedic surgery.
- Use of vitamin D by people with osteoporosis.
- Percentage of people who have been recommended therapy for osteoporosis.
- Number of people who are investigated and treated for osteoporosis after a fracture.
- Osteoporosis mortality.

- Hip fracture mortality.
- Mortality associated with rheumatoid arthritis.

Other issues

Two other issues of importance were raised during the consultation meetings.

The first related to the appropriateness of having a standard denominator across all the indicators. The general feeling amongst participants was that the chosen denominator for any indicator should be relevant to what is being measured, and that if the indicators were to be meaningful this requirement should override any desire for standardisation.

The second issue related to the indicator definitions. Several indicators implied that there should be some sort of optimal value, for example, waiting time to see a specialist, or the number of specialists available. It was suggested that national or regional guidelines might be available that would inform these definitions, or alternatively, guidelines from overseas could be appropriate. Particularly for indicators involving cut-off values, it was felt that if an evidence-based or consensus-based optimal level existed, this should be used in preference to an arbitrary cut-off.

4 Core indicator set

Following completion of the stakeholder consultations, feedback was provided to the NAMSCAG Data Working Group. Taking the views of the stakeholders into account, the Working Group and representatives of the AIHW finalised the composition of the core indicator set (Table 4). Several of the previously short-listed indicators were dropped from the set while others were modified. Four new indicators (numbers 1.3, 2.4, 5.1 and 5.2) were added, based on suggestions received at the consultation meetings. In total the final set consisted of 16 indicators, of which two (1.1 and 1.2) are already reported as part of the NHPA risk factors indicator set. Operational definitions for these 16 indicators are provided below.

Table 4: National indicators for monitoring osteoarthritis, rheumatoid arthritis and osteoporosis

Category and number	Indicator
1 Risk factors	
1.1	Proportion of persons aged 18 years or over who are not engaged in sufficient physical activity to confer a health benefit. (a)
1.2	Proportion of persons aged 18 years or over who are overweight or obese.(a)
1.3	Proportion of persons aged 2–17 years who are overweight or obese.
2 Prevalence	
2.1	Prevalence of osteoarthritis among persons aged 25 years or over.
2.2	Prevalence of rheumatoid arthritis.
2.3	Prevalence of osteoporosis among persons aged 40 years or over.
2.4	Prevalence of arthritis among Aboriginal and Torres Strait Islander persons aged 25 years or over.
3 Quality of life	
3.1	Quality of life among persons aged 25 years or over with osteoarthritis.
3.2	Quality of life among persons with rheumatoid arthritis.
3.3	Quality of life among persons aged 40 years or over with osteoporosis.
4 Health service use	
4.1	Waiting time to see a rheumatologist for diagnosis of rheumatoid arthritis.
4.2	Number of primary total hip replacements for arthritis.
4.3	Number of primary total knee replacements for arthritis.
4.4	Number of hospital separations for minimal trauma hip fractures among persons aged 40 years or over.
5 Mortality	
5.1	Death rates for rheumatoid arthritis as the underlying cause of death.
5.2	Death rates for rheumatoid arthritis as an associated cause of death.

(a) These indicators are reported as part of the NHPA risk factors indicator set.

Operational definitions

The remainder of this chapter is devoted to the operational definitions of the core indicator set. Operational definitions are quantifiable descriptions of the indicators; they define what is to be measured and how the measure is to be constructed. This allows the same concept to be reported consistently and reliably over time and by different people.

The definitions presented below follow a standard format, providing for each indicator a rationale for its inclusion in the set, the statistic or measure to be reported, the numerator and denominator to be used, existing or potential data sources, and any notes, cautions or further instructions for calculation or interpretation of the results.

Risk factor indicators

Two risk factors were chosen for indicator-based monitoring of osteoarthritis, rheumatoid arthritis and osteoporosis, namely physical inactivity and excess weight. Three indicators have been constructed for these two risk factors, with excess weight being split into separate indicators for adults and children. This allows for different data sources to be used if required, and also enables comparisons with international data on overweight and obesity. Since it is extremely difficult to measure physical activity levels in children, the indicator for physical activity covers adults only.

1.1 Proportion of persons aged 18 years or over who are not engaged in sufficient physical activity to confer a health benefit

Rationale	Regular physical activity has been shown to improve muscle fuction and physical performance. Participation in weight-bearing activity is positively associated with bone density, leading to a lower risk of osteoporosis. Physical activity also improves balance, coordination and mobility, reducing the risk of falls.
Statistic	Percentage (of population aged 18 years or over).
Numerator	Number of persons aged 18 years or over reporting less than 150 minutes of physical activity (accrued over at least 5 sessions) per week.
Denominator	Population aged 18 years or over.
Data sources	National Physical Activity Surveys; National Health Surveys (NHS); jurisdictional CATI surveys.
Notes	The national physical activity surveys are conducted intermittently and may not be a reliable regular source of data for this indicator. The NHS, conducted every 3 years, may be a more practical choice for regular reporting at the national level. This survey collects data on the duration and frequency of walking, moderate and vigorous activites undertaken for exercise, sport or recreation during a two-week period.

1.2 Proportion of persons aged 18 years or over who are overweight or obese

Rationale	Excess body weight is the most important preventable risk factor for osteoarthritis, particularly that affecting the knees. Increased load on the joints, changes in movement and gravitational stresses all contribute to the increase in risk. In addition, weight gain among people who have osteoarthritis hastens progression of the disease and increases the risk of disability.
Statistic	Percentage (of population aged 18 years or over).
Numerator	Number of persons aged 18 years or over who have a body mass index of 25 or more.
Denominator	Population aged 18 years and over.
Data sources	NHS; jurisdictional CATI surveys; incidental national health measurement surveys.
Notes	Body mass index (BMI) should be calculated as weight (kg) divided by squared height (m). If available, measured height and weight should be used in preference to self-reported information. However, since measured information is collected irregularly, whereas self-reported information from the NHS is available every 3 years, self-reported data may be more useful for regular monitoring.

1.3 Proportion of persons aged 2–17 years who are overweight or obese

Rationale	The association between excess weight and osteoarthritis may be established early in life. High BMI at age 18 years is associated with an increased risk of total hip replacement for osteoarthritis (Karlson et al. 2003).
Statistic	Percentage (of population aged 2–17 years).
Numerator	Number of persons aged 2–17 years who have a body mass index indicating they are overweight (or obese) for their age and sex (see notes).
Denominator	Population aged 2–17 years.
Data sources	NHS; jurisdictional CATI surveys; incidental health measurement surveys.
Notes	Body mass index should be calculated as weight (kg) divided by squared height (m). For persons aged 2–17 years, the age–sex specific cutoffs for overweight developed by Cole et al. (2000) should be used. If available, measured height and weight should be used in preference to self-reported (or proxy-reported) information. There are no recent national measured data on height and weight in children. Measured data are available from a couple of states and this may be useful for validating self-reported data. However, for regular national monitoring, the self- or

proxy-reported information collected in the NHS will be the most practical choice.

Prevalence indicators

Prevalence is the number of cases (of a disease, condition or risk factor) existing in a population at a point in time. It is one of the most commonly used population health measures and a good indicator of the burden of disease on society, in terms of the number of people affected and the potential need for health services. Four indicators of prevalence have been developed for national monitoring of osteoarthritis, rheumatoid arthritis and osteoporosis in Australia: one general indicator for each of the conditions, plus a fourth indicator looking at arthritis among Aboriginal and Torres Strait Islander peoples. Different age ranges have been chosen for each indicator to best reflect the biological course of disease development and provide the most useful window on the burden of each disease.

2.1 Prevalence of osteoarthritis among persons aged 25 years or over

Rationale	Osteoarthritis is the most common type of arthritis in Australia. It is a major cause of pain and disability, and has a considerable overall impact on society due to its high prevalence.
Statistic	Percentage (of population aged 25 years or over).
Numerator	Number of persons aged 25 years or over reporting that they had been told by a doctor or nurse that they had osteoarthritis.
Denominator	Population aged 25 years or over.
Data sources	NHS; jurisdictional CATI surveys.
Notes	Self-reported information on osteoarthritis is considered to have good specificity but poor sensitivity. That is, the majority of persons who report osteoarthritis do actually have it, but many people who have osteoarthritis do not report it. Therefore estimates based on self-reported information may underestimate the true prevalence of osteoarthritis.

2.2 Prevalence of rheumatoid arthritis

Rationale	Rheumatoid arthritis affects people of all ages, causing substantial disability and activity limitations, and leading to premature mortality.
Statistic	Percentage (of population).
Numerator	Number of persons reporting that they had been told by a doctor or nurse that they had rheumatoid arthritis.
Denominator	Total population.
Data sources	NHS; jurisdictional CATI surveys.
Notes	Self-reported information on rheumatoid arthritis is believed to overestimate the prevalence of the condition. Misunderstanding with respect to other terms used to describe rheumatic diseases and other musculoskeletal conditions, particularly the historical use of the word ‘rheumatism’, contributes to this problem.

2.3 Prevalence of osteoporosis among persons aged 40 years or over

Rationale	Osteoporosis contributes considerably to fractures, disability and premature mortality in Australia. There is a natural reduction in bone mineral density with age from the fifth or sixth decade. The rate of bone loss is accelerated in women following menopause.
Statistic	Percentage (of population aged 40 years or over).
Numerator	Number of persons aged 40 years or over reporting that they had been told by a doctor or nurse that they had osteoporosis.
Denominator	Population aged 40 years or over.
Data sources	NHS; jurisdictional CATI surveys.
Notes	The prevalence of undiagnosed osteoporosis is unknown but believed to be relatively high. Increases in osteoporosis prevalence may indicate greater awareness and diagnosis of the condition, not necessarily a greater number of actual cases. Trend data will need to be interpreted with caution.

2.4 Prevalence of arthritis among Aboriginal and Torres Strait Islander persons aged 25 years or over

Rationale	The prevalence of arthritis among Aboriginal and Torres Strait Islander Australians is around twice that among other Australians (ABS 2006b). The biological reasons for this difference are unclear, but may be connected with the higher risk of injury among Indigenous Australians, particularly those aged 25–44 years (ABS & AIHW 2005).
Statistic	Percentage (of Indigenous population aged 25 years or over).
Numerator	Number of persons aged 25 years or over identifying as Aboriginal and/or Torres Strait Islander and reporting that they had been told by a doctor or nurse that they had arthritis.
Denominator	Aboriginal and Torres Strait Islander population aged 25 years or over.
Data sources	NHS (Indigenous supplement); National Aboriginal and Torres Strait Islander Health Survey (NATSIHS).
Notes	This indicator refers to 'arthritis' as a whole rather than a specific type since the remote NATSIHS does not distinguish between the various types of arthritis. It is believed that a large proportion of arthritis among Indigenous Australians is osteoarthritis.

Quality of life indicators

The impact of arthritis and musculoskeletal conditions on quality of life can be considerable. The major contributors to reduced quality of life are pain and disability, and the consequences of these in terms of impaired physical functioning, activity limitations (at work, at home and in leisure time), reduced social interaction and poor psychological health (for example, depression, anxiety, low self-efficacy, poor self-image and fear). Three indicators relating to quality of life have been included in the core indicator set, one for each of the focus areas. The age ranges chosen for each indicator match those chosen for the relevant prevalence indicators, since these define the population of interest in each case.

A variety of instruments are available to measure quality of life, both in the general population and specifically among people with arthritis and osteoporosis, but few of these have been used at the national or jurisdictional level in Australia. The instrument most commonly used in national and jurisdictional health surveys in Australia at present is the Kessler 10 Psychological Distress Scale (Kessler et al. 2002). However, many of the stakeholders consulted did not consider this to be an appropriate tool for the purposes of these indicators. One instrument that has been used both in national surveys and in some jurisdictional surveys is the 12-item short form questionnaire, the SF-12 (Ware et al. 1996). Although it is acknowledged that the SF-12 is a generic instrument and may not cover all the impacts of each condition on quality of life, it has the advantages of being internationally validated, easy to administer and able to be compared across different health conditions. In addition, the SF-12 items are contained within the SF-36 (short form, 36 items) instrument, so data for these indicators can be obtained from surveys that use either instrument. The Assessment of Quality of Life (AQoL) instrument (Hawthorne et al. 1999) would also be useful for these indicators. It is intended that the AQoL be included in the next national mental health survey, to be conducted in 2007. Either of these tools could be used for the purposes of national indicator-based monitoring of osteoarthritis, rheumatoid arthritis and osteoporosis in Australia. However, as the AQoL may be used to produce a single measurement scale, it may be a more practical choice in this context.

3.1 Quality of life among persons aged 25 years or over with osteoarthritis

Rationale	Osteoarthritis can seriously compromise quality of life, particulary for people who are severely affected. The major symptom is pain, which can lead to disability, limitations in the activities of daily living, and poor mental health.
Statistic	Mean.
Numerator	Average AQoL score among persons aged 25 years or over who report having been told by a doctor that they had osteoarthritis.
Denominator	Not applicable.
Data sources	2007 National Survey of Mental Health and Wellbeing.
Notes	It is intended that the AQoL be included in the 2007 mental health survey, but the final survey item list has not been determined. An alternative measure of quality of life (such as the SF-12) may need to be used; this is available from the Survey of Disability, Ageing and Carers. It is also not yet clear whether information will be available

separately for the different types of arthritis.

3.2 Quality of life among persons with rheumatoid arthritis

Rationale	The quality of life of persons with rheumatoid arthritis is severely affected by their disease. Functional and psychosocial impacts may include inability to perform activities of daily living, work restrictions, reduced social participation and loss of independence.
Statistic	Mean.
Numerator	Average AQoL score among persons who report having been told by a doctor that they had rheumatoid arthritis.
Denominator	Not applicable.
Data sources	2007 National Survey of Mental Health and Wellbeing.
Notes	As for indicator 3.1.

3.3 Quality of life among persons aged 40 years or over with osteoporosis

Rationale	Osteoporotic fractures may seriously compromise quality of life and reduce independence in the elderly. A large proportion of people with hip fractures do not regain their former posture and mobility. This may lead to increased need for assistance and a reduction in social activities. Fear of falling may also lead to a loss of confidence and self-restriction of activities.
Statistic	Mean.
Numerator	Average AQoL score among persons aged 40 years or over who report having been told by a doctor that they had osteoporosis.
Denominator	Not applicable.
Data sources	2007 National Survey of Mental Health and Wellbeing.
Notes	As for indicator 3.1. It is not clear whether information on osteoporosis will be available from the 2007 mental health survey. An alternative source of data on quality of life (such as the Survey of Disability, Ageing and Carers) may need to be used.

Indicators of health service use

The long duration of osteoarthritis, rheumatoid arthritis and osteoporosis, and the pain and disability they cause, results in ongoing contact with the health system. This includes contact with general practitioners, specialists and allied health professionals in the community setting, as well as treatment in hospitals. Four indicators of health service use for osteoarthritis, rheumatoid arthritis and osteoporosis have been chosen for inclusion in this set: waiting time for diagnosis of rheumatoid arthritis; numbers of primary total hip and knee replacements; and hospital separations for hip fractures.

4.1 Waiting time to see a rheumatologist for diagnosis of rheumatoid arthritis

Rationale	Early diagnosis and intervention in rheumatoid arthritis are central to effective management of the disease. The amount of time a person waits is a good indicator of the effectiveness and responsiveness of health care.
Statistic	Median.
Numerator	Median waiting time between initial referral/GP visit and consultation with a rheumatologist.
Denominator	Not applicable.
Data sources	Unknown.
Notes	It is possible that data may be able to be obtained through the Australian Rheumatology Association. This is being investigated.

4.2 Number of primary total hip replacements for arthritis

Rationale	Total hip replacement is a cost-effective treatment for severe arthritis of the hip. The number of these procedures is increasing in many countries, including Australia.
Statistic	Number and rate per 100,000 population.
Numerator	Number of elective primary total hip replacement procedures performed during 1 year.
Denominator	Total population.
Data sources	Australian Orthopaedic Association National Joint Replacement Registry; AIHW National Hospital Morbidity Database.
Notes	ICD-10-AM procedure codes for primary total hip replacement are 49318-00 and 49319-00. Only separations with the principal diagnosis of arthritis (ICD-10-AM codes M00–M25) should be included. A variety of factors may influence the number of total hip replacements performed. For example, increased numbers could indicate a higher prevalence of osteoarthritis, more rapid progression of the disease, or changes in orthopaedic practice. Decreased numbers could indicate improved early management, reduced capacity of health services to perform the procedure, or a decrease in osteoarthritis prevalence. Trend data will need to be interpreted with caution.

4.3 Number of primary total knee replacements for arthritis

Rationale	Total knee replacement is a cost-effective treatment for severe arthritis of the knee, and the number of these procedures has been increasing.
Statistic	Number and rate per 100,000 population.

Numerator	Number of primary total knee replacement procedures performed during 1 year.
Denominator	Total population.
Data sources	Australian Orthopaedic Association National Joint Replacement Registry; AIHW National Hospital Morbidity Database.
Notes	ICD-10-AM procedure codes for primary total knee replacement are 49518-00, 49519-00, 49521-00, 49521-01, 49521-02, 49521-03, 49524-00, 49524-01 and 49534-00. Only separations with the principal diagnosis of arthritis (ICD-10-AM codes M00–M25) should be included. As for indicator 4.2, trends in the number of knee replacement procedures will need to be interpreted with caution.

4.4 Number of hospital separations for minimal trauma hip fractures among persons aged 40 years or over

Rationale	Hip fractures are commonly caused by osteoporosis and may result in disability, loss of independence and premature mortality. In the vast majority of cases, the patient would be admitted to hospital for treatment.
Statistic	Number and rate per 100,000 population (aged 40 years or over).
Numerator	Number of hospital separations of persons aged 40 years or over with a principal diagnosis of hip fracture.
Denominator	Population aged 40 years or over.
Data sources	AIHW National Hospital Morbidity Database.
Notes	ICD-10-AM diagnosis code for hip fracture (fracture of the femur) is S72. Separations with an external cause indicating major trauma (for example, motor vehicle accidents) should be excluded. Unspecified falls are to be included. Only separations with the following ICD-10-AM external cause codes should be counted: W00–W08, W18, W19, W22, W50, W51 and W54.8. An additional diagnosis of osteoporosis may or may not be recorded for fracture separations. However, it is considered likely that the majority of hip fractures without major trauma in people aged 40 years and over would be osteoporotic in nature. For the purposes of this indicator, all hip fractures (excluding major trauma) should be included, regardless of whether or not osteoporosis is recorded.

Mortality indicators

Arthritis and musculoskeletal conditions are not major contributors to mortality, accounting for around 1% of all deaths in Australia. However, of the deaths that are attributed to arthritis and musculoskeletal conditions, around 20% are due to rheumatoid arthritis. Survival among people with rheumatoid arthritis is on average 5–10 years less than in the general population.

5.1 Death rates for rheumatoid arthritis as the underlying cause of death

Rationale	Rheumatoid arthritis significantly increases the risk of premature mortality, with a risk of death 2–3 times that of persons without rheumatoid arthritis.
Statistic	Rate per million population.
Numerator	Number of deaths where rheumatoid arthritis was listed as the underlying cause of death.
Denominator	Total population.
Data sources	AIHW National Mortality Database.
Notes	ICD-10 codes for rheumatoid arthritis are M05 and M06. The underlying cause of death is 'the condition, disease or injury initiating the sequence of events leading to death' (AIHW 2004). With advances in the treatment and management of rheumatoid arthritis, it would be hoped that deaths from the disease would become less common. Annual data on causes of death are available approximately 12–14 months following the end of each year. For example, data on deaths registered in 2002 became available early in 2004.

5.2 Death rates for rheumatoid arthritis as an associated cause of death

Rationale	The lifespan of people with rheumatoid arthritis is on average 5–10 years shorter than that of people without rheumatoid arthritis. The leading causes of death among people with rheumatoid arthritis are cardiovascular disease and infection.
Statistic	Rate per million population.
Numerator	Number of deaths where rheumatoid arthritis was listed as an associated cause of death.
Denominator	Total population.
Data sources	AIHW National Mortality Database.
Notes	ICD-10 codes for rheumatoid arthritis are M05 and M06. An associated cause of death is 'any condition, disease or injury, other than the underlying cause, contributing to death' (AIHW 2004). Information on associated causes of death are available from 1997 onwards.

5 Future directions

The AIHW and the NAMSCAG Data Working Group, with input from experts and stakeholders, have developed a core set of indicators for monitoring osteoarthritis, rheumatoid arthritis and osteoporosis. The set consists of 16 indicators, covering risk factors, prevalence, quality of life, health service use and mortality. The indicators are consensus-based and grounded in a conceptual framework; a defined set of criteria guided their development. Monitoring and reporting against these indicators will allow for the tracking and prediction of relevant health outcomes, inform decision making and assist evaluation of public health strategies.

When reporting indicators, it is relevant to look at the distribution of each measurement—for example, across income groups, by demographic characteristics (such as sex, age and ethnicity) or between geographic locations. This can reveal disparities in health and health care, and identify areas where further investigation might be warranted. For example, examining the distribution of joint replacement procedures across geographic regions might reveal areas where provision appears low. Although it is important to consider the reasons for variations, the distribution of an indicator provides valuable information that can prompt investigation and lead to improvements in health and health services.

Development of the indicators was a time-consuming, and sometimes tedious, process. Stakeholder consultations in six jurisdictions added greatly to the time spent on the project. However, this stage of the process was immensely valuable, resulting in a great deal of useful advice and thoughtful comments that contributed to a relevant and widely acceptable set of indicators.

Now that the core set has been established, the indicators need to be widely disseminated and regularly reported against. As part of this process, various data development activities need to be implemented. Scoping of potential sources of data for the rheumatology waiting time indicator (number 4.1) should be a priority. Alternative data sources for the three quality of life indicators (numbers 3.1, 3.2 and 3.3) also need to be investigated, both for immediate reporting purposes and as a secondary option should the information obtained in the next National Survey of Mental Health and Wellbeing not contain detailed information for all three focus conditions.

In addition, data development and conceptual work for those indicators that were considered important but not immediately able to be reported (those classified as category 2(ii) in Table 2, p. 13) should be undertaken. Although these indicators are not part of the core set, they do highlight areas where there are important information needs that are not currently met. Inclusion in the set could be considered at a later date, once the concepts are more clearly developed and data collection is feasible (or occurring).

As with any project of this nature, it is important that there be evaluation of the indicators, to determine whether they are useful and appropriate. This cannot happen immediately, since indicator-based reporting is often a driver for data development activity, and there needs to be time for this activity to catch up with reporting. The current Budget initiative relating to these conditions, *The Better Arthritis and Osteoporosis Care Program*, is funded until 2010. That may be an opportune time to review the indicator set, in order to consider the requirements of any new strategies or policy directions that are introduced.

Evaluation of indicators should consider not only whether the set is comprehensive and meets current information needs, but also whether the individual indicators meet quality criteria such as validity and reliability. The European Community Health Indicators Working Party (European Community Health Indicators Working Group 2001) detail a number of general criteria for indicator selection that also provide a useful set of criteria against which to evaluate indicators. These criteria, listed in Box 2, relate both to the indicator set as a whole and to the individual indicators contained within it. Evaluation, therefore, should involve examination of the qualities and usefulness of the existing indicators, as well as consideration of the relevance and comprehensiveness of the set as a reflection of current information needs and policy priorities. As with the initial development process, changes to the core set following evaluation should be consensus-based and subject to consideration by stakeholders.

Box 2: Evaluation criteria for indicators

As a set, indicators should:

- *be comprehensive*
- *be coherent and conceptually consistent*
- *relate to policy priorities and community interests.*

Individually, indicators should:

- *be guided by scientific principles*
- *meet methodological and quality criteria (such as validity, sensitivity, specificity, reliability and comparability)*
- *be flexible, for use at different organisational levels*
- *be based initially on existing data, but also indicate data needs and development areas.*

Source: *Adapted from European Community Health Indicators Working Group 2001.*

The National Centre for Monitoring Arthritis and Musculoskeletal Conditions and its steering committee, the Data Working Group, will be central players in indicator-based reporting of arthritis and osteoporosis and related data development activities. As with the indicator development process, the involvement of a range of stakeholders in these activities will be crucial to their success. With the endorsement of the National Chronic Disease Strategy and the National Service Improvement Frameworks by Australian Health Ministers in 2005, it is likely that new or 'headline' indicator sets, covering a range of health conditions, will be developed. The indicators for arthritis and osteoporosis described herein would be useful components of such a set.

Data development, indicator-based monitoring and evaluation are long-term goals, to be thought of in terms of years rather than months. But the realisation of these goals can only contribute to a better evidence base on which to build future public health strategies and policies for arthritis and osteoporosis.

Appendixes

Appendix 1: Members of the National Arthritis and Musculoskeletal Conditions Advisory Group (NAMSCAG) Data Working Group/Steering Committee

The members of the NAMSCAG Data Working Group to September 2006 (to be thereafter known as the Data Working Group/Steering Committee) are:

Professor Nick Bellamy (Chair)
Mayne Medical School, University of Queensland

Dr Kuldeep Bhatia
Arthritis, Asthma and Environmental Health Unit, AIHW

A/Prof. Flavia Cicuttini
Department of Epidemiology and Preventative Medicine, Monash University

Professor Robert Cumming
Centre for Education and Research on Ageing, Concord Hospital

Professor Peter Ebeling
Department of Medicine, University of Melbourne

Mr Michael Fisher
Asthma and Arthritis Section, Australian Government Department of Health and Ageing

Professor Graeme Jones
Menzies Centre for Population Health Research, Menzies Research Institute

Professor Lyn March
Department of Rheumatology, Royal North Shore Hospital

Dr Richard Osborne
Centre for Rheumatic Diseases, University of Melbourne

A/Prof. Anne Taylor
Population Research and Outcome Studies Unit, SA Department of Human Services

Ms Pam Webster
Carers Australia

Appendix 2: Participants in the national workshop and stakeholder consultation meetings

Dr Mike Ackland	Victorian Department of Human Services
A/Prof. Michael Ahern	Australian Rheumatology Association
Ms Carolyn Allen	Pharmaceutical Society of Australia
Mr Zahid Ansari	Victorian Department of Human Services
Mr Jag Atrie	WA Department of Health
Ms Raelene Baker	Queensland Health
Ms Josie Barac	Australian Bureau of Statistics
Ms Hilda Bastian	Consumers Health Forum
Professor Nick Bellamy	University of Queensland
Ms Jenny Bennett	Arthritis SA/Osteoporosis SA
Dr Kuldeep Bhatia	Australian Institute of Health and Welfare
Mr Ken Black	Australian Bureau of Statistics
Ms Judy Briggs	Queensland Health
Dr Helena Britt	Family Medicine Research Centre
Professor Peter Brooks	University of Queensland
A/Prof. Rachelle Buchbinder	Monash University
Ms Lucy Busija	University of Melbourne
Ms Kirrily Campbell	Queensland Health
Dr Ben Canny	Endocrine Society of Australia
Dr John Carnie	Victorian Department of Human Services
Mr Dermot Casey	Australian Government Department of Health and Ageing
Dr Wilbur Chan	The Prince Charles Hospital
Dr Ching Choi	Australian Institute of Health and Welfare
A/Prof. Flavia Cicuttini	Monash University
Mrs Jenny Cleary	NT Department of Health and Community Services
Professor Les Cleland	Royal Adelaide Hospital
Dr Laurence Clemens	Bone and Joint Decade Victoria
Dr Jim Codde	WA Department of Health
Ms Kaye Cole	Health Issues Centre
Ms Toni Collins	Victorian Department of Human Services
Professor Maria Crotty	Flinders University
Ms Maggie Crowe	Royal Perth Hospital
Professor Robert Cumming	Concord Hospital

Mr Brian Curren	Rural Doctors Association of Australia
Mr David Davidson	Australian Orthopaedic Association National Joint Replacement Registry
Professor Ric Day	St Vincent's Hospital
Professor Peter Disler	Victorian Rehabilitation Research Institute
Dr Paul Dugdale	ACT Department of Health & Community Care
Professor John Eisman	Garvan Institute of Medical Research
Ms Paula Elliott	Royal College of Nursing
Mr Craig Engstrom	Bone and Joint Decade Queensland
Dr Joy Eshpeter	Australian Government Department of Health and Ageing
Ms Margo Eyeson-Annan	NSW Health
A/Prof. David Findlay	Australia and New Zealand Orthopaedic Research Society
Mr Ric Forlano	Arthritis Foundation of WA
A/Prof. Michael Frommer	National Health Priority Performance Advisory Group
Dr Howard Galloway	Australian Musculoskeletal Imaging Group
Ms Nadine Garland	Arthritis NSW
Ms Susan Garner	Australian Government Department of Health and Ageing
Ms Irene Gibbons	Carers Australia
Ms Tiffany Gill	SA Department of Health
Ms Sally Goodspeed	Australian Bureau of Statistics
Ms Sally Green	Australasian Cochrane Centre
Ms Jane Griffin-Warwicke	Australian Bureau of Statistics
Ms Linda Halliday	ACT Health
Dr Paddy Hanrahan	Bone and Joint Decade WA
Professor Mark Harris	Joint Advisory Group on General Practice and Population Health
A/Prof. John Hart	Monash University
Dr Catherine Hill	The Queen Elizabeth Hospital
A/Prof. Michael Hooper	Concord Repatriation General Hospital
Ms Dale Howe	Albury Base Hospital
Dr Charles Inderjeeth	Australian Society for Geriatric Medicine
Dr Paul Jelfs	SA Department of Human Services
Mr Matt Jennings	Liverpool Hospital
Mr Brian Johnston	The Australian Council on Healthcare Standards
A/Prof. Graeme Jones	Menzies Research Institute
Dr Louisa Jorm	NSW Health

Ms Isolde Kauffman	Australian Government Department of Health and Ageing
Dr Fary Khan	Melbourne Health
Ms Bridget Kirkham	Arthritis Research Taskforce
Dr Alex Klestov	Royal Brisbane and Women's Hospital
Ms Stephanie Knox	Family Medicine Research Centre
A/Prof. Marissa Lassere	St George Hospital
Ms Lyn LeBlanc	Australian Nursing Council
Ms Gillian Leach	Arthritis SA/Osteoporosis SA
Dr Richard Madden	Australian Institute of Health and Welfare
Ms Ros Madden	Australian Institute of Health and Welfare
Dr Paul Magnus	Australian Institute of Health and Welfare
Ms Helena Maher	La Trobe University
A/Prof. Lyn March	Royal North Shore Hospital
Dr Guy Marks	Australian Centre for Asthma Monitoring
Ms Elizabeth Martin	La Trobe University
Mr Tony McCartney	National Aboriginal Community Controlled Health Organisation
Ms Jonette McDonnell	Australian Government Department of Health and Ageing
Ms Joy McLaughlin	Office of Aboriginal and Torres Strait Islander Health
Ms Jean McQuade	Arthritis Foundation of WA
Ms Katie Mickel	Australian Physiotherapy Association
Dr Craig Munns	Westmead Hospital
Dr Kevin Murray	Princess Margaret Hospital
Mr John O'Brien	Queensland Health
Ms Lin Oke	Australian Association of Occupational Therapists
Dr Richard Osborne	University of Melbourne
Ms Carole Owen	Tasmanian Department of Health and Human Services
Ms Kath Philip	Australian Physiotherapy Association
Dr Nathan Pinskier	Royal Australian College of General Practitioners
Ms Gayle Pollard	Queensland Health
A/Prof. Richard Prince	Western Australian Institute for Medical Research
Dr Susanna Proudman	Royal Adelaide Hospital
Ms Kay Richards	Australian Council on Healthcare Standards
Ms Elizabeth Rohwedder	WA Department of Health
Ms Jeanette Scott	Chronic Disease Network
Ms Margaret Scott	NSW Health
Mr John Slater	NSW Health

Dr Margaret Smith	Biology Society of Australia and New Zealand
Mr Peter Somerford	WA Department of Health
Ms Natalie Spearing	University of Queensland
Dr Margaret Stevens	WA Department of Health
Dr Andrew Taylor	Royal Perth Rehabilitation Hospital
Ms Anne Taylor	SA Department of Human Services
Dr Tim Threlfall	WA Department of Health
Ms Sandra Tulk	Queensland Health
Ms Anne Turner	Queensland Health
Mr Bob Unger	Arthritis Foundation of Queensland
Ms Janet Wale	Cochrane Consumer Network
Ms Pam Webster	Carers Australia
Mr David Whelan	SA Department of Health
Mr Bruce Whitby	SA Department of Health
Dr James Williamson	Sir Charles Gairdner Hospital
Mr Tony Woollacott	SA Department of Human Services
Ms Inge Young	WA Department of Health

References

ABS (Australian Bureau of Statistics) 1998. Mental health and wellbeing of adults, Australia: confidentialised unit record file 1997. ABS cat. no. 4329.0. Canberra: ABS.

ABS 2004. 2003 Disability, ageing and carers: summary of findings. ABS cat. no. 4430.0. Canberra: ABS.

ABS 2006a. 2004–05 National health survey: summary of results. ABS cat. no. 4364.0. Canberra: ABS.

ABS 2006b. National Aboriginal and Torres Strait Islander health survey, Australia, 2004–05. ABS cat. no. 4715.0. Canberra: ABS.

ABS & AIHW (Australian Institute of Health and Welfare) 2005. The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples. ABS cat. no. 4704.0. Canberra: ABS.

AIHW 2003. The Active Australia Survey. AIHW cat. no. CVD 22. Canberra: AIHW.

AIHW 2004. Australia's health 2004. AIHW cat. no. AUS 44. Canberra: AIHW.

AIHW 2005. Australian hospital statistics 2003–04. AIHW cat. no. HSE 37. Canberra: AIHW.

AIHW: Rahman N, Bhatia K & Penm E 2005. Arthritis and musculoskeletal conditions in Australia, 2005. AIHW cat. no. PHE 67. Canberra: AIHW.

Australian Orthopaedic Association National Joint Replacement Registry 2004. Annual report. Adelaide: Australian Orthopaedic Association.

Cole T, Bellizzi M, Flegal K & Dietz W 2000. Establishing a standard definition for child overweight and obesity worldwide: international survey. British Medical Journal 320:1240–3.

European Community Health Indicators Working Group 2001. Design for a set of European Community health indicators. Bilthoven, The Netherlands: National Institute of Public Health and the Environment.

Hawthorne G, Richardson J & Osborne R 1999. The Assessment of Quality of Life (AQoL) instrument: a psychometric measure of health-related quality of life. Quality of Life Research 8:209–24.

Henry M, Pasco J, Nicholson G, Seeman E & Kotowicz M 2000. Prevalence of osteoporosis in Australian women: Geelong osteoporosis study. Journal of Clinical Densiometry 3:261–8.

Karlson E, Mandl L, Aweh G et al. 2003. Total hip replacement due to osteoarthritis: the importance of age, obesity, and other modifiable risk factors. American Journal of Medicine 114:93–8.

Kessler R, Andrews G, Colpe L et al. 2002. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. Psychological Medicine 32:959–76.

Murray J & Lopez A 1996. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Cambridge, Massachusetts: Harvard University Press.

National Health Performance Committee 2001. National Health Performance Framework report. Brisbane: Queensland Health.

The EuroQol Group 1990. EuroQol—a new facility for the measurement of health-related quality of life. Health Policy 16:199–208.

Ware JJ, Kosinski M & Keller S 1996. A 12-item short-form health survey: construction of scales and preliminary tests of reliability and validity. Medical Care 34:220–33.