

# Understanding the needs of consumers with musculoskeletal conditions



Consumers' perceived needs of health information, health services and other non-medical services:  
A systematic scoping review



MONASH University



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## Executive summary

This report is a systematic scoping review, which details the breadth of perceived needs of consumers with musculoskeletal conditions. The review explores the health information (109 studies), health services (161 studies) and non-medical services (53 studies) needs of consumers with the following conditions:

- inflammatory arthritis - specifically rheumatoid arthritis (RA) and ankylosing spondylitis (AS)
- osteoarthritis (OA)
- back pain
- neck pain and
- osteoporosis (OP)

This review has identified a number of key issues that consumers living with musculoskeletal conditions have in relation to health information, health services and non-medical services (ie services not directly related to health care that affect consumers' lives). Overall there was a lack of high quality evidence from the consumer perspective, regarding health information, health services and non-medical services needs relating to musculoskeletal conditions. However despite this lack of evidence, the findings across the different musculoskeletal conditions tended to be complementary and consistent, suggesting there is a reasonable web of evidence from which generalisable conclusions can be made.

### Consumers' perceived health information needs (page 10)

Consumers' desired high quality, accurate information with simple explanations of their condition, delivered in a supportive and non-judgemental fashion. Consumers were found to seek information in order to gain control of their health condition, to improve function, to understand their prognosis and to take action to improve their health state and quality of life. They wanted general information regarding their condition, its management (pharmacological, non-pharmacological), and strategies to manage flares. Consumers also desired information regarding lifestyle factors to assist in the management of their conditions such as diet and exercise. The use of different media to convey health information was also identified as a need, suggesting that multimedia options may be an important complement to face-to-face communication. Support from peers in sharing information was also identified as important.

These results demonstrate that there is much to learn regarding the role of different forms of non-personalised information delivery, including understanding the health consumers' preferences for different modes of delivery or their relative efficacy and comparative effectiveness. It is likely that the various forms of information delivery may be able to be used to supplement usual care, to reduce the pressure on the healthcare system, including the use of non-medical personnel to aid in information transfer. Better understanding of the relative utility of different forms of media may be helpful in achieving better health outcomes for people living with musculoskeletal conditions.

### Consumers' perceived health services needs (page 28)

Health services needs identified in the studies tended to be similar for consumers across the musculoskeletal conditions examined in this review. Consumers were found to see benefit of medications, but they were concerned about the potential for side effects and addiction and were wary of procedural interventions. Those with back and neck pain perceived a strong need for an accurate diagnosis in order to legitimise their pain. Allied health and complementary medicine were seen as useful adjuncts to medical therapy, but were not seen as curative. Individualised information and exercise programs were preferred to group and 'off the shelf' interventions.

Health service delivery by healthcare providers who take a thorough, holistic approach to consumers' health care, have good communication skills, and allow consumers to take an active role in their own management and to do this in an empathetic and understanding fashion was preferred. Consumers wanted to receive clear and consistent information, including an explanation of why they have pain. There was a request that care be delivered at a convenient time and place to the individual.

Consumers perceived the main barriers to healthcare services to be cost, followed by access issues, related to waiting times for appointments and referrals, and the convenience of the healthcare provider's location. Compliance with allied health programs was identified as problematic due to lack of time, transport, cost and a variety of other factors. Social obligation also presented an impediment to attending to their own health, particularly for women.

Some condition-specific health information needs were also identified. In particular, those with back and neck pain expressed a strong need for a definite diagnosis that they believe is required in order to legitimise their pain and to formulate a clear treatment plan.

### Consumers' perceived other non-medical services needs (page 52)

This review has identified that people with musculoskeletal conditions also have a number of common needs outside the domain of health care. They require practical help within the home to enable them to look after themselves, the burden of which often fell to family members. Environmental factors impacted on their ability to function both inside and outside the home and in the work environment. They appreciated peer support and needed social outlets. For a variety of reasons, they felt a loss of social connections which was exacerbated by loss of employment that diminished their sense of wellbeing. The workplace was important in terms of identity, financial security and social connections: maintaining employment was a high priority for consumers with musculoskeletal conditions. Facilitation of safe transport and disability parking permits were also desirable.

## Limitations

This review is based on limited data from studies which examined issues that consumers with musculoskeletal conditions have in relation to health information, health services and other services needs. It has been possible to draw conclusions because a number of common issues emerged across the different conditions included in the review. Nevertheless it is important to take these results in context. The lack of identification of a need cannot be taken to mean that no need exists: it may not have been examined in the published studies. For example, for some conditions where there are well established therapies, such as in osteoporosis, much of the focus of studies examining consumer needs was on optimising drug compliance. Thus understanding consumers' needs relating to this aspect of care was over represented. In addition, most studies aimed at assessing consumers' needs had little focus on the services already provided. Furthermore, many of the studies examined very specific issues. As this review unfolded it was clear that significant gaps remain in the knowledge base in this area. These need to be addressed by specific research targeted to identify consumers' perceived needs. For example, no data were identified regarding the characteristics of consumers with back pain and their information needs or their use of the internet in meeting their perceived needs. Needs-based research will need to be aligned with studies examining consumers' knowledge and the availability of information and health services in order to provide a needs assessment of the situation for future healthcare and health policy planning and delivery.

## Aligning consumers' perceived needs with the health system in order to achieve better health outcomes

This review has identified a number of areas of importance to optimise consumer outcomes for musculoskeletal conditions. Improving communication; using a team approach where non-medical staff may provide a complementary role in care by supplementing health information delivery; and providing cheaper, more accessible service using new technology; may improve satisfaction and health outcomes. Consumers accept supplementary care from non-medical personnel and may be increasingly comfortable using other methods of information delivery and communication with their healthcare providers than traditional visits. Better understanding their needs may allow more effective alternative systems of health care delivery.

However it can also be seen that what consumers identified as needs were not always in line with clinical guidelines and what is considered evidence-informed best practice. For example, the need for a firm diagnosis for back pain driving the use of imaging is at odds with best practice. Interventions at the community level, to improve knowledge and expectations around this condition and others, are likely to be required to shift these beliefs and thus modify consumer need for diagnostic information and healthcare services. In other cases some needs may not have been identified. This may be in part because some of these needs are being addressed and so not apparent in the studies examined, and in other cases because the questions have not been asked. Consumers wanted more information regarding lifestyle factors and how they can manage their conditions. Healthcare providers need to be able to convey this information to better meet consumers' needs. However it is likely that for many of these questions the data are not available: the consumer need should be incorporated into the direction of future research. The focus of researchers needs to be brought into line with that of their main stakeholder, the consumer. In addition, a number of these needs require community wide strategies to address them.

To address consumers' needs and fill gaps in knowledge, a broad and multi-level response is required. Research to obtain answers to consumers' unanswered questions is necessary to supplement the evidence base. For other aspects, better understanding methods of communication, alternative methods of health care delivery and functional needs are required in order to determine how best to support consumers with musculoskeletal conditions. Improved integration of consumer needs is likely to enable alignment of consumers with the healthcare providers' aims of therapy, leading to better outcomes in co-care for musculoskeletal health, healthcare system utilisation and efficiency.

## Key recommendations

Based on the systematic review findings, three levels of recommendations for action are proposed.

### 1. System-level recommendations

- a) The burden of disease associated with chronic musculoskeletal conditions, particularly the disability and quality of life impacts associated with pain, mental health and mobility impairment, need to be explicitly reflected in national and jurisdictional health policy, strategy and resourcing plans. In particular, policies, frameworks and strategies for chronic health conditions should explicitly refer to the burden of disease of musculoskeletal conditions, both as primary conditions and co-morbidities with other health states.
- b) At a population level, accessible and accurate public health information about the impact and effective prevention and management of musculoskeletal conditions is essential for consumers. At a care provider level, individual practitioners (both medical and non-medical) should have access to contemporary health information about effective management strategies for musculoskeletal conditions. In particular, information about contemporary and evidence-based pain coping strategies is essential.
- c) Accessible services, including medical and allied health services, are essential for optimal management of musculoskeletal conditions; they are also identified by consumers as necessary. Development of strategies to ensure sustainable access to a skilled health workforce, including medical and non-medical practitioners, in urban and non-urban areas is a priority for healthcare providers and administrators.
- d) Supporting access to allied health and multidisciplinary care should be prioritised across health settings and particularly in primary care. These modes of service delivery are required to achieve optimal outcomes for people with musculoskeletal conditions. In particular, the lack of sustainable funding models poses a significant barrier to their use.

- e) An increased public health awareness of musculoskeletal health is needed, for example through mass media public health campaigns. In particular, it remains important to address the misconception that arthritis is an inevitable part of ageing and an 'older person's disease', as well as changing expectations of management, particularly regarding the role of imaging in the management of back pain and the role of active coping strategies for effective management of persistent pain.
- f) Musculoskeletal conditions pose a threat to an individual's social connections and social participation. These affect occupation and job security. A system to facilitate optimal function in the workplace, without jeopardising job security would prolong consumers' productive lives, improve their quality of life and maximise retirement wealth.
- g) Given the burden of musculoskeletal conditions, healthcare providers should have a good understanding of the impact of these conditions on consumers' lives, and be appropriately trained in the evidence-based management of the common musculoskeletal conditions. In the absence of requisite skills and knowledge to effectively manage musculoskeletal conditions, clear pathways and models of care should be available to health professionals to appropriately on-refer and coordinate care.

## 2. Health service-level recommendations

### a) Messages to consumers

- i) Conditions associated with persistent musculoskeletal pain that are not necessarily linked to a structural pathology (eg back or neck pain) need to be legitimised by healthcare providers and society. Consumers need to receive consistent messages from healthcare providers about the legitimacy of their pain and a thorough explanation of the likely absence of a relationship between pain and structure. Consumers require education regarding the need to stay physically active, and take a practical and pragmatic approach to coping with pain, informed by a person-centred, biopsychosocial approach to management, underpinned by contemporary pain science evidence.
- ii) Consumers require information regarding effective treatment options for musculoskeletal conditions. Whilst consumers seek this information from healthcare practitioners, particularly from medical practitioners, they may also obtain useful information from other information sources. Useful sources may include nurses and allied health providers, valid and reputable organisations such as different countries' arthritis organisations or disease-specific foundations that provide information on the internet or by pamphlet, and also peer support groups.

### b) Services

- i) Whilst participation in self-management programs may not consistently improve function or health outcomes, they may relieve pressures on healthcare practitioners to provide all health information. Self-management and support groups may also provide complementary information, particularly regarding coping strategies for consumers with musculoskeletal conditions and emotional and quality of life support.
- ii) The use of audio-visual material may be particularly useful for consumers who do not speak the primary language of their country of residence. These and written materials may supplement information provided by healthcare practitioners, diminishing the need for face-to-face information provision. This should be coupled with better direction by healthcare practitioners toward internet based, reliable sources of information.
- iii) In addition to cost, other significant barriers to care include locality of services, compliance and lack of time. Providing flexibility of provision of care (eg after hours, and community-based centres) may be important to obtaining optimal health outcomes. For consumers residing in non-urban areas, alternative care delivery models may be considered. These may include coordinated care with non-medical personnel and telehealth services.
- iv) Healthcare providers should be able to provide consumers with information enabling them to overcome their functional and mobility deficits. Healthcare and other facilities need to be designed taking these factors into account, and to enable consumers to access these facilities. Mobility deficits need to be considered by those tasked with the design of infrastructure and resources.
- v) Consumers value coordinated care. This may be facilitated by improved practitioner communication or co-location of services to provide multidisciplinary care. While there is a preference for care services to be co-located, other options may include digital connections between providers and services.
- vi) The provision of transparent information that is accessible to the public regarding workplace rights would be reassuring to consumers with musculoskeletal conditions.

### 3. Healthcare provider-level recommendations for action

- a) Healthcare providers should aim to provide information regarding strategies to improve daily function in consumers with musculoskeletal conditions, delivered using plain language, and accessible in multiple formats (written, digital etc).
- b) It is important for healthcare providers to be aware that consumers' information requirements about their musculoskeletal conditions are not dependent on disease severity. All consumers should be provided with information regarding prognosis, management options and individualised coping strategies.
- c) When providing information regarding management options for a person's musculoskeletal condition, healthcare providers should tailor this to the person's current state of health and the problems posed by their musculoskeletal condition and their other health and/or social problems.
- d) Healthcare practitioners need to have a good understanding and knowledge base of musculoskeletal conditions so that they can instil confidence in their patients. This is to address current consumer perceptions of a lack of knowledge among healthcare practitioners, including general practitioners, which acts as an impediment to creating a trusting therapeutic relationship.
- e) Healthcare providers caring for consumers with back pain need to consider the common consumer expectations around this condition, such that it is common for consumers to desire a definite diagnosis, to expect imaging and receive a biomechanical or structural explanation for their pain. To address these issues and enable effective management, education is required.
- f) The importance and safety of exercise in the management of inflammatory arthritis, osteoarthritis, back pain and osteoporosis is important to impart to consumers with these conditions.
- g) Healthcare providers need to provide a non-judgemental and open forum for consumers to discuss their use of, and preferences for, complementary and alternative medicines. Healthcare providers should also be able to access evidence concerning the safety and effectiveness of complementary and alternative medicines in order to address consumers' questions and counsel them appropriately.

### 4. Research recommendations

- a) Ongoing research is important to better understand consumers' perceived needs, by asking them directly what they perceive their needs to be. This will enable the healthcare provider and services to better meet evolving consumers' needs.
- b) Whereas for some musculoskeletal conditions, such as osteoporosis, the consumer's knowledge base is known to be poor, for others it is less well known. To develop more effective information provision strategies, better data regarding consumers' knowledge of their condition, matching this to their perceived health information needs and the essential information that healthcare providers need to impart to provide best practice evidence-based care is required.
- c) Consumers desire information regarding how lifestyle factors, particularly dietary composition and exercise, affect their musculoskeletal conditions. Whereas for some conditions this has been studied, such as the role of exercise in back pain or osteoarthritis, for others the information is less clear, such as how dietary factors affect back pain. Ongoing research is required to identify how foods and exercise may affect the different musculoskeletal conditions.
- d) Research to identify the precipitants of flares of musculoskeletal conditions, for back pain in particular, is important to provide consumers with more control of their condition, and facilitate appropriate activity.
- e) The safety and effectiveness of complementary and alternative medicines, used alone or in conjunction with conventional medical therapy, requires further research. Although consumers use these widely, there is a tendency for conventional medicine to ignore these.

## Abbreviations

AS	Ankylosing spondylitis
BMD	Bone mineral density
CALD	Culturally and linguistically diverse
CAM	Complementary and alternative medicine
CLBP	Chronic low back pain
DEXA	Dual energy x-ray absorptiometry
DMARD	Disease modifying antirheumatic drug
GP	General practitioner
HCP	Healthcare practitioner
LBP	Low back pain
MSK	Musculoskeletal
OA	Osteoarthritis
OP	Osteoporosis
PsA	Psoriatic arthritis
RA	Rheumatoid arthritis

# 1. Introduction



# 1 Introduction

Musculoskeletal disease is a major public health burden. In the Global Burden of Disease Study 2010, back pain and osteoarthritis were identified as major contributors to the global burden of disease, as well as osteoporosis/osteopenia, and to a lesser degree the inflammatory arthritides (rheumatoid arthritis and ankylosing spondylitis)<sup>1</sup>. Whilst these chronic conditions impose significant burden in terms of disability years, they have a lesser impact on mortality, and are often a secondary concern to treating health practitioners. Compounding this problem is that, for the non-inflammatory and non-metabolic musculoskeletal conditions (neck and back pain and osteoarthritis), established disease modifying therapies are limited, other than weight loss and exercise. While for these conditions weight loss and exercise therapy may be useful in improving symptoms, success is both difficult to achieve and sustain. Exercise therapy is also potentially costly to implement, particularly once disease is entrenched. In contrast, the inflammatory arthritides and osteoporosis/osteopenia have more established effective therapies, thus the role of lifestyle on these conditions may not be fully understood or addressed by healthcare practitioners since the focus of care tends to be on the prescription of drug therapies. Indeed, although there are guidelines for therapy for these conditions, many of them inadequately address lifestyle and life issues experienced by consumers who thus tend to use a variety of self-identified strategies to support themselves (forced self-management).

For these chronic conditions, a team or 'co-care' approach is considered best practice for optimal management, ie consumers and their health professionals (eg general practitioners, specialists, physiotherapists, occupational therapists, pharmacists, chiropractors etc.). For this to be successful, the consumer is required to play a central role; and have some level of health literacy<sup>2</sup>. Therefore aligning the consumer's perceived needs with those of their health professionals will be helpful in optimising health outcomes. It is also important to understand the consumers' perspective of need – which may be diametrically opposed to the healthcare provider's perception of the situation.

In order to align the aims of the consumer with those of the healthcare professional and other stakeholders (such as their families and carers), it is necessary to understand what the consumer perceives their own needs to be in relation to their health conditions. The dimensions of need that may assist healthcare providers and key stakeholders to better align with those of consumers include: consumers' perceived needs relating to health information, health services and their perceived needs of other non-medical services. The aim of this work was to identify the existing data on consumer needs (health information, health service and other non-medical service needs) relating to the major musculoskeletal conditions (rheumatoid arthritis and ankylosing spondylitis, representing the inflammatory arthritides, osteoarthritis, back pain, Neck pain and osteoporosis/osteopenia).

## 1.1 Brief methods

This study was a systematic scoping review whose aim was to identify the breadth of evidence regarding consumer needs related to musculoskeletal health. This review comprised of a systematic search followed by data extraction and the results presented according to the themes that emerged from the identified studies.

### 1.1.1 Systematic search

In order to perform a thorough and comprehensive search, inclusive search strategies were created to capture studies which evaluated:

- all aspects of consumers' perceived needs relating to health information, health services and their perceived needs of other non-medical services and
- the major musculoskeletal conditions (rheumatoid arthritis and ankylosing spondylitis, representing the inflammatory arthritides, osteoarthritis, back pain, Neck pain and osteoporosis/osteopenia).

Studies were only included in the review if they explored both of these domains.

Equivalent search strategies capturing both of these domains were developed in four major health sciences electronic databases (MEDLINE, CINAHL, EMBASE and PsycInfo).

Terms encompassing the consumer perspective were included in the search strategy to ensure that studies relating to consumer preference, needs, satisfaction, experience, attitudes, beliefs and concerns, opinions, expectations and perception were identified. The concept of need was also included, using a variety of constructs including needs, preferences, service, retrieval, transfer, finding, understanding and evaluation.

The search strategy developed for this review was composed of a five search strategies:

1. the consumer
2. dimensional need (health information/ health services/ other non-medical services)
3. needs strategy (outlined above)
4. consumer perspective
5. musculoskeletal conditions

These strategies were combined to identify relevant studies. Within each area of need a search was performed to identify studies relating to each condition.

### 1.1.2 Data extraction study characteristics

From each of the relevant studies the following data was extracted for:

- Participants: specific conditions, how participants were sourced (ie from the community, or hospital) age and gender
- Study methods: inclusion criteria of the studies, methods used eg in depth interviews, focus groups, semi- structured interviews

### 1.1.3 Presentation of results

For each area of need and each condition data from across the studies was then grouped according to the emerging themes and subthemes. For each of the consumers perceived area of need the results were discussed and summarised to draw out common and divergent themes between musculoskeletal conditions.

## 1.2 Document structure

This review is structured according to the consumer needs that were examined (health information, health services and other non-medical services), for each of the five conditions of interest (see figure 1). At the end of each consumer needs section, the combined findings from all musculoskeletal conditions are summarised and discussed. An overall conclusion relating to the whole report is provided as the last section. All tables have been placed in the back of the document in the “Tables’ section.

**Figure 1: Structure of the document**

Chapter	Conditions examined					Key consumer needs summary
1 Introduction						
	Rheumatoid arthritis and ankylosing spondylitis	Osteoarthritis	Back pain	Neck pain	Osteoporosis and bone health	All conditions
2 Health information needs 2.1 and 2.2	2.3	2.4	2.5	2.6	2.7	2.8
3 Health services needs 3.1 and 3.2	3.3	3.4	3.5	3.6	3.7	3.8
4 Other non-medical service needs 4.1 and 4.2	4.3	4.4	4.5	4.6	4.7	4.8
5 Conclusions						
6 Tables						
7 References						

**“When you are  
diagnosed with  
it, you are not  
given enough  
information”**

**(Mann, 2011<sup>30</sup>)**



## 2. Consumers' perceived needs regarding health information



## 2 Consumers' perceived needs regarding health information

### 2.1 Introduction to consumers' perceived health information needs

In considering consumers' perceived health information needs, we included a variety of dimensions of health information:

- a) *Why consumers may seek health information*  
This search included terms designed to cover concepts including consumers information seeking to learn about the musculoskeletal condition, to understand it, to educate themselves about why the condition occurs or what makes it worse or better, to enable them to manage the condition better, to make treatment decisions, to look after themselves better and to fill their perceived knowledge gaps.
- b) *What content may be desired*  
The content that was desired by consumers and whether it was information, education, guidance etc.
- c) *Factors that may relate to methods of information delivery: at an individual level*  
The different health care providers for the musculoskeletal conditions examined
- d) *What sources consumers may use to seek health information other than from health care professionals*  
Potential sources of health information were included. These included different forms of media, including local and mass media, print, audio-visual, electronic, digital, online, social media (including the most common social media platforms), different instruments used to access information including the telephone, computers, tablets, smart phones, television, radio, newspaper, publications, magazines, posters, handouts, etc.
- e) *Barriers and facilitators to consumers obtaining health information*  
Factors that consumers may perceive as impeding their ability to obtain health information were sought, including barriers and health literacy. Positive factors that may have been considered to help consumers fulfil their health information needs were also considered.

The search strategy was refined in each of the four major health sciences electronic databases. This search strategy was applied to each of the musculoskeletal conditions examined to identify the literature related to consumers' perceived health information needs. Studies that were relevant were identified and information extracted. This information was collated and studies that addressed similar themes were grouped, with sub-themes extracted.

The results relating to the various themes and sub-themes identified were combined and presented across the different musculoskeletal conditions examined. The combined results were discussed and contrasted.

### 2.2 Search results

The search strategies returned 17,818 papers, of which 109 were identified as relevant for inclusion in this review.

## 2.3 Health information: Rheumatoid arthritis and ankylosing spondylitis

### 2.3.1 Description of included studies

Most of the included studies were from the United Kingdom or Europe<sup>3-20</sup> with the remainder from the United States of America<sup>21,22</sup> and Asia<sup>23</sup>. The majority of participants were recruited from rheumatology outpatient clinics<sup>3,4,6,7,10-12,14-21,23</sup>. Two studies included patients recruited from inpatient wards<sup>8,20</sup> while four studies recruited patients from existing disease registries or databases<sup>5,9,13,22</sup>.

Most studies involved only people with rheumatoid arthritis<sup>3,4,6-8,10-17,19-23</sup>. Of the remainder, one included a mixed population including people with RA, psoriatic arthritis (PsA) and hand osteoarthritis, although those with rheumatoid arthritis were analysed separately<sup>7</sup>. One study included only patients with ankylosing spondylitis<sup>5</sup> and two included patients with both rheumatoid arthritis and ankylosing spondylitis (analysed together)<sup>9,18</sup>.

### 2.3.2 Results: Consumers' perceived health information needs regarding inflammatory arthritis

Five key themes emerged from the included studies relating to perceived health information needs of consumers with inflammatory arthritis. These themes were:

1. reasons for seeking health information
2. demographic differences in health information needs
3. content of health information
4. preferred information delivery
5. communication methods and barriers to meeting health information needs

#### 2.3.2.1. Reasons for seeking health information

Four qualitative studies identified factors related to the underlying motivation for seeking health related information<sup>3,10,15,17</sup>. Factors were mainly around consumers' desire to gain control or ownership over their health<sup>15,17</sup>, and for practical purposes to help them live with their disease<sup>10,15,17</sup> and prepare for the future<sup>3,10</sup>.

#### 2.3.2.2. Differences in information needs according to consumer-related factors: Gender, age, education/employment/ socio-economic status and disease related parameters

Nine studies identified differences in consumers' perceived health information needs based on demographic factors<sup>5,7,12-14,16,21-23</sup>. Whilst five studies found female consumers had higher information needs<sup>5,7,21-23</sup>, two found no gender difference<sup>13,14</sup>. Similarly, three studies suggested that younger patients<sup>5,13,22</sup> tended to have greater information needs, but one did not<sup>7</sup>. One study found younger patients were more likely to seek information online and had a lower preference for written information<sup>5</sup>. Three studies found that higher levels of education and current employment were associated with stronger preferences for information<sup>16,21,23</sup> but this was not supported by findings in three other studies<sup>7,13,14</sup>. There were no consistent associations between disease duration<sup>7,13,14</sup>, disease activity or physical functioning<sup>7,13,23</sup> and information needs.

#### 2.3.2.3. Consumers' perceived needs regarding the content of health information

In 18 of the included studies, consumers identified specific content areas in which they desired information related to their disease<sup>3-14,17,18,20-23</sup>. Most consumers desired general information about "the disease itself"<sup>9,10,14,18,22</sup>, however there was less interest in purely factual information about disease pathophysiology and course<sup>5,6</sup>. Nine studies found that consumers expressed a need for information about pharmacological management including rationale, side effects and alternatives<sup>3,4,6,10,14,17,18,22,23</sup>. Participants in four studies wanted information about exercise and physical therapy including potential positive or negative effects on joints and specific exercise instructions<sup>3,9,11,14</sup>. In addition to more medical aspects of the disease, participants in nine studies also placed moderate importance on receiving information about psychosocial and self-management issues<sup>3,5,6,8,9,12-14,18</sup>. Examples included information about coping with the emotional impact of the disease<sup>3,12,13</sup>, social support<sup>6,13</sup>, and self-help strategies<sup>3,12,13,18</sup>. In particular, coping with the disability and pain associated with the disease<sup>3,8</sup> and maximising function and performance in everyday activities<sup>6,8,9,18</sup> were raised, with a need for information that was practical and targeted to their situation<sup>5,8</sup>. Other identified areas of information need were related to information about pain management<sup>3,14</sup>, information about relevant services and facilities<sup>13,18</sup> and summaries of new research or developments in their disease<sup>5,6</sup>. Although there was in general a high demand for information, consumers in three studies described a concern that "too much" information, particularly negative information, could generate anxiety<sup>3,17,20</sup>.

#### **2.3.2.4. Preferred information delivery and communication methods**

Consumers' preferences for various methods of information delivery were evaluated in ten studies <sup>3,5,6,8,10,12,13,15,18,19</sup>. While the rheumatologist was the preferred source for medical information (ie disease, treatments) in a face-to-face setting <sup>3,6,19</sup>, other sources were also deemed to have strengths for certain types of information.

In terms of preferences for different modes of information delivery, one-on-one communication was favoured for disease based information <sup>3,6</sup>, but also had a perceived role for emotional and quality of life issues <sup>3,12</sup> and in the setting of languages other than English <sup>10</sup>. Written information or leaflets were viewed as a popular complementary source, useful for additional or more detailed information and as a memory aid that could be referred to according to need <sup>3,5,19</sup>. Written information was also by far deemed to be the most useful form of information delivery in regards to information about health services <sup>13</sup>. Videos were viewed as useful for sharing information and visual cues <sup>3</sup>, while consumers from culturally and linguistically diverse (CALD) backgrounds identified bilingual educational CDs as useful and more accessible than written material <sup>10</sup>. The internet was also a source of further information, but consumers raised concerns regarding quality and the high volume of material <sup>15</sup>. Group sessions were also an acceptable format for communication of information around psychosocial and self-management issues, with a major benefit being the ability to share ideas, socialise and learn from other individuals with a consumer perspective of living with their disease <sup>3,5,15</sup>.

Factors related to the way in which information was conveyed was also identified as important. Many consumers expressed the need for positive and optimistic information <sup>3,5,15</sup> and information tailored to their specific needs <sup>3,8,12,18</sup> rather than general information. Consumers also identified the importance of clear explanations, appropriate terminology, timely information and having adequate time to obtain information <sup>12,18,19</sup>.

#### **2.3.2.5. Consumers' perceived barriers to meeting health information needs**

Barriers identified by consumers to meeting their information needs included lack of knowledge by clinicians in particular areas of interest (eg exercise prescriptions) <sup>5,11</sup>, poor access to or hesitancy to use reliable information sources and the lack of ongoing information over the course of the disease <sup>3,5,12</sup>. Difficulties with communication due to a language barrier was problem specific for consumers from CALD backgrounds <sup>10</sup>.

## 2.4 Health information: Osteoarthritis

### 2.4.1 Description of included studies

Twenty six relevant studies were identified. Of these, 11 were from the United Kingdom<sup>24-33</sup>, four from the United States of America<sup>34-37</sup>, two each from Germany<sup>7,38</sup> and France<sup>39,40</sup>, and one each from Canada<sup>41</sup>, Australia<sup>42</sup>, the Netherlands<sup>43</sup>, Taiwan<sup>44</sup>, Hong Kong<sup>45</sup>, Kuwait<sup>46</sup> and an unknown source<sup>47</sup>. There was one multi-centre study conducted in Finland, Iceland and Sweden<sup>48</sup>. The diagnosis of osteoarthritis was made in three studies using the American College of Rheumatology's criteria<sup>7,41,45</sup>, using radiographic change and pain in five studies<sup>24,26-28,44</sup>, by self-report in five studies<sup>25,32,35,37,47</sup>, by chart review in three studies<sup>36,38,43</sup>, by clinical diagnosis in three studies<sup>30,31,48</sup>, and by undefined methods in five studies<sup>34,39,40,42,46</sup>. Jinks examined knee pain, but not necessarily knee osteoarthritis<sup>29</sup>.

The included studies had a female predominance, with two studies including only female participants<sup>46,47</sup> and 19 studies having a higher proportion of females to males<sup>7,25-28,30-32,34-36,39-41,43-45,48,49</sup>. Two studies had equal numbers of male and female participants<sup>33,37</sup>, one study had more males<sup>29</sup> and one study did not specify the gender profile of participants<sup>42</sup>.

### 2.4.2 Results: Consumers' perceived health information needs regarding osteoarthritis

Five main themes emerged from the included studies relating to the perceived health information needs of consumers with osteoarthritis. These themes were:

- 1) demographics of consumers seeking health information
- 2) language used in osteoarthritis
- 3) source of health information
- 4) consumer's satisfaction and dissatisfaction with health information provision
- 5) consumers' perceived gaps in health information

Results from individual studies relating to each of these themes are presented below.

#### 2.4.2.1 Demographic factors and variation of consumers' perceived health information needs

Three studies explored demographics of consumers<sup>7,35,48</sup>. Dragoi<sup>7</sup> and Mora<sup>35</sup> evaluated the gender differences in health information needs and found that females had higher educational needs<sup>7</sup>. In particular, women asked more questions about their condition, surgical management options and the risks and benefits of surgery<sup>35</sup>. Stark reported that patients with higher education and those with depression or anxiety who were awaiting hip joint replacement surgery had more unfulfilled knowledge expectations and wanted more information<sup>48</sup>. In contrast, in those awaiting hip joint replacement surgery there was no correlation found between the length of hospital stay and the difference between health information needs<sup>48</sup>.

#### 2.4.2.2 Consumers' perceived needs regarding language used to convey health information

Four studies examined consumers' language preferences with osteoarthritis<sup>29,33,37,40</sup>. Barker found that many terms used in osteoarthritis are misunderstood by consumers or have different connotations, such as "rheumatism", "inflammation", "cartilage" and "rehabilitation"<sup>33</sup>. For example, some consumers interpreted the term "effusion" as fusion of bones, and consumers did not want this word associated with their arthritis<sup>33</sup>. Consumers were less familiar with "osteoarthritis" than "arthritis" and considered it less serious than rheumatoid arthritis, but frequently confused it with osteoporosis, particularly amongst women<sup>33</sup>. Moreover, consumers reported negative connotations with a number of words and phrases. Jinks found that consumers perceive "wear and tear" as being linked to ageing and reinforced a lack of effectiveness of treatments<sup>29</sup>.

Two studies reported consumers' preferences with communication style<sup>37,40</sup>. Consumers want clear communication of individualised care plans from their healthcare provider<sup>37,40</sup>. Consumers also reported that inappropriate gestures generate anxiety and that silence from the practitioner was interpreted as the doctors' "powerlessness"<sup>40</sup>.

## **2.4.3 Consumers' preferences relating to sources of health information**

### **2.4.3.1 Information provided by health professionals**

Eight studies evaluated consumers' utilisation of health professionals for information <sup>24,30,37,38,42,45,47</sup>. Consumers seek health information from someone with specialist knowledge of arthritis, such as physicians, other health professionals in clinics and nurse practitioners <sup>30,38,47</sup>. Ilic found that consumers typically relied on their doctor for general medical information <sup>42</sup> and Rosemann reported that most consumers trusted information from their general practitioners about medications <sup>38</sup>. However, consumers wanted more convenient access to healthcare providers <sup>37</sup>. Furthermore, Parsons reported that some consumers felt that there are no consistent healthcare professional-led information sessions about osteoarthritis <sup>24</sup>.

### **2.4.3.2 Information provided by the internet**

Five studies examined the consumers' use of the internet for health information <sup>30,34,36,42,50</sup>. Consumers use the internet as a source of information <sup>34,40,42</sup> and to share their experiences with others <sup>34</sup>. In particular, consumers accessed the internet when information needs were not met <sup>30,36</sup>. Consumers have also expressed interest in using an arthritis website to access health information <sup>36</sup>. Most interest with using the internet was from consumers less than 56 years of age and those with routine internet use <sup>36</sup>. However, Ilic found that although accessing medical information from the internet is convenient, some consumers thought the credibility and reliability of the online information was variable <sup>42</sup>.

#### **2.4.2.3.3. Information provided by social media and print material**

Consumers' use of other media, including printed materials, television and video recordings for health information were evaluated in five studies <sup>25,32,43,45,47</sup>. Baird reported that consumers seek information about arthritis through print media or television <sup>47</sup>. Cuperus <sup>43</sup> and Grime <sup>32</sup> also found that some consumers read information booklets. Cuperus reported that whilst some patients used the information booklet as a tool to remind them about topics to discuss with their doctor, others felt that booklets were not useful <sup>43</sup>. Perceived barriers to using the information booklet included the consumer's perception that osteoarthritis is untreatable <sup>43</sup> and if the information booklet was difficult to read <sup>32</sup>. Other reasons not to use information booklets included the consumer believing they knew the information in the booklet, consumers not wanting to know everything about osteoarthritis, consumers not paying attention to osteoarthritis or consumers feeling sufficiently supported by their healthcare providers <sup>43</sup>. Furthermore, Saroop-D'Souza found that 80% of participants found an information video useful but only 48% found it relevant <sup>25</sup>.

#### **2.4.2.3.4 Information provided by laymen including support groups, family and friends**

Four studies examined the consumers' use of support groups, family and friends for health information <sup>24,45-47</sup>. Al-Taiar and Parsons reported that consumers considering surgical management sought information from other people who have had a total knee replacement <sup>24,46</sup>. Consumers also seek information about arthritis from classes or listening to friends <sup>47</sup>.

### **2.4.2.4 Consumers' satisfaction and dissatisfaction with information provision**

#### **2.4.2.4.1 Satisfaction with information provided**

Three studies reported on consumers' satisfaction with the provision of health information <sup>38,40,48</sup>. Baumann found that consumers generally thought the advice and response to questions from their healthcare practitioners was good <sup>40</sup>. Rosemann reported that consumers felt well informed about the cause and pathomorphology of disease, and that their general practitioners tried to motivate them and explain the effects of lack of exercise and being overweight <sup>38</sup>. They also thought that information about medication side effects was not that important because they were aware that many of the side effects mentioned on medication package inserts never occur <sup>38</sup>. Furthermore, Stark found that consumers' knowledge expectations were most fulfilled about symptoms related to osteoarthritis <sup>48</sup>.

#### **2.4.2.4.2 Dissatisfaction with health information**

In comparison, 11 studies examined consumers' discontent with the provision of health information<sup>24,26-29,31,39,40,43,46,48</sup>. Consumers were dissatisfied with the amount of information received and the perceived lack of understanding and unclear explanations<sup>24,26,28,31,39,40,43,48</sup>. Baumann also reported that some consumers thought that healthcare practitioners were frequently not explicit enough when discussing the diagnosis or therapeutic options<sup>40</sup>. Consumers have also expressed discontent with the limited information provided by doctors in terms of management options, medications and recent developments<sup>29,40</sup>. Al-Taiar and Parsons found that consumers felt that advice regarding surgical options was inadequate and often came very late which led to longer delays in undergoing surgery<sup>24,46</sup>. Some consumers noted a difference between private and public sector doctors in the way they provide information and explanations about joint replacement operations<sup>46</sup>. Moreover, consumers waiting for joint replacement surgery also found that they had little information regarding health maintenance, exercise, use of walking aids, weight control and symptom relief<sup>24</sup>. Some consumers thought there was a contradiction in the advice and information given by some healthcare providers, which was perceived as a lack of knowledge on behalf of healthcare practitioners<sup>31</sup>. Consumers felt that they had to ask for health information, rather than be provided information spontaneously by health professionals<sup>40</sup>. Victor reported that some consumers perceived this information gap as marginalisation by health providers<sup>27</sup>.

#### **2.4.2.5 Consumers' perceived gaps in information provision**

##### **2.4.2.5.1 Gaps in information about diagnosis**

Three studies examined consumers' perceived gaps regarding diagnostic information<sup>7,30,40</sup>. Baumann found that consumers want information about the origins of disease<sup>40</sup> and Dragoi reported that a high percentage of consumers expressed interest in receiving education about their arthritis<sup>7</sup>. Mann also found that consumers have a strong desire for improved information about osteoarthritis<sup>30</sup>.

##### **2.4.2.5.2 Gaps in information about management options and prevention**

Eight studies explored consumers' perceived gaps in information about the management and prevention of osteoarthritis<sup>30-32,34,35,38,40,48</sup>. Consumers want more information about management strategies for osteoarthritis, particularly about medications<sup>31,40</sup>, assistive devices<sup>31</sup>, diet and weight management<sup>30</sup>, exercise therapy and occupational therapy<sup>30,31</sup>, symptom control<sup>30</sup> and self-management strategies<sup>32,34</sup>. They also want information regarding local services<sup>31</sup>, support groups<sup>38</sup> and financial support<sup>48</sup>. Moreover, consumers felt that they lacked information about surgical management options<sup>30</sup>, especially details about joint replacement surgery, as well as the risks and benefits of surgery<sup>35</sup>. Brosseau and Mann found that consumers require more osteoarthritis management information to help them cope with daily life and self-manage their osteoarthritis<sup>30,40</sup>. They also felt that more information enabled them to communicate with their practitioners and become partners with their healthcare providers in the management their disease<sup>40</sup>. In addition, consumers wanted more information about prevention of osteoarthritis in their children and grandchildren<sup>40</sup>.

##### **2.4.2.5.3 Gaps in information about prognosis**

Consumers' perceived gaps in information about prognosis was evaluated in two studies<sup>30,40</sup>. Baumann found that consumers require more information about the prognosis and outlook of osteoarthritis, and that "information can help them accept the diagnosis and the uncertainty and doubt about the future that goes with it"<sup>40</sup>. Mann reported that consumers' desire improved information about the likely progression of osteoarthritis, especially at the time of diagnosis and in the early stages of osteoarthritis<sup>30</sup>.

##### **2.4.2.5.4 Gaps in the source of information**

Two studies reported on consumers' perceived gaps in the health information sources<sup>37,44</sup>. Kao found that consumers did not know where to find information about osteoarthritis and that there were few informational tools to help consumers understand their disease<sup>44</sup>. Bayliss reported that consumers want information in writing to aid understanding and recollection of information<sup>37</sup>.

## 2.5 Health information: Back pain

### 2.5.1 Description of included studies

Most of the 37 included studies were from the United Kingdom or Europe<sup>52,60-62,64,65,67,69-80,82,83,85-87,89,90</sup> with the remainder from the United States of America<sup>56,58,68,81,88,91</sup>, Australia<sup>59,66</sup>, and one each from Iran<sup>84</sup>, Israel<sup>57</sup> and New Zealand<sup>63</sup>. The majority of participants were recruited from primary practice<sup>52,57,62,66,74,76,80,82,83,88,91</sup>, with some participants recruited from pain clinics<sup>58-60,66,68,85-87,89</sup>, hospital and rehabilitation clinics<sup>56,61,64,65,71,75,79</sup>, specialist spine and osteopathy clinics<sup>69,70,72</sup> and some from the general public<sup>63,71,73,77</sup>, two from research centres<sup>78,84</sup> and one from an occupational health clinic<sup>81</sup>.

The duration of back pain was either undefined or mixed in 13 studies<sup>52,57,63,70,71,76-78,80,82,83,88,90</sup>, chronic (>3 months) in 22 studies<sup>58-62,64,65,67-69,72-75,79,84-87,89,91</sup> and three studies evaluated participants with acute back pain<sup>56,66,81</sup>.

### 2.5.2 Results: Consumers' perceived health information needs regarding back pain

Two major areas of need emerged from the identified studies relating to perceived health information needs among consumers with back pain. The main areas of need centred around:

- 1) information content
- 2) information delivery.

Results from individual studies relating to each of these themes is presented in the following text and tables.

#### 2.5.2.1 Consumers' perceived health information needs

##### 2.5.2.1.1 General information content

Eight studies illustrated consumers' need for general information for back pain<sup>57,62,63,71,72,81,84,90</sup>. There were two key areas of content that consumers were interested in: basic factual information about back pain<sup>57,71,84</sup> and general information regarding the nature of back pain, its characteristics and attributes<sup>62,63,72,81</sup>.

Consumers were keen to obtain a broad spectrum of explanations on general aetiology of back pain<sup>57</sup>. Participants in Young's study were frustrated and perceived their partners and family to be affected by their inability to participate in activities, wanting to improve their understanding of back pain<sup>90</sup>. Consumers believed they lacked knowledge about back pain, and thus required general information and facts regarding back pain<sup>63,76,84</sup>. To better understand this condition, many also expressed the need for education in regard to the nature of back pain<sup>62,63,72,81</sup>.

##### 2.5.2.1.2 Information about diagnosis, cause/aetiology

Twenty four studies showed that consumers perceive a need for a diagnosis for back pain and/or an explainable cause of low back pain<sup>57,60-62,66,67,69-71,73-80,82,84-87,89,91</sup>. Findings commonly stated participants' need for an "exact" diagnosis of back pain for a variety of reasons, including the validation and legitimisation of consumers' symptom<sup>61,73,85,87,91</sup>. Some examples were "I'm not making this up"<sup>91</sup>, "...keen to 'justify' their symptoms"<sup>61</sup> and "...there's a tendency for people to assume 'oh what a waster!'"<sup>73</sup>. The lack of a diagnosis was associated with frustration, such as "...there's nothing wrong with you, you're really very unfit...I felt stupid"<sup>67</sup>. Some participants also felt that their pain could not be substantiated without a specific diagnosis, for example "...people say to you, 'well, what's the problem?' and...I really don't know'. It makes you feel so stupid"<sup>75</sup>. Lack of a diagnosis was reported by consumers to indicate that health professionals did not know what they were doing, which resulted in a perceived lack of a therapeutic relationship with the health practitioner<sup>77,78</sup>. Participants in Ong's study stated that they required the diagnosis as the starting point for therapy<sup>78</sup>.

Most consumers identified the need to know the cause of symptoms<sup>57,60-62,66,67,69-71,73-80,82,85-87,89,91</sup>. Many were dissatisfied with being told that the pain was "age related" or "wear and tear"<sup>60,67</sup>. Some consumers demanded and were insistent on requiring a biomechanical or physical explanation<sup>67,79,87</sup>. In a study by Toye, consumers identified that both a physical and psychological explanation were relevant<sup>87</sup>.

##### 2.5.2.1.3 Imaging believed required for diagnosis

Seven papers found that imaging was believed to be essential in the assessment of low back pain<sup>52,57,66,77,80,85,91</sup>. This was thought to be required to confirm the diagnosis, identify structural damage and to identify the cause of back pain. Two studies identified the relief consumers felt when a structural cause was found as a cause of back pain<sup>70,85</sup>.

##### 2.5.2.1.4 Prognosis, including future disability and effect on work capacity

One of the aspects of health information needs is interest in knowing the natural history of back pain, shown by 13 studies<sup>61,63,66,68,69,71-73,78,80-82,87</sup>. Participants in each study were interested in information regarding prognosis of back pain, in particular its favourable prognosis and its benign nature. Low back pain was commonly associated with significant fears<sup>61,68,73,82</sup> with some concerned regarding future disability<sup>61,68,73,82</sup>, eg "...I could end up in a wheelchair..."<sup>82</sup>. Coole found consumers were interested in information regarding work capacity, particularly knowing one's ability to work with back pain<sup>61</sup>.

##### 2.5.2.1.5 Information regarding precipitation of flares

Consumers' need to know about potential precipitants of flares for back pain was identified in four studies<sup>61,62,84,87</sup>. Participants attributed this need to the unpredictable nature of back pain flares<sup>61,62</sup>. A group of participants believed this will help to deconstruct fear<sup>87</sup>.

### 2.5.2.1.6 General information regarding back pain management

Eighteen studies found that consumers wanted information regarding the management of back pain<sup>52,60,62,63,68-70,72,73,76,79,80,82,84-86,88,90</sup>. Many participants were interested in information on general treatment options, including pharmacological and non-pharmacological strategies<sup>52,62,68,69,73,76,79,82,86,90</sup>. Consumers were interested in being provided with information regarding the available options. Non-pharmacological treatments are much valued. Participants specifically desired information regarding the role of physiotherapy, osteopathy, postural advice and back muscle exercises<sup>52,63,69,70,72,76,79,80,86</sup>. They also wanted to know which physical activities would be beneficial and which would not, in order to avoid flares of back pain<sup>63,69,70,72,80,90</sup>. Consumers in studies by Campbell, Corbett, Toye and Young identified the need for information to help them psychologically deal with back pain and improve their ability to cope<sup>60,62,86,90</sup>. When coping with back pain, maintaining independence was valued by many participants<sup>60-62,68,69,73,88,90</sup>. With regards to pharmacological strategies, consumers in a study by Liddle were interested to know the role and efficacy of analgesia in symptom control<sup>73</sup>. Participants in only one study expressed the need for information on complementary therapy<sup>82</sup>.

### 2.5.2.1.7 The need for individualised information regarding back pain management

Consumers' desire for personalised or tailored treatment for back pain was identified in six studies<sup>56,63,65,68,73,83</sup>. They believed management should be specific to their own circumstances, taking into account their other health conditions<sup>56</sup>, age<sup>65</sup>, specific lifestyle needs<sup>65,68,73</sup>. Darlow's results illustrated the importance of consumer-specific advice as consumers were more likely to reject advice if it conflicted with their lived experience, life goals and beliefs<sup>63</sup>. Participants in Skelton's study felt they already knew the general principles and were frustrated when healthcare workers did not provide more specific exercise advice<sup>83</sup>.

### 2.5.2.1.8 Information regarding pain management

Consumers' perceived needs related to health information regarding pain management in back pain were described in five studies<sup>61,68,73,80,88</sup>. Whilst consumers desired general information regarding pain management, this included both pharmacological and non-pharmacological options<sup>68</sup>. Participants in Coole's study wanted information regarding safety and side effects of pharmacological therapies<sup>61</sup>.

### 2.5.2.1.9 Information regarding management of flares and preventive measures

Consumers' perceived needs regarding health information relating to the management of flares and prevention of back pain was described in seven studies<sup>60,63,71,73,81,83,90</sup>. Three of these found that consumers wanted information about how to deal with flares when they occurred<sup>63,71,73</sup>. They valued information that did not conflict with their previous lived experience, and desired practical information that could be applied under difficult circumstances, such as at work<sup>63,83</sup>. Five studies also identified the need for information regarding how they may prevent back pain<sup>60,63,73,81,90</sup>.

### 2.5.2.1.10 Self-management strategies

The focus of six studies was on consumers' perceived needs regarding health information relating to self-management strategies in back pain management<sup>59,69,74,76,84,89</sup>. Most participants wanted to learn specific exercises that they could perform to manage their back pain<sup>59,69,74,84</sup>. Participants in MacKichan's study were interested in knowing the limit of exercise in self-managed back pain<sup>74</sup>.

### 2.5.2.1.11 Information regarding support services

Four studies identified consumers' need for information regarding support services<sup>58,59,61,71</sup>. Briggs and Layzell identified the need for information regarding health services<sup>59,71</sup>. Bowman described the need for information regarding non-medical support, from social networks and support groups<sup>58</sup>. Coole identified the need for information regarding work-specific support services, for example information from employer regarding absence management policy<sup>61</sup>.

## 2.5.2.2 Consumers' perceived needs relating to the mode of delivery of health information

Consumers' perceived needs related to the mode of delivery of information relating to back pain was examined in ten studies<sup>59,60,64,65,69,76,79,82,86,89</sup>. The needs related to the quality of information provided, the language and tone used and the sources of information.

### 2.5.2.2.1 Need for high quality information

Consumers described the need for high quality health information regarding back pain in three studies<sup>59,76,86</sup>. With regards to the quality of information provided by various healthcare practitioners, participants valued valid, trustworthy and consistent information<sup>76,86</sup>. They disliked conflicting and discordant advice<sup>76,86</sup>. Briggs' participants were not satisfied with the quality of information obtained from general practitioners<sup>59</sup>.

### 2.5.2.2.2 Need for health information to be delivered in a suitable tone and in understandable language

Consumers in seven studies commented on the desire for health information to be delivered in a suitable tone and understandable language<sup>64,65,69,76,79,89</sup>. Consumers' perceived the need for information to be communicated in an open and clear way<sup>64,65,69,79,89</sup>, with emotional support<sup>64,65,89</sup> and using simple language without medical jargon<sup>69,79,89</sup> and with acceptable tone<sup>76</sup>. Participants in Scheermesser's study preferred information to be delivered in their own language<sup>79</sup>.

### 2.5.2.2.3 Source of information

Four studies described the need for advice on how to source information regarding back pain<sup>59,60,69,76</sup>. Two of these identified the need for advice regarding where to obtain information<sup>59,69</sup>. Studies by Campbell and McIntosh found the use of alternative, non-healthcare professionals may provide conflicting information that was not that helpful for the consumers<sup>60,76</sup>.



**“Not knowing the reason for my pain is extremely stressful and frustrating. This makes me angry and I feel it alters my personality to a degree”**

**(Vroman, 2008<sup>197</sup>)**

## 2.6 Health information: Neck pain

### 2.6.1 Description of included studies

Four relevant studies were identified: three studies were from Sweden<sup>87-89</sup> and one from Germany<sup>90</sup>. Consumers were recruited from general practice clinics<sup>89,90</sup>, physiotherapy clinics<sup>89</sup>, spine clinic<sup>88</sup> or from participants in an inpatient rehabilitation program<sup>87</sup>. Three studies included consumers with neck pain of variable causes<sup>88-90</sup>; two of these involved a mixed population of consumers with neck and back pain<sup>88,89</sup>, the third included consumers with neck pain secondary to whiplash associated disorders<sup>87</sup>.

### 2.6.2 Results: Consumers' perceived health information needs regarding neck pain

Three key areas of need related to the perceived health information needs of consumers with neck pain emerged. These were:

- 1) reasons for seeking health information, including desired content
- 2) barriers to seeking health related information
- 3) desirable characteristics of communication of health information

#### 2.6.2.1 Reasons for seeking health information, including desired content

Information regarding motives for seeking health information and the desire for this information by consumers was described in four studies<sup>87-90</sup>. Two studies reported reasons for seeking information, which included confirmation and recognition of symptoms<sup>90</sup> and to facilitate access to pain relief and treatment options<sup>89</sup>. All four studies addressed desired content of information<sup>87-90</sup>. Two studies examining the need for a concrete diagnosis produced discrepant findings. Scherer described consumers having little interest in obtaining a concrete diagnosis or information in general about their condition from their general practitioner<sup>90</sup>. Consumers in this study were consulting their general practitioner in regards to their undifferentiated neck pain, many had disease duration over one year, eight had a precipitating trauma and 30% were unemployed or retired. In contrast, Stenberg found that consumers reported appreciating a diagnosis, as well as a precise explanation for their symptoms and information about prognosis<sup>89</sup>. These consumers had undifferentiated neck or back pain, most of three months duration or less, almost all consumers were working, and the majority were presenting to a physiotherapist as a first line consult rather than their doctor. Consumers appeared to desire information about self-management in two of the studies<sup>87,88</sup> and some consumers also reported a desire for information about treatment options and medication side effects<sup>88</sup>. Only one study, by Jenkinson, described preferences related to methods of information delivery, albeit indirectly<sup>88</sup>; most consumers desired printed leaflets or website details as a source of supplementary information.

#### 2.6.2.2 Barriers to seeking health related information

Consumers' perceived barriers to seeking health related information were identified in two studies<sup>89,90</sup>. They included waiting times at GP clinics and disagreements with the advice of their practitioners<sup>90</sup>, as well as a fear of being judged, having their symptoms dismissed or being labelled as "neurotic" or a "whiner"<sup>89,90</sup>.

#### 2.6.2.3 Manner of information delivery, including language and emotional considerations

Three studies identified consumer perceived needs related to information delivery<sup>87,89,90</sup>. Scherer identified consumer preferences in terms of language with some consumers preferring concrete or metaphoric terms when referring to their condition<sup>90</sup>. Ehrenborg<sup>87</sup> and Stenberg<sup>89</sup> found emotional needs of consumers related to health information delivery methods. These included the need to be taken seriously, to feel safe and respected, to be listened to and included<sup>87,89</sup> and to be viewed as a unique individual<sup>90</sup>.

## 2.7 Health information: Osteoporosis and bone health

### 2.7.1 Description of included studies

Twenty one studies were relevant to the review. Of these, six each were from the United States of America<sup>91-96</sup> and Canada<sup>97-102</sup>, four from the United Kingdom<sup>103-106</sup>, two from Denmark<sup>107,108</sup> and one each from Spain<sup>109</sup>, Slovakia<sup>110</sup> and Turkey<sup>111</sup>. The inclusion criteria for participants in each study was varied, with nine studies including participants with diagnosed osteoporosis<sup>91-93,103,104,108-111</sup>, two studies with participants with osteopenia or osteoporosis<sup>102,106</sup>, and one study including participants who were taking either prescribed or over-the-counter medications<sup>97</sup>. Three studies included participants with clinically diagnosed osteoporosis on the basis of fragility/low impact fractures<sup>96,98,99</sup> and one study included participants with a history of falls<sup>105</sup>. Four studies included participants in which the diagnosis of osteoporosis was unknown at the time of recruitment<sup>94,95,100,101</sup> and one included individuals with and without osteoporosis<sup>107</sup>. Subjects were selected from a broad range of sources. Seven studies recruited participants from hospitals<sup>93,94,99,104,106,108,111</sup>, with two including community fracture clinics<sup>100,101</sup>. One study recruited patients from specialists' offices<sup>109</sup>. Eight studies used community-based programs including community bone clinics, osteoporosis organisations and community centres for recruitment<sup>91,92,95-97,102,103,105</sup>. One study did not identify the source of study participants<sup>110</sup> and two used a pre-existing database of patients<sup>98,107</sup>.

### 2.7.2 Results: Consumers' perceived health information needs regarding osteoporosis and bone health

Five key areas of need were identified regarding consumers' perceived health information needs. These themes were:

- 1) consumers' perceived health information needs regarding osteoporosis
- 2) consumers' perceived needs regarding information about osteoporosis medications
- 3) demographic factors and variation of consumers' perceived health information needs related to osteoporosis
- 4) consumer expectations regarding health information communication
- 5) consumer preferences relating to osteoporosis and sources of information.

#### 2.7.2.1 Consumers' perceived need for the content of health information

##### 2.7.2.1.1 Need for health information – what is osteoporosis, risk factors and implications

Twelve studies reported on consumer perceived needs of health information regarding osteoporosis<sup>91,95,96,98,99,103-107,109,110</sup>. Consumers wanted more information regarding osteoporosis as a medical condition and how to diagnose osteoporosis<sup>95,96,103,106,109,110</sup>. They also wanted to know about the risk factors for the development of osteoporosis<sup>105</sup>, how to prevent osteoporosis<sup>95,96</sup> and the risks and implications of having osteoporosis, including why falls posed a risk to them<sup>104,105</sup>. Rothmann reported that consumers had limited knowledge about osteoporosis<sup>107</sup> and Meadows found that few consumers reported being referred to their family physician or seeking information regarding osteoporosis following a fracture<sup>99</sup>. A single study by Feldstein found that consumers confused osteoporosis with osteoarthritis, which promoted the idea that osteoporosis was inevitable and benign consequence of ageing<sup>96</sup>. Mazor reported that some women were dissatisfied with the communication with their physician, and the consequences of osteoporosis were not explained clearly<sup>91</sup>. In contrast, Meadows found that some consumers felt that communication with their physician about bone health was irrelevant for them and it was not a topic that they sought information about<sup>98</sup>. Also, some consumers blamed their fractures on various circumstances, and information about bone health was neither retained nor provided stimulus to behaviour modification<sup>98</sup>.

##### 2.7.2.1.2 Need for health information regarding investigations

There were five studies that examined consumers' perceived needs of information pertaining to investigations<sup>91,94,97,100,105</sup>. Consumers have reported receiving no information about why certain investigations were requested<sup>105</sup> and a lack of communication regarding the test results<sup>91,100</sup>. A single study found that some consumers felt that a knowledge of their bone mineral density test results created confusion about their risk of fracture<sup>100</sup>. However other studies found that consumers were interested in receiving a copy of their bone densitometry report and receiving information relating to their test results<sup>91,94,97</sup>. Some consumers felt that reviewing their bone mineral density results was helpful in evaluating the status of their osteoporosis and it motivated them to either start or continue treatment<sup>97</sup>.

##### 2.7.2.1.3 Need for health information regarding treatment direction

Five studies reported on consumers' perceived information needs regarding treatment<sup>92,95,106,107</sup>. Consumers want more information about treatment options for osteoporosis<sup>95,106,107</sup>. Mazor found that consumers felt that they received limited explanations from their physicians about the need for treatment<sup>91</sup>. Furthermore, Solimeo reported that male consumers with osteoporosis felt that they had limited knowledge concerning treatment for osteoporosis in men and were dismayed by the lack of male-specific data<sup>92</sup>.

##### 2.7.2.1.4 Need for health information regarding lifestyle modifications

There were three studies that evaluated consumer perceived needs of information pertaining to lifestyle modifications for osteoporosis<sup>91,103,110</sup>. A single study reported that consumers preferred to receive advice regarding lifestyle modifications rather than prescription medications for the management of osteoporosis<sup>91</sup>. Consumers believed information regarding lifestyle factors was important<sup>110</sup> and that they did not receive enough information regarding lifestyle changes such as exercise and nutrition<sup>103,110</sup>. Consumers felt that their general practitioners did not support their preference for self-care (eg exercise programs) and they want their general practitioner to have more confidence, knowledge and certainty when discussing options for physical activity<sup>103</sup>.

## **2.7.2.2 Consumers' perceived needs for information about osteoporosis medications**

### **2.7.2.2.1 Consumers' expectations about health information pertaining to medications**

Four studies evaluated consumer expectations about the provision of medication information<sup>91,93,96,97</sup>. Consumers reported confusion and receiving limited information about the indication for therapy, the duration of treatment and the consequences of stopping their medications<sup>91,93,96</sup>. Consumers wanted more information about the expected effects of their medications<sup>97</sup>. They also wanted to know how effective the prescription medications were, and how to tell if they are working<sup>91,100</sup>.

### **2.7.2.2.2 Consumers' concerns regarding the amount of information received**

There were four studies that reported on consumers' concerns about the amount of information received about osteoporosis medications<sup>93,96,97,102</sup>. Consumers want more information about pharmacotherapy for osteoporosis management<sup>96,97,102</sup>. In particular, participants in a study aimed at examining attitudes towards calcium replacement wanted clearer information regarding the multiple formulations of calcium supplementation<sup>102</sup>. Iversen also reported that consumers felt that their primary care providers do not provide sufficient instruction about how to take the medications<sup>93</sup>.

### **2.7.2.2.3 Lack of clarity relating to medication information**

Five studies examined consumers concerns regarding the lack of clarity relating to medication information<sup>93,97,101,102,106</sup>. Participants felt that the information was sometimes inconsistent, confusing and unclear and suggested altering medication instructions to make them more understandable and improve their confidence in the recommendations<sup>97,106</sup>. A single study described participants' uncertainty with supplements and medications, dosages and durations of treatment<sup>101</sup>. Another study also identified that the information regarding calcium supplements was not always consistent and this caused confusion<sup>102</sup>.

### **2.7.2.2.4 Information relating to medication adherence**

There were three studies that evaluated consumers' health information needs to improve medication adherence<sup>96,97,106</sup>. Besser identified that consumers felt there was a need for greater emphasis on the importance of routine to improve medication adherence<sup>106</sup>. Participants in Lau's study wanted suggestions from physicians to make managing their osteoporosis medications more easily<sup>97</sup>. Consumers also reported that tips for routinising medication use facilitated long-term adherence<sup>96</sup>.

### **2.7.2.2.5 Information regarding adverse drug effects**

Consumers in four studies felt there was a need for clear communication and greater understanding regarding the adverse effects of osteoporosis medications<sup>96,97,106,108</sup>. Whilst some participants wanted more information regarding side effects<sup>97</sup>, others were concerned about the long list of side effects<sup>96</sup>. Participants in one study wanted more information regarding the long-term effects of medications<sup>106</sup>.

## **2.7.2.3 Demographic factors and variation of consumers' perceived health information needs**

There were two studies that explored the demographics of consumers seeking health information<sup>96,103</sup>. Feldstein found that younger patients were more likely to want health information, and they were more likely to have a better understanding of osteoporosis<sup>96</sup>. In a study comparing the experiences of osteoporotic Caucasian and South Asian women, McKenna reported that South Asian patients were less inclined to contact the National Osteoporosis Society as they anticipated that language barriers to impact their understanding<sup>103</sup>. Instead they relied more on their general practitioners, the community and family for health information<sup>103</sup>.

## **2.7.2.4 Consumer expectations regarding health information communication**

### **2.7.2.4.1 Effective information delivery**

Four studies reported on consumers' perceived need for effective information delivery<sup>93,95,102,106</sup>. Patients felt there was a need for reliable and cohesive information<sup>102</sup>. Participants in two studies suggested communication aids such as written medical information and visual images to improve understanding and confidence<sup>93,106</sup>. One study found patients wanted to understand why osteoporosis had not been discussed by their family physician<sup>95</sup>. Besser reported that patients reported negative relationships with their doctors due to poor communication<sup>106</sup>.

### **2.7.2.4.2 Adequate consultation length**

Adequate consultation length was identified by eight qualitative studies as an important issue for patients<sup>91,93,97-100,104,106</sup>. Patients felt that a lack of time during consultations affected their relationship with doctors and increased anxiety<sup>106,108</sup>. They reported feeling rushed and unable to ask questions during consultations with their physicians<sup>91,93,99</sup>. Also, the time restraints during consultations affected the physician's ability to address consumers' concerns<sup>93,97</sup>. Patients valued health professionals who had time to listen, answer their questions regarding osteoporosis and address individual concerns<sup>98,104</sup>.

## **2.7.2.5 Consumer preferences relating to sources of information**

### **2.7.2.5.1 Health information from healthcare professionals**

Seven studies examined consumers' perceived need of healthcare professionals as the providers of health information<sup>93,94,97,99,102-104</sup>. Many studies found that consumers seek information regarding osteoporosis from their general practitioners and other healthcare professionals such as pharmacists<sup>93,94,97,99,102-104</sup>. Physicians and pharmacists were perceived as credible sources of information, but some consumers thought that physicians did not have enough time for explanations<sup>93</sup>. McKenna reported that general practitioners were the preferred source of information<sup>103</sup>. Meadows found that patients felt that family physicians were a useful source of information but very few sought information from their family doctor<sup>99</sup>.

### **2.7.2.5.2 Health information from support groups, friends and family**

There were seven studies that evaluated consumers' perceived needs of health information from support groups, friends and family<sup>91,97-99,102,103,109</sup>. Patients report seeking health information from family and friends, as well as other people with osteoporosis<sup>91,102,108,110</sup>. Support groups, including group-based education programs and national osteoporosis societies were also sources of information for consumers with osteoporosis<sup>103,104</sup>. Consumers value group based education programs so they can share their experiences to gain confidence and security with other patients with the same medical condition<sup>104</sup>. However, patients have found the information obtained from these sources to not always be helpful, and at times conflicting<sup>102,108</sup>. Solimeo reported that male patients with osteoporosis felt they could not locate appropriate support groups<sup>92</sup>.

### **2.7.2.5.3 Health information from the internet, social media and print media**

Six studies examined consumers' perceived needs of health information from the internet, social media and print media<sup>93,99,103,104,108,110</sup>. Patients seek health information relating to osteoporosis from the internet<sup>99,103,104,108,110</sup>. However, Hansen reported that patients do not always find the information from the internet helpful. They also utilise print material from women's magazines, written information from national osteoporosis societies, pharmaceutical company brochures, medication package inserts and labels, hospital newsletters, newspapers and books<sup>99,103,104,110</sup>. Other forms of communication, including the radio and television, are other sources of health information for consumers with osteoporosis<sup>110</sup>.

## 2.8 Health information needs: Overall summary

### 2.8.1 Overall results: Consumers' perceived health information

The systematic reviews performed to identify consumers' perceived health information needs relating to inflammatory arthritides (rheumatoid arthritis and ankylosing spondylitis), osteoarthritis, back and neck pain and osteoporosis identified a number of common areas of need.

The findings related to consumers' perceived health information needs are tabulated in Table 1. This demonstrates where findings were identified as applicable to multiple conditions. These results can be classified accordingly:

- reasons for seeking health information
- identification of consumer factors related to consumers' perceived need
- content requirements
- factors associated with information delivery and communication
- barriers to health information needs being met

#### 2.8.1.1 Reasons for seeking health information

Consumers sought information to gain control or ownership in most musculoskeletal conditions, including in those with **inflammatory arthritis**<sup>15,17</sup>, **osteoarthritis**<sup>7,30,40</sup>, **back pain**<sup>53,59,60,80,84,86</sup> and **osteoporosis**<sup>96,99,105-107,109,110,112</sup>. However in the only study in **neck pain** addressing this issue, consumers were not keen on seeking out information or advice regarding their condition<sup>90</sup>. Those with **inflammatory arthritis**<sup>15,17,113</sup>, **back**<sup>53,57</sup> and **neck pain**<sup>87</sup> wanted information in order to improve their daily function. Only those with **back pain**<sup>51</sup> commented on the need to improve their psychological function. Only consumers with **back**<sup>53,114</sup> and **neck pain**<sup>89</sup> sought information regarding a specific diagnosis for their condition in order to legitimise their symptoms. Understanding their prognosis was an important reason for seeking information for those with **inflammatory arthritis**<sup>3,113</sup>, **osteoarthritis**<sup>30,40</sup> and **back pain**<sup>57,59,61,69,79,83,86,114</sup>. However, the emphasis in those with **back pain** was the need to reassure patients about the benign nature of **back pain**, in the absence of red flags<sup>60,61,66,68,79</sup>. Understanding the impact their condition may have on their work capacity was important for those with **inflammatory arthritis**<sup>3</sup> and **back pain**<sup>80,114</sup>.

Consumers were concerned about their families. Those with **back pain**<sup>75</sup> wanted information to help their families understand their condition. The identification of preventive strategies for children and grandchildren was important to those with **osteoarthritis**<sup>40</sup>.

#### 2.8.1.2 Identification of consumer factors related to consumers' perceived health information needs

There were fewer studies addressing this aspect of health information needs across the conditions, with most information drawn from studies relating to **inflammatory arthritis**. Females consistently required more health information than males, in both **inflammatory arthritis**<sup>5,7,21-23</sup> and **osteoarthritis**<sup>7,35</sup>. Younger people tended to have higher information needs regarding **inflammatory arthritis**<sup>5,13,14</sup> and **osteoporosis**<sup>96</sup>, although one study in **inflammatory arthritis**<sup>7</sup> found no association. Similarly, there were varying findings regarding level of education and information needs, with some studies in **inflammatory arthritis**<sup>16,21</sup> and **osteoarthritis**<sup>48</sup> identifying a higher need in those who had attained a higher level of education; while in others with **inflammatory arthritis**<sup>13,14,115</sup> no relationship was found. Employment related to higher health information needs in those with **inflammatory arthritis**<sup>21,23</sup>. Those with **osteoarthritis** and anxiety or depression were found to have higher information needs<sup>48</sup>. Disease related factors were inconsistently related to health information needs in those with **inflammatory arthritis**. Disease duration was inconsistently related to health information needs with Dragoi's study<sup>7</sup> showing longer duration to be associated with higher needs but Meesters' <sup>14</sup> finding shorter disease duration was associated with higher needs. Disease activity was not associated with information needs in Funahashi's study<sup>23</sup>, and weakly correlated with information needs in the domains of movement, feelings and treatment in the study by Dragoi<sup>7</sup>. Prior disease modifying antirheumatic drug (DMARD) adverse reactions and higher levels of fatigue were associated with increased likelihood of seeking information<sup>22</sup>.

### 2.8.1.3 Content requirements

Across all the conditions, **inflammatory arthritis**<sup>3,9,14,18,22,113</sup>, **osteoarthritis**<sup>24,26-28,31,39,40,43,46,48</sup>, **back pain**<sup>53,59,60,75,80,84-86</sup>, **neck pain**<sup>87</sup> and **osteoporosis**<sup>95,99,103,105-107,109,110,112</sup>, most consumers wanted general information about the condition and its nature. However, some with **neck pain** were not keen on obtaining information or advice about their condition upon visiting doctors<sup>90</sup>, and others with **osteoporosis**<sup>98</sup> felt bone health was irrelevant to them. Whilst many consumers were content with the amount of information received in **inflammatory arthritis** some wanted more information<sup>6,7,9,12,21</sup>, and others less<sup>3,17,20</sup>, being concerned that too much information could generate anxiety.

Obtaining a definitive diagnosis and a cause of their symptoms was a priority for those with **back pain**<sup>51,53,56-59,61,62,64-69,72-74,76,83-85,114,116,117</sup> and **osteoporosis**<sup>95</sup>, but not universally for those with **neck pain**<sup>89,90</sup>. The need for imaging in order to obtain a definitive diagnosis was seen in those with **back pain**<sup>50,65,68,76,83,85,117</sup> and **osteoporosis**<sup>95</sup>. Consumers with **back pain**<sup>55,70,77,79,86,118</sup> valued specific information about managing their condition. Those with **inflammatory arthritis** wanted information on helping them cope with everyday living<sup>6,8,15,17,113</sup>. Information regarding pharmacological management, its rationale, side effects and how to take the medications was desired by those with **inflammatory arthritis**<sup>3,4,6,14,17,18,22,23,113</sup>, **osteoarthritis**<sup>29,38,40</sup>, **back pain**<sup>61,67,68,81,114</sup>, **neck pain**<sup>88</sup> and **osteoporosis**<sup>91,93,96,97,101,102,106</sup>. However, participants in one study with **osteoarthritis**<sup>38</sup> thought they already knew about the side effects, that this information was available in the package insert, and that most of these side effects did not occur. Information regarding the role of physiotherapy, exercise therapy and their effect on structure was a priority to consumers with **inflammatory arthritis**<sup>3,9,11,13,14</sup>, **osteoarthritis**<sup>24,30</sup>, **back pain**<sup>49,50,57,60,67,68,75,86</sup>, **neck pain**<sup>87</sup> and **osteoporosis**<sup>91,103,110</sup>. Consumers with **inflammatory arthritis**<sup>11</sup> and **back pain**<sup>60,73</sup> sought to identify whether exercise or certain movements could be detrimental. Consumers with **back pain** were interested in information regarding complementary and alternative medicines<sup>50,67,69,79,86</sup>, including osteopathy, heat and cold applications, relaxation and massage therapy.

Information on how their condition may affect them regarding their psychosocial status, and advice to help with their emotional response was seen as important to consumers with **inflammatory arthritis**<sup>3,12,14</sup> and **back pain**<sup>51</sup>. In contrast, those with **neck pain** in the only study that addressed it, preferred to avoid psychosocial themes in their consultations with their doctors<sup>90</sup>. Self-management information, including information regarding social supports and self-help groups, was required by those with **inflammatory arthritis**<sup>3,5,13,14,18</sup>, **osteoarthritis**<sup>30,32,34,38,40,47</sup>, **back pain**<sup>57,62,64,74,82,84,117</sup> and **neck pain**<sup>87</sup>. This incorporated pain management for those with **inflammatory arthritis**<sup>3,14</sup>, **osteoarthritis**<sup>27,29</sup>, **back pain**<sup>61,68,79,81,114</sup> and **neck pain**<sup>87,88</sup>. Those with **back pain** wanted information about flares, and how to prevent them<sup>53,60,73,84,88,114</sup>. Information regarding how to manage flares of **inflammatory arthritis** and **back pain**<sup>59,61,86</sup>, as well as how to prevent flares in **back pain**<sup>51,70,75,80,86</sup> was desired. Consumers wanted to know whether changing lifestyle factors, such as diet and weight management, could affect **osteoarthritis**<sup>38,40</sup>, **neck pain**<sup>88</sup> or **osteoporosis**<sup>91,103,110</sup>. The need for information regarding weight management and exercise by those with **osteoarthritis** is aligned with best practice, as recommended in most guidelines<sup>119</sup>. Consumers wanted information regarding the availability of specific health services, including those that were present locally, for people with **inflammatory arthritis**<sup>13,18</sup>, **osteoarthritis**<sup>30,31</sup>, **back pain**<sup>59,78,82,114</sup> and **neck pain**<sup>88</sup>. Information regarding the existence of support groups was desired by those with **inflammatory arthritis**<sup>3,5,15</sup> and **osteoarthritis**<sup>38</sup>. Consumers with **osteoarthritis** wanted information regarding financial support<sup>48</sup>.

### 2.8.1.4 Factors associated with information delivery and communication

Consumers saw a benefit in obtaining health information from a wide variety of healthcare professionals, not just medical practitioners regarding **inflammatory arthritis**<sup>30,38,45,47</sup>, **osteoarthritis**<sup>30,38,47</sup> and **osteoporosis**<sup>97,103,112</sup>. General practitioners were seen as a reliable source of information in **osteoarthritis**<sup>38,42</sup> and **osteoporosis**<sup>93,97,99,103</sup>. Practice nurses were seen as an approachable and valuable source of information by those with **inflammatory arthritis**<sup>6</sup> and **osteoarthritis**<sup>30,38,47</sup>. Information from trained patient volunteers was valued by those with **inflammatory arthritis**<sup>12</sup>. Consumers identified face-to-face communication with a rheumatologist as their preferred source of information about their condition and treatment regarding **inflammatory arthritis**<sup>6</sup>. In those with **inflammatory arthritis**, personal, face-to-face communication was preferred to obtain information regarding their disease, emotional and quality of life issues<sup>3</sup>, and particularly for those who did not speak English, as this enabled the opportunity for a two-way interaction, allowing them to ask questions<sup>8,113</sup>.

The use of printed material was examined by a few studies, mainly indirectly. It was seen as useful as a memory aide, and a way of providing more detailed information to those with **inflammatory arthritis**<sup>3,5,19</sup>, **osteoarthritis**<sup>37,45</sup>, **neck pain**<sup>88</sup> and **osteoporosis**<sup>93</sup>. Visual cues were preferred to demonstrate risk for some consumers with **osteoporosis**<sup>93</sup>. It was seen as being particularly useful for providing health services information for those with **inflammatory arthritis**<sup>13</sup>. However one study in **osteoarthritis** exploring how consumers used the booklet "Care for **osteoarthritis**" found that conceptually whilst consumers believed written information to be of use, they did not find the booklet to be useful<sup>43</sup>. Consumers accessed printed material from a variety of sources, including drug company information, to obtain information regarding **inflammatory arthritis**<sup>6,13</sup>, **osteoarthritis**<sup>45,47</sup>, **back pain**<sup>51,64</sup> and **osteoporosis**<sup>93,99,103,110,112</sup>.

The role of audio-visual material was not widely examined. For consumers from CALD backgrounds, educational CDs were preferred to written information in **inflammatory arthritis**<sup>113</sup>. They were believed to be useful for sharing information in those with **inflammatory arthritis** around coping mechanisms<sup>3</sup>. One video recording used in **osteoarthritis** was seen to be useful by most consumers, who found they learned new information<sup>25</sup>. The internet was seen as a useful source by some consumers with **inflammatory arthritis**<sup>15</sup>, **osteoarthritis**<sup>34,36,42,45</sup> and **osteoporosis**<sup>103,108,110</sup>, but not by others<sup>5,15,42</sup>. Whilst some consumers were concerned about the reliability and difficulty identifying credible information from the high volume available concerning **inflammatory arthritis**<sup>5,15</sup>, **osteoarthritis**<sup>42</sup> and **osteoporosis**<sup>108</sup>, others did not use it because they thought it was not suitable for the communication of information regarding **inflammatory arthritis**<sup>3</sup>. Those with **osteoarthritis** saw the internet as a way of obtaining alternative information<sup>42</sup>. The internet was seen as a useful source of information by younger people with **inflammatory arthritis**<sup>5</sup> and **osteoarthritis**<sup>36</sup> in those with routine access.

Support groups, both formal and informal were desired. Formal groups were perceived as useful as a source of information regarding emotional and quality of life issues, self-management techniques and relationship advice by those with **inflammatory arthritis**<sup>3,5,15</sup>. Consumers with **inflammatory arthritis**<sup>3,5,15</sup>, **osteoarthritis**<sup>38</sup>, **back pain**<sup>78</sup> and **osteoporosis**<sup>99,103,108,112</sup> sought out and used formal groups. Those with **osteoarthritis** sought information from friends and others with the condition<sup>24,45-47</sup>, as did those with **osteoporosis**<sup>103,108,112</sup>.

Some consumers were unsure of where to find information about their musculoskeletal condition, particularly relating to **osteoarthritis** and **back pain**<sup>42,44,57,82</sup>. This represents an area of concern, given these are the two most common conditions and points to the need for population-based education strategies.

There were a number of common characteristics related to desirable methods and manner of information transfer across the musculoskeletal conditions examined. Those with **inflammatory arthritis** identified the need for information to be conveyed in positive and optimistic terms<sup>3,5,15</sup>. Consumers appreciated information provided in a supportive fashion, with a sense that the healthcare provider respected them, legitimised pain and took their concerns and condition seriously, relating to **osteoarthritis**<sup>27</sup>, **back pain**<sup>54,120</sup> and **osteoporosis**<sup>91,103</sup>. Consumers desired reliable and consistent information regarding **back pain**<sup>64,72,82</sup> and **osteoporosis**<sup>102</sup>. They value specific information, tailored to their condition, rather than generalities, especially regarding **inflammatory arthritis**<sup>3,8,12,18</sup> and **back pain**<sup>55,61,70,77,79,86</sup>. A clear explanation, delivered without using jargon or medicalised terms is desired by those with **inflammatory arthritis**<sup>12,113</sup>, **osteoarthritis**<sup>37,40</sup>, **back pain**<sup>54,55,57,67,69,74</sup> and **osteoporosis**<sup>91</sup>. Consumers did not understand words that clinicians may take for granted, with confusion noted between “**osteoporosis**” and “**osteoarthritis**”, and confusion between “effusion” and bony “fusion” in the study by Barker<sup>33</sup>. There was a varied response to the use of “wear and tear”, where although it was easily understood, the term was perceived by some to have negative, pessimistic connotations regarding their condition, **osteoarthritis**<sup>29</sup> or **back pain**<sup>51,56</sup>. In addition, longer consultation lengths were desired by consumers with **inflammatory arthritis**<sup>12,18</sup>, **osteoarthritis**<sup>36</sup> and **osteoporosis**<sup>106,108</sup>.

### 2.8.1.5 Barriers to health information needs being met

Consumers with **inflammatory arthritis**<sup>5,11</sup>, **osteoarthritis**<sup>31</sup>, **back pain**<sup>82</sup> and **osteoporosis**<sup>106</sup> felt that their general practitioner's lack of knowledge about their condition was a barrier to their information needs being met. Consumers with **inflammatory arthritis** also reported other barriers such as: poor access to reliable sources of information<sup>3,5</sup>; a lack of ongoing communication<sup>12</sup> and language barriers in non-English speakers<sup>113</sup>. Limited access to the healthcare provider, including long waiting times for appointments contributed to information needs being unmet for consumers with **inflammatory arthritis**<sup>3,5</sup>, **osteoarthritis**<sup>24</sup> and **neck pain**<sup>90</sup>.

The provision of conflicting information from various sources caused insecurity in those with **back pain**<sup>72</sup>, **neck pain**<sup>90</sup> and **osteoporosis**<sup>102</sup>. Consumers with **neck pain** were also concerned about speaking frankly because of a fear of being judged by the healthcare practitioner<sup>90</sup>.

## 2.8.2 Discussion

Although a comprehensive review was performed, it identified limited literature relating to consumers' perceived need for health information related to musculoskeletal conditions. Nevertheless, it has raised a number of interesting questions and evidence gaps. This review identified that the reasons why consumers seek health information varied according to condition. For inflammatory arthritis, osteoarthritis and osteoporosis this appeared to relate to control over their condition, while for neck and back pain the need for a definitive diagnosis and legitimisation of symptoms were more important. The need for legitimisation was accompanied by a need for more information regarding occupation, and prognosis with respect to work capacity. In addition, perhaps reflecting the lack of specific and successful therapy for back pain, there was more emphasis on self-management, as well as management and prevention of flares. Consumers with back pain were wary of authority, be it employers or healthcare providers, which could potentially interfere with the therapeutic relationship between themselves and their healthcare providers.

Healthcare providers should be aware that this review has indicated that women and younger individuals require more information regarding their musculoskeletal conditions than men and older individuals. However in order to meet these needs, other forms of information delivery may be used rather than direct contact with the healthcare provider or specialist. The use of practice nurses, trained providers or volunteers are accepted by consumers as a valuable source of healthcare information. Similarly, better understanding of how the internet and social media is used may enable more efficient information delivery. For example, if the internet and reliable websites are used to deliver factual information, these may be discussed during consultation with the healthcare provider, in order to direct the focus onto the specific issues of consumers. This may help to better address the consumers' health information needs particularly in consultations that appear to be shorter than desired by the consumer.

A potential limitation of the included studies is that although compensable status is a known determinant of outcome in back pain, this was not included in the descriptions of the study populations; health information needs may differ accordingly.

Although health information needs were generally similar for osteoporosis, they differed slightly in focus. The literature relating to osteoporosis tended to focus on the initiation of secondary prevention strategies and the use of medications, particularly bisphosphonates, with a single study focused on calcium replacement<sup>102</sup>. Although the need for calcium replacement may change with increasing evidence demonstrating the potential harm from this therapy<sup>121</sup>. It may be that this focus on the role and use of medication reflected the maturity of the field (ie management of osteoporosis) or the funding sources of the primary studies. There was a consistent unmet need for information regarding self-management strategies including optimisation of lifestyle factors, with many consumers concerned about the predominant focus on medication in the management of this condition<sup>91,103,110</sup>. However this may be medically appropriate, as effective medical therapy exists for osteoporosis, with limited evidence for a significant effect of lifestyle interventions affecting secondary prevention.

The results of this review must be taken in context of the available literature, as there was a lack of studies performed that directly addressed the study question. Thus, much information was obtained indirectly from studies that asked a different primary question. Lack of evidence of a perceived need for health information it cannot be assumed that the need does not exist, as it may be that there has been no relevant study in which consumers have been able to express their need in order for it to have been documented in the literature. The literature has been obtained from a variety of health care settings and countries. For some conditions, the health care settings span the available system, ranging from the general community to tertiary care. For other conditions, some areas may be less well represented, such as the community. Many of the studies were small and may not be representative of the target population. Needs may differ according to the healthcare systems and different cultural settings, which vary in different areas and countries.

As the focus of this review was from a consumers perspective, much of the literature covering this area is qualitative in nature. The review was therefore performed as a thematic synthesis of the literature<sup>122</sup>, which focused on the identification of areas of need, searching for themes, and grouping these to display the evidence as an argument. In the interests of performing a comprehensive review, all relevant studies were included, although poor quality studies received limited emphasis in the overall interpretation. This review aimed to identify consumers' perceived health information needs. It did not capture consumers' knowledge. Thus there is the potential for a mismatch between consumers' perceived information needs, their knowledge and what health care providers and experts in the area believe the important issues are. It is likely that knowledge and need are not aligned, as exemplified by Meadows' who showed that the women in their study did not feel the need to know about osteoporosis despite having experienced fragility fractures<sup>98</sup>. This review also identified a similar trend in osteoarthritis, where consumer perceived health information needs were not well aligned to the main messages that osteoarthritis experts believe consumers required<sup>123</sup>. How the consumers' perceived needs are related to adequate knowledge or the relevant management guidelines for their conditions is unknown. We have limited the review to only studies performed since 1990. This is because the health care system and treatments have changed for most conditions since then. Indeed, given the changing scene with regard to media, social media and internet use, even studies relating to the use of the internet in 2004 may be irrelevant now, as the use of the internet is rapidly expanding. It is surprising that so few studies have been done to examine consumers' needs and preferences of information provision using internet usage. A better understanding of consumers' views of the internet and its strengths may allow information providers to better match their stakeholder's information needs, in a cost effective and comprehensive manner. It may be that these will change rapidly as this technology evolves. Another important limitation of this review is that information relevant to adults (over the age of 18) was examined. Thus generalisations to adolescents are not appropriate, as this group may have specific care needs<sup>124</sup>. Despite its limitations, this search is the result of comprehensive searches of four complementary databases. Both qualitative and quantitative studies were identified, many with complementary and consistent findings. The search strategies were broad, and the relevant studies were a small percentage of those searched, suggesting we were likely to have captured relevant material.

### 2.8.3 Conclusions

This review found that consumers desire high quality, accurate, simple explanations of their condition, delivered in a supportive and non-judgemental fashion. Their aims are to gain control of their health condition, to improve function and to understand their prognosis. These aims are consistent with a desire to improve health literacy related to their condition. They need general information regarding their condition, its management (pharmacological, non-pharmacological), and strategies to manage flares. Lifestyle factors should not be ignored. The use of different media may be complementary to face-to-face communication. Support from peers was welcomed.

It raises more questions however regarding the role of different forms of non-personal information delivery, including limited knowledge regarding consumer preferences for different formats and their relative efficacy in imparting accurate information to consumers. Different formats may be able to be used for complementary tasks. For example, general information may be able to be provided using online videos, allowing face-to-face time with a healthcare provider to be used to impart individualised strategies to manage their condition. Better understanding the relative utility of different forms of media may be helpful in achieving better health outcomes regarding musculoskeletal conditions. This field is likely to undergo significant changes as the use of the internet and available options expands rapidly. Understanding consumers' needs and preferences for information content and delivery, as well as understanding the available options may enable more effective information delivery and improve health outcomes for musculoskeletal conditions.

# 3. Consumers' perceived needs regarding health services



## 3 Consumers' perceived needs regarding health services

### 3.1 Introduction to consumers' perceived health services needs

In considering consumers' perceived needs regarding health services we considered a variety of dimensions of health services in the search strategy.

These areas included:

- a) the health services and providers that may be used by consumers in the management of musculoskeletal conditions
- b) the settings in which health services may be used or sought, including primary, secondary and tertiary care, as well as community based care
- c) the practitioners, that consumers may seek healthcare from, including conventional and complementary service providers, were searched by name.
- d) the treatments (pharmacological and non-pharmacological) and devices using their names and by class of intervention, including pain management and rehabilitation
- e) factors, including barriers, that may affect access to health services including cost, situation, urban versus rural, scarcity of resources, payment for care or therapy and access to specialists

The search strategy was refined and run in each of the four major health sciences electronic databases. This search strategy was applied to each of the significant musculoskeletal conditions to identify the literature related to consumers' health services needs. Studies that were relevant were identified and information extracted. This information was collated and studies that addressed similar themes were grouped, with sub-themes extracted.

The results relating to the various themes and sub-themes identified were combined and presented across the different musculoskeletal conditions examined. The combined results were discussed and contrasted.

### 3.2 Search results

The search strategies returned 6,248 papers, of which 161 were identified as relevant for inclusion in this review.

## 3.3 Health services: Rheumatoid arthritis and ankylosing spondylitis

### 3.3.1 Description of included studies

Of the 24 included studies, most (ie 16) involved only people with rheumatoid arthritis<sup>19,113,125-138</sup>. Inclusion criteria for these studies was rheumatoid arthritis defined either by American Rheumatology Association criteria<sup>19,113,125,132,135,138</sup>, by a rheumatologist<sup>126-129,133,134</sup>, or by other unspecified criteria<sup>130,131,136,137</sup>. Two studies included mostly patients with rheumatoid arthritis<sup>139,140</sup>, while three studies included either undefined or a smaller proportion of rheumatoid arthritis patients combined with musculoskeletal conditions including osteoarthritis, fibromyalgia, polymyositis or unspecified inflammatory arthritis<sup>141-143</sup>. One study contained an unspecified number of patients with psoriatic arthritis in a population of psoriasis patients<sup>144</sup>, one study included a majority of patients with unspecified inflammatory arthritis<sup>145</sup> and one study included patients with "chronic arthritis" of unspecified aetiology<sup>146</sup>. Most studies were from the United Kingdom<sup>19,113,127,129,131,133-137,139,145</sup> and the United States of America<sup>126,130,140,141,143,144</sup>, with a few from the Netherlands<sup>138,142</sup>, Australia<sup>128</sup>, Sweden<sup>125</sup>, Canada<sup>146</sup> and Japan<sup>132</sup>. Participants were recruited predominantly from hospital outpatient clinics<sup>19,113,125-127,129,132,139,140,143,145</sup>, private or community rheumatology clinics<sup>128,130,133,135-137</sup> and databases<sup>134,138,141,144</sup>.

### 3.3.2 Results: Consumers' perceived health service needs regarding inflammatory arthritis

The four key themes identified were:

- 1) communication and desired characteristics of health professionals
- 2) aspects of follow-up care
- 3) factors relating to care seeking
- 4) allied health and complementary and alternative medicine (CAM) use.

#### 3.3.2.1 Perceived communication needs

Seven studies focused on consumers' perceived needs related to communication and the relationship between patients with inflammatory arthritis and their healthcare practitioners<sup>19,125,130,133,135,136,139</sup>.

##### 3.3.2.1.1 Characteristics of healthcare provider

In all of these studies, a holistic and positive consultation with healthcare providers was valued. Attributes important in healthcare interactions included empathy, understanding attitudes and feeling listened to being particularly emphasised<sup>19,133,135,139</sup>. A good relationship with healthcare providers was important to many patients<sup>19,125,130</sup>, while a holistic approach was also favoured by some<sup>136,139</sup>.

##### 3.3.2.1.2 Communication

The importance of clear explanations and provision of information was important to many participants, with some expressing frustration at perceived mixed messages<sup>19,133</sup>.

##### 3.3.2.1.3 Involvement in decision making

The desire to be involved in decision making was identified in four studies<sup>19,125,133,136</sup>. Participants valued feeling listened to, being actively involved in decision making, being offered different treatment choices and the ability to lead conversations.

##### 3.3.2.1.4 Sharing experiences with other patients

Two studies identified consumers who expressed a desire to talk with other people with rheumatoid arthritis for further information or emotional support<sup>133,136</sup>.

#### 3.3.2.2 Consumers' perceived needs regarding aspects of care

Patient perceived needs related to the technical aspects of care in clinics were explored in eight studies<sup>19,125,133-136,139,145</sup>.

##### 3.3.2.2.1 Length of consultation

Three studies identified a desire for an adequately long consultation<sup>133,135,139</sup>. Many consumers were unhappy with perceived inadequate consultation time with practitioners, particularly disliking when the consultation felt rushed or inadequate<sup>133,135,139</sup>. This was particularly disliked in secondary care<sup>139</sup>.

##### 3.3.2.2.2 Preferences for follow-up care

Two studies reported the preference for follow up by a specialist for inflammatory arthritis<sup>139,145</sup>. In two studies consumers highlighted the importance of having sufficient access and choices with regards to rheumatology follow-up<sup>125,136</sup>, while one study explored the specific times patients preferred for appointments<sup>145</sup>. The vast majority of consumers in Douglas' study<sup>145</sup> expressed the desire to be followed up in secondary care and in a location close to their home. Consumers in the study by Arthur<sup>139</sup> identified continuity of care as an important aspect of follow-up.

### 3.3.2.2.3 *Timely care, accessible review, specialist referral and access in times of need*

Three studies identified the need for the provision of timely care<sup>19,133,135</sup>. Consumers valued the importance of having access to their practitioners in times of need between follow-up appointments<sup>19,135</sup>. Many consumers expressed frustration at long wait times for investigations and to see practitioners, valuing clinics that ran efficiently to reduce these wait times<sup>133,135</sup>. Pollard identified consumers who were frustrated with perceived delays in referral for specialist management of their disease<sup>135</sup>.

### 3.3.2.3 *Barriers/predictors of care seeking behaviour*

Predictors of care seeking and perceived barriers were explored in eight studies<sup>113,126,127,129,130,134,142,144</sup>.

#### 3.3.2.3.1 *Patient related factors*

Seven studies explored consumer perceived barriers and predictors of care seeking<sup>113,126,127,129,130,134,144</sup>. Increased age was associated with increasing health care seeking behaviour<sup>130</sup>. Bad previous experience with consultation<sup>126</sup> discouraged care seeking, exemplified by those with psoriatic arthritis, as they had "given up"<sup>144</sup>. Other consumers delayed presentation as they misattributed symptoms<sup>113,134</sup>, denied them or ignored them<sup>113</sup>, others believing that seeking specialist care may negatively influence treatment<sup>127</sup>, or be the last resort<sup>129</sup>.

#### 3.3.2.3.2 *Disease related factors*

Disease factors were explored in three of the studies<sup>129,130,144</sup>. Higher disease activity was found to be a predictor of care seeking in two of the studies<sup>129,144</sup>. Fraenkel found that consumers who were minimally or severely impacted by their disease were not open to treatment alternatives (even if they were clinically warranted), while those who were moderately impacted by their disease were more open to treatment alternatives<sup>130</sup>.

#### 3.3.2.3.3 *External factors*

Seven of the studies explored external factors that influenced care seeking<sup>113,127,129,130,134,142,144</sup>. Insurance status influenced the use of physician visits. Financial or funding issues were identified as significant impediments to accessing health care<sup>127,134,142,144</sup>. Family members were influential in care seeking behaviour, although the direction of effect was not consistent: some advocated for care seeking<sup>113,129</sup>, but other family members did not<sup>113</sup>. Other external factors which were perceived to affect access of healthcare included location of services<sup>142</sup>, misdiagnosis by healthcare providers<sup>134</sup> and consumers' role responsibilities within their families<sup>127,130</sup>.

### 3.3.2.4 *Use of allied health and complementary and alternative medicine*

There were seven studies that investigated complementary and alternative medicine use in consumers with inflammatory arthritis<sup>128,131,132,137,140,142,143</sup> and two studies that investigated use of allied health services<sup>141,146</sup>.

#### 3.3.2.4.1 *Modalities and prevalence of use*

The prevalence of consumers who had ever used complementary and alternative medicine ranged from 60 to 76%<sup>128,132,142,143</sup>. The most commonly used forms of complementary and alternative medicine were dietary supplements<sup>128,132,137,140,142,143</sup>, manual therapies (eg chiropractic, massage)<sup>128,142,143</sup>, and topical treatments<sup>128,140</sup>. There were many other modalities less frequently reported including prayer, acupuncture, mind-body therapies (eg meditation, relaxation) and electrical stimulators. Iversen<sup>141</sup> found a low rate of recent physiotherapy use within the previous six months while Feldman<sup>146</sup> found a low referral rate to physiotherapy and occupational therapy amongst healthcare providers in chronic arthritis, although most patients who felt they required these modalities received these services (96%).

#### 3.3.2.4.2 *Perceived benefits, motivations to use and predictors of complementary and alternative medicine and allied health use*

The most commonly reported reasons for using complementary and alternative medicine were symptom relief where conventional treatments were perceived to have failed<sup>131,132,137,140,143</sup> and to complement conventional therapies in disease management<sup>140,142,143</sup>. Other reported motivators for use included desire to minimise medication use and associated side effects, other negative experiences with conventional therapies and belief that these modalities would cure their disease. Some reported predictors of complementary and alternative medicine use were female sex<sup>128,132</sup>, younger age<sup>132</sup>, higher education<sup>142</sup>, and longer time from disease diagnosis<sup>132</sup>, although these were not consistent between studies.

#### 3.3.2.4.3 *Disclosure of complementary and alternative medicine use*

There was variable reporting of complementary and alternative medicine use to treating physicians among the studies, with one study finding low reporting rate<sup>132</sup>, two studies finding high reporting rates<sup>140,142</sup> and one study finding approximately even rates of reporting and non-reporting<sup>143</sup>. The most common reasons provided for not reporting complementary and alternative medicine use to physicians included considering it unnecessary<sup>140,142</sup>, fearful of physician reaction<sup>142</sup> and forgetting<sup>143</sup>. Rao<sup>143</sup> identified predictors of disclosing complementary and alternative medicine use to treating physicians including: female sex, white ethnicity, college education and regular complementary and alternative medicine use.

#### 3.3.2.5 *Miscellaneous*

A study by van der Vaart explored the benefits of consumers accessing their own electronic medical records, with some perceived benefits including: feeling involved and improving the quality of their care<sup>138</sup>.

## 3.4 Health services: Osteoarthritis

### 3.4.1 Description of included studies

Most of the included studies were from the United Kingdom, United States of America or Australia<sup>27,28,30,140,145,147-153</sup>. The remainder of the studies were from Canada<sup>39,146,154</sup>, France<sup>40</sup>, Hong Kong<sup>45</sup> or Taiwan<sup>44</sup>. The majority of subjects were recruited from general practice or subspecialty outpatient clinics<sup>27,28,30,44,45,140,145-149,151,152,155</sup>. Other studies recruited patients from existing disease registries<sup>150</sup>, files of care<sup>39</sup>, pharmacy customers<sup>40</sup> and joint replacement surgery waiting lists<sup>153,154</sup>.

Most studies involved only people with osteoarthritis<sup>27,28,30,39,40,44,45,140,147-153</sup>. Of the remainder, one included a mixed population including people with inflammatory arthritis, connective tissue disease and degenerative joint disease<sup>145</sup>. The other two studies included patients with both rheumatoid arthritis and osteoarthritis<sup>146,154,155</sup>.

### 3.4.2 Results: Consumers' perceived health service needs regarding osteoarthritis

Eight key themes emerged from the included studies relating to perceived health service needs of patients with osteoarthritis. These themes were:

- 1) consumer-physician interaction
- 2) pharmacological therapy and pain management
- 3) physiotherapy and exercise therapy
- 4) complementary and alternative medicine (CAM)
- 5) joint replacement surgery
- 6) access and waiting times
- 7) health system interface
- 8) other service needs

#### 3.4.2.1 Aspects of consumers' perceived health service needs relating to consumer-physician interaction

Five qualitative studies identified factors relating to the consumer-physician interaction<sup>28,39,40,45,152</sup>.

##### 3.4.2.1.1 Willingness to try physician or preference for physician

Chan identified that consumers sought medical assistance from primary care providers and orthopaedic specialists quite late, only seeking medical help when their social lives or daily activities was affected by their osteoarthritis<sup>45</sup>. Alami identified that consumer perceived physician competence was related to physicians' estimated reputation, age and training and these factors conveyed a sense of security to the consumers<sup>39</sup>. They valued being in an individualised relationship.

##### 3.4.2.1.2 Concerns with physician/undesirable characteristics of consumer provider relationship

Four studies identified numerous factors relating to dissatisfaction with the practitioner<sup>28,39,40,152</sup>. These included insufficient practitioner knowledge about osteoarthritis<sup>28,39,40</sup>, trivialisation of osteoarthritis<sup>28,39</sup>, an emphasis on analgesic therapies only<sup>28,39</sup>, rejection of complementary and alternative medicine options<sup>39</sup> and poor practitioner communication skills<sup>40</sup>. Alami reported that confidence in the practitioner seemed to determine the consumer-physician relationship and this depended on a number of factors, including a feeling of being in a specific and individualised relationship with the care provider<sup>39</sup>. This feeling was related to the interpersonal and communication skills of the physician and an ability to adopt a holistic patient approach<sup>39</sup>. Manias reported that consumers felt uncomfortable speaking about medications during medical consultations due to lack of time and embarrassment about asking for information<sup>152</sup>. Consumers felt more comfortable requesting drug information from pharmacists because they listened to consumer concerns<sup>152</sup>.

#### 3.4.2.2 Aspects of consumers' perceived health service needs relating to pharmacological therapy and pain management

##### 3.4.2.2.1 Willingness to try pharmacological therapy or preference for pharmacological therapy

Three studies discussed consumers factors relating to preferences for pharmacological therapy<sup>39,149,152</sup>. Manias found that most consumers preferred to use only medications to manage osteoarthritis and not non-pharmacological means<sup>152</sup>. The primary reason for preferring to use only medications included the ease of using drugs compared to time and effort required to participate in non-pharmacological treatments<sup>152</sup>. Fraenkel identified the relative importance of numerous characteristics of disease modifying medications for osteoarthritis<sup>149</sup>. This study found that medication benefit was the most influential factor, followed by risk, cost and administration route<sup>149</sup>. Almost 60% of consumers were willing to accept substantial risk in order to prevent progression of osteoarthritis<sup>149</sup>. Interestingly, Alami identified that consumers consider dietary supplements as natural alternatives to pharmacological medications, and as such are desirable<sup>39</sup>.

#### **3.4.2.2.2 Expectations of pharmacological therapy**

Four studies identified consumers' expectations of pharmacological therapy<sup>27,39,140,150</sup>. The areas of health where consumers prioritised improvements included pain management and improvements in mobility and function<sup>27</sup>. Hauber found that the most desirable outcomes in pain management include eliminating ambulatory pain and reducing difficulty doing daily activities<sup>150</sup>. Eliminating severe resting pain and severe stiffness were also important benefits<sup>150</sup>. Alami found that the consumers' views on treatment differed depending on whether knee osteoarthritis was considered an occasional or chronic problem<sup>39</sup>. Symptomatic relief was the expectation of consumers with sporadic knee pain<sup>39</sup>. However, the expectations of those with chronic knee pain included a disease modifying treatment or a medication that reduced osteoarthritis progression<sup>39</sup>. Consumers views towards pharmacological therapy in this study were paradoxical – drugs were considered both therapeutic and noxious, and the general attitude was designated as “the less drug therapy possible”<sup>39</sup>. Rao reported that consumers wished a single medicine instead of multiple medications could be used to treat their arthritis<sup>140</sup>.

#### **3.4.2.2.3 Perceived benefit and concerns regarding pharmacological therapy**

Alami was the only study that explored consumer satisfaction with pharmacological therapy for osteoarthritis<sup>39</sup>. Local topical treatments were associated with the idea of analgesic relief. This was considered positively by consumers for numerous reasons including the ability for self-administration and concurrent massage. Oral medications were useful as periodic symptom helpers, however, consumers considered this as an occasional therapy and not a long term solution. The rapidity of action and efficacy of corticosteroid injections was emphasised, however consumers worried about the potential for weakening the cartilage in the component injected. Alami found that hyaluronic acid injection was thought to be a less aggressive procedure and thus viewed with a more positive image<sup>39</sup>. Conversely however, Kao found that consumers perceived hyaluronic acid injections to be damaging to the cartilage and thus viewed with a negative image<sup>44</sup>. Five studies identified the importance of consumer concerns with pharmacological therapy<sup>39,44,150-152</sup>. Of these studies, the main theme that emerged was the fear of medication side effects<sup>39,44,150,151</sup>. Cardiovascular side effects were considered to be the biggest concern by consumers<sup>150,151</sup>. Medication impact on the liver, kidney and stomach was also considered to be significant<sup>44,151</sup>. Hauber found that acceptable risk was dependent on the baseline level of ambulatory pain<sup>150</sup>. Out-of-pocket costs and financial constraints impacted the consumers' ability to pay for the medications and also impacted the choice to continue the medication<sup>151,152</sup>. Manias found that consumers perceived chronic conditions such as diabetes and ischaemic heart disease had a greater impact on their overall health than did osteoarthritis and thus they rationalised their medications by omitting an analgesic unless their osteoarthritis pain was particularly severe<sup>152</sup>. Other concerns with pharmacological therapy included medication schedule complexity<sup>151,152</sup>.

#### **3.4.2.3 Consumers' perceived health services needs related to physiotherapy and exercise therapy**

##### **3.4.2.3.1 Preference and perceived benefits for physiotherapy and exercise**

There were four studies that discussed consumers perceived need for physiotherapy and exercise therapy<sup>27,39,45,155</sup>. Chan identified that consumers sought physical therapists for knee osteoarthritis<sup>45</sup>. Victor identified that those' with knee osteoarthritis wanted to achieve better health through participation in exercise and losing weight<sup>27</sup>. Consumers also engaged in exercise to reduce pain and strengthen muscles<sup>45</sup>. Alami found that consumers believed that exercise therapy was essential after knee surgery and important in osteoarthritis for analgesic relief and to increase muscle strength<sup>39</sup>. Feldmann identified that although 26% of consumers with chronic arthritis felt that they required rehabilitation, the majority of these (96%) did not receive these services<sup>155</sup>.

##### **3.4.2.3.2 Concerns with, and barriers to using, physiotherapy and exercise**

Four studies identified factors related to consumers' perceived barriers to physiotherapy and exercise. Ackerman and Chan explored the barriers to physiotherapy and exercise therapy<sup>45,147</sup>. Ackerman identified that disinterest was the most common reason for not participating<sup>147</sup>. Other barriers included physical limitation, distance and transport difficulties, work commitments, time commitment required, family commitments and carer role, and preference for course scheduling and venue<sup>147</sup>. Also an exercise program that did not take into account their multi-site presentation was a barrier to participation<sup>40</sup>. Chan also identified that patients with knee osteoarthritis needed to reduce or adjust exercise secondary to pain<sup>45</sup>. Most patients preferred to attend an exercise session or course during the day, with few people favouring the evening or weekend<sup>147</sup>. Feldmann identified that consumers' perceived need for physiotherapy was lower in those with lower self-efficacy<sup>155</sup>.

#### **3.4.2.4 Perceived needs of complementary and alternative medicine (acupuncture, osteopathy, massage therapy, local heat therapy, prayer)**

##### **3.4.2.4.1 Willingness to try complementary and alternative medicine or preference for complementary and alternative medicine**

Three studies discussed consumers' willingness to try complementary and alternative medicine and their satisfaction with this service<sup>39,140,148</sup>. Rao reported that 90% of consumers with osteoarthritis regularly used complementary and alternative medicine or had done so in the past<sup>140</sup>. Desire for pain relief was the most commonly identified factor influencing use of unconventional therapy<sup>140</sup>. Other reasons for complementary and alternative medicine usage included trying to reduce conventional medicine intake and delay time to surgery<sup>39</sup>.

#### **3.4.2.4.2 Perceived benefits, satisfaction and barriers to the use of complementary and alternative medicine**

There were a number of factors that contributed to consumer satisfaction with complementary and alternative medicine. This included the accessibility and empathy of practitioners, in addition to their communication skills and holistic approach to patient care<sup>39</sup>. Another study identified that consumer acceptability of complementary and alternative medicine may be maximised by taking into account a number of factors including patient information, flexibility in the appointment system, sufficient space and staffing<sup>148</sup>. The main barrier to complementary and alternative medicine usage, as identified by Chan, was the cost of the service<sup>45</sup>.

#### **3.4.2.5 Consumers' perceived needs regarding joint replacement**

Three studies explored consumers' beliefs on joint replacement for osteoarthritis<sup>30,39,153</sup>. Joint replacement was desired to occur as late as possible according to one study<sup>39</sup>. This was related to surgical fears, which included anaesthesia, nosocomial infections and apprehension about poor surgical results<sup>39</sup>. A study by Mann found that consumers believed joint replacement surgery to be the only effective treatment option for osteoarthritis<sup>30</sup>. McHugh reported a patient wanting to withhold information about his medical conditions (which may have precluded him from having a total hip replacement) to avoid further pain and comorbidity from the hip<sup>153</sup>. Access to joint replacement surgery was also a concern for consumers, in addition to inconsistency between different clinicians' advice regarding joint replacement surgery<sup>30</sup>.

#### **3.4.2.6 Consumers' perceived needs regarding health service access and waiting times**

Four studies explored the accessibility of health services for consumers with osteoarthritis<sup>30,45,145,154</sup>. Douglas found that weekday, morning appointments were preferred by the majority of consumers<sup>145</sup>. However, with regards to seeking medical assistance for osteoarthritis, 75% of consumers would prefer to attend the hospital site closest to their home rather than their local primary care centre<sup>145</sup>. Patients believed that GPs were generally too busy to spend much time discussing osteoarthritis and were not specialists in arthritis<sup>30</sup>. Consumers wanted access to specialist knowledge and advice regarding osteoarthritis and expressed a desire to have easy access to someone with specialist knowledge in arthritis in order to avoid bothering the GP unnecessarily, eg a practice nurse<sup>30</sup>. Mann also found that consumers believed osteoarthritis to be a low priority in healthcare<sup>30</sup>. There was no clear association found between maximum acceptable waiting time and symptomatic burden of osteoarthritis in one study<sup>154</sup>. Chan found that one of the main factors affecting choice of medical assistance included treatment cost<sup>45</sup>.

#### **3.4.2.7 Consumers' perceived needs of orthoses and physical aids**

Five studies explored consumers' perceived needs of use of physical aids in relation to osteoarthritis<sup>28,39,44,45,153</sup>. To relieve knee discomfort, some consumers used auxiliary devices including kneecaps, braces and gait aids<sup>44,45</sup>. Alami reviewed consumers' perceptions of gait assistance devices<sup>39</sup>. Consumers appreciated the increased feeling of stability with a knee orthosis but had aesthetic concerns regarding the orthosis<sup>39</sup>. Another study by Thomas found that consumers with foot osteoarthritis preferred fashionable footwear and had aesthetic concerns regarding bunions being visible<sup>28</sup>. Insoles were considered favourably and considered complementary options to decrease weight bearing on the affected side<sup>39</sup>. Gait aids and wheelchairs were accepted by consumers as only transient options as they implied old age and loss of autonomy<sup>39</sup>. One study by McHugh identified that consumers had little awareness of the kinds of living aids or home adaptations that were available through social services or by assessment from an occupational therapist<sup>153</sup>.

#### **3.4.2.8 Consumers' perceived need for osteoarthritis profile**

One study found that the minimal media coverage of osteoarthritis was unacceptable<sup>40</sup>. Consumers felt that the official recognition of osteoarthritis as a disability would give it legitimacy in the eyes of the community and their immediate circle<sup>40</sup>. It would also enable consumers to apply for state assistance<sup>40</sup>. Consumers wanted more knowledge about osteoarthritis and information about how to self-manage pain in other joints should it manifest<sup>40</sup>.

## 3.5 Health Services: Back pain

### 3.5.1 Description of included studies

Eighty studies were relevant to the systematic review. Of these, 28 were from the United Kingdom<sup>40,45,50,51,59,64,69,71,72,74,114,116,156-169</sup>, 20 from the United States of America<sup>76,79,80,170-185</sup>, nine from Australia<sup>82,83,186-190</sup>, five from Germany<sup>54,55,191-193</sup>, four from Sweden<sup>89,194-196</sup>, three from New Zealand<sup>197-199</sup>, two each from Netherlands<sup>68,200</sup> and Switzerland<sup>67,201</sup>, and one each from Israel<sup>85</sup>, Ireland<sup>118</sup>, Spain<sup>202</sup>, Denmark<sup>203</sup>, Morocco<sup>204</sup>, South Africa<sup>205</sup> and Norway<sup>57</sup>. The duration of back pain was either undefined or mixed in 61 studies<sup>40,45,50,54,59,64,67-69,71,72,74,79,80,83,85,89,114,116,156-158,160,162,165-167,169-173,175-178,180-185,187-197,199-202,204,205</sup> and 19 studies reported on chronic back pain<sup>51,55,76,82,118,159,161,163,164,168,174,177,179,186,198,203,206</sup> (>4 weeks duration). There were no studies on acute back pain alone (<4 weeks duration).

### 3.5.2 Overall results: Consumers' perceived health service needs regarding back pain

Three main areas of consumers' perceived health service needs relating to back pain emerged from the review. These themes were:

- 1) consumers' perceived needs of medical services
- 2) consumers' perceived needs of allied health and non-pharmacological therapy
- 3) consumers' perceived needs of healthcare providers.

These results are shown under these three main subheadings in the following sections.

### 3.5.3 Results: Consumers' perceived medical service needs relating to back pain

Four areas of need were identified from the included studies relating to consumer perceived needs of medical services of patients with back pain. These themes were:

- 1) the consumers' perception of the medical practitioner in the management of back pain
- 2) the role of pharmacological management and concerns with medications
- 3) the role of interventional therapies
- 4) the role of imaging.

#### 3.5.3.1 Consumers' perceived health service needs regarding medical practitioners

##### 3.5.3.1.1 The role of the doctor and strengths of the doctor

Twenty studies discussed the consumers' perceived role of the medical doctor in the management of back pain<sup>51,66-69,79,83,85,114,156,164,176,178,186-188,192,198,199,207</sup>. Consumers described their reasons for seeking medical care to include discovering the cause of pain<sup>68,83,85,176,178,187</sup>, to obtain medications for pain<sup>79,114,188,207</sup>, to receive advice and to discuss options for back pain management<sup>79,186</sup>, to receive sickness certification<sup>69,207</sup> and legitimization of their back pain<sup>164</sup>. General practitioners or medical specialists were consulted for pain relief, for general wellbeing and for fostering self-management strategies<sup>188,198</sup>. Consumers also consider consultation with general practitioners as an opportunity to explore alternative medicines<sup>69,79</sup>. Furthermore, consumers visit their general practitioner for a referral to specialist medical or surgical services<sup>192</sup>. Campbell and Rogers commented that consumers viewed medical doctors, rather than practitioners not allied with medicine, as being seen to be generally more knowledgeable about their pain<sup>51,187</sup> and Darlow reported that consumers thought that doctors could provide individual assessment of their back pain<sup>199</sup>. Westmoreland found that consumers perceived the strengths of the general practitioner to include continuity of care, listening and counselling skills<sup>156</sup>.

##### 3.5.3.1.2 Preference to see the doctor and satisfaction with the doctor

Factors related to consumers preferences to see medical practitioners and their satisfaction with doctors were identified in six studies<sup>50,67,72,165,180,181</sup>. Carey reported that 25% of adults with acute severe back pain sought care from a doctor whilst 61% of adults did not seek any health care<sup>180</sup>. Scheermesser reported that 50% of consumers would like to have seen their doctor more frequently in rehabilitation programs<sup>67</sup>. Consumers have described having faith in doctors and a dependence on doctors and professions allied to medicine<sup>165</sup>. Fifty-one percent of consumers thought that specialist referral was valuable<sup>50</sup> and consumers have reported reluctance from the general practitioner to refer them to a specialist<sup>72</sup>. A single study by Carey found that those who saw orthopaedic surgeons have reported higher satisfaction than those who saw primary healthcare providers<sup>181</sup>.

### 3.5.3.1.3 Inadequacies of the doctor

Ten studies reported on the consumers' perceived inadequacies of the doctor<sup>51,59,64,72,85,118,156,178,207,208</sup>. Coole and Liddle reported that consumers feel there is little to be gained by consulting their general practitioner about their back pain<sup>118,207</sup>. Some patients believe that their general practitioner lacks specialist knowledge about back pain<sup>59,64,72</sup> and are disappointed that their general practitioners have not provided them with a cause for their pain<sup>64,178</sup>. Patients feel that the doctors' primary focus is on prescribing pain medications<sup>51,118</sup> and they are dissatisfied with the protracted and ineffective episodes of care that centre around the prescription of medications and rest, as well as the delay in referring to physiotherapy<sup>208</sup>. Consumers complained that doctors have a superficial approach to the management of back pain, lack empathy and have a tendency to be dismissive or delegitimise symptoms<sup>51,85,156,208</sup>. Consumers also felt that once certain pathological causes of back pain were eliminated, doctors appeared to slacken their investigations into the aetiology of pain<sup>85</sup> and some consumers sought private investigations or physical therapy instead<sup>207</sup>. Furthermore, consumers felt that their consulting time with their doctor was restricted and therapeutic options were limited, ineffective or inappropriate<sup>156,208</sup>. Some consumers were disappointed that they did not receive individually tailored 'expert' treatment<sup>59</sup>. Consumers also reported that they had not received any advice or support in relation to work and that there was little evidence of communication between their general practitioner and other clinicians or employers<sup>207</sup>.

### 3.5.3.1.4 Characteristics of consumers more likely to seek medical care

The characteristics of consumers more likely to see a medical doctor for their back pain were described in three studies<sup>173,176,182</sup>. It has been reported that 98% of consumers sought medical care due to difficulty with normal activity and 95% of consumers wanted to find the cause of their pain<sup>176</sup>. Consumers with greater pain and more severe functional impairment were more likely to seek medical help for their symptoms<sup>173,182</sup>.

## 3.5.3.2 The role of pharmacological management and concerns with medications

### 3.5.3.2.1 Role of medications and preference for medications

Twelve studies examined consumers' perceived needs related to back pain and medications<sup>50,66-68,72,83,157,163,172,184,198,207</sup>. Of these papers, five studies reported that consumers preferred medications<sup>50,66,67,83,172</sup>. Some consumers expected analgesics for the management of acute back pain<sup>83</sup> and some believed that medications were a slightly more useful option than doctors<sup>50</sup>. Furthermore, narcotic use has been reported in one study to be associated with consumers satisfaction<sup>172</sup>. Consumers perceive medications as being used to relax muscles, reduce inflammation, provide pain relief, enable activity and prevent worsening of back pain<sup>163</sup>. However, Buchbinder found that only 20% of consumers presenting to an academic Emergency Department with back pain requested analgesics for their back pain, and those that did utilised strategies of mitigation, indirection and deference which suggested that they were aware of the intricacies of their requests<sup>184</sup>. Other studies of consumers attending either rehabilitation or pain management programs found that the consumers were generally dismissive of medication as a treatment<sup>114</sup> and felt that drugs were neither important nor appropriate in the management of back pain<sup>157</sup>. Furthermore, consumers have described their primary care provider as being too "keen to dish out drugs" and consumers viewed medication use as treating symptoms rather than managing the actual problem with their back pain<sup>72</sup> and would only take medications if strictly necessary<sup>68</sup>. Crowe also found that most consumers were generally resistant to taking medication regularly<sup>198</sup>.

### 3.5.3.2.2 Concerns regarding medications

Consumers have concerns regarding medications, which were reported in eight studies<sup>67,158,163,168,179,184</sup>. Several papers highlighted fear of medication side-effects and the potential for addiction and desensitisation<sup>158,163,179</sup>. Many consumers felt trapped in a vicious cycle of increasing pain and consumption of drugs<sup>67</sup>. Some felt that their lives were dominated by pain and medications<sup>158</sup>. They are also concerned about the impact of medications on their work<sup>207</sup>, and the effect of painkillers on their sleep<sup>66</sup>. Consumers have also reported confusion about medications and a lack of explanation by their healthcare provider when medications were prescribed<sup>168</sup>. Furthermore, consumers also expressed a reluctance to request analgesics for fear of stigmatisation<sup>184</sup>.

### 3.5.3.3 The role of interventional therapies: injections and surgical interventions

Four studies explored consumers' preferences for interventional treatment for back pain<sup>163,179,201,203</sup>. A single study by Lyons assessed preferences for injection therapy and found that most consumers avoided injections and would "rather live with the pain"<sup>179</sup>. Four studies also examined preference for surgical management<sup>163,203,201,179</sup> with two studies reporting that consumers would rather avoid surgery and viewed surgical intervention as a last resort<sup>163,179</sup>. Consumers were willing to wait two years for the effects of conservative treatment to avoid surgery<sup>203</sup>. In comparison, Lacroix stated that consumers felt that "there comes a moment when an operation becomes inevitable"<sup>201</sup>. Consumers who preferred surgical intervention were more likely to be male, have higher pain scores and have pain for a longer duration of time<sup>203</sup>.

### 3.5.3.4 The perceived need for imaging

Seven studies examined the consumers' perception of the use of imaging in the evaluation of their back pain<sup>50,68,76,83,176,178,186</sup>.

#### 3.5.3.4.1 Preference for imaging

Consumers wanted imaging of their spine to find a diagnosis of their back pain<sup>50,68,83</sup>. Hoffman reported that most patients expected their general practitioner to refer them for an x-ray, particularly if they felt that their pain was severe<sup>83</sup>. Amonkar found that more than 60% of participants thought that back x-rays were a positive investigation<sup>50</sup>.

#### 3.5.3.4.2 Role of imaging

Many consumers felt that x-rays provided reassurance as well as confirmation of their general practitioner's diagnosis<sup>83</sup>. Furthermore, imaging that showed a physical defect seemed to provide closure<sup>76</sup> and relief<sup>186</sup> for consumers and they sought diagnostic imaging as a means to legitimise their back pain<sup>176,178</sup>.

#### 3.5.3.4.3 Characteristics of patients requesting imaging

Only one study by Wilson examined the characteristics of consumers requesting imaging. Radiology utilisation was associated with the severity of back pain and a history of osteoporosis<sup>170</sup>.

### 3.5.4 Results: Consumers' perceived needs of allied health and complementary and alternative medicine related to back pain

Three areas of perceived need emerged from the identified studies relating to consumer perceived needs relating to allied health and non-pharmacological therapies of patients with back pain. These themes were:

- 1) consumers' perceived needs of complementary and alternative therapies
- 2) consumers' perceived needs of physiotherapy
- 3) consumers' perceived needs of chiropractic therapy.

#### 3.5.4.1 Consumers' perceived needs of complementary and alternative therapies (CAM)

##### 3.5.4.1.1 Willingness to try complementary and alternative medicine

Eight studies reported consumers' willingness to try complementary and alternative medicine with mixed results<sup>67,69,76,156,174,175,185,193</sup>. Of these studies, four studies found that consumers are willing to try complementary and alternative medicine, mostly in the form of massage therapy, spinal manipulation and local heat therapy<sup>76,156,174,193</sup>. Astin reported that 4.4% of consumers relied primarily on complementary and alternative medicine<sup>185</sup>. Also, Sherman found in a population of consumers with chronic non-specific back pain recruited from integrated health systems to participate in a study comparing acupuncture and usual care, that one third of participants at baseline wanted acupuncture<sup>175</sup>. However, Scheermesser reported in a study of consumers with chronic back pain recruited from a Rehabilitation Centre Clinic prefer western medical treatment to complementary and alternative medicine. Skelton found that primary care patients viewed complementary and alternative medicine as experimental or a desperate measure when their pain became intolerable or when medical doctors were unavailable for consultation<sup>69</sup>.

##### 3.5.4.1.2 Perceived benefit and satisfaction with complementary and alternative medicine

There were seven studies that explored consumers' satisfaction with, and perceived benefit of, complementary and alternative medicine<sup>85,156,159,163,185,198,208</sup>. Consumers felt that complementary and alternative medicine could relax muscles, stimulate nerves, manipulate and loosen joints and provide pain relief<sup>156,163,185</sup>. May and Crowe reported that some consumers felt that heat therapy<sup>40,198</sup> and massage therapy were effective<sup>208</sup>. Consumers thought the complementary and alternative medicine practitioners were more empathetic and understanding and had better diagnostic skills compared to medical doctors<sup>85,156,159</sup>. Complementary and alternative medicine practitioners were also perceived to provide longer consultations that allowed more time for thorough examination and explanation of the diagnosis<sup>156</sup>. Furthermore, Westmoreland found that consumers thought there were psychological benefits of complementary and alternative medicine, including reassurance, removal of fear and a positive approach<sup>156</sup>.

##### 3.5.4.1.3 Concerns with complementary and alternative medicine

Some consumers have concerns with complementary and alternative medicine that were addressed in four papers<sup>51,69,156,163</sup>. Consumers commented on the fear of needling and pain from acupuncture<sup>163</sup>. Westmoreland reported on consumers' apprehensions with adverse psychological effects of spinal manipulation including fright and embarrassment<sup>156</sup>. Furthermore, Campbell found that consumers believe that complementary and alternative medicine therapies provide limited transitory effects, which were perceived to stand outside of the medical model, and Skelton reported that some consumers questioned its legitimacy and feared being ripped off<sup>51,69</sup>.

#### 3.5.4.2 Consumers' perceived needs of physiotherapy

##### 3.5.4.2.1 Willingness to try physiotherapy and exercise therapy

Ten studies that identified consumers preference for, and willingness to try, physiotherapy and exercise therapy<sup>50,68,116,118,189,190,198,202,208,209</sup>. Participants see the benefits of exercise and some value physiotherapy and osteopathy more than medical doctors<sup>50,118,190,198</sup>. May reported that consumers thought exercises were an important part of the management problem and expected physiotherapy as management of their back pain<sup>116,208</sup>, however, Schers commented that some would ask for a referral to physiotherapy only when symptoms would last for at least a few weeks<sup>68</sup>. In a study by Ferreira, consumers thought that physiotherapy would have to improve their symptoms by 42% for them to perceive it to be a worthwhile intervention<sup>189</sup> and most consumers prefer exercising only when pain reappears rather than continual exercise therapy<sup>202</sup>. Cooper reported that consumers want direct access to physiotherapy and some thought that it would be helpful if they were able to telephone the physiotherapist, using it as a form of helpline for back pain management<sup>209</sup>.

### 3.5.4.2.2 *Perceived benefit of physiotherapy and exercise therapy*

Six papers identified the consumers' perceived benefits of physiotherapy and exercise therapy<sup>67,163,190,191,202,210</sup>. Of these studies, the main themes that emerged were that physiotherapy and exercise therapy results in temporary relief of pain<sup>156,163,190</sup>, prevents worsening of back pain<sup>163,202</sup> and helps with mobility and function<sup>163</sup>. It also is perceived as being helpful for injuries, muscle strengthening, reducing stiffness, realigning the spine and releasing the nerves<sup>156,163</sup>. Furthermore, consumers believed that physiotherapy and exercise therapy fosters health promotion<sup>210</sup>, addresses their personal needs<sup>191</sup>, improves mental state<sup>163,191</sup> and helps with weight loss<sup>163</sup>. Grimmer reported that consumers expected symptom relief at the end of the first treatment<sup>190</sup>. Whilst consumers in Heyduck's study had high expectations of rehabilitation<sup>191</sup>, those in Medina-Mirapeix's study recognised the potential difficulties of adhering to an exercise program<sup>202</sup>.

### 3.5.4.2.3 *Individualising physiotherapy and exercise therapy*

Four studies reported the consumers' preference for individualising physiotherapy and exercise therapy<sup>118,161,202,210</sup>. Consumers desire advice regarding suitable lifestyle adaptations and they wanted physiotherapy to be tailored to the individuals' health needs<sup>118,161,210</sup>. They also felt that supervision and follow up of their exercise program was important<sup>118</sup> and that health professionals were rarely effective in enabling them to continue increased physical activity unless there was regular contact<sup>161</sup>. Furthermore, consumers wanted reassurance from the practitioner that they were performing the exercises correctly<sup>118</sup>.

### 3.5.4.2.4 *Concerns with physiotherapy and exercise therapy*

Consumers concerns related to physiotherapy and exercise therapy were explored in four studies<sup>156,163,202,210</sup>. Dima reported that consumers were afraid of injuring their back with physiotherapy and exercise and they feel sore after manipulation, which they believe may cause further damage to their back<sup>163</sup>. Slade found that consumers felt that gyms were intimidating and prevented them from engaging in exercise. They also reported that compliance was difficult, especially when they lacked confidence in correct exercise technique<sup>210</sup>. Medina-Mirapeix also found that consumers were concerned about their ability to adhere to an exercise program<sup>202</sup>. Furthermore, consumers were concerned about the lack of a specific diagnosis given by physiotherapists and that the treatments were ineffective<sup>156</sup>.

## 3.5.4.3 *Consumers' perceived needs related to chiropractic therapy*

### 3.5.4.3.1 *Willingness to try chiropractic therapy*

Two studies reported on consumers' willingness to try chiropractic therapy<sup>179,180</sup>. Lyons' study found that participants recruited from chiropractic and general practice clinics considered chiropractors as primary therapy rather than complementary treatment for back pain<sup>179</sup>. Carey reported that 13% of adults with acute severe back pain sought care from a chiropractor<sup>180</sup>.

### 3.5.4.3.2 *Perceived benefit, expectations and concerns with chiropractic therapy*

Eight studies described patients' perceived benefit, satisfaction and expectations of chiropractic therapy<sup>85,179-181,194,195,211</sup>. Carey found that consumers were the most satisfied with chiropractic care compared to orthopaedic surgeons or medical practitioners<sup>181</sup>. Borkan reported that consumers felt that non-orthodox practitioners (including chiropractors) and folk healers were more empathetic, knowledgeable and had better diagnostic skills and effective therapies<sup>85</sup>. Three studies commented that consumers who saw chiropractors were satisfied with their management<sup>177,181,211</sup>. According to Sigrell's results, consumers expected chiropractors to provide an accurate diagnosis and explain the cause of pain<sup>194</sup>, as well as offer advice about training and exercises<sup>195</sup>. Consumers also expected that they should feel better and be free of symptoms with chiropractic therapy<sup>195</sup> and they wanted hands-on treatment or spinal manipulation from their chiropractors to treat the cause of pain<sup>179</sup>. One study explored the consumers' concerns with chiropractic therapy<sup>179</sup>. Lyons concluded that some consumers found chiropractic adjustments to not relieve their back pain for several treatments or that it provided short-term relief and produced side effects such as muscle pain<sup>179</sup>.

### 3.5.4.3.3 *Characteristic of patients preferring chiropractic therapy*

Three studies explored the characteristics of patients that preferred chiropractic therapy<sup>173,180,182</sup>. Chiropractic care was more commonly preferred in males compared to females<sup>180</sup>. There were conflicting conclusions about the age range of consumers preferring chiropractic therapy<sup>173,180</sup>. Employed individuals, higher income and self-funded patients were more likely to seek care from chiropractors<sup>173,180</sup>. Other characteristics of consumers preferring chiropractic care included those with more favourable attitudes towards self-directed treatment and active behavioural involvement, consumers who were more opposed to prescription medications, consumers who expressed confidence in the ability of their chosen health provider, those with acute back pain, consumers with back pain that did not begin at work and consumers who attributed the cause of their back pain to disc disease<sup>173,180</sup>. Furthermore, the proportion of chiropractic patients seeking care is greater in those with functionally disabling symptoms<sup>182</sup>.

### **3.5.5 Results: Consumers' perceived needs related to the characteristics of healthcare providers relating to back pain**

Four areas of need emerged from the included studies relating to consumer perceived needs of healthcare providers. These themes were:

- 1) good communication between patient and healthcare providers
- 2) information provision needs
- 3) aspects of care from healthcare providers
- 4) barriers to health care.

#### **3.5.5.1 Consumers' perceived needs of characteristics of healthcare providers regarding communication**

##### **3.5.5.1.1 Good communication skills**

Twelve studies explored the consumers' perceived importance of good communication skills<sup>54,55,66,69,80,166,179,186,194,201,210</sup>. Open, consumer-centred communication was important and consumers wanted to be given an opportunity to discuss their problems<sup>54,55,69,179</sup>. Consumers also value healthcare providers that communicate well and provide good clear explanations without medical jargon<sup>166,186,194,201,210</sup>. Furthermore, consumers prefer the communication style of the healthcare provider to be encouraging and personalised to the individual<sup>54,80,166,186,210</sup>.

##### **3.5.5.1.2 Shared decision making, respect and being listened to**

There were three studies that reported on the consumers' perceived need to be included in shared decision making<sup>89,171,186</sup>. Consumers believe that their encounters with healthcare provider should be consultative rather than prescriptive and they are eager to work with their clinicians in their own care<sup>89,171,186</sup>. Seven studies explored the consumer's need to be listened to, given the opportunity to relate their experience and be treated with respect<sup>66,72,169,179,186,201,212</sup>. Lyons found that some consumers felt frustrated when healthcare providers did not listen and prioritised other health conditions over their back pain<sup>179</sup>.

##### **3.5.5.1.3 Empathy, understanding and confidence**

Empathy and understanding are characteristics that consumers value, which were examined in seven studies<sup>66,79,80,116,186,205,208,210</sup>. Consumers prefer care-providers to be non-judgemental and empathetic to their situation<sup>66,79,116,186</sup>. Slade and May found that consumers felt a lack of empathy<sup>186,208</sup> and prejudice from the healthcare provider and that practitioners did not perceive their patients as capable of understanding pathology and management<sup>210</sup>. Also, Soeker found that some consumers thought that medical doctors did not understand their work environment and the psychosocial stressors that could aggravate their back pain<sup>205</sup>. Bush reported that consumers with more confident healthcare providers were more satisfied with the information they received about their back pain<sup>183</sup>.

#### **3.5.5.2 Consumers' perceived needs related to the characteristics healthcare providers regarding information provision**

##### **3.5.5.2.1 Diagnosis and finding a cause of pain**

Consumers want their healthcare providers to provide a diagnosis or a cause of their back pain<sup>66,71,74,76,89,118,160,166,196,197,199,200</sup>. This is a recurring theme that was explored in 11 studies. Andersson found that receiving diagnostic support and excluding pathology were reasons for consumers to seek conventional care<sup>196</sup>. Slade reported that consumers felt angry or frustrated if professionals could not fulfil the expectations of a diagnosis-treatment-cure pathway<sup>186</sup>.

##### **3.5.5.2.2 Information provision by healthcare providers**

Fifteen studies reported the consumers' perceived need for the provision of health information from healthcare providers<sup>64,79,89,116,171,177-179,181,186,200,201,204,210</sup>. Consumers want direction from their healthcare provider, reassurance and information about the cause of their pain and activities they should avoid which may aggravate their pain<sup>79,89,200,201</sup>. Lyons found that consumers prefer the information to be given clearly with diagrams and they want assistance to access reliable information<sup>179</sup>. High proportions of consumers have reported lack of instruction about how to take care of their back<sup>64,186</sup>. The most frequently cited area of dissatisfaction was an inadequate explanation of the problem and poor understanding of what was wrong<sup>116,178,179,186,211</sup>. Furthermore, Weiner found that misinformation, lack of information and dissatisfaction with health care encounters drive consumers to seek health care<sup>171</sup>. Bahouq reported that consumers believe that healthcare providers should integrate management of sexual problems in back pain consulting<sup>204</sup>. In addition, four papers have highlighted that consumers want healthcare providers to provide congruent information and consistent recommendations<sup>72,89,179,199</sup>.

### **3.5.5.2.3 Legitimation**

Consumers' need for healthcare providers to legitimise symptoms was examined in three studies<sup>197,205,210</sup>. Slade found that consumers felt stigmatised by health professionals, the community, friends and families, the workplace and other people living with back pain<sup>210</sup>. Moreover, they were angry and frustrated in their search for legitimacy and validation<sup>210</sup>.

### **3.5.5.3 Consumers' perceived needs regarding aspects of care related to back pain**

#### **3.5.5.3.1 Type of approach to health care: holistic, personalised, emotionally supportive and encouraging**

Four studies evaluated the consumers' preferences for types of approaches to health care<sup>79,89,166,196</sup>. Andersson and Stenberg found that consumers appreciated a holistic approach. Andersson reported that some have found conventional medical therapy to be reductionist with a focus on disease compared to a holistic framework, which is perceived to facilitate increased treatment response, support and empowerment<sup>196</sup>. Stenberg and Cooper found that consumers wanted assessment and treatment to be personalised<sup>89,166</sup>. Kawi reported that consumers valued the emotional support and encouragement provided by their healthcare providers<sup>79</sup>.

#### **3.5.5.3.2 Thorough assessment, time and effort, continuity of care**

Four studies reported that consumers want a thorough assessment from their healthcare provider<sup>50,69,72,181</sup>. Amonkar found that over 90% of consumers considered it valuable for doctors to perform a physical examination, although only 70% of doctors placed importance on this<sup>50</sup>. Carey reported that the strongest correlates of satisfaction were the consumers' responses to questions about the quality of the provider's history taking, examination and explanation of the problem<sup>181</sup>. Furthermore, the healthcare provider's time was highly valued and consumers have expressed their concerns about the amount of time spent with their healthcare provider<sup>116,212</sup>. Consumers also desire continuity of care from their healthcare provider<sup>89,116,160,186</sup>.

#### **3.5.5.3.3 Qualifications and technical skills**

Two studies evaluated consumers' perceived importance of the healthcare provider's qualifications and technical skills<sup>82,169</sup>. Bishop found that consumers consider a practitioner's qualifications and technical skills important<sup>169</sup>. Briggs reported that some consumers feel that general practitioners have inadequate knowledge and skills<sup>82</sup>.

#### **3.5.5.3.4 Collaboration between health providers**

Two studies that reported on the consumers' perception of collaboration between healthcare providers<sup>179,186</sup>. Lyons reported that some consumers feel that there is a strained professional relationship between medical doctors and chiropractors<sup>179</sup>. Slade found that consumers value collaboration and shared decision-making in the management plan<sup>186</sup>.

#### **3.5.5.3.5 Consumer perceived needs regarding barriers to care related to back pain**

Consumers reported several barriers to care<sup>59,66,74,82,118,161,162,166,179,186,196,202,212</sup>. Consumers have concerns regarding the financial expenses of back pain management and they have found the financial burden unmanageable and an obstacle to consistent attendance at exercise programs<sup>179,196,210</sup>. Consumers are also dissatisfied with lengthy waiting times for referrals, investigations and healthcare appointments<sup>66,74,118,166,212</sup>. They have concerns regarding the accessibility to healthcare and longer-term support for their back pain<sup>59,166,179</sup>, particularly in rural settings<sup>82</sup>. Furthermore, consumers report facing a conflict between knowing they should adhere to treatment (such as exercise therapy), however bad weather, poor social supports, a lack of personal time and family commitments were common obstructions<sup>161,162,202</sup>.

**“Sometimes I wish...  
my doctor and employers  
would get in touch with  
each other because -  
maybe it’s just me, but  
I think when I ring up  
work... I feel sometimes...  
they don’t believe me.”**

**(Coole 2010<sup>207</sup>)**



## 3.6 Health services: Neck pain

### 3.6.1 Description of included studies

Seven relevant studies were identified. Four studies were from Sweden<sup>88,89,196,213</sup>, two from the United Kingdom<sup>156,214</sup> and one from Norway<sup>215</sup>. Consumers were recruited from a variety of sources in the different studies, including general practice clinics<sup>89</sup>, rehabilitation programs<sup>213,215</sup>, physiotherapy clinics<sup>89</sup>, osteopathy clinics<sup>156</sup>, specialty pain<sup>214</sup> and spine<sup>88</sup> clinics and from participating in a randomised controlled trial<sup>196</sup>. Most studies included consumers with neck pain of variable or unspecified causes<sup>88,89,156,196,214,215</sup> with the remaining study investigating consumers with neck pain secondary to whiplash associated disorders<sup>213</sup>. Four of the seven studies involved a mixed population of consumers with neck and back pain<sup>88,89,156,196</sup>.

### 3.6.2 Results: Consumers' perceived health service needs regarding neck pain

Three main themes and numerous sub-themes arose from the search relating to patient perceived health service needs in those with neck pain. These were:

- 1) relationship with healthcare provider
- 2) management strategies
- 3) access to care.

#### 3.6.2.1 Consumers' perceived health service needs regarding their relationship with their healthcare provider

Emotional considerations and factors related to communication were central to the perceived success of the provider relationship from the consumers perspective. Consumers highlighted the importance of feeling as if their symptoms were being taken seriously by their healthcare practitioner<sup>88,89,196</sup> and a need for their practitioner to be empathetic towards their suffering and needs<sup>88,156,214,215</sup>. They wanted practitioners to seem interested in their problem<sup>88,214,215</sup>, willing to listen to their viewpoint<sup>89,213-215</sup> and take their opinions on board<sup>89,213,214</sup>. Consumers wanted to be in an environment where they felt safe<sup>89</sup> and were treated with respect and dignity<sup>88</sup>.

#### 3.6.2.2 Consumers' perceived health service needs regarding management strategies

Three studies referred to the perceived role of the physical examination<sup>88,156,214</sup>, with differing preferences identified in each of the studies. While some patients felt the examination was important<sup>214</sup> or beneficial<sup>156</sup>, others did not express strong views either way<sup>88</sup>. Upon engaging with health services consumers appreciated diagnostic support in one study<sup>196</sup>. Consumers expressed a desire to play an active role in their management and decisions about their care<sup>88,89,213</sup>. In regards to pain management, they preferred a multidisciplinary approach including physical therapies rather than pharmacological treatments alone<sup>156,214</sup>. Self-help strategies were viewed as valuable in three studies<sup>88,196,213</sup>. In five studies patients identified the importance of continuity of care as an aspect of their healthcare provision<sup>88,89,156,213,215</sup>. Consumers also wanted their management plans to be tailored to their individual needs rather than an "off-the-shelf" approach<sup>89,215</sup>. They also valued an interdisciplinary management approach<sup>89,196,213,215</sup> including a role for complementary therapies<sup>196</sup>, reflecting a desire for a holistic perspective towards care<sup>89</sup>.

#### 3.6.2.3 Consumers' perceived health service needs and access to care

The third major area of need identified in relation to consumers health service needs was around access to care. Unacceptable waiting times for an appointment were a barrier to optimal health service provision in three studies<sup>88,156,196</sup>, as was inadequate consultation time when an appointment was obtained<sup>88,156,196</sup>. Affordability was also a factor considered by consumers in terms of accessing desired health services<sup>156,196</sup>. Consumers in one study reported a need for easier and more personal communication options with healthcare providers<sup>196</sup>.

## 3.7 Health services: Osteoporosis and bone health

### 3.7.1 Description of included studies

Thirty two relevant studies were identified. Of these, 12 were from the United States of America<sup>91,93,96,216-224</sup>, six from Canada<sup>97,100,101,225-227</sup>, three from the United Kingdom<sup>103,106,115</sup>, two from Denmark<sup>107,108</sup>, two multicentre studies<sup>228,229</sup>, and one each from the Netherlands<sup>230</sup>, Slovakia<sup>110</sup>, Germany<sup>231</sup>, Australia<sup>232</sup>, Spain<sup>233</sup>, Israel<sup>234</sup> and Argentina<sup>235</sup>. The inclusion criteria for study participants varied across studies. Ten studies included participants diagnosed with osteoporosis or osteopenia<sup>93,103,106,110,218,221,222,228,229,232</sup>, six had consumers with a history of fragility fractures<sup>96,100,101,219,225,227</sup>, six had consumers treated for osteoporosis<sup>97,220,224,230,234,235</sup>, five had consumers with osteoporosis based on BMD measurements (T score >-2.5)<sup>91,107,108,216,223</sup>, three included individuals at high risk of osteoporotic fractures<sup>217,233</sup> and three studies provided no definition of osteoporosis<sup>115,226,231</sup>. There were only two studies in which the population was chosen without regard initially for being at high risk of osteoporosis or having osteoporosis: one assessed only preferences for medication regimen<sup>115</sup> the other examined attitudes towards screening and was purposively selected from a larger randomised controlled study<sup>107</sup>. Twenty-two studies examined only female participants<sup>91,96,97,103,106-108,110,216,218,219,221-224,228,229,231-235</sup> and the remaining 10 studies evaluating a predominance of women<sup>93,100,101,115,217,220,225-227,230</sup>.

### 3.7.2 Results: Consumers' perceived health service needs regarding osteoporosis and bone health

Four main areas of consumers' perceived needs emerged from this review:

- 1) consumers' perceived needs of healthcare providers in the management of their bone health
- 2) consumers' perceived needs of pharmacotherapy for osteoporosis
- 3) consumers' perceived needs of non-pharmacological management of osteoporosis
- 4) consumers' perceived needs of investigations for osteoporosis.

#### 3.7.2.1 Consumers' perceived needs of healthcare providers in the management of their osteoporosis and bone health

##### 3.7.2.1.1 Consumers' preference for seeing the doctor and role of the doctor

Consumers' preference for seeing a doctor for their osteoporosis and the perceived role of the doctor was identified in seven studies<sup>91,93,96,97,103,108,227</sup>. Four studies found that consumers sought care from the doctor for their bone health<sup>91,93,97,103</sup> with one study reporting that consumers believed and trusted specialists such as endocrinologists and rheumatologists more than their primary care physician<sup>93</sup>. Feldstein found that consumers who had sustained a fracture advocated for standardised protocols for integrating and involving specialists in the management of osteoporosis<sup>96</sup>. Consumers perceive the role of the doctor to perform a thorough examination<sup>108</sup>, provide osteoporosis information and education<sup>96,103,108,227</sup>, initiate screening for osteoporosis<sup>96,227</sup>, prescribe and monitor treatment<sup>91,96,97,227</sup> and provide support<sup>97</sup>.

##### 3.7.2.1.2 Desirable characteristics of the doctor

Four studies reported on consumers desired characteristics of doctors in the management of osteoporosis<sup>97,106,108,224</sup>. Besser found that consumers wanted to be involved with decisions related to osteoporosis treatment<sup>106</sup>. Lau and Rizzoli reported the consumers wanted follow up from healthcare providers for support and monitoring of medications<sup>97,224</sup>. Also, consumers wanted their osteoporosis to be taken seriously<sup>108</sup> and to be able to discuss medication problems and concerns<sup>97</sup>. Furthermore, Lau reported that consumers wanted non-judgemental care from their doctors<sup>97</sup>.

##### 3.7.2.1.3 Dissatisfaction with the doctor and concerns about the doctor

Consumers' dissatisfaction and concerns with their doctor relating to their osteoporosis management was recognised in five studies<sup>91,93,103,106,216</sup>. Consumers perceived poor communication, lack of definitive answers regarding osteoporosis and poor continuity of care to be barriers to a good relationship with their doctor<sup>106,216</sup>. Besser and Iversen found that consumers were dissatisfied with the lack of time during consultations, and felt that they were unable to ask questions or raise issues with medications with their doctors<sup>93,106</sup>. Consumers were disappointed with the strong focus on medications and expressed distrust when doctors were too quick to recommend medications<sup>91,103</sup>. Consumers perceived poor communication, lack of definitive answers regarding osteoporosis and poor continuity of care to be barriers to a good relationship with their doctor<sup>106,216</sup>.

### **3.7.2.2 Consumers' needs of pharmacotherapy**

#### **3.7.2.2.1 Preference for medications and role of medications**

The consumers' preference for medications and the perceived role of pharmacotherapy was examined in 11 studies<sup>91,97,101,106,217,219,220,223,225,227,233</sup>. Some studies found that consumers had a preference for pharmacological management of osteoporosis<sup>97,101,106,217,220,225,227</sup>. In particular, consumers that had been told of the diagnosis of osteoporosis<sup>219,223</sup>, those that had a good relationship with their doctor or trusted their doctors<sup>101,220</sup>, those who believed they were susceptible to fractures<sup>220</sup>, those that had previous bone mineral density (BMD) testing<sup>219</sup> and those that believed in the effectiveness of medications<sup>223</sup> were more willing to take medications. Consumers perceived the role of pharmacotherapy was to help eliminate symptoms, help avoid further deterioration in bone health, replace something they cannot obtain through diet alone, provide extra strength for the bone and improve bone density<sup>91,101</sup>. A single study that compared consumers' preference for pharmacotherapy versus hip protectors found that they preferred bisphosphonates for the management of their osteoporosis, however, older consumers were more likely to avoid prescription medications and preferred hip protectors<sup>217</sup>. However, Mauck reported that most women who were admitted to a tertiary hospital after a fragility fracture were either unaware of osteoporosis or had never considered pharmacological treatment<sup>219</sup>. Several studies reported that consumers did not prefer pharmacotherapy for osteoporosis management<sup>91,97,101,227</sup>. Some consumers viewed osteoporosis as a consequence of ageing and did not perceive a need for medications<sup>91</sup>, and some wanted a drug holiday from bisphosphonate treatment<sup>227</sup>. Also, some consumers preferred lifestyle modifications rather than pharmacotherapy for osteoporosis management<sup>91,97,227</sup>. Mazor found that some consumers were confused about the use of medications, and believed that they would reduce pain<sup>91</sup>.

#### **3.7.2.2.2 Concerns about medications**

Several studies reported consumers' concerns with osteoporosis pharmacotherapy<sup>91,93,97,101,106-108,221,223,230,235</sup>. They were worried about side effects with medications<sup>91,93,97,101,106-108,221,223,230,235</sup>, drug interactions and polypharmacy<sup>106,235</sup>, potential for addiction and overdosing<sup>106</sup> and dislike of chemicals<sup>97,106</sup>. Some consumers expressed distrust of medications<sup>223</sup> and of pharmaceutical companies<sup>106</sup>. Iversen reported that consumers found the method of medication administration and instructions difficult to understand and remember<sup>93</sup>. Dissatisfaction with their doctor or the physician's attitude were other reasons for consumers to not want pharmacotherapy for the management of osteoporosis<sup>101,235</sup>. Also, some studies reported specific concerns that consumers had with pharmacotherapy, including the potential for jaw osteonecrosis, gastrointestinal side effects, breast and oesophageal cancer, thrombotic effects and cardiovascular events<sup>97,107,230,235</sup>. Consumers were unwilling to take medications if they had family members or friends that had experienced adverse events, or if they heard about side effects from the media<sup>91,97</sup>. Also, consumers who believed they had good health, were concerned about medications for a condition that was otherwise asymptomatic and those with a family member that had osteoporosis with no complications were less likely to perceive a benefit with pharmacotherapy<sup>107,221</sup>.

#### **3.7.2.2.3 Preferable therapeutic attributes of medications**

Twelve studies examined the consumers' preferred therapeutic attributes of osteoporosis pharmacotherapy<sup>115,218,222,224,229-232,234</sup>. They wanted osteoporosis medications to be effective<sup>218,222,228,229</sup>, to not interact with other medications<sup>224</sup>, have fewer side effects<sup>224,229</sup>, and be easier to administer<sup>222,224,228</sup>. A single study evaluating combination packaging of bisphosphonates and calcium supplementation found that consumers preferred the ease and convenience of combination packaging<sup>231</sup>. Some studies found that consumers preferred weekly to daily or monthly dosing<sup>218,222,228,232</sup>, however, other studies reported a preference for monthly<sup>110,230</sup>.

### **3.7.2.3 Consumers' perceived needs of non-pharmacological management**

#### **3.7.2.3.1 Calcium and vitamin D**

Consumers' desire for calcium and vitamin D supplementation was found in four studies<sup>96,97,225,226</sup>. These studies found that consumers wanted these supplements for osteoporosis management. They expressed more willingness and comfort with taking supplements than prescription medication<sup>96</sup> and perceived them to be more natural and safe<sup>97</sup>.

#### **3.7.2.3.2 Exercise therapy**

Consumers' perceived needs for exercise therapy was identified in two studies that found they see a role for exercise for osteoporosis management<sup>225,226</sup>.

#### **3.7.2.4 Consumers' perceived needs of investigations for osteoporosis**

Three studies described consumers' perceived need for investigations for the diagnosis of osteoporosis<sup>91,107,227</sup>. Consumers see a role for bone mineral density testing for diagnostic evaluation<sup>91,227</sup>. Rothmann found that consumers interpreted screening for osteoporosis as an opportunity to get reassurance about bone health and to take care of their own health<sup>107</sup>. Three other studies evaluated the consumers' perceived need for investigations for ongoing surveillance of bone health<sup>91,106,227</sup>. Consumers wanted feedback from dual energy x-ray absorptiometry (DEXA) scans to evaluate the efficacy of pharmacotherapy<sup>91,106</sup>. Sale reported that consumers felt that they had to nag their physicians and follow up their own results<sup>227</sup>.

## 3.8 Health services: Overall summary

### 3.8.1 Overall results: Consumers' perceived health service needs

The systematic review identified a number of common consumer perceived health services needs across the different conditions (inflammatory arthritides (rheumatoid arthritis and ankylosing spondylitis), **osteoarthritis**, **back and neck pain** and **osteoporosis**). Health service need were classified according to medical services, allied health and complementary medicine. Across these we also identified the desirable characteristics of those healthcare providers and health services.

Of the musculoskeletal conditions examined, the most significant literature focused on **back pain**. However it can be seen on review of the summary tables (Tables 2-4) that there was significant overlap across the conditions. These summary tables relate to:

- 1) consumers' perceived needs of medical services
- 2) consumers' perceived needs of allied health and complementary and alternative medicine
- 3) consumers' perceived needs of health service providers and services

#### 3.8.1.1 Consumers' perceived needs for medical services (Table 2)

##### 3.8.1.1.1 Needs related to health services provided by the medical practitioner

###### 3.8.1.1.1.1 Role of the doctor, and strengths of the doctor

Whilst the doctor was seen as central to consumers accessing health services and health care management, the role of the doctor was not the subject of any studies in **inflammatory arthritis**, **osteoarthritis**. The doctor was seen as central to providing pain relief and providing self-management advice in most of the conditions studied.

Regarding the need for health services related to **back pain**, the doctor was seen to be necessary to provide an accurate diagnosis<sup>66,68,69,85,176,178,187</sup>, to legitimise pain<sup>37,69,164,207</sup>, in part, by providing sickness certificates<sup>69,207</sup>, to act as a conduit to additional care from specialists and other healthcare practitioners<sup>79,186,193,236</sup>, to provide medication<sup>79,114,207</sup>, relieve pain<sup>67,68,188</sup>, provide advice and education about prevention, self-management and counselling<sup>51,68,79,86,176,186,198</sup>. Similarly, related to **neck pain**, the doctor was seen to be important in providing continuity of care<sup>87-89,156,237</sup>, listening<sup>87,214,237</sup>, and self-management advice<sup>87,88,196</sup>.

Regarding the need for health services related to **osteoporosis**, the doctor's role was to provide an accurate diagnosis<sup>108</sup>, to refer to other relevant health practitioners<sup>93,96</sup> and provide overall management<sup>93,96,97,103,227</sup> and to prescribe medications<sup>91,96,97,227</sup>.

###### 3.8.1.1.1.2 Preference to see, and satisfaction with, the doctor

The primary care medical practitioner was seen as necessary to provide referral to specialist care in those with **back pain**, despite consumers perceiving a reluctance, on the part of the primary care practitioner, to refer patients<sup>50,72,193</sup>. Consumers expressed faith in the doctor regarding the provision of care regarding **inflammatory arthritis**<sup>125,136</sup>, **back pain**<sup>50,67,165,180</sup> and **osteoporosis**<sup>91,93,108</sup>.

###### 3.8.1.1.1.3 Consumers' dissatisfaction with the doctor

Consumers identified inadequacies regarding the doctor. All identified problems were relevant to the perceived need of health services related to **back pain**. In **back pain**<sup>51,59,64,72,85,118,178,207</sup>, **osteoarthritis**<sup>39</sup> and **osteoporosis**<sup>216</sup> consumers were dissatisfied with doctors who were seen to take a superficial approach, and display a lack of knowledge. There was dissatisfaction with doctors who had a tendency to delegitimise pain and were dismissive of symptoms relating to **back pain**<sup>64,79,156</sup>, and in those with **osteoarthritis**<sup>39</sup> and **neck pain**<sup>156</sup>. Doctors deemed to "just give medications" and not provide a variety of therapeutic options did not provide satisfaction in those with **back pain**<sup>51,118,156,208</sup> or **osteoporosis**<sup>72,91,103</sup>. Consumers aspired to doctors who communicated with allied health practitioners and provided timely referrals in the management of **back and neck pain**<sup>87-89,196,207,208,237</sup>.

###### 3.8.1.1.1.4 Characteristics of patients more likely to seek medical care

Consumers sought medical care more frequently for **inflammatory arthritis**<sup>144</sup> and **back pain**<sup>173,176,182</sup> if they were more functionally impaired. Those with **inflammatory arthritis** sought health care during a flare<sup>129</sup>.

Identification of characteristics of consumers more likely to seek medical care was only examined in those with **inflammatory arthritis**. Care seeking occurred during a flare of disease<sup>129</sup>, in those with older age<sup>130</sup>, and often as a last resort<sup>129,144</sup>. In two studies it was noted that it was not uncommon for consumers to delay care seeking for **inflammatory arthritis**, as they misattributed symptoms to another condition<sup>113,134</sup>.

### 3.8.1.1.2 Role of pharmacological management and concerns with medications

#### 3.8.1.1.2.1 Role of medications and patients' preferences for medications

The perception of need for medications was not addressed in the **inflammatory arthritides**. There were some contradictory findings regarding the perception of the role of medications in those with **back pain**, **osteoporosis** and **osteoarthritis**. Whilst in some studies, consumers expected medications and considered them useful, in other studies, consumers expressed resistance to regular use and, only taking medications as a last resort - three studies in **osteoarthritis**<sup>39,152</sup>, four in **back pain**<sup>68,163,179,198</sup> and **osteoporosis**<sup>91,97,217,219</sup>. One consumer professed resistance to taking medications, particularly for an asymptomatic condition, ie **osteoporosis**<sup>107</sup>. Consumers tended to be wary of side effects in the studied conditions. This was particularly common in studies regarding the use of medications in **osteoporosis**, with 11 studies identifying this concern<sup>91,93,97,101,106-108,221,223,230,235</sup>. This was also of concern in those with **osteoarthritis**<sup>39,44,151</sup> and **back pain**<sup>114,158,163,179</sup>. There was a perception that the benefit was greater than the fear of dependency or side effect regarding the use of analgesics in **back pain**<sup>66</sup>. Regarding the use of medication related to **back pain** there were single studies that noted a preference for medication use and passive therapy rather than active therapy<sup>67</sup>, and that narcotic use was associated with consumer satisfaction<sup>172</sup>.

#### 3.8.1.1.2.2 Concerns regarding medications

Consumers expressed a number of concerns relating to medications. This was especially in studies of **back pain**, where there was a fear of addiction and stigmatisation noted in five studies<sup>66,67,163,179,184</sup>, and also one study relating to **osteoporosis**<sup>106</sup>. Consumers desired clear information regarding how to take the prescribed medication for **back pain**<sup>168,179</sup> and **osteoporosis**<sup>93</sup>. The cost of medication was concerning to those with **osteoarthritis**<sup>151,152</sup> and **osteoporosis**<sup>235</sup>. Consumers were cautious of therapy for **osteoporosis** in particular, being concerned about drug interactions, polypharmacy, mistrust of doctors and pharmaceutical companies<sup>106,221,235</sup>.

### 3.8.1.1.3 Role of interventional procedures, injections and surgery

Surgery was seen as a last resort for those with **osteoarthritis**<sup>39</sup> and **back pain**<sup>163,179,201</sup>. In both conditions, consumers were concerned about possible complications<sup>39,163</sup>.

The perceived need for surgery for **back pain** was associated with higher levels of pain, and shorter duration of pain although there was no difference related to income, the amount of sick leave available or the expectations of surgical results<sup>203</sup>. Most of this information relates to the role of health services for **back pain** regarding interventional procedures. The only study describing attitudes towards injections for **back pain** found that consumers avoided injections, stating they would rather "live with pain"<sup>179</sup>.

#### 3.8.1.1.4 Perceived role of imaging

##### 3.8.1.1.4.1 Preference for imaging

This need was identified particularly in relation to **back pain**. There is a perceived need of those with **back pain** to undergo imaging<sup>50,68,83</sup>. This was associated with higher pain severity in one study<sup>170</sup>.

##### 3.8.1.1.4.2 Role of imaging

The need for imaging in **back pain** was driven by a need to identify a diagnosis underlying the consumer's **back pain**, thus legitimising the pain<sup>76,83,176,178,210</sup>. Consumers were relieved by a definitive diagnosis.

In contrast, in relation to **osteoporosis**, imaging was required for diagnosis and monitoring of therapy<sup>91,106,227</sup>.

### 3.8.1.2 Consumer needs of allied health and complementary and alternative medicine (Table 3)

#### 3.8.1.2.1 Non-traditional allied health (acupuncture, osteopathy, massage, local heat therapy)

##### 3.8.1.2.1.1 Willingness to try, or preference for, complementary and alternative medicine

Consumers were willing to try complementary and alternative medicine for the **inflammatory arthritides**<sup>128,132,140,142,143</sup>, **osteoarthritis**, **back pain** and **osteoporosis**. However, the expectations regarding the success of complementary and alternative medicine were lower than for conventional medicine, with it being perceived to be useful as an adjunct only<sup>140</sup>, or a desperate measure<sup>143</sup>, where conventional approaches have failed<sup>137</sup>.

##### 3.8.1.2.1.2 Perceived benefit, and satisfaction of, complementary and alternative medicine

Complementary and alternative medicine was expected to provide some relief from symptoms related to inflammatory arthritis<sup>131,132,140,143</sup>, **back pain**<sup>156,163,185,198</sup> and **osteoarthritis**<sup>140</sup>.

### 3.8.1.2.1.3 Concerns with complementary and alternative medicine

The cost of complementary and alternative medicine was seen as problematic for consumers with inflammatory arthritis<sup>137,140</sup>, **osteoarthritis**<sup>45</sup> and **back pain**<sup>51</sup>, particularly when complementary and alternative medicine was ineffective<sup>140</sup>. Aligned with the belief that complementary and alternative medicine was likely to be less effective than conventional medicine, consumers with **back pain** believed that the effect would be transitory<sup>51</sup>, or only able to provide limited relief<sup>51,69</sup>. They were also concerned about the possibility of “painful needling” and the adverse psychological effects of spinal manipulation<sup>156,163</sup>. Consumers with inflammatory arthritis variably disclosed their use of complementary and alternative medicine to their treating healthcare providers, with non-disclosure related to a sense that it was not important, or that the physician may disapprove of their using complementary and alternative medicine<sup>142,143</sup>.

### 3.8.1.2.2 Physiotherapy and exercise therapy

#### 3.8.1.2.2.1 Willingness to try, or preference for, physiotherapy and exercise

Physiotherapy was widely perceived as being necessary in the management of **back pain**<sup>50,68,116,118,190,198,202,208,209</sup>, **osteoarthritis**<sup>27,39,45,146</sup>, and inflammatory arthritis<sup>141,146</sup>.

#### 3.8.1.2.2.2 Perceived benefit of physiotherapy and exercise

Physiotherapy was seen to provide relief for both **back pain**<sup>163,190</sup> and **osteoarthritis**<sup>27,39</sup>. Exercise was also thought to relieve pain in those with **back pain**<sup>67,202</sup> and **osteoarthritis**<sup>27,45</sup>. Consumers with **back pain** believed that physiotherapy would have rapid benefits, even after the first session<sup>190,191</sup>.

#### 3.8.1.2.2.3 Individualising physiotherapy and exercise

It was perceived to be more beneficial if exercise and physiotherapy programs were individualised rather than seemingly “off the shelf” for those with **osteoarthritis**<sup>40,147</sup>, **back pain**<sup>118,161,210</sup> and neck pain<sup>89,237</sup>.

#### 3.8.1.2.2.4 Concerns with physiotherapy and exercise

The main concern regarding physiotherapy was the difficulty in maintaining compliance with the program for those with **osteoarthritis**<sup>45,147</sup> and **back pain**<sup>202,210</sup>. Whilst some participants with inflammatory arthritis in Ackerman’s study were concerned about a lack of benefit<sup>147</sup>, those with **back pain** were concerned about the possibility of injury<sup>163</sup>.

### 3.8.1.2.3 Chiropractic therapy

The role of chiropractors was only evaluated in the context of **back pain**.

#### 3.8.1.2.3.1 Willingness to try chiropractor or preference for chiropractors

Some consumers with **back pain** perceived chiropractors to be the primary healthcare practitioner of choice<sup>179,182</sup>. The role of chiropractors was not evaluated in the other conditions.

#### 3.8.1.2.3.2 Perceived benefits, expectation and concerns with chiropractors

Chiropractors were perceived as being associated with higher satisfaction than other healthcare providers in this context<sup>177,180,181,211</sup>. They were perceived as being more likely to provide an accurate diagnosis than other practitioners<sup>85,194,195</sup>. They were also perceived by consumers in one study to be more empathetic and knowledgeable<sup>85</sup>.

#### 3.8.1.2.3.3 Characteristics of consumers preferring chiropractors

Three studies identified the characteristics of consumers seeking chiropractic care<sup>173,180,181</sup>. However these found some conflicting results. Carey found men, who were less than 60 years of age and attributed their pain to disc disease being more likely to seek chiropractic care<sup>180</sup>. In those who attended a chiropractor for **back pain**, Sharma found that there was a high proportion of self-paying patients, who were older, with higher income, who were also opposed to prescription drug use<sup>173</sup>.

#### 3.8.1.2.4 Use of orthoses/physical aids

The perception of need of orthoses and physical aids were only addressed in studies relating to **osteoarthritis**. Whilst mobility aids were considered necessary, their use, was not well accepted because they were seen to imply old age and loss of autonomy<sup>39,45,39,45</sup>. Knee braces were perceived as useful<sup>39,44</sup>, although aesthetic concerns interfered with their use<sup>39</sup> and that of therapeutic footwear<sup>28</sup>. In one study in the UK, those with **osteoarthritis** had little awareness that there were living aids and home adaptations that were available through social services or by assessment from an occupational therapist or nurse for those waiting for a joint replacement<sup>153</sup>.

### 3.8.1.3 Characteristics of healthcare providers (Table 4)

#### 3.8.1.3.1 Communication needs

##### 3.8.1.3.1.1 Good communication skills

Clear and accurate explanations of the condition and management was valued by those with inflammatory arthritis<sup>19,133</sup>, **osteoarthritis**<sup>39,40</sup>, **back pain**<sup>54,69,166,179,210</sup> and neck pain<sup>96</sup>. No studies were identified for **osteoporosis**. In studies with inflammatory arthritis<sup>19,125,133,136</sup>, **osteoarthritis**<sup>28,39</sup> and **back pain**<sup>54,55,69,166,179,210</sup> participants, consumer-centred communication and participation in decision making was desired. A supportive, open communication style was valued in those studies with inflammatory arthritis<sup>19,125,136,139</sup>, **back pain**<sup>54,55</sup> and **osteoporosis**<sup>97,108</sup> participants. The use of simple language rather than jargon was also appreciated<sup>166,186,201</sup>.

##### 3.8.1.3.1.2 Shared decision making, respect and being listened to

Healthcare providers that listened to consumers with inflammatory arthritis<sup>19,133,139</sup>, **osteoarthritis**<sup>40,152</sup>, **back pain**<sup>72,79,169,186,205,210,212</sup> and neck pain<sup>87,214,237</sup> were valued. Consumers wanted to be able to play an active role in their management of inflammatory arthritis<sup>19,125,136</sup>, **back pain**<sup>89,171,186</sup>, neck pain<sup>87-89</sup> and **osteoporosis**<sup>93,97,103,106</sup>. Being respected and trusted was important to consumers with inflammatory arthritis<sup>125,130</sup>, **back pain**<sup>186,210</sup>, neck pain<sup>88,89,196</sup> and **osteoporosis**<sup>97,108</sup>. Consumers expressed frustration when healthcare providers did not prioritise their musculoskeletal condition, including those with **osteoarthritis**<sup>39</sup>, **back pain**<sup>179</sup>, and neck pain<sup>88,89,196</sup>. Consultations of adequate time were desired by consumers with **osteoarthritis**<sup>28,40</sup>, **back pain**<sup>116,210,212</sup>, neck pain<sup>88,156,196</sup> and **osteoporosis**<sup>93,106,224</sup>.

##### 3.8.1.3.1.3 Empathy, understanding and confidence

An understanding and empathetic provider was desired by consumers with inflammatory arthritis<sup>133,135,139</sup>, **back pain**<sup>66,116,208,210</sup>, neck pain<sup>88,156,214,237</sup> and **osteoporosis**<sup>108</sup>. Alami and Bush noted that those with inflammatory arthritis and **back pain**, respectively, wanted a confident provider<sup>39,183</sup>. A provider who took a non-judgemental approach was desired by those with **back pain**<sup>210</sup> and **osteoporosis**<sup>97</sup>.

#### 3.8.1.3.2 Information provision

##### 3.8.1.3.2.1 Diagnosis and finding a cause of pain

Consumers with **back pain** consistently wanted their provider to give them a diagnosis underlying their pain<sup>66,74,76,86,89,117,118,160,166,196,197,200</sup>. This was perceived necessary to justify their pain<sup>66</sup>. The need for information regarding a diagnosis was noted by participants in the study by Hansen, regarding **osteoporosis**<sup>108</sup>.

##### 3.8.1.3.2.2 Information provision by healthcare providers

Consumers with **back pain** consistently described the need for clear, consistent, non-conflicting and adequate information regarding their condition<sup>64,79,86,89,116,171,178,179,186,201,210,211</sup>. This need was also desired by those with inflammatory arthritis<sup>19,133</sup>, **osteoarthritis**<sup>39,147</sup> and **osteoporosis**<sup>106,108</sup>. In addition, consumers with **back pain** wanted their healthcare provider to explain the cause of their pain<sup>79,89,211</sup>. Those with neck pain wanted advice regarding self-management and the role of rest<sup>87,88,196</sup>. This was similar to those with **back pain**<sup>64,89,178,186,200,201,210</sup>. Participants with **back pain** in the study by Bahouq requested information regarding the management of sexual problems<sup>204</sup>.

##### 3.8.1.3.2.3 Legitimation

Consumers needed to legitimise their symptoms that were attributed to **osteoarthritis**<sup>152</sup> and **back pain**<sup>100,197,205,210</sup>.

#### 3.8.1.3.3 Aspects of care

##### 3.8.1.3.3.1 Type of approach to health care: Holistic, personalised, emotionally supportive, encouraging

Holistic and personalised care was appreciated by consumers with inflammatory arthritis<sup>136,139</sup>, **osteoarthritis**<sup>28,39</sup>, **back pain**<sup>79,89,166,196</sup> and neck pain<sup>89,196</sup>.

##### 3.8.1.3.3.2 Thorough assessment, time and effort, continuity of care

Consumers desired practitioners who performed thorough clinical assessments, including a physical examination, when managing their **back pain**<sup>50,69,72,181</sup>, neck pain<sup>88,156,214</sup> and **osteoporosis**<sup>108</sup>. Consumers wanted to feel that their provider had spent adequate time with them discussing and managing their inflammatory arthritis<sup>133,135,139</sup>, **back pain**<sup>116,212</sup>, neck pain<sup>88,156,196</sup> and **osteoporosis**<sup>93,106,224</sup>. Continuity of care was valued by those with inflammatory arthritis<sup>139</sup>, **back pain**<sup>89,116,160,210</sup>, neck pain<sup>87-89,156,237</sup> and **osteoporosis**<sup>74,96,97,106,227</sup>.

### 3.8.1.3.3.3 Qualifications and technical skills

Specialist qualifications, reputation and knowledge were deemed to be important by consumers in the management of **osteoarthritis**<sup>39,40</sup> and **back pain**<sup>82,169</sup>. Specialist knowledge was not seen to be discipline specific, and consumers with **osteoarthritis** in the study by Mann would be satisfied with a practice nurse who had specialist knowledge<sup>30</sup>.

### 3.8.1.3.3.4 Collaborative approach between healthcare providers

Consumers desired a collaborative approach between the different healthcare practitioners involved in the care of their **back pain**<sup>179,186,196</sup> and neck pain<sup>87,196,237</sup>.

### 3.8.1.3.3.5 Convenience of care provision

The convenience of where and when specialty care was provided was important to consumers with inflammatory arthritis<sup>125,238</sup> and **osteoarthritis**<sup>238</sup>. An accessible healthcare practitioner was desired by consumers with inflammatory arthritis<sup>19,133,135</sup>, **osteoarthritis**<sup>30,195,238</sup> and neck pain<sup>88,156,196</sup>.

### 3.8.1.3.4 Sharing experiences with other patients

Consumers with inflammatory arthritis perceived value in sharing their experiences with other people with their condition<sup>133,136</sup>.

### 3.8.1.3.5 Barriers to care

There were a number of common barriers to management and health care across the conditions. Cost was a barrier to care for those with inflammatory arthritis<sup>134,142,144</sup>, **osteoarthritis**<sup>45,151,152</sup>, **back pain**<sup>179,196,210,212</sup> and neck pain<sup>156,196</sup>. Poor access was attributed to rurality and long waiting times by those with inflammatory arthritis<sup>134,142</sup> and **back pain**<sup>59,66,74,82,118,166,179,212</sup>. Poor compliance with physiotherapy and exercise prescription in those with **osteoarthritis** was attributed to a lack of time, distance, work and family commitments and time and venue preferences<sup>147</sup>. In those with **back pain**, poor compliance was attributed to cost, lack of rural services, lack of time, family commitments and difficulty with transport<sup>82,161,162,179,196,202,210,212</sup>. The consumer's sense of social obligation was also a potential barrier to management of inflammatory arthritis<sup>130</sup> and **osteoarthritis**<sup>147</sup>. Poor communication was also identified by consumers as an impediment to optimal management of **back pain**, neck pain<sup>196</sup> and **osteoporosis**<sup>106</sup>.

## 3.8.2 Discussion

There are limited studies in which consumers have been directly asked for their preferences regarding health services related to musculoskeletal conditions. However within this review are a number of questions that have been more extensively studied in a single condition, such as the use of imaging in back pain and medication regimen preferences in osteoporosis.

There is a more complete body of literature in back pain, addressing consumer perceived needs of health services, compared to the other conditions. Some of the areas of work may be driven by the stigma associated with these conditions<sup>239</sup>. Back pain warrants attention because of the large associated burden, which has been estimated as imposing the highest cost in terms of disability years in the Global Burden of Disease Study 2010<sup>240</sup>. The economic costs in the USA in 2004-5 were estimated at US\$187 billion<sup>241</sup>. The costs of imaging have been estimated to consume up to 39% of direct costs of back pain<sup>242</sup>.

Thus there is the potential to reduce the associated health care spending as a better understanding of the consumer and their needs of health services eventuates; and as the consumer plays an increasing role in demanding these investigations and interventions. These factors explain the preponderance and focus of studies regarding imaging and need for a diagnosis in back and neck pain. Thus there are a number of areas that are specific to back and neck pain regarding health services. These stem from the discrepancy between imaging and symptoms and the role of psychosocial factors in these conditions and their prognosis<sup>243</sup>. This may create an atmosphere of uncertainty for consumers, healthcare providers, employers and co-workers. It is possible that this accounts for the previously described perceived needs for legitimisation, a firm diagnosis and the consumer pre-occupation with imaging. Other studies are focused on interventions that are relevant only to back pain, such as consumer perception of management by chiropractors.

Another area of potentially biased focus relates to osteoporosis. Osteoporosis is a silent condition, identified either by screening or following a minimal trauma fracture. The identified studies did not examine attitudes to screening in a general population, with the exception of the study by Rothmann<sup>107</sup>, but this examined attitudes towards screening in only 20 women recruited to address this issue, which did not differentiate women without osteoporosis<sup>107</sup>. Osteoporosis has had good, effective treatment since the 1990s with the use of bisphosphonates. However there are a number of bisphosphonates on the market with similar efficacies but with different treatment frequencies, eg daily, weekly, monthly or annually. A number of studies address consumer preferences around this question, some funded by pharmaceutical companies, others have no stated funding source. Thus these studies are focused and relevant only to osteoporosis and may not be applicable to medication regimes used in the other conditions.

The data in this report are limited around studies evaluating a single question. Consumers with each condition may not have been provided the forum in which to express their needs. Thus a lack of information or identified need may not indicate a lack of perceived need. Nevertheless there are significant similarities in perceived need between the different conditions, so it is likely that many of these perceptions of need are generalisable. It is also unclear whether perceived need is met by existing services or how much funding affects this. Whether these are matched requires further study, and findings are likely to be specific to different countries and healthcare funding systems.

Similarly, expectations of health service requirements may be affected by the country and availability of health services and the local health system. Many of these studies were performed in the UK, the USA, Canada and Australia. Whereas there is a component of socialised medicine in the UK, Canada and Australia, in the USA, the system differs. This may impact on the need for health services and the focus of the study. There were few studies from Eastern Europe and the developing world.

There was considerable consistency across the different conditions regarding the perception of health services needs, including attitudes towards the role of the doctor and the desirable characteristics of healthcare practitioners. There was also consistency with regards to the role and concerns related to the use of medications and other interventions; the use of allied health and complementary and alternative medicine; and desirable characteristics of healthcare practitioners and their assessments. The few studies relating to consumer perceived barriers to healthcare, also had consistency in their findings.

Where various health services are recommended in the management of these musculoskeletal conditions, it is more important to identify whether consumers perceive the need for these services, and whether the services exist in that environment. For example, exercise programs are often recommended in guidelines for the management of knee osteoarthritis<sup>119,244</sup>. Thus a lack of perceived need for these in the management of knee osteoarthritis may occur as a result of poor knowledge. As an extension it is useful to focus on what the barriers are to participating in exercise programs. Although only identified in two studies, the findings were consistent and plausible regarding time constraints<sup>40,147</sup>.

There were a number of identified gaps in the search. Whilst there were a number of studies examining the different regimens available for bisphosphonates in managing osteoporosis, it was surprising that no studies were identified that examined consumer preferences to different injection regimens and infusions related to the inflammatory arthritides, given the number of biological therapies available, and that this may be one of their distinguishing features. However, this may reflect the maturity of therapy for the different conditions, with treatment options being established since the early 1990s for osteoporosis but a selection only being available for the inflammatory arthritides since the late 2000s. It may also relate to the biology of the conditions, with osteoporosis being a more homogeneous condition but the inflammatory arthritides more varied, and with less predictable response to drug therapy. Thus the consumers' primary concern is that the treatment is effective. The imperative of efficacy of treatment is of greatest potential impact for those with inflammatory arthritis as the biological therapy has the most marked impact on objectively measurable outcomes. Nevertheless, with the state of flux in the market, and the entry of biosimilars, the need to assess the different regimens may be more important in the near future.

### 3.8.3 Conclusions

This review has identified that consumers with a variety of musculoskeletal conditions have similar health services needs in general.

- They desire medical care, see benefit (in general) of medications, but are concerned about the potential for side effects and addiction. They are wary of procedures. Those with back and neck pain perceive a strong need for an accurate diagnosis in order to legitimise their pain.
- Allied health and complementary and alternative medicine are seen as useful adjuncts to medical therapy, but are not seen as curative. Individualised programs are preferred to group, off the shelf interventions.
- Consumers prefer healthcare providers who take a thorough, holistic approach to their health care, have good communication skills, allow them to take an active role in their own management and do this in an empathetic and understanding fashion. They want to receive clear and consistent information, including an explanation of why they have pain. Care should be dispensed at a convenient time and place to the individual. They perceive the main barriers to health care services to be cost, followed by access issues, related to waiting times for appointments and referrals, and location. Compliance with allied health programs is problematic, due to lack of time, transport, cost and a variety of other factors. Social obligation may also present an impediment to attending to their own health, particularly for women.

There are also issues specific to some conditions. In particular, those with back and neck pain perceive a strong need for a definite diagnosis that they believe is required for legitimisation of their pain and for a clear treatment plan.

Although this review is comprehensive in terms of identifying the available studies and using established systematic review methodology to in developing search strategies and applying those the four major electronic health databases it is important to take this review in context. The results on which these conclusions are base is founded on a limited number of studies, biased in part by the over representation of studies on back pain. Whether all the perceived needs are similar for all the conditions is unclear as these questions may not have been asked to consumers across all conditions, particularly related to barriers to care. It is also uncertain what the consumer perceived needs for currently existing health services are.



**“There’s one thing I’d like to add to all of that is listen. Listen to me. And listen to what I ‘m trying to tell you . . . they’re not listening.”**

**(Slade, 2009<sup>262</sup>)**

# 4. Consumers' perceived needs regarding other non-medical services



## 4. Consumers' perceived needs regarding other non-medical services

### 4.1 Introduction to consumers' perceived needs regarding other non-medical services

In considering consumers' perceived needs regarding other non-medical services, to ensure a broad and comprehensive search was performed, we considered a variety of dimensions of other non-medical services. We considered where consumers may seek other forms of help and use other services to overcome issues related to their musculoskeletal condition. Thus we considered how the consumer may function in the home, including regarding their ability to perform activities of daily living and their social function. We considered how having a musculoskeletal condition may affect their occupation and work environment, and what services may be considered. We also considered how the consumer may interact with their general environment and travel within it.

Thus the search was designed to capture whether the consumer may perceive a need for the use of other non-medical services:

- a) inside the home related to function within the home and the ability to care for themselves. Thus terms related to different dwelling places were included and those related to daily function and self-care.
- b) within the work environment, including occupation, employment, unemployment and disability.
- c) within their social milieu, relating to family, friends and the wider community.
- d) negotiating the environment outside the home, relating to public spaces and transport, incorporating architecture and different forms of public transport.
- e) financial and legal needs, including those from whom they may seek help from.

The search strategy was refined in each of the four major health sciences electronic databases. This search strategy was applied to each of the significant musculoskeletal conditions examined to identify the literature related to consumer perceived needs regarding other non-medical services. Studies that were relevant were identified and information extracted. This information was collated and studies that addressed similar themes were grouped, with sub-themes extracted.

The results relating to the various themes and sub-themes identified were combined and presented across the different musculoskeletal conditions examined. The combined results were discussed and contrasted.

### 4.2 Search results

The search strategies returned 7,641 papers, of which 53 were identified as relevant for inclusion in this review.

## 4.3 Other non-medical services: Rheumatoid arthritis and other inflammatory arthritides

### 4.3.1 Description of included studies

Inflammatory arthritis was diagnosed clinically in all eight studies<sup>245-251</sup> except one, which recruited participants according to their use of assistive devices and did not describe the basis upon which they were classified as having an inflammatory arthritis<sup>252</sup>. The most common diagnosis was rheumatoid arthritis<sup>245,246,248-251</sup>, with some studies including more general "rheumatological disease"<sup>247,252</sup> and one study also including consumers with fibromyalgia<sup>250</sup>. Consumers were usually recruited through an outpatient clinic<sup>245-249,251,252</sup> although on one occasion through a self-management<sup>250</sup> program. One study recruited from an inpatient population as well as outpatient clinic<sup>249</sup>. All but one study selected predominantly female participants<sup>252</sup>. Data were most commonly from Europe - Norway<sup>250</sup>, the Netherlands<sup>245</sup>, Switzerland<sup>251</sup>, Denmark<sup>248</sup>, Estonia<sup>249</sup> and England<sup>246</sup> - with the remainder from North<sup>247</sup> and South America<sup>252</sup>.

#### 4.3.2 Results: Consumers' perceived other non-medical service needs regarding inflammatory arthritis

This review identified six main areas of need, including:

- 1) activities of daily living
- 2) social connectedness
- 3) self-help and peer groups
- 4) environmental modifications
- 5) financial needs
- 6) occupational needs.

#### 4.3.2.1 Activities of daily living both inside and outside the home

Consumers' need for assistance with activities of daily living, both inside and outside the home was identified in six studies<sup>246-250,252</sup>. Consumers indicated they received assistance with some daily tasks in multiple studies<sup>246-250</sup>. In one study of rheumatoid arthritis, 93% of people received assistance<sup>247</sup>. In some cases, this assistance came from their children<sup>246</sup>. However, consumers were not directly asked if they needed more help. They were often living alone (29%)<sup>249</sup> and concerned about getting assistance when required<sup>247</sup>. Compared to amputees, consumers with musculoskeletal conditions were less able to adjust to their circumstances and had less independence<sup>252</sup>. Consumers wanted to explore tools to make work and activities of daily living easier<sup>250</sup>.

#### 4.3.2.2 Social connectedness

Four studies discussed consumers' needs for social connectedness<sup>246,248,249,252</sup>. Loneliness and withdrawal were common problems<sup>248,249</sup>, exacerbated by losing work<sup>246,248</sup>. Loneliness was most common in consumers living alone<sup>249</sup>, with barriers to social connectedness including lack of understanding<sup>248</sup>, financial difficulties, mobility problems and fear of crime<sup>249</sup>. Assistive devices also made some consumers feel embarrassed or "weird"<sup>252</sup>.

#### 4.3.2.3 Self-help and peer groups

The value of peer groups for support and connectedness was highlighted in four studies<sup>247,248,250,251</sup>. Consumers were widely interested in self-help groups<sup>247</sup>. Self-help groups helped with coping and self-management through support, recognition and legitimisation of each other's experiences and problems<sup>248,250</sup>. These groups enabled consumers to build new relationships<sup>248,250</sup> and confide in sympathetic people. Groups also helped provide role models to show that normality is possible<sup>248</sup>. Peer groups for physical activity were desirable<sup>251</sup>.

#### 4.3.2.4 Environmental modifications

Consumers' environmental needs were examined in three studies<sup>249,251,252</sup>. Areas for environmental modification were found in the home, workplace and outdoors<sup>251,252</sup>. Consumers valued security and were concerned about falling victim of crime due to perceived weakness or invalidity<sup>249</sup>.

#### 4.3.2.5 Financial needs

Consumers' needs for financial security and support in general were shown in two studies<sup>247,249</sup>. Financial stress, both regarding present and future financial situation, was found to be common in both studies. Consumers in one study conducted in Estonia<sup>249</sup> reported that their financial concerns limited their socio-cultural experiences. They also reported that their basic needs were not met, as they lived in suboptimal home conditions, with food restriction and inadequate heating and running water<sup>249</sup>.

#### 4.3.2.6 Occupational needs

Consumers' work related needs were discussed in six studies<sup>245-250</sup>. All studies reinforced the consumers' desire to continue work in order to maintain a normal life. Continuing to work was seen as crucial to financial security<sup>249,250</sup>. Work was considered important to self-esteem and to identity<sup>248</sup>, as well as providing social networks<sup>248</sup>. Disability pensions were seen as a "last resort"<sup>250</sup>, with 25% of people worried about losing their job<sup>249</sup>. Many factors were identified to improve work retention and conditions including travel arrangements (parking, working from home)<sup>245</sup>, flexibility of hours and conditions<sup>245,246</sup> and ergonomics and accommodations in the workplace<sup>245,246</sup>. Consumers wanted more information about their work-related rights<sup>245,250</sup>.

## 4.4 Other non-medical services: Osteoarthritis

### 4.4.1 Description of included studies

Five relevant studies were identified. They were from Asia <sup>44,45</sup>, the Middle East <sup>46</sup> and Europe <sup>40,167</sup>. Studies involved between 17–96 participants (median in all studies 31), with a predominance of female participants in all studies. Mean age ranged from 49.6 to 65 years. Participants were recruited from the outpatient setting in all studies, from orthopaedic clinics <sup>44,46</sup>, magazine advertising <sup>167</sup>, pharmacies <sup>40</sup> or primary care <sup>45</sup>. Of those recruiting from medical centres, one was a private GP practice <sup>45</sup>, one was a public hospital <sup>46</sup> and in one study it was not stated whether the medical centres were public or private <sup>44</sup>. In three studies consumers had osteoarthritis affecting the knee joint <sup>44-46</sup>, whereas in one study osteoarthritis affected the hands <sup>167</sup>. Diagnosis of osteoarthritis was clinical in three studies <sup>45,46,167</sup>, using radiological criteria in one study <sup>44</sup> and based on medications in another study <sup>40</sup>. Severity of included osteoarthritis was not always stated, with two studies specifying that osteoarthritis was mild <sup>44</sup> and end-stage in another <sup>46</sup>.

### 4.4.2 Results: Consumers' perceived other non-medical service needs regarding osteoarthritis

Six key areas of need emerged from the included studies related to consumers' perceived other non-medical service needs related to osteoarthritis. These related to:

- 1) assistance with activities of daily living
- 2) exercise/leisure activities
- 3) social participation
- 4) financial security
- 5) occupational needs
- 6) transport.

#### 4.4.2.1 Perceived needs related to daily functioning

Four studies <sup>44-46,167</sup> discussed difficulties facing consumers regarding activities of daily functioning. Daily activities were limited by pain <sup>44</sup>. A key theme emerged that people with osteoarthritis were concerned about needing help from others <sup>44-46,167</sup>. This particularly applied to household chores, either from within the family or from external sources <sup>44-46,167</sup>. In some cases this extended to a sense of "failure" to fulfil social obligations, eg to look after children or partners <sup>46</sup>. Consumers acknowledged that support from partners is very important in their daily life and that they may struggle to live alone <sup>167</sup>. Being clean and well-presented was important to people with hand osteoarthritis <sup>167</sup>, who were found to have trouble with fine motor tasks including buttoning, lacing up shoes and hair-brushing. Moreover, these patients <sup>167</sup> struggled with payment systems, eg handling money and change, as well as cell phones, cutlery and computers. Having gadgets with an accessible design and assistive devices limited these issues and improved daily functioning <sup>167</sup>.

#### 4.4.2.2 Exercise and leisure-related needs

Four studies identified by this review <sup>44-46,167</sup> identified the presence of barriers to exercise and leisure uptake in people with osteoarthritis. Bukhave <sup>167</sup> found that consumers substituted different forms of activity to enable exercise as their disease progressed. Main concerns regarding exercise were pain, inability to continue activities previously enjoyed <sup>44</sup>, missing out on activities with others <sup>46</sup> and need to engage in more sedentary activities <sup>167</sup>. Patients were worried by their inability to exercise <sup>45</sup>.

#### **4.4.2.3 Social participation needs**

Four studies <sup>40,45,46,167</sup> identified issues relating to social participation of consumers with osteoarthritis. All studies concluded that osteoarthritis could significantly limit consumers social participation to a variable degree. Chan <sup>45</sup> identified services which could be improved to alleviate the impact of osteoarthritis on social participation. Chan <sup>45</sup> identified lack of suitable transport options as a key limitation to social participation; if transport facilities were more accessible, for example being within walking distance, participants were more likely to attend. Bukhave also identified mobility restriction as an issue <sup>167</sup>, which Al-Taïar identified impacted on family activities so consumers did not get "left alone at home" <sup>46</sup>. Inability to participate in some group activities also limited consumers' social contact <sup>167</sup>. Two studies <sup>45,167</sup> identified particular issues with looking after grandchildren; with limitation in their ability to lift toddlers, change nappies and fasten belts. Baumann <sup>40</sup> reported difficulties with communication and understanding between consumers and their doctors as well as social networks. Consumers felt that osteoarthritis was not considered a "real" disease leading to disability, with limited community support. Consumers reported difficulty with self-expression, with media coverage of and research into osteoarthritis felt to be limited <sup>40</sup>.

#### **4.4.2.4 Financial needs**

Two studies <sup>44,45</sup> investigated financial needs. Studies focused on both the cost of health-seeking behaviour <sup>45</sup> and the financial impact of reduced work due to illness <sup>44</sup>.

#### **4.4.2.5 Occupational needs**

Three studies <sup>44,45,167</sup> identified consumers' needs related to work. All three studies highlighted the consumers need for a flexible workplace. Bukhave identified flexibility in work arrangements as being helpful <sup>167</sup>. Consumers identified the need to take regular breaks and for environmental modification. However, often technical aids and modifications of the work environment were not in place <sup>167</sup>. Ultimately, failure of these modifications required consumers to leave their current employment <sup>44,45,167</sup>.

#### **4.4.2.6 Transport needs**

Three studies <sup>44,45,167</sup> investigated service needs related to transport. One study <sup>45</sup> suggested that services to increase accessibility to public transport would improve consumers' ability to socialise. In consumers with hand osteoarthritis <sup>167</sup>, supports to facilitate transport-related tasks including opening doors, holding the steering wheel and using bicycle hand brakes were necessary. The use of public transportation by people with hand osteoarthritis was limited by their inability to hold straps or poles <sup>167</sup>. Kao's <sup>44</sup>

## 4.5 Other non-medical services: Back pain

### 4.5.1 Description of included studies

Of the 18 included studies, 12 were from the United Kingdom<sup>51,74,114,207,253-260</sup>, two from Australia<sup>210</sup> and one each from the United States of America<sup>76</sup>, Israel<sup>85</sup>, Iran<sup>84</sup> and South Africa<sup>205</sup>. Participants were recruited from pain management clinics in five studies<sup>51,74,253,257,260</sup>, from rehabilitation and physiotherapy departments in five studies<sup>114,205,207,256,259</sup> family care practices in three studies<sup>76,85,255</sup>, from the community in three studies<sup>210,256</sup>, rheumatology departments in two studies<sup>84,258</sup> and from workplaces in two studies<sup>254,256</sup>.

The duration of back pain was unspecified in 11 studies<sup>74,85,114,205,207,253,254,256-259</sup>, greater than eight weeks in three studies<sup>210,255</sup>, greater than 12 weeks/90 days in two studies<sup>84,260</sup>, greater than six months in one study<sup>76</sup> and one year in another<sup>51</sup>. There were no studies examining acute back pain (<4 weeks duration). There was a predominance of female participants in the included studies, with six studies having a higher proportion of females to males<sup>210,255,256,258,260</sup> and two studies only evaluating females<sup>84,254</sup>. Four studies had approximately equal numbers of male and female participants<sup>76,114,207,259</sup> and four studies had more males<sup>74,85,205,253</sup>.

There were two studies that did not specify the gender profiles of the participants<sup>51,257</sup>. The average age of the participants included in the studies were middle-aged (40 to 65 years of age)<sup>76,84,85,114,205,207,210,253-255,258-260</sup>. There were two studies that did not specify the age profiles of the participants<sup>254,256</sup> and three studies provided the age ranges of included consumers but not the average age<sup>51,74,257</sup>.

### 4.5.2 Results: Consumers' perceived other non-medical service needs regarding back pain

Five main areas of need emerged from the included studies relating to back pain patients' perceived needs of other health services:

- 1) occupational needs
- 2) social support
- 3) financial support
- 4) auxiliary devices
- 5) assistance with the home environment.

#### 4.5.2.1 Consumers' with back pain perceived other service needs relating to occupation

##### 4.5.2.1.1 Workplace assistance

Eight studies explored consumers' perceived needs for workplace assistance<sup>51,85,205,207,254,255,259</sup>. Reid found that 42% of employed consumers with back pain had problems at work<sup>255</sup>. Borkan found that consumers felt a strong social pressure to maintain employment and that absence from work is associated with social disapproval<sup>85</sup>. Borkan also found that some people reported that limitations at work due to their back pain could provoke anxiety, especially when they have to modify or change jobs<sup>85</sup>. Consumers also expressed guilt that other colleagues and managers were taking on their workload and felt pressure to return to work<sup>254</sup>. Some consumers needed a third party, such as a family member or health professional, to "stand up for them" and tell them they could not go back to work<sup>254</sup>. Ryan reported that many consumers noted that a gradual return to work after a period of leave due to back pain allowed them to satisfy their employers, whilst also recognising their physical limits<sup>254</sup>. Soeker found that consumers had problems with the physical components of the job<sup>205</sup> and Campbell reported that consumers felt that poor working conditions and manual labour contributed to their back pain<sup>51</sup>. Some people were angry and dissatisfied about the limited education provided about techniques to prevent back pain such as lifting or handling<sup>51</sup>, and they felt that the lack of adequate help with work modifications could lead to further sickness absence<sup>207</sup>. Furthermore, some consumers felt that safer working environments could have prevented their injuries<sup>205</sup>. Many consumers have also reported not receiving any advice or support in relation to work<sup>207,253</sup>, and if advice was given, they felt that it was out of context<sup>207</sup>. Consumers have described how healthcare providers would advise work avoidance and be more inclined to provide sickness certification, rather than strategies to help maintain employment<sup>207</sup>. Coole found that only a minority of consumers received support formally through occupational health services, and of the ones who did, some perceived the suggested modifications to be inappropriate or ineffective<sup>259</sup>. Some also questioned the validity of the occupational health consultations as they were generally conducted away from the worksite<sup>259</sup>. Soeker found that many consumers were not involved in decisions pertaining to alternative job placement strategies after they had been injured<sup>205</sup>.

#### **4.5.2.1.2 Employer attitudes and assistance**

Six studies evaluated consumers' experiences with employers and the perceived assistance from their employers<sup>114,205,207,253,259,260</sup>. Some felt cautious about disclosing their back problems for fear of it affecting their job security<sup>114</sup>. Consumers also reported that employers lacked understanding, were unsympathetic and would only take them seriously if they had sickness certification<sup>114,205,253</sup>. Some consumers also found that their employers were unhelpful in providing suitable workplace equipment<sup>259</sup>. These negative experiences with employers reinforced feelings of self-doubt or inefficacy, and some people would fear going back to work and would rather adopt the sick role<sup>205</sup>. Consumers felt that they needed managers who were informed<sup>205</sup>. They also wanted their employers to communicate with their healthcare providers to better understand their situation, and to improve the working environment, especially with regard to injury management strategies<sup>207,259</sup>. Furthermore, Brooks found that consumers want flexibility from their employers, primarily to allow them to attend medical appointments<sup>260</sup>.

#### **4.5.2.2 Consumers' perceived needs relating to financial support**

Five studies explored consumers' needs for financial support<sup>74,76,205,253,257</sup> relating specifically to insurance, compensation and disability claims.

##### **4.5.2.2.1 Needs related to insurance issues**

Dealing with the administration related to disability benefits was seen as being time consuming<sup>76,205</sup>. Allegretti reported that consumers believed that a lack of adequate health insurance was a barrier to effective management of back pain<sup>76</sup>. Studies by Allegretti and Soeker found that consumers felt that the management of their back pain was compromised by the insurance system's inefficient administrative procedures<sup>76,205</sup>.

##### **4.5.2.2.2 Needs related to compensation and disability claims**

Consumers wanted legitimisation of their back pain, otherwise they could not receive compensation<sup>257</sup>. However some felt that their compensation claims alienated them from former colleagues<sup>74</sup>. Furthermore, many consumers were reliant upon state disability benefits and were fearful that their benefits may be taken away<sup>74</sup>. Several consumers had their applications for statutory support rejected, which reinforced their sense of loss<sup>253</sup>.

#### **4.5.2.3 Consumers' perceived needs relating to social supports**

Six studies examined consumers' needs of social support<sup>84,85,210,253,258</sup>. Consumers felt that their social networks and community engagements suffered as a result of disconnection from work and social activities due to their back pain<sup>85,253</sup>. Tavafian found that social pressure was mentioned by women as a source of stress and accounted for their back pain<sup>84</sup>. Some consumers reported that back pain focus groups are therapeutic<sup>85,210</sup>. Slade found that consumers wanted to develop back-specific social support networks built on shared experiences<sup>210</sup>. Furthermore, consumers with back pain valued spousal support<sup>258</sup>.

#### **4.5.2.4 Consumers' perceived needs relating to auxiliary devices**

One study reported on consumers' needs for auxiliary devices<sup>85</sup>. Borkan found that consumers have identified certain environmental factors as either the source of their pain, or aggravating their pain, including improper chairs with lack of lumbar support and inappropriate footwear<sup>85</sup>.

#### **4.5.2.5 Consumers' perceived needs relating to assistance with the home environment**

Five studies identified consumers' needs for assistance in their home environment<sup>84,85,255-257</sup>. Consumers report the need for help with household chores and gardening<sup>84,85,255-257</sup>, especially during acute flares of pain<sup>256</sup>. However, help was not always available<sup>84</sup>. In particular, women felt burdened with housework, which causes further stress that aggravates their back pain<sup>84</sup>. Women also reported problems with childcare<sup>255</sup>.

“What you need  
is someone who’s  
sympathetic, who’s  
competent, who could  
enable things and  
who knows what is  
available”

(Mann 2011<sup>30</sup>)



## **4.6 Other non-medical services: Neck pain**

### **4.6.1 Description of included study**

One relevant study<sup>87</sup> was identified. It was performed in Sweden, and examined participants with whiplash associated disorders who had completed an Interdisciplinary Rehabilitation Program.

### **4.6.2 Results: Consumers' perceived other non-medical service needs regarding neck pain**

In terms of consumers' perceived other services needs, consumers in this study identified the importance of participating in a regular discussion group. Seeing others in a similar situation achieve success provided the stimulus for others to push themselves to do the same.



**“I think sometimes it is to do with legitimizing the pain, because if someone can say I have got this and that is why I have got the pain, then perhaps other people will accept it more.”**

**(Toye, 2010<sup>71</sup>)**

## 4.7 Other non-medical services: Osteoporosis and bone health

### 4.7.1 Description of included studies

Two studies were identified as relevant for inclusion in this review. One of the studies originated from the United States of America<sup>96</sup> and the other from Canada<sup>226</sup>. The US study recruited subjects from a non-profit health maintenance organisation<sup>96</sup> and the Canadian study recruited participants from a post-fracture osteoporosis initiative program<sup>226</sup>. Both the studies recruited patients for whom secondary prevention was relevant, as all included participants had a history of osteoporotic fracture/s<sup>96,226</sup>.

### 4.7.2 Results: Consumers' perceived other non-medical service needs regarding osteoporosis

Two common other non-medical service needs emerged from the two identified studies<sup>96,226</sup>:

- 1) the importance of diet and supplements
- 2) the importance of exercise in the management of osteoporosis.

Consumers in both studies were willing and comfortable to eat a healthy diet and to take supplements to improve their bone health. One participant in Sale's study "just decided to take the calcium and vitamin D again to maintain the calcium levels in my bones for as long as possible"<sup>226</sup>. Others identified eating green leafy vegetables and nuts, as well as including dairy products and salmon<sup>226</sup>. The importance of diet was appreciated by participants in both studies<sup>96,226</sup>.

Similarly, consumers in both studies identified the importance of exercise for maintaining bone health and avoiding fractures<sup>96,226</sup>. Consumers in Sale's study identified walking, lifting weights, weight exercises and tai chi to be helpful<sup>226</sup>. However, some individuals were actively avoiding exercise perceived as dangerous such as skiing, skating and bicycle riding. Sale<sup>226</sup> described a degree of caution in the consumers, who took more care in day-to-day ambulation, changing their lifestyle to avoid risky situations, such as the subway at peak hour. They used aids and devices such as the use of "coil things" to fit over shoes to prevent slipping in winter, extra rubber mats in the shower and gait aids such as a cane with a pick and walkers<sup>226</sup>.

## 4.8 Other non-medical services: Overall summary

The systematic review identified a number of studies examining consumers' perceived need of other non-medical service. Among those with inflammatory arthritides (rheumatoid arthritis and ankylosing spondylitis), **osteoarthritis**, **back pain**, **neck pain** and **osteoporosis** identified a number of common areas of need were identified. Non-medical services encompasses a variety of options, including services used to facilitate life in the home, social landscape, navigating the physical environment, the work environment and financial needs. Although the need for other services was examined in all conditions, the available data was limited for **neck pain** and **osteoporosis**.

The findings related to consumers' perceived other services needs are shown in Table 5. This table focuses on findings to demonstrate those that were applicable to multiple conditions. These results have been classified into the following areas of need:

- 1) assistance to carry out daily activities in and outside the home
- 2) self-help, peer support
- 3) exercise and leisure related needs
- 4) social connectedness
- 5) environmental modifications needed
- 6) transport needs
- 7) financial security/support
- 8) occupational need

### 4.8.1 Overall results: Consumers' perceived other non-medical service needs (Table 5)

#### 4.8.1.1 Assistance to carry out daily activities in and outside the home

Consumers with most of the examined musculoskeletal conditions identified a need for practical, physical and emotional support, which often fell on family members. Aids, techniques and devices were desired by those with **inflammatory arthritis**<sup>246-250</sup>, **osteoarthritis**<sup>167</sup> and **osteoporosis**<sup>226</sup>. For women with **osteoarthritis**<sup>46,167</sup> and **back pain**<sup>84</sup> there was an ongoing need to care for the family regardless of their musculoskeletal condition. In addition to these needs, consumers with **osteoarthritis** identified a need for help with chores due to reduced mobility, with self-care and a need to be accompanied when they go out<sup>45,46,167</sup>.

#### 4.8.1.2 Self-help, peer support

There was interest in peer support groups from those with **inflammatory arthritis**<sup>247,248,250</sup>, **osteoarthritis**<sup>40</sup>, **back pain**<sup>85,210</sup> and **neck pain**<sup>87</sup>. These were valued in order to be able to share experiences, validate/legitimise their problems and to gain support from their peers.

#### 4.8.1.3 Exercise and leisure related needs

The need to exercise was identified by consumers with **osteoarthritis**<sup>27,39</sup> and **osteoporosis**<sup>224</sup>. There was a single study in those with **inflammatory arthritis** that examined consumers' beliefs about exercise<sup>251</sup>. It found that consumers sought group exercise classes<sup>251</sup>. Those with **osteoarthritis** expressed a need to attend social leisure activities, but found that **osteoarthritis** impacted on this<sup>45,46,167</sup>.

#### 4.8.1.4 Social connectedness

The importance of social connections was identified by consumers with **inflammatory arthritis**<sup>246,248,249</sup>, **osteoarthritis**<sup>40,45,46,167</sup> and **back pain**<sup>85,253,258</sup>. Within this, maintaining employment was seen as important by those with **inflammatory arthritis**<sup>246-250</sup> as loss of employment was noted to exacerbate social isolation. A lack of understanding by others was identified as having a significant impact on consumers with **inflammatory arthritis**<sup>248,252</sup> and **osteoarthritis**<sup>40</sup> social interaction. Those with **inflammatory arthritis** identified that social connections were limited by financial constraints<sup>249</sup>. The functional deficits associated with **osteoarthritis** reduced the ability of women with **osteoarthritis** to care for their grandchildren<sup>45</sup>. A group of female consumers with **back pain** found social pressures a source of stress which impacted on **back pain**<sup>84</sup>.

#### 4.8.1.5 Environmental modifications needed

Environmental modifications were seen as necessary in the home by those with **inflammatory arthritis**<sup>252</sup>, **osteoarthritis**<sup>44,167</sup> and **back pain**<sup>85,255,257</sup> in the workplace by those with **inflammatory arthritis**<sup>245,246</sup> and **back pain**<sup>205,259</sup>, and outdoors, by those with **inflammatory arthritis**<sup>250-252</sup> and **osteoporosis**<sup>226</sup>. Those with **inflammatory arthritis** expressed a need for physical safety as they felt they were at increased risk of crime because of their physical impairment<sup>249</sup>. Those with **osteoarthritis** were found to need disability parking permits, which were hard to obtain<sup>40</sup>. Consumers from Taiwan found they needed to plan their journeys because they required a seated toilet seat as they were unable to squat<sup>44</sup>. This finding is reflected in a recent study that has shown that those with lower limb **osteoarthritis** were less likely to use neighbourhood facilities like those found in parks, than those without<sup>261</sup>.

#### 4.8.1.6 Transport needs

Difficulty with transportation was common to those with **inflammatory arthritis**, **osteoarthritis** and **osteoporosis**. Those with **inflammatory arthritis** and **osteoarthritis** noted a need for appropriate provision for parking<sup>40,245,252</sup>. For example, they had to plan their trips, either avoiding peak hour in the subway to prevent falls<sup>226</sup>, or according to seated toilet availability<sup>44</sup>. Those with **osteoarthritis** needed access to parking permits and found public transport problematic. In addition, they had difficulty with the mechanics of driving and using a car, including holding onto the steering wheel, opening doors and handling the petrol cap<sup>167</sup>.

#### 4.8.1.7 Financial security/support

Those with **inflammatory arthritis**<sup>247,249</sup> and **osteoarthritis**<sup>44</sup> identified the need for financial security. Consumers with **inflammatory arthritis** in Estonia<sup>249</sup> identified the need for adequate finances to purchase food and medication. Consumers with **back pain** noted that lack of health insurance and the administrative burden of the benefit systems were barriers to obtaining health care<sup>76,205</sup>. They required financial compensation for **back pain**<sup>74,253,257</sup>.

#### 4.8.1.8 Occupational needs

Consumers with **inflammatory arthritis**<sup>246-250</sup> and **osteoarthritis**<sup>45,167</sup> had a strong need to maintain employment and avoid the disability pension. They also wanted better knowledge of their work related rights and social security entitlements. Those with **inflammatory arthritis**<sup>246-250</sup> and **osteoarthritis**<sup>44</sup> and **back pain**<sup>259,260</sup>, desired a workplace with the possibility of flexible hours and ability to change the type of work they did according to their musculoskeletal condition<sup>133,245</sup>. Those with **inflammatory arthritis**<sup>133,245</sup> and **back pain**<sup>167</sup> needed the possibility for environmental change at the worksite to accommodate their functional deficits, such as lifts, parking allowances and ergonomic workstations. There was a sense of frustration with employers who did not provide aids and preventive information regarding **back pain**<sup>44,167</sup>.

Consumers with **back pain** wanted advice that was relevant to their workplace and aimed at rehabilitation<sup>167</sup>. They wanted to avoid social pressures and a sense of inequality at work. They projected a strong need for a supportive employer, with communication between their employer and healthcare providers<sup>44,45,167</sup>.

### 4.8.2 Discussion

There were few studies directly assessing consumer perceived needs related to non-medical services. It must be noted that a limitation of these data are that there were few studies directly addressing consumer perceived need of non-medical services. Thus, much of the information extracted was obtained from data obtained from studies that did not directly address the review question. There is the potential for a consumer need to exist, but not have been captured by the existing studies: therefore a lack of evidence must not be taken to indicate a lack of need, unless the question has been directly asked. For example, whilst studies relating to **inflammatory arthritis** and **osteoarthritis** identified the need for more accessible transportation, no studies were identified that addressed this issue in those with **back pain**. It cannot be assumed that people with **back pain** do not perceive the need for more accessible transportation since they also experience significant disability and functional impairment<sup>1</sup>: it may be that the need exists but has not been identified in the literature because it has not been asked of these consumers. However, it is also possible that the need does not exist. Thus where there is a lack of studies addressing a question, to clarify this, further studies will be required.

In addition, for some conditions, such as **neck pain** and **osteoporosis**, surprisingly few studies were available. In the case of **osteoporosis**, an asymptomatic condition until the occurrence of a fragility fracture, this may be because primary and secondary prevention relies on effective pharmacological therapy. Thus the lack of perceived need for other services is not surprising. It is also possible that consumer perceived needs may not be aligned to the availability and accessibility of services. In addition, some consumer needs may be underestimated if the services are already available. Whether the facilities to meet the consumers' perceived needs are present or available, and are matched requires further study. To identify consumers' perceived needs of other services, further studies will be required that more directly answer this question.

Most of the available literature around this review question originates from the UK, the USA, Canada and Australia, and to a lesser extent other European countries and a few studies from Asia. There are few studies from Eastern Europe, South and Central America, the Middle East and Africa. The need for other services is likely to vary considerably in different countries with diverse social systems, as are the services available. For example, in the study by Sale performed in Canada, a need for use of a cane with a pick in winter to avoid falls was noted<sup>226</sup>: this would be irrelevant to those dwelling in more temperate climates, without snow. This was further highlighted by the study from Estonia by Laidme<sup>249</sup>. Whereas in other studies in other countries, needs of peer group support were noted, in this study, basic needs, such as adequate food, heat, hot running water and the opportunity to wash were noted. These would be assumed to have been met by consumers concerned with accessing a support group.

There were areas of limited consistency across the different conditions regarding the types of other service needs identified. This may be because of the differing ages of onset of the condition, the functional deficits and the varying success of treatment options in the various conditions studied. Thus, for example, few studies were found addressing the other services needs of those with **osteoporosis**. This may be because this condition is silent until a fracture occurs. Even then, few services are perceived as necessary as management depends on effective pharmacotherapy. In contrast, **inflammatory arthritis** may begin early in life, and greatly impact function. Thus the need for peer support and coping strategies may be greater. Alternatively, the capture of this need may reflect studies that perform assessments of existing services, inadvertently by the different studies, and peer support services may be better developed for **inflammatory arthritis**, where arthritis foundations play an umbrella stakeholder role. In contrast, for **back pain**, that has no umbrella stakeholder organisation, there is little focus on self-help groups, although there is a perceived need.

Despite the limitations of this suite of searches, we present the results of comprehensive searches of four complementary databases. Although complementary and consistent data from qualitative and quantitative studies were identified, the data was limited. Broad search strategies were used, and a small proportion of those studies identified were deemed to be relevant.

### 4.8.3 Conclusions

This review has identified that people with musculoskeletal conditions have a number of common needs. They require practical help within the home, which often falls to family members. Environmental factors impact on their ability to function, both inside the home, and outside the home and in the work environment. They appreciate peer support. For a variety of reasons, they feel a loss of social connections which is exacerbated by loss of employment. The workplace is important in terms of identify, financial security and social connections: maintaining employment is a high priority for consumers with musculoskeletal conditions. Facilitation of safe transport and disability parking permits are also desirable.

However, this review is based on a limited data. Whether the identified needs are common to all the conditions with associated similar functional deficits is not clear as these questions have not been addressed by existing identified studies. Questions remain about whether the consumer perceived needs are matched by existing services, and whether there is a lack of knowledge regarding access. These findings are incompletely contextualised: it is important to consider whether these issues are condition specific or related to the impact of loss of socio-economic status with a chronic health condition.

# 5. Conclusions



## 5 Conclusions

This report details the consumers' perceived health information, health services and other non-medical service needs of consumers with inflammatory arthritis (rheumatoid arthritis, ankylosing spondylitis), osteoarthritis, back pain, neck pain and osteoporosis. Comprehensive summaries of the review are detailed in previous chapters.

Although the management of these conditions requires, and is largely driven by, consumer perceived need, there are limited data relating to the consumers' perceived needs. Specifically, not all questions are addressed in each of the targeted conditions. Thus, if a need has not been identified in this review it does not indicate that the need does not exist, unless it has been directly addressed by identified studies. Nevertheless, there were many common areas of need across these conditions, with few conflicting results.

There are a number of significant gaps identified in what is known about consumers' perceived needs that need to be addressed by further research. Filling these gaps will help to better identify and characterise consumers' needs relating to musculoskeletal conditions. This may enable healthcare providers and other stakeholders to better target intervention strategies in order to obtain better musculoskeletal health outcomes.

# 6. Tables



## 6 Tables

**Table 1: Summary: Consumers' perceived health information needs**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain*	Osteoporosis*
<b>Reasons for seeking health information</b>					
Gain control/ownership	2	3	6	1	5
Legitimation of symptoms			5	1	
Improve function	1		1	1	
Improve psychological function			1		
Prognosis – improve planning	2	2	8		
Prevention of disease in children, grandchildren		1			
To help families understand	1				
Impact on work capacity	1		2		
<b>Consumer related factors affecting information needs</b>					
Females have higher information needs than males	5	2			
Younger patients (esp. online, lower written needs)	3				
Higher education related to higher needs	3	1			
Current employment related to higher needs	2				
Disease duration, activity and function NOT related	1				
Consumers with depression/anxiety had higher needs		1			
<b>Content required</b>					
General information	6	10	8	1	11
Pharmacological management: rationale, side-effects, how to take medication	9	3	3	1	8
Pharmacological management: thought they knew side effects		1			
Complementary therapy			4		
Exercise and physical therapy, including effect on structure	6	1	8	2	
Psychosocial issues	3		1	1	
Self-management: emotional impact, social support, self-help	5	2	2	1	
Every day living	3				
Pain management	2	2	8	1	1
Flare prevention			4		
Flare management	1		4		
Services available including surgery, including local services	3	2	4	1	
Diet and weight management, lifestyle modification		1		1	3
More information required than is provided	5				
Concern too much information could generate anxiety	3				
Support groups	1	1			
Financial services		1			
Definitive diagnosis, cause of symptoms			24	1	
Imaging required			7		
Specific management information required			6		
<b>Information delivery and communication methods</b>					
Rheumatologist preferred source, face-to-face	1				
One-on-one preferred for disease based information,	1				

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
One-on-one preferred for emotional and quality of life issues,	1				
One-on-one preferred for non-English speaking background	1				
General practitioner as an information source		2			1
Other knowledgeable healthcare providers or volunteer acceptable as a source of information (not GP)	2	3			1
<b>Written material, visual images</b>					
Memory aide, more detailed information	3	2		1	1
Too general so not useful	1				
Resource pack, to be used as required	1				
Health services information	1				
Booklets not useful, or not relevant		1			
Use a variety: magazines, national societies, brochures, newsletters, books	2	2	2		5
Non-English speaking background: prefer educational CD to written information	1				
Sharing information, visual cue	1				
<b>Internet as a source of information</b>					
Useful	1	3			
Not useful	2				
Unclear reliability of information	2	1			2
Way to share information with others		1			
Younger patients, and those with regular access		1			
<b>Support groups</b>					
Information required	3				
Patients seek out others with same condition		2			3
Seek classes		21			2
Friends	1	2			2
Group sessions: useful for psychosocial and self-management	3				
Unclear where to find information		1			
<b>Method of information transfer</b>					
Positive and optimistic information delivery desired	3				
Supportive tone, sense of being taken seriously, respected		1	2		1
Reliable, consistent information			3		1
Specific information rather than generalities	4		3		
Clear explanation: simple language, timely	1	2	6		1
Use of language that is misunderstood		1			1
Use of language with negative connotations, eg "wear and tear:	1	2			
Adequate time available for information provision	2				8
<b>Barriers to meeting information needs</b>					
Lack of health practitioner's knowledge	2		1		1
Poor access to reliable sources	2				
Lack of ongoing communication	1				
Language barriers	1				
Poor access to healthcare provider, waiting times		1		1	1
Conflicting information, from different providers			1	1	
Fear of being judged/ symptoms dismissed				1	

**Table 2: Summary: Consumers' perceived needs for medical services**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
<b>Needs related to health services provided by the medical practitioner</b>					
<b>Role of the doctor and strengths of the doctor</b>					
Desire exact diagnosis			7		1
Legitimation of pain, sickness certificates			4		
Source of additional care			6		2
Prescription of medication			3		4
Pain relief		2	2		1
Prevention advice			1		
Self-management advice			7	3	
Continuity of care, listening and counselling skills			5	5	
<b>Preference to see the doctor and satisfaction</b>					
Specialist referral desired, but may be avoided by GP			3		
Faith in medical practitioners	2		4		3
<b>Inadequacies of the doctor</b>					
Superficial approach, GP lack knowledge		1	8		1
Tendency to delegitimise pain, dismissive of symptoms		1	4	1	
"Just give medications", limited options			4		2
Dialogue between GP and allied health, timely referral			2	5	
<b>Characteristics of patients more likely to seek medical care</b>					
More functional impairment	1		3		
Flare	1				
Seen as last resort	1				
Age	1				
Delayed as patients misattributed symptoms	2				
<b>Role of pharmacological management and concerns with medications</b>					
<b>Role of medications and patients' preference for medications</b>					
Medication's considered useful and expected		1	3		7
Not consider medications					2
Medications used as last resort, resistant to use regularly		2	4		4
Perception of side effects affected willingness to take		3	4		11
Perception of benefit greater than fear of dependency/side effects		3	1		
Prefer passive treatment (rest, medication) to active therapy			1		
Narcotic use associated with patient satisfaction			1		
<b>Concerns regarding medications</b>					
Clear information regarding how to take medication			2		1
Stigmatisation associated with analgesic request, fear of addiction			5		1
Costs		2			2
Drug interactions, polypharmacy					2
Mistrust of doctors, pharmacology companies, prescription					3

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
<b>Role of interventional procedures, injections and surgery</b>					
Avoid injections			1		
Preference for surgery: last resort		1	2		
Concern regarding surgery with inherent risks		1	1		
Willing to wait 2 years before considering it			1		
Women more reluctant to have surgery			1		
More keen to have surgery if higher pain, shorter duration of pain: no difference with income, sick leave, expectation regarding results			1		
<b>Perceived need for imaging</b>					
<b>Preference for imaging</b>					
Expect radiographic imaging, and GP to request if asked			3		1
Higher pain severity			1		
<b>Role of imaging</b>					
To legitimise pain			5		
Relief when a cause was identified, closure			4		
Diagnosis, monitoring					4

**Table 3: Summary: Consumers' perceived needs of allied health and complementary and alternative medicine and alternative medicine**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain*	Neck pain*	Osteoporosis*
<b>Non-traditional allied health (acupuncture, osteopathy, massage, local heat therapy)</b>					
<b>Willingness to try CAM or preference for CAM</b>					
Many willing to try, esp. if no additional cost	5	4	6		4
CAM seen as desperate measure, adjunct only	4	1	2		
<b>Perceived benefit of CAM and satisfaction of CAM</b>					
Relief from symptoms	4	1	3		
CAM practitioners more empathetic, better communication, more time		1	3		
<b>Concerns with CAM</b>					
Transitory effects			2		
Limited relief as outside medical model, question legitimacy			1		
Concern re side effects (needling, manipulation)			2		
Cost prohibitive	2	1	1		
Non-disclosure to medical practitioners: variable	4				
<b>Physiotherapy and exercise therapy</b>					
<b>Willingness to try or preference for physiotherapy and exercise</b>					
Perceived as useful component of management	2	4	10		
Exercise beneficial		3	4		2
<b>Perceived benefit of physiotherapy and exercise</b>					
Physiotherapy beneficial, relief		2	2		
Exercise beneficial, provides relief		3	2		
High expectations: benefit after one session			2		
<b>Individualising physiotherapy and exercise</b>					
Individualised exercise promoted compliance		2	3	2	
<b>Concerns with physiotherapy and exercise</b>					
Concern that not beneficial		1			
Concern re injury			1		
Compliance difficult		2	2		
<b>Chiropractic therapy</b>					
<b>Willingness to try chiropractor or preference for chiropractors</b>					
Some people considered chiropractors primary health care choice			2		
<b>Perceived benefits, expectation and concerns with chiropractors</b>					
More empathetic, knowledgeable, better diagnostician			1		
Higher satisfaction than other health practitioners			4		
More likely to get accurate diagnosis			2		
<b>Characteristics of patients preferring chiropractors</b>					
Examined in 3 studies, conflicting results			3		
<b>Use of orthoses / physical aids</b>					
Orthoses		1			
Gait aid/wheel chair		2			
Braces		1			
Footwear		1			

**Table 4: Summary: Consumers' perceived needs relating to the characteristics of healthcare providers involved in the management of musculoskeletal conditions**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
<b>Communication needs</b>					
<b>Good communication skills</b>					
Clear, accurate explanation	2	2	6		1
Patient centred participation in communication	4	1	6		
Appropriate language, no jargon			3		
Supportive, open communication	4		2		2
<b>Shared decision making, respect and being listened to</b>					
Listened to	3	1	4	3	
Take an active role in treatment	3		3	3	4
Wanted to be respected, trust	2		3	3	2
Wanted MSK condition to be prioritised: frustrated when not		1	1	3	
Time with practitioner		2	3	3	3
<b>Empathy, understanding and confidence</b>					
Confident provider		1	1		
Understanding and empathy	3		6	4	1
Non-judgemental			1		1
<b>Information provision</b>					
<b>Diagnosis and finding a cause of pain</b>					
Require diagnosis			12		1
Justify pain			1		
<b>Information provision by healthcare providers</b>					
Clear, consistent, adequate information, non-conflicting	2	1	15		2
Explanation of pain			3		
Direction regarding self-management, rest			5	3	
Advice regarding sexual problems related to MSK condition			1		
<b>Legitimisation</b>					
Need to legitimise symptoms related to stigma from healthcare providers		1	3		
<b>Aspects of care</b>					
<b>Type of approach to health care: Holistic, personalised, emotionally supportive, encouraging</b>					
Appreciate holistic, individualised approach	2	2	3	2	
<b>Thorough assessment, time and effort, continuity of care</b>					
Thorough assessments, including physical examination			4	3	1
Time spent	3		2	3	3
Continuity of care, follow up consultation	1		4	5	4
<b>Qualifications and technical skills</b>					
Reputation, specialist knowledge		2	2		
<b>Collaborative approach between healthcare providers</b>					
Appreciated collaboration between healthcare practitioners			2	3	
<b>Convenience of care provision</b>					
Rheumatology review convenient in terms of time and place	2	1			
Access	3	2		3	

**Table 4: Summary: Consumers' perceived needs relating to the characteristics of healthcare providers involved in the management of musculoskeletal conditions (continued)**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
<b>Sharing experience with other patients</b>					
Support from others with their condition	2				
<b>Barriers to care</b>					
Cost	3	3	4	2	
Poor access due to rurality, waiting time	2		7	3	
Poor compliance with physiotherapy/exercise multiple reasons		1	4		
Social, role responsibility	1	1			
Communication				1	1

**Table 5: Summary: Consumers’ perceived other non-medical service needs**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
<b>Assistance to carry out daily activities in and outside the home</b>					
Requires practical support	4	4	5		
Support from family, concerned about getting help	1	3	1		
Require techniques and aids to help	1	1			
Needs to be accompanied when going out		1			
Mobility limitations impact on ability to do chores		3			
Obligation to continue to care for family despite condition		2	2		
Extra cost to enable help		1			
Self-care help required		1			
Special equipment, assistive devices, orthoses		2			1
Role of good diet					1
<b>Self-help, peer support</b>					
Shared experiences	2			1	
Validation/legitimisation of problems	2	1			
Support and recognition from peers	1			1	
Interested in self-help groups	2		3		
<b>Exercise and leisure related needs</b>					
Need to do exercise, may be modified		3			2
Seek physical activity group program	1				
Need to attend social/leisure activities		3			
<b>Social connectedness</b>					
Loss of social connections, exacerbated by work loss	3	3	2		
Importance of work in social networks	2				
Lack of understanding	2	1			
Impacted by financial constraints	1				
Give up looking after grandchildren		1			
Social pressure a source of stress			1		
<b>Environmental modifications needed</b>					
Home	2	1	1		
Workplace	2		3		
Outdoors including ramps, parking spaces, space for movement	2				1
Fear of crime, at increased risk due to physical impairment	1				
Parking permits (disability), limited access		1			
Need to plan for seated toilet on excursions		1			
<b>Transport needs</b>					
Transport needs	1	2			1
Parking permits (disability), limited access	2	1			
Trouble with the mechanics of driving		1			
Public transport problematic		1			

**Table 5: Summary: Consumers' perceived other non-medical service needs (continued)**

\*Number of studies that identified each specific issue

	Inflammatory arthritis*	Osteoarthritis*	Back pain *	Neck pain *	Osteoporosis*
<b>Financial security / support</b>					
Financial hardship	2	2			
Restricted food stuff/impact on ability to purchase medication	1				
Lack of health insurance a barrier to care			1		
Administrative burden of benefit system impact on care			2		
Require financial compensation/benefit			3		
<b>Occupational needs</b>					
Maintain employment	5	3			
Knowledge of work related rights and social security entitlement	2	1			
Avoid disability pension	1	1			
Maintain normality: life, social, professional, personal identity	1				
Flexible hours, type of work, change demands of work	2	3	1		
Environmental change; lifts, ergonomics, parking	2		3		
Failure of employer to provide aids/preventive information		1	4		
Advice received irrelevant to workplace, avoid work rather than rehabilitation			3		
Problems at work: social pressure, equality at work			3		
Supportive employer			4		
Communication between employer and occupational health providers/GP			2		

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