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Arthritis and disability

Prepared for:
Arthritis Australia

October 2014

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Abbreviations

AA	Arthritis Australia
AS	Ankylosing spondylitis
CRPD	*UN Convention on the Rights of Persons with Disabilities*
CRS	Commonwealth Rehabilitation Services
DVA	Department of Veterans Affairs
GP	General Practitioner
HACC	Home and Community Care
ICF	The International Classification of Functioning, Disability and Health
JIA	Juvenile idiopathic arthritis
OA	Osteoarthritis
PBS	Pharmaceutical Benefits Scheme
PA	Psoriatic arthritis
RA	Rheumatoid arthritis
SPRC	Social Policy Research Centre
SP	Spondyloarthropathy
SLE	Systemic lupus erythematosus
SS	Sjögren's syndrome
VI	Vision impairment
WHO	World Health Organisation

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Executive Summary

Arthritis Australia commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to carry out research on the lived experience of people with arthritis related conditions. This report outlines the methods, findings and implications of the research.

Arthritis is the second leading cause of disability and the most common cause of chronic pain in Australia; it is the most prevalent long-term health condition, affecting 3 million people or about 15 per cent of the population. Studies are available on the health costs and loss of productivity associated with arthritis, but not as much is understood about the extent to which arthritis is associated with disability – who is affected, how people are affected, what helps people cope with their condition day to day, and how support services can be improved. Improving understanding of the disability impact of arthritis is particularly important given the transition in Australia to the National Disability Insurance Scheme and the impact this may have on service availability and delivery.

The research design involved mixed methods. A literature review focused on policy, programs, support and service models relevant to arthritis and disability in both Australian and international literature. A consumer roundtable and in-depth interviews with people with arthritis-related disability provided qualitative data. An online survey was conducted to provide quantitative and qualitative data to determine the extent to which the findings from the literature review, consumer roundtable, and interviews, were applicable to a broader population of people with arthritis in Australia.

A total of 819 people with arthritis volunteered to participate in this study through the consumer group (13), interviews (28), and the online survey (778). Participants were recruited through the membership networks of state and territory affiliates of Arthritis Australia, and other organisations including Lupus NSW, Carers Australia, Council on the Ageing, and Pain Australia. Participants in the interviews were people who self-identified as having disability resulting from their arthritis, and were selected to ensure representation across states and territories, women and men, people with arthritis and their carers, people with different types of arthritis, and people who had experienced arthritis for different lengths of time. Participation in the group discussion and online survey was open to anyone with arthritis or caring for someone with arthritis, regardless of whether it caused disability.

Research participants were representative of the broader Australian population living with arthritis with respect to age distribution, with 64 per cent of participants aged less than 65 years. However, women (84 per cent of participants) and people with rheumatoid arthritis (35 per cent) were over-represented, while people identifying as Aboriginal or Torres Strait Islander or from a culturally and

linguistically diverse community[1] were under represented. This is likely to reflect the membership base of the organisations through which participants were recruited.

The information provided by participants was analysed thematically against the rights in the *UN Convention on the Rights of Persons with Disabilities* in the areas of health, habilitation and rehabilitation, work and employment, standard of living and social protection, and family and social participation. In addition the Personal Wellbeing Index was used to measure participants' quality of life and compare it with that of the Australian population as a whole.

The breadth of the analysis was based on the information provided by the participants and therefore may not be comprehensive across all themes. The findings of the research have not been prioritised as this is specific to each person.

Research participants requested that follow up interviews be conducted in 12–24 months to track their progress and to see whether anything has changed.

Key findings

Many people with arthritis experience disability, with more than one-third of participants (37 per cent) reporting that their arthritis always limits their ability to engage in daily activities, and a further 54 per cent reporting that it sometimes limits their ability to engage in daily activities.

People with arthritis report significantly lower wellbeing compared with the general Australian population with the greatest adverse impact occurring in the domains of health, employment and finances.

The impairment associated with arthritis varies significantly, depending on the type and severity of the condition, the presence of other health conditions, and the time since diagnosis. The level of disability experienced by people with arthritis also depends on a variety of factors, including access to informal and formal support, flexibility in the workplace, and the availability of measures for social protection.

Where arthritis causes disability, people become socially excluded across one or more and sometimes all life domains – study, work, family and social participation. In particular, people's capacity to work is adversely affected by arthritis, with implications for their ability to meet the often high costs of managing their condition and to maintain an adequate standard of living.

People with arthritis-related disability may require short-term, long-term or permanent access to formal support, including both services and financial support.

[1] Defined as speaking a language other than English at home.

They have different needs which cannot be addressed with one response; responses need to be flexible to suit individual needs and circumstances.

Arthritis not only affects the person who has the condition, it also affects their carers, family, neighbours and friends, who often provide physical, emotional and financial support. The impact can include loss of income due to caring responsibilities, changes to relationships (e.g. partners become carers), reduced social participation, and a lower overall quality of life.

Access to financial support, appropriate health care and formal care appears to reduce the barriers experienced by people with arthritis in their ability to engage in daily life activities.

Personal wellbeing

People with arthritis recorded significantly lower wellbeing scores compared to the general Australian population (mean score of 64.0 compared to 77.6). Significantly lower wellbeing scores were evident across all domains but scores were substantially lower in the area of health (46.7 compared to 74.6).

The wellbeing of carers of people with arthritis was also significantly lower than that of the general population (66.0 compared to 77.6) and was similar to that of the people they support.

Health

The research investigated people's experience, and the barriers and facilitators to accessing quality, appropriate health care (physical, emotional and psychosocial), from initial diagnosis to ongoing care. The research found:

- Substantial delays between first symptoms of arthritis and diagnosis were common. Two-thirds of survey participants experienced delays of longer than 12 months to receive a diagnosis and of these, half were diagnosed five or more years after first symptoms presented.

- The quality of treatment provided to people with arthritis varied from no treatment ('it's age' or 'it's growing pains') to comprehensive treatment, either by a general practitioner, specialist or both. The quality of information provided to people about their disease and its treatment also varied widely.

- The cost of medications used to treat the disease and relieve symptoms was high, both in terms of the cost of individual medications and the number of different medications and supplements required, not all of which are subsidised under the Pharmaceutical Benefits Scheme (PBS) for people with arthritis.

- Almost half of participants had another health condition or disability which complicated the management of their arthritis and vice versa, particularly in relation to medication.

- Participants reported that pain and fatigue were overlooked in the treatment of their arthritis and few participants were offered options or advice on managing these symptoms.

- Effective arthritis management usually requires a team of health care professionals but accessing them is often difficult and expensive. Participants also reported that health services were complex and fragmented, and that they experienced difficulties navigating services and finding an appropriately skilled provider that met their needs.

- Living with arthritis adversely affected emotional wellbeing both for the person with arthritis and their carer, and this was often ignored in their treatment plan.

Habilitation

The research investigated people's access to habilitation and rehabilitation.[2] The research found:

- Nearly all participants (95 per cent) reported that their arthritis limited their ability to engage in daily activities, with 37 per cent reporting that they were always limited and 54 per cent reporting that they were sometimes limited in their ability to engage in daily activities due to their condition.

- Participants who identified as either always or sometimes having limited ability to engage in daily activities as a result of their arthritis then identified which activities were most affected: 34 per cent said their arthritis had a severe or profound impact on being able to manage their home or garden, 22 per cent on being able to undertake domestic activities, and 5 per cent on undertaking basic personal care.

- Participants reported making a range of changes to their living circumstances to accommodate their arthritis, from buying aids and equipment, modifying their homes, to relocating to more accessible homes.

[2] Habilitation is services that help a person learn, keep, or improve skills and functional abilities that they may not be developing, for example using a cane, guide dog or sign language. Rehabilitation is services that help a person improve skills that have been lost, for example regaining lost skills or functioning after a stroke or head injury.

Work and study

The research investigated people's experience and the barriers and facilitators to accessing and maintaining employment and study. The research found:

- Participants reported that the ability to participate in the workforce was important for social participation as well as to meet medical costs and maintain an adequate standard of living.

- Of the participants who were of working age (aged less than 65 years, 63 per cent), 74 per cent were employed full or part-time (57 per cent full-time and 43 per cent part time), 37 per cent were not in the labour force, and 15 per cent were studying full or part-time.

- The labour force participation rate for survey participants was 44 per cent, compared to the national participation rate of around 65 per cent. People who were younger when the condition started were more likely to be out of the workforce than those with onset at a later age.

- 67 per cent of all participants reported that arthritis had affected their work or study, now or in the past; 23 per cent reported that they were permanently unable to work or study because of their condition; 68 per cent were restricted in the type of work or study they could do; and 65 per cent were restricted in their hours of work or study. In addition, 35 per cent reported that they required workplace modifications and 14 per cent reported that they needed ongoing assistance to participate in work or study.

- Nearly all participants of working age who were not in the labour force reported that arthritis had affected their participation in the workforce (93 per cent). They were also more likely than those who were employed to report that their arthritis had restricted the type of work or study they could do (79 per cent) or the hours they could work (72 per cent). Half of participants who were not in the labour force reported that they were permanently unable to work or study because of their arthritis.

- For participants of working age who were not in the labour force, almost half were 55-64 years old, i.e. close to retirement age.

- 43 per cent of research participants had retired, of whom 25 per cent were under the age of retirement – this may include people who planned to retire early and those who were forced to retire early because of their arthritis.

- Participants with osteoarthritis, rheumatoid arthritis and other forms of arthritis were less likely to be in the labour force compared with other participants. People who were not in the labour force were also more likely to

have experienced symptoms at a much younger age than those who were employed.

- The extent to which people were able to work or study depended on whether they needed to and were able to work flexibly, work reduced hours, or have access to a modified workplace.

Standard of living and social protection

The research investigated the implications of people's lived experience of arthritis in terms of being able to attain and maintain an adequate standard of living for themselves and their family. The research found:

- Participants reported that the financial consequences of arthritis were detrimental due both to the high costs associated with living with the condition and the loss of income due to reduced capacity to work. The financial impact of having arthritis also affected other areas of their social participation and wellbeing.

- Costs included ongoing medical care, the high and continual cost of medication, aids and equipment, home help and maintenance services, personal care and transport.

- Two-thirds of participants said that they were financially worse off due to having arthritis; 16 per cent reported that they struggled to meet their expenses due to the financial impact of their arthritis, while 5 per cent reported that they were much worse off and needed financial support. Many of the participants reported compromising their ongoing health care and other basic needs (food and utilities) to meet the cost of medication.

- 33 per cent of participants relied on public financial support (e.g. Disability Support Pension or Age Pension). Of those receiving public financial support, 21 per cent were under 65 years of age and therefore were likely to be receiving disability or other support rather than the Age Pension.

- Participants reported that accessing social protection was complex and difficult. Participants noted that available support was not flexible enough to respond to fluctuations in the severity of their disease (disease flares).

- Government support for ongoing medical costs was identified by participants as a high priority, particularly given the chronic nature of arthritis, the fluctuations of the disease, and the high cost of medication and treatment.

Family and social participation

The research investigated people's experience, barriers and facilitators of being included and participating in their family and community. The research found:

- The extent to which people's family and social participation was affected by their arthritis depended on the level of impairment caused by their condition, personal circumstances, and the availability of informal and formal support at home and in their place of work or study.

- Nearly all participants (84 per cent) identified informal support from immediate family members as their main source of support for personal care, domestic activities and managing their arthritis. This was due to the proximity of family, the lack of access to flexible services, or because they could not afford formal services due to reduced income.

- For people whose arthritis caused significant disability, greater formal support at home, work or study would improve their social participation.

- Arthritis affected children – they may have arthritis themselves or they may have a sibling or parent with arthritis, affecting family dynamics or requiring them to take on caring responsibilities.

- Some women chose not to start a family because of their arthritis, as the prolonged period off their medication could have long-term effects on the severity and prognosis of their condition.

- The impact of arthritis was not limited to the people with arthritis but also affected their carers, family, neighbours and friends:

    - physically, especially older carers who are also likely to have arthritis or other health conditions

    - emotionally – in terms of isolation, changed relationships, financial hardship, and the impact on their own social participation

    - financially – in reducing or limiting their capacity to work.

Services and support needs

Participants identified a number of service and support needs concerning information requirements, informal support (family and friends, community and arthritis support groups), formal support (health care, medication, social protection and home care), and other areas (employment, home modifications, equipment, and public awareness).

- People with arthritis, their families and carers, need access to better information about their condition, including: medication and side effects; managing pain and fatigue; support groups and emotional support available; aids and equipment and how to source them; and the availability of social and disability services and how they can be accessed.

- Some participants with arthritis rely heavily on informal support, in particular from family and friends. Family and friends need to be supported to be able to sustain this role.

- Increased community awareness and understanding of arthritis – including amongst health practitioners, policy makers and employers – could also improve support for people with the condition.

- Local or online support groups help meet the needs of people with arthritis and could be expanded to target specific age groups and conditions.

- There is a clear need to identify and improve formal support, from providing better ongoing health care beyond diagnosis, increasing the coverage of necessary medications under the PBS, to improving awareness of the disabling impact of arthritis in the provision of social protection and social services.

Increasing recognition in the broader community of the nature and impact of arthritis, and the fact that it affects people of all ages – and not just older people – would help address many of the service and support needs identified.

Implications of this research

This report reflects the voices of people with arthritis who are trying to hold down a job, raise a family, and participate in the life of the community, while managing the disabling effects of their condition. They face significant challenges due to the complexity and fragmentation of health services, inflexibility in the social support sector, and limited awareness in the community of the impact of living with arthritis.

Many people with arthritis experience disability and require support – both short-term and long-term – depending on the nature of the condition, the impact it has on them, and their personal circumstances.

It is not clear to what extent the National Disability Insurance Scheme (NDIS) will support people with arthritis or whether any existing support services provided will be affected. A risk is that where services (from State and other providers) are transitioning to the NDIS, access to support currently available might be reduced.

This research suggests that:

- The disabling impacts of arthritis need to be recognised in the community as well as by government, service providers, employers and educators.

- The NDIS should recognise the severely disabling and fluctuating effects of arthritis. Some people with arthritis will need NDIS individual packages.

- Other formal support services need to be identified for people with arthritis, made available both flexibly and long-term, and be provided to people who do not qualify for an individualised package under the NDIS but who still need formal support.

- The provision of services should be monitored during the transition to the NDIS to ensure that services are maintained for people with arthritis who require them.

1 Introduction

Arthritis Australia commissioned the Social Policy Research Centre (SPRC) at UNSW Australia to undertake research on the lived experience of people with arthritis and other musculoskeletal conditions. The aim of this research was to increase understanding of the disabling impacts of arthritis and musculoskeletal conditions on individuals and on their quality of life, and to gain a better understanding of the service and support needs of people with arthritis. The research examines the lived experience of adults and children with different forms of arthritis, and the experience of families and carers who support them. The research also identifies some of the financial implications of arthritis, both in terms of costs and income forgone, for both people with arthritis and their carers.

Arthritis Australia is the peak arthritis consumer organisation, providing support and information to people with arthritis, as well as advocacy and resources for community awareness and understanding. Arthritis organisations in each state and territory also provide support to people with arthritis.

1.1 Prevalence of arthritis in Australia and associated costs

Although arthritis is often referred to as a single disease entity it is, in fact, an umbrella term for more than 100 medical conditions that affect the musculoskeletal system, especially the joints where two or more bones meet.

Arthritis is the most common long-term health condition in Australia, affecting 3.3 million people or about 15 per cent of the population (ABS 2013). According to the Australian Bureau of Statistics (ABS), more than half of people with arthritis had osteoarthritis (55.9 per cent), 13.6 per cent had rheumatoid arthritis, and 37.3 per cent had an unspecified type of arthritis (ABS 2013). Prevalence is higher amongst women than men (17.7 per cent compared with 11.8 per cent) (ABS 2013). Women aged 45 years and over are considerably more likely to have arthritis than men. In particular, at ages 75 years and over, 60 per cent of women have arthritis compared with 42 per cent of men (ABS 2013).

Although arthritis prevalence increases with age, people of all ages are affected including children; 58 per cent of people with arthritis are aged between 25 and 64 years (Arthritis and Osteoporosis Victoria 2013). Arthritis results in significant costs to the national economy both in terms of direct costs to the health system, which are currently over $4 billion a year (Arthritis and Osteoporosis Victoria 2013), and in indirect costs such as loss of earnings and productivity (Arthritis Australia 2012). Loss of GDP as a result of early retirement due to arthritis was recently estimated to be $9.4 billion (Schofield et al. 2013), while in 2007, the total economic cost of

arthritis (including lost productivity and wellbeing) was estimated at $24 billion (Access Economics 2007).

1.2 Arthritis and disability

Arthritis is the second leading cause of disability and the leading cause of chronic pain in Australia. Nearly 600,000 people, or 15 per cent of all those with disability, report arthritis as their main disabling condition (ABS 2012). Of these, one in four experience severe or profound core activity restrictions (ABS 2010).

Arthritis-related problems include pain, fatigue, stiffness, inflammation and damage to joint cartilage – the tissue that covers the ends of bones enabling them to move against each other – and surrounding structures. As a result, people with arthritis can experience significant loss of function, notably manual dexterity, strength and mobility; deformity; and pain and fatigue. Arthritis can interfere with a person's ability to undertake basic daily living tasks and can have a significant impact on their quality of life. Different types of arthritis can cause varying degrees of functional impairment. Impairment is usually chronic and progressive and is often overlaid with 'flares' of disease activity which cause unpredictable, episodic bouts of severe pain, immobility and functional decline, interspersed with periods of reduced disability or disease remission.

The impact of arthritis on a person can vary significantly, depending on a number of factors including: type of arthritis; age at onset; any delay in diagnosis; treatment received; general health; the extent of joint damage and deformity caused; the side effects of long-term medication; and the presence of co-morbid conditions.

Arthritis is often referred to as a 'hidden disability'. A person with arthritis may not have a visible disability but may endure constant pain, joint restriction, chronic fatigue and associated functional and mobility issues.

Although arthritis is not yet curable, early diagnosis and intervention may delay the progression of the disease and may reduce the number of people experiencing arthritis-related disability. For people with rheumatoid arthritis in particular, early diagnosis and treatment, ideally within 12 weeks of symptom onset, is critical. Early intervention can reduce the severity and disability associated with rheumatoid arthritis by one-third (Finckh et al. 2006).

1.3 Research purpose and scope

The purpose of this research was to improve understanding of the disability impact of arthritis by investigating;

- who is affected

- how people are affected (people with arthritis and their carers) physically, emotionally, socially and financially
- what helps people affected to manage the impact of their condition, and
- how support for people with arthritis-related disability can be improved.

This study explored the experiences of people living with a variety of arthritis types including osteoarthritis and inflammatory forms of arthritis such as rheumatoid arthritis, ankylosing spondylitis, juvenile idiopathic arthritis and Still's disease. The study also included people for whom joint pain is a symptom of other diseases and where the arthritis is considered to be secondary to the main disease, including psoriatic arthritis, haemochromatosis and systemic lupus erythematosus.

Although arthritis is a leading cause of disability, anecdotal evidence suggests that people with arthritis-related disability have only limited access to formal support from disability care services (Arthritis Advisory Group) and obtaining access to support services is further complicated by the often episodic nature of arthritis-related disability. It is difficult to plan for a condition that is episodic and many appropriate organisations and programs do not have the flexibility to provide support during the acute phase of the disease.

By improving understanding of who is affected and how, as well as identifying what helps people manage and how services can be improved, the results of this research can inform priorities for promoting policy change or providing new support programs for people with arthritis-related disability.

1.4 National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) was launched in five sites in July 2013 to provide long-term, high quality support for people who have a permanent disability that significantly affects their communication, mobility, self-care or self-management. The scheme aims to deliver:

- A lifetime approach, with long-term funding that will change with needs
- Choice and control, allowing people to control what support they receive and when
- Social and economic participation, encouraging people to live to their full potential within the community
- Early intervention, investing in remedial and preventative intervention.

This report will be a useful reference for the NDIS and other service designers considering the disability support needs of people with arthritis. In particular, it clarifies the disabling impact of arthritis and highlights the often episodic, as well as chronic nature of the condition. While the NDIS eligibility criteria recognise that a

person with impairments which are chronic and / or episodic in nature may be considered to have a permanent disability[3], it is not yet clear how people with arthritis will fare in the scheme's assessment processes. In the past for example, some people with arthritis have been denied access to disability services because their condition has been considered a medical condition and not a disability, despite the associated activity limitations.

While most people with arthritis will not require an individualised package of support, a substantial number will have significant disability warranting long-term support (Tier 3). Others will be assessed as Tier 2 participants. Current indications are that Tier 2 participants will need to rely on existing systems of referral and support. These are the same systems that currently result in many people not receiving disability support because their arthritis is not understood to be a disability. An additional concern is that many of the existing programs also appear to have uncertain futures as they are absorbed into the NDIS through current funding arrangements.

1.5 Structure of this report

Sections 2 to 4 provide an overview of the research methods, framework for analysis and an overview of the research participants.

Sections 5 to 7 describe the research findings. Section 5 identifies how people are affected in terms of their personal wellbeing, health, living circumstances, study and work, standard of living, family and social participation. Section 6 describes what helps people manage their condition. Section 7 identifies areas that can be improved, in terms of formal and informal support, information and public awareness.

Section 7.5 summarises the key findings, including the financial consequences of arthritis and considerations for the implementation of the NDIS.

[3] *National Disability Insurance Scheme Act 2012*

2 Research design

The research used a multi-method approach to provide a comprehensive account of the disabling impacts of arthritis on the lives of people with different forms of arthritis, their families and carers. The focus is on what support people need to maximise their quality of life and participation.

Ethics approval was obtained from the UNSW Human Research Ethics Committee (Reference HC13115). All research participants were voluntary, provided consent and their contributions are de-identified.

The first phase of the research included the research plan and a review of the literature**.** The second phase of the research involved data collection. This included a key informant roundtable, in-depth interviews with individuals with arthritis-related disability, and an online survey of people with arthritis. A summary of participants is provided in Table 2, Section 4.

The research explores both informal and formal support available to people with arthritis-related disability. Informal support includes assistance from family, friends, networks and the broader community; whereas formal support includes paid support available through government, non-government and private services.

2.1 Literature review

The literature review focused on policy, programs, support and service models relevant to arthritis and disability within the life domains identified in the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD). It investigated both Australian and international literature for information on the support required by people with arthritis to maximise their quality of life and their social and economic participation.

The literature review examined evidence relating to barriers for people with arthritis to exercise their human rights in the following areas:

- People's experience of accessing quality, appropriate health care (physical, emotional and psychosocial), from initial diagnosis to ongoing care, and the identification of any barriers and facilitators
- People's experience of accessing and maintaining employment and the identification of any barriers and facilitators
- Access to habilitation and rehabilitation as a facilitator to their life and enjoyment of these human rights
- The implications of people's lived experience of arthritis in terms of being able to attain and maintain adequate standards of living for themselves and for their family

- People's experience of being included and participating in family and society and the identification of any barriers and facilitators.

Two gaps that were identified in the literature review were the impact of arthritis in life areas aside from work (the impact on workforce participation is well documented – see Appendix A: Literature review, section 3.3) and the impact of juvenile idiopathic arthritis (beyond treatment, for example in terms of education, family life, and participation). Both warrant more detailed investigation in the future.

The full literature review is attached at Appendix A: Literature review. Both the gaps and the key findings of the literature review are explored in this research through the roundtable and in-depth interviews.

2.2 Consumer roundtable

The consumer roundtable was held in June 2013 and involved 13 participants, including one carer and one arthritis educator. Participants were predominantly women (2 men attended), came from different States, and had different types of arthritis. The group discussed the lived experience of arthritis in the context of the core objectives of the CRPD, particularly health, habilitation and rehabilitation, work and employment, standard of living and social protection[4], and participation (social and family). A summary of the issues raised is attached at Appendix B: Summary of roundtable.

2.3 In-depth interviews

The interviews aimed to understand the experience of the person with arthritis and the impact it had on their everyday life. The interviews used a 'discovery interview' format (Ali and Gray 2006), which encouraged individuals to tell the story of their experience, rather than answer prescribed questions. The standardised structure adapted from Ali and Gray 2006 was used to offer prompts to participants to assist them to tell their story. It describes the chronological stages of a person's journey through an illness or disability and aims to trigger significant memories. The prompts used were:

- Type of arthritis
- Initial symptoms, how soon it was diagnosed and how it is treated

[4] Social protection, as defined by the United Nations Research Institute for Social Development, is concerned with preventing, managing, and overcoming situations that adversely affect people's wellbeing. Social protection consists of policies and programs designed to reduce poverty and vulnerability by promoting efficient labour markets, reducing people's exposure to risks, and enhancing their capacity to manage economic and social risks, such as unemployment, exclusion, sickness, disability and old age.

- How arthritis has impacted on everyday life in terms of home, being part of the community, and work life, and what changes have been made
- What support is offered now
- What support was not provided but could have helped
- What support could help in the future
- Aspirations, future plans and goals.

Potential interviewees were identified by Arthritis Australia and their partner organisations on the basis of having arthritis related disability. From the list of possible participants provided, SPRC selected interviewees to ensure representation across each state and territory, women and men, people with arthritis and their carers, people experiencing different type of arthritis, and people who had been living with their symptoms of arthritis for different lengths of time. SPRC contacted all possible participants to arrange time for a telephone interview and twenty-eight telephone interviews were conducted from June to August 2013. Each participant provided written consent and was reimbursed for their expenses with a $40 gift voucher. Interviews lasted between 45 and 90 minutes. Each interview was recorded and transcribed with the permission of the participant. A summary of the interview findings are presented in Appendix C: Summary of interviews.

2.4 Survey

The data collected through the roundtable and the interviews, in combination with the literature review, were used to develop an online survey (Appendix D: Online survey). The survey was distributed by SPRC via its newsletter, as well as through the networks of Arthritis Australia and state and territory arthritis organisations and other organisations including Lupus NSW, Carers Australia, Council on the Ageing, and Pain Australia. The survey was also made available in hard copy for people who did not have access to a computer. No one took the opportunity to complete the survey by telephone.

The survey was open for three weeks in October 2013 to anyone with arthritis or caring for someone with arthritis to respond about how arthritis affects day to day living and the extent to which people with arthritis experience disability.

The recruitment for survey participants mostly targeted people with arthritis and may have resulted in a less representative sample of people with arthritis than one drawn at random. For example, participants may have engaged with an arthritis organisation due to the severity, type, or impact of their condition.

3 Frameworks for analysis

3.1 UN Convention on the Rights of Persons with Disabilities

Australia ratified the *UN Convention on the Rights of Persons with Disabilities* (UNCPRD) in 2008. The UNCRPD is a significant legal and policy advance establishing legally binding obligations for those states that become a party to the Convention. The Convention establishes international standards in a human rights framework that affirms people with disabilities as rights bearers rather than objects of welfare.

The UNCRPD recognises disability as a part of human diversity and embraces a whole of government approach. The Convention recognises the dynamic relationship between impairment and disability where a person's impairment can limit their ability to engage in daily life activities. Central to its implementation is recognition of the importance of specific impairment related supports in parallel with broader infrastructure and non-discrimination measures.

Implementation of the UNCRPD has been the basis for and guiding framework of much recent policy development in Australia. The National Disability Strategy and the National Disability Insurance Scheme are central pillars of Australia's implementation of the Convention. These policies recognise the right of people with disability to be participating members of their community. The UNCRPD rights recognise the need for people to receive appropriate supports and reasonable adjustments to be able to participate meaningfully. Rights such as health, habilitation and rehabilitation, education and employment, standard of living, and family and social participation, provide a framework for an inclusive and accessible society that respects the rights of persons with disability.

The rights established under the UNCRPD were used for the thematic analysis of the data gathered from the literature review, consumer roundtable, in-depth interviews and survey.

3.2 Appreciative inquiry

Appreciative inquiry is a form of analysis that seeks to identify what is working, rather than merely identifying problems (Rogers & Fraser 2003). Appreciative inquiry begins by using stories of positive experiences to identify themes and what has helped people to achieve their goals. Participants are not led or directed in any way.

Research participants are generally more interested in appreciative inquiry and are more forthcoming with information. Appreciative inquiry also stresses the use of findings for decision-making and action, and it is often used as part of a process

whereby the themes are taken back to participants with proposed strategies, processes and systems to address any issues raised (in this case the Project Advisory Group and final report).

Appreciative inquiry was used in the consumer round table, the in-depth interviews, and the survey wherever possible. The data from each was then grouped thematically under the rights identified under the UNCRPD (see Section 3.1 above).

Appreciative inquiry cannot always be relied upon to gain an understanding of all weaknesses in a system – therefore this method was used in conjunction with other tools including the use of the Personal Wellbeing Index and other survey questions.

3.3 Personal Wellbeing Index

Personal wellbeing can affect both confidence and resilience, which may be linked to the ability to identify and achieve goals. To assess this, the research investigated how satisfied participants are in their daily life, both in terms of overall satisfaction and satisfaction with specific aspects of their life, to determine their wellbeing.

The Personal Wellbeing Index (International Wellbeing Group 2006) was used in the survey to measure people's feelings about themselves to determine their quality of life in comparison with the general population. The standard components of the wellbeing index relate to standard of living, health, what you are achieving, personal relationships, how safe you feel, community connectedness, future security, and spirituality. The data collected can then be compared against other datasets, including a dataset for the broader Australian population.

3.4 International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) is a classification of health and health-related domains developed by the World Health Organisation (WHO). These domains are classified from individual and societal perspectives by a list of body functions and structures, and a list of activity and participation domains, all of which are considered within the context of environmental factors. The ICF measures health and disability at both individual and population levels and is the international standard to describe and measure health and disability.[5]

The ICF acknowledges that every person can experience a reduction or diminution in health and as a result experience some degree of disability, and recognises disability as a universal human experience. Shifting the focus from cause to impact

[5] http://www.aihw.gov.au/disability/technical-definitions-of-disability/

places all health conditions on an equal footing and allows them to be compared using the metric of health and disability. In addition, because the ICF considers the social aspects of disability, this prevents disability from being seen only as a 'medical' or 'biological' dysfunction. By including environmental factors in the contextual analysis the ICF acknowledges the impact of the environment on the person's functioning (WHO 2001).

The ICF was used in this research to test that the literature review and survey design were comprehensive.

3.5 Presentation of the research data

The data contained in this report include qualitative data (interviews, roundtable and survey) and quantitative data (survey). The data were analysed in terms of the key research questions and in the themes identified in the UNCRPD. Quotes from participants are used to illustrate and expand on the findings of the survey data. The breadth of the analysis is based on the information provided by participants and therefore may not be comprehensive across all themes identified.

The source of the data presented in this report is identified according to the survey question. All quotes in this report are made by people with arthritis or carers of people with arthritis who participated in the survey and interviews. The names are all pseudonyms.

Note that the implications and findings of this research are not prioritised. People with arthritis have different needs and priorities depending on their individual situation and these priorities change over time as their personal circumstances and condition change.

4 Summary of research participants

4.1 Number of participants

The research included a total of 819 contributions across the consumer roundtable, interviews and surveys (some people possibly contributed through more than one method; Table 1). Participation in this research was open to people living in Australia with arthritis, and/or caring for someone with arthritis.

Table 1: Sample sizes

Method	Number of participants
Consumer roundtable	13
Interviews (telephone)	28
Online survey (arthritis)	720
Online survey (carers)	58
Total	819

Notes:
A total of 1,173 people attempted to complete the survey, of which 778 provided complete or mostly complete responses.

Note that due to the small number of people completing the online carers survey, the quantitative data from this survey was excluded from the analysis (other than the descriptive statistics) as the results were not statistically comparable. The qualitative data from the survey of carers are used throughout this report.

4.2 Demographics

Table 2 below presents the characteristics of all research participants by number of participants (n).

Table 2: Summary of research participants

Demographics of participants		Consumer roundtable n=13	Interviews n=28	Survey (arthritis) n=720	Survey (carers) n=58	Total n[4]
Gender	Female	11	23	496	20	550
	Male	2	5	95	6	108
People with arthritis or carers	Arthritis	11	25	720		756
	Carers	1	3	58		62
	Educator	1		-		1
Location	ACT	1	5	46	1	53
	NSW	8	7	343	16	374
	NT	0	0	0	0	0
	QLD	1	5	65	5	76
	SA	1	1	23	0	25
	TAS	1	2	14	1	18
	VIC	0	3	65	3	71
	WA	1	5	39	1	45
Identifying as CALD or ATSI[1]	CALD	1	2	67	2	72
	ATSI	0	0	11	0	11
Age (years)[2]	Under 25		3	6	0	9
	25-34		5	26	1	32
	35-44		5	55	6	66
	45-54		4	103	6	113
	55-64		6	186	10	202
	65-74		3	166	3	172
	75+		2	57	1	60
Condition (may have one or more)	Rheumatoid arthritis	7	18	245		270
	Juvenile idiopathic arthritis	2	8	10		20
	Psoriatic arthritis	1	2	55		58
	Osteoarthritis	2	5	472		479
	Ankylosing spondylitis	1	2	45		48
	Other form of arthritis[3]	3	6	143		152
Number of types of arthritis	1			479		
	2			150		
	3			51		
	4			12		
	5			3		

Source: Survey, Section C – Your arthritis, Section F – About you.

Notes:
1. CALD – Culturally and Linguistically Diverse, ATSI – Aboriginal and Torres Strait Islander
2. Age groups aligned to ABS data. Consumer roundtable members were not asked their age or the number of types of arthritis they had.
3. Other forms of arthritis include Sjögren's syndrome, fibromyalgia, systemic lupus erythematosus and others
4. For the survey, not all participants answered every question, e.g. 125 people did not indicate which state they were from

4.2.1 Type of arthritis

Of the survey participants, 67.9 per cent had osteoarthritis, 35.3 per cent had rheumatoid arthritis, and 36.4 per cent had other forms of arthritis (note that people identified as having more than one type of arthritis). There is a higher proportion of participants with rheumatoid arthritis than the general population and this may be a

reflection on the way the question was asked by both our survey and the Australian Bureau of Statistics or of the membership of the arthritis organisations through which the survey was promoted.

A number of participants identified as having more than one type of arthritis. Of the survey participants, 69 per cent identified as having only one type of arthritis, 22 per cent identified as having two types, and 9 per cent had three or more types. Three people identified as having 5 types of arthritis. An overview of the main types of arthritis identified by participants, their symptoms, and their impacts are provided in Appendix E: Overview of arthritis types. Note that for statistical reasons, Sjögren's syndrome, fibromyalgia, systemic lupus erythematosus (SLE) and other non-identified types of arthritis are grouped under the category 'other' as the survey response rate for these types of arthritis was low. This in no way reflects the significance or similarities in the symptoms or disabling impacts these types of arthritis have on people – impacts of each of the diseases are described using qualitative data within this report.

4.2.2 Age and gender

The Australian Bureau of Statistics reports that the prevalence of arthritis increases with age, from less than 1 per cent of people aged less than 25 years to 52 per cent of people aged 75 years and older. Prevalence is higher amongst women than men (17.7 per cent compared with 11.8 per cent) In particular, at ages 75 years and over, 60 per cent of women have arthritis compared with 42 per cent of men (ABS 2013)– see Figure 1 below (ABS, 2013).

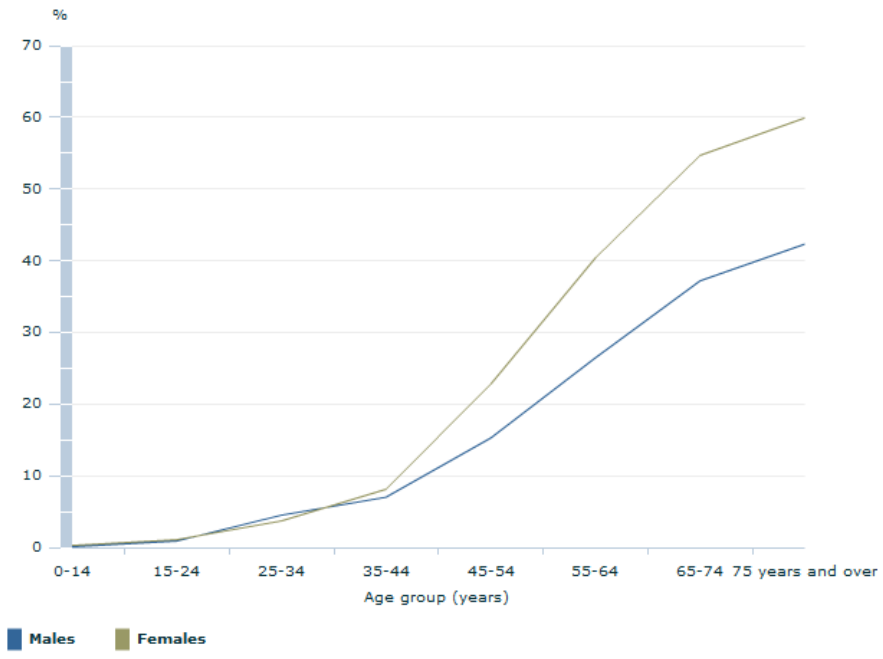

Figure 1: Proportion of persons with arthritis in Australia, 2011–2012

(Source: ABS, 2013)

The age distribution of participants in this research was similar to that of the Australian population with arthritis although the research captured less of the 75+ age group compared to other age groups. This may have been due to the online format of the survey (although paper copies were provided on request), the length of the survey, and the way in which the survey was distributed (mainly via Arthritis organisations, possibly reflecting their membership).

The survey results confirmed that arthritis is not only an older person's disease, with 16 per cent of survey participants being less than 45 years old and 64 per cent under 65 years old and therefore of working age.

Women were over-represented in this research, comprising 84 per cent of research participants compared to 60 per cent of all people with arthritis.[6] Again, this is likely to reflect the way that participants in the research were engaged.

Age at diagnosis

The survey also identified the age at which the symptoms of arthritis were first experienced (Table 3): 49 per cent of participants were 44 years old or less when they first experienced symptoms of arthritis; women were more likely than men to experience symptoms of arthritis at a younger age (58 per cent of women compared to 39 per cent of men surveyed); and all forms of arthritis except osteoarthritis first affected the majority of participants under the age of 44 (Table 5). Note that women are overrepresented in the survey group and these results should be read with caution.

Table 3: Age when participants first experienced symptoms of arthritis (all, male, female)

Years	All (n=594) %	Male (n=94) %	Female (n=490) %
Under 25	18	13	19
25-34	14	5	18
35-44	17	21	21
45-54	20	22	25
55-64	12	26	13
65-74	3.5	9	4
75+	0.5	4	0
Total	100	100	100

Source: Survey, Section C – Your arthritis

Notes:
There are some disparities between N and the male/female figures as some participants did not answer the gender question. 126 people preferred not to give their age.

[6] http://www.aihw.gov.au/arthritis-and-musculoskeletal-conditions/

Table 4: Age when first experiencing symptoms of arthritis, by type of arthritis (% of survey participants)

Years	Rheumatoid arthritis %	Juvenile idiopathic arthritis %	Osteoarthritis %	Psoriatic arthritis %	Ankylosing spondylitis %	Other forms %
Under 25	20	89	13	33	55	26
25-34	20		14	28	21	22
35-44	23	11	21	17	14	21
45-54	20		29	13	10	20
55-64	13.5		16	9		8
65-74	3		6			2
75+	0.5		1			1

Source: Survey, Section C – Your arthritis

Notes:
Includes people with more than one type of arthritis – age at first symptoms of arthritis
Results for JIA are not statistically comparable due to the small number of people identifying as having JIA (n=9).

4.2.3 Location

Most survey participants lived in major cities (72 per cent) or inner regional areas (24 per cent) – see Table 5. Just over half of the participants lived in NSW. This may reflect differences in the way the survey was promoted through the different state and territory arthritis organisations. Representation from other States and Territories was good except for the Northern Territory. Whilst the survey was also distributed to other disability organisations, Medicare Locals, and through SPRC mailing lists, no one from Northern Territory participated in this research.

Table 5: Location of survey participants by ABS classification of remoteness

Method	Per cent of participants
City	72
Inner regional	24
Outer regional and remote	4

Source: Survey Section F – About you, converted to Australian Standard Geographical Classification Zones (ABS); n=593.
Note: Only one participant was from a remote area.

4.2.4 Hard to reach groups

Some groups were more difficult to reach in the interviews despite purposive sampling across age, type of arthritis and location. This included the survey where people from an Aboriginal and Torres Strait Islander background were under represented against the general population (1.3 per cent of participants identified as

being from an Aboriginal and Torres Strait Islander background against a general population of 2 per cent).[7] Participation in this research by people from a culturally and linguistically diverse (CALD) background was somewhat higher at 8.8 per cent. However, this group is still under represented in this research based on recent Census statistics (20.2 per cent of the population) and the Australian Health Survey (13.5 per cent).[8]

The under representation of people from both Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds may be due to the way in which this survey was distributed, as well as cultural differences in the way this disease is identified and managed.

4.3 Carers of people with arthritis

Family members are often called upon to provide informal care and support for people with arthritis to varying degrees. This can include being a carer for an older relative, caring for a partner, caring for a child, or supporting another relative or friend.

The survey was open to carers of people with arthritis and 58 carers participated. Three-quarters of the carers participating in the survey were female, 25 per cent of all carers were under 45 (reflecting parents of children with juvenile idiopathic arthritis, partners of women with arthritis with young children, or people looking after their parents), 20 per cent were aged between 45–55 years old, 37 per cent were aged 56–64, and 15 per cent were 65 and over. This is not a representative sample – the AIHW report on primary carers of people with arthritis shows that 43 per cent of primary carers of people with severe or profound disability due to arthritis were aged over 65 years and most carers (54 per cent) were male (AIHW 2010). Carers, particularly those over 65 years of age, may have their own health concerns, including arthritis, and may have physical limitations in providing that caring role.

The majority of carers who responded to the survey (82 per cent, n=22) relied on private income – this includes employment, own business, superannuation or family. Given the age range of carer participants in the survey it could be assumed that many do not yet have access to superannuation and therefore are either working or relying on family for financial support. Fifteen per cent of carers (n=4) reported that they were in receipt of some form of public support.

Additional information was provided by other research participants about the care and support provided to them by family members demonstrating the extent to which people relied on informal carers. The response rate for carers is low, possibly due to

[7] Source 2011 Census of Population and Housing; 2 per cent of the Australian population over 18 are Indigenous where Indigenous includes both Aboriginal and Torres Strait Islander, Torres Strait Islander and Aboriginal.
[8] Source 2011 Census of Population and Housing, CALD defined in this survey as people over 18 speaking language at home other than English. Note that in the Australian Health Survey, the proportion of people identifying as CALD that have arthritis is 13.5 per cent (ABS, 2013).

the fact that most people don't identify themselves as carers or, perhaps because their caring role meant they did not have time to complete the survey.

4.4 Case study: Juvenile idiopathic arthritis

This case study is based on an interview with the parents of a child with juvenile idiopathic arthritis. Tom [not his real name] is five years old and lives with his parents and brother in a major city. Tom had symptoms at 6 months of age but it took 18 months before he was diagnosed with Still's Disease (systemic onset juvenile idiopathic arthritis) and referred to a specialist. The time delay in diagnosis is not isolated to this child and his family. The symptoms of his JIA have had a significant impact on his development:

> He'd wake up five or six times, every night, from about roughly six months of age screaming in agony. He still sleeps with us and he is nearly five because he's just so insecure… he keeps feeling for us because he's just terrified to sleep alone.

They also manage the emotional impact on their other child, such as sleeping arrangements, behaviour at school, and stress about witnessing the pain and treatment.

Three and a half years after diagnosis his parents are beginning to see small movements forward:

> He will go outside and have a little bounce on the trampoline which is actually a big milestone because once upon a time he couldn't even do that.

Tom and his parents continue to travel between two capital cities for ongoing and emergency treatment because of the allocation of funding and visiting rights for specialists.

> There were only four rheumatologists here, and only one sees children but they are not a paediatric rheumatologist, so we also see a paediatric rheumatologist, a GP, a rheumatologist, and a paediatrician [in different hospitals in different locations].

The need to travel between different specialists also raises the need for consistent and accessible hospital records or e-records. When parents take children to the local hospital emergency department, staff do not know how to deal with the disease.

Both parents are health and social care professionals and are actively involved in their local community trying to improve the services for children with JIA and their

families. They are concerned about managing the side effects of medications. They said:

> When Tom was younger, we rushed him to the hospital emergency, [but] no one seemed to understand what was going on. When they realised he was on Naprosyn and Methotrexate, they just threw their hands in the air and sent us home saying “if it gets worse bring him back”. …Tom also has psychological issues; we don’t know whether it’s the pain or the medication. The paediatric rheumatologist tends to think it may well be the medication – a steroid psychosis type problem.

Tom’s parents have developed an information kit for families, and work with medical and pharmacy students to provide insight into the life of a child with JIA. Their aim is for their son to be managed within a multidisciplinary team, with co-ordinated care of his medical treatment, and social care supports similar to that already established in oncology and diabetic services.

4.5 Case study: Rheumatoid arthritis

This case study is based on an interview with a young woman with rheumatoid arthritis. Margaret [not her real name] is 45 years old. She started to experience the symptoms of rheumatoid arthritis when she was 21 years old. At the time she was playing a lot of sport and had just undergone knee surgery. Eight weeks after the surgery her arm and wrist became very swollen and she was in a great deal of pain. Her GP quickly sent her for blood tests and she was diagnosed with sero-negative rheumatoid arthritis. Margaret was referred to a specialist who started medication but she was not provided with any relief and remained unwell and was unable to manage her own personal care for some time.

Nine years ago Margaret was changed to a biologic medication, which she says has completely changed her life. Margaret she says it took a long time to be prescribed that medication because of the complicated process required for prescribing the drug under current PBS criteria.

The current medication prevents the frequent admissions to hospital she experienced before she started this medication.

> I haven’t been back to hospital since I have been on this medication. Before that there have been times when I have been so bad I have had to be taken to Emergency and they’ve had to admit me because you know it gets into everything. If it gets into your jaw, you can’t eat, and if it is a severe flare up you can’t even breathe properly.

Margaret has been able to continue working as she had very understanding employers. Currently she runs her own business which gives her more freedom and flexibility but:

> [I get] exhausted and tired from dealing with the pain … [however] I really have become a little bit more attuned to my body and my health, so I think I am in a better position now than I ever have been.

Nevertheless Margaret added:

> As you get older … you struggle with it more as it impacts on other things. A lot of the times, if something goes wrong the doctors say "oh it's your arthritis" so there is not the extra assistance and help to get you better again.

The effect of the disease and the medication side effects also affect her work and family life.

> Apart from living with the pain and not being as mobile as I would like, it also affects your overall wellness and I am often extremely tired and I can get sick quite easily because of medications that I take to suppress my immune system … and there are also the side effects.

Margaret moved from one state capital to another five years ago:

> I had the best specialist, the one that got me on the biologic, she was outstanding, I could see her if I was unwell, I would call her on her mobile and she would organise to see me, she went above and beyond, a really caring specialist.

When Margaret moved, she found she could not get in to see a specialist; they were not taking any patients:

> I explained that … what I needed was a specialist to be able to provide me with my medication, because I can't get it without seeing a specialist … I ended up ringing the hospital and said if you don't get me in to see a specialist, … I will be admitting myself.

It took Margaret six weeks to see a specialist who she now sees every six months. However, needing this ongoing level of treatment has cost implications:

> It's a very expensive illness, you've got nothing to cover it, nothing for out of pocket expenses … your specialist isn't covered, you either pay over and above for the GP, you have got to pay for the medication … even for analgesics and things to manage the pain, because you always have a level of pain.

Margaret considers herself to be a lucky person:

> My husband and I have been together since before I had my arthritis so he has seen me well, and he has also seen me extremely ill, he has been a fantastic support for all those years.

She also has a 10 year old daughter which was very difficult due to health issues:

> They didn't think that I would be able to have children, so that was a gift but … I was very unwell.

The majority of her support is informal. Margaret recalls when she was living in the UK she had a rheumatology nurse that was at the local hospital clinic:

> You could actually get in to see the rheumatology nurse whenever you needed to and she would provide advice, she would help ... Sometimes you just had bad days and you actually need to go and sit down and talk to someone and tell them what is going on … To be able to have access to a health professional when you need to, is really important ... I have never known that to be available in Australia – from my personal experience it was the only time I have ever had any kind of support really – very beneficial support outside of the family.

In the future, Margaret wanted a range of allied health or alternative treatments to be more available.

> Probably because I'm getting older … things like physio, being able to have a therapeutic massage help me to keep going … For instance I am starting to have problems with my feet … after 24 years of having rheumatoid arthritis.

Margaret has just been provided with a care plan which allows her three visits to a podiatrist and two to a physiotherapist.

> If your care plan is divided between two allied health services it's not usually until your third visit to get treatment or relief ... If you could have five physio visits and five podiatry visits then that might be a bit more worthwhile.

Margaret discussed the importance of raising awareness about the effects of arthritis in the wider community by helping Arthritis Australia change understanding of what arthritis is.

> People believe arthritis is an old people's disease and it's a very silent disease because you can look at somebody and don't know they actually have it … It's also not being treated properly and there is a lot that other people could do if they better understood how the disease

impacts on people's lives and realised that it's so widespread and affects so many people … One of the things I'm quite passionate about, is for bureaucrats to understand the importance of preventive health and ongoing health maintenance. If you focus on the overall wellbeing of a patient, it eliminates future costs and trauma which often happens as a result of their health not being appropriately and holistically managed in the first place.

5 How people are affected

5.1 Personal wellbeing

The research investigated how satisfied participants were in their daily life, both overall and with respect to specific aspects, to determine their wellbeing. Personal wellbeing can be interpreted as an outcome or goal and can also affect both confidence and resilience, which may be linked to the ability to identify and achieve goals and aspirations.

5.1.1 Quality of life

The Personal Wellbeing Index (PWI) (International Wellbeing Group, 2006) was used in the survey to measure people's feelings about themselves to determine their quality of life and the results were compared to the general population (Table 6).

Table 6: Participant Personal Wellbeing Index scores

	Participants (arthritis)	Participants (carers)	Australian general population [a]
Life as a whole	64.0***	66.0***	77.6
Personal Wellbeing Index	64.4***	67.3***	75.3
Standard of living	70.0***	74.0***	77.8
Health	49.7***	65.3***	74.6
Achieving in life	62.5***	65.7**	73.6
Personal relationships	69.8***	69.3***	79.4
How safe you feel	70.5***	71.0***	79.1
Community connectedness	64.8***	64.7	71.1
Future security	60.8***	62.7**	71.1
Spiritual/religious	67.4***	66.0***	78.6

Source: Survey Section B – Your wellbeing
Notes:
Scale 0-100.
*–*** denoted significant difference in scores with *** being most significant - Significance tested using t-tests of survey responses compared with normative population, significance * p<0.05, ** p<0.01 and *** p<0.001
[a] Normative scores taken from Australian Unity Wellbeing Index report 29, September 2013 (Cummins & Perera 2013)

Although most people had wellbeing scores within the normal range for Australians (50–100), the average score for people with arthritis (64.0) was significantly lower statistically than the Australian average of 77.6, both on the overall score and across most domains (see Figure 2). The greatest difference, as would be expected, was

recorded for health, with people with arthritis scoring much lower in this domain than the general population.

Figure 2: Personal wellbeing index scores (participants with arthritis compared with their carers and the general population)

Source: Survey Section B – Your wellbeing, Cummins & Perera 2013

Notably, the average wellbeing score of carers responding to the survey is also significantly lower than the general population (66.0) and is similar to the score for people with arthritis. This is discussed further in Section 4.3 and likely reflects the lack of access to information, respite, physical and financial support, issues relating to workforce and social participation, and the overall impact on family life.

The survey identified a difference in wellbeing between the types of arthritis – for example people with osteoarthritis had a mean wellbeing of 67.6, whereas people with rheumatoid arthritis had a mean wellbeing of 65.0 (compared to the average for all people with arthritis of 66.4, and the background population of 75.3). The results for people with other forms of arthritis are not comparable due to the small number of responses (see Table 7).

Table 7: Personal Wellbeing Index Scores by type of arthritis (one type)

	n=479 [a]	Wellbeing score (mean)	Normative score [b]
Rheumatoid arthritis	128	65.0	
Juvenile idiopathic	7	68.9	
Psoriatic arthritis	25	61.1	
Osteoarthritis	298	67.6	
Ankylosing spondylitis	13	62.8	
Other form of arthritis [c]	8	62.2	
All		66.4	75.3

Source: Survey, Section B – Your wellbeing, Section C – Your arthritis

Notes:
a Number of participants having one type of arthritis only
b Normative scores taken from Australian Unity Wellbeing Index report 29, September 2013 (Cummins & Perera 2013)
c Other forms of arthritis include Sjögren's syndrome, fibromyalgia, systemic lupus erythematosus and others

Over 30 per cent of survey participants identified as having more than one type of arthritis. As expected, the level of personal wellbeing decreased as the number of types of arthritis increased (Table 8).

Table 8: Personal Wellbeing Index Scores by number of types of arthritis

	n=695[a]	Wellbeing score (mean)	Normative score (general population)
1	479	66.3	
2	150	66.1	
3	51	57.7	
4	12	59.1	
5	3	51.9	
All			75.3

Source: Survey, Section B – Your wellbeing, Section C – Your arthritis

Notes:
a Number of participants having one to five types of arthritis
b Normative scores taken from Australian Unity Wellbeing Index report 29, September 2013 (Cummins & Perera 2013)

Personal wellbeing scores also varied by state and were highest in Victoria (67.4) and lowest in the ACT (60.4).

Participants identifying as from an Aboriginal and Torres Strait Islander and culturally and linguistically diverse background both had a noticeably lower sense of personal wellbeing (58.8 and 59.5 respectively); however, for the Aboriginal and Torres Strait Islander group the sample was too small (n=11) to determine any statistical difference between the groups. The culturally and linguistically diverse group was larger (n=67) and the difference in score was significant.

There was little difference between the personal wellbeing of people in the under 30, 30–44 and 45–64 year age groups, but the personal wellbeing of those surveyed who were over 65 years older was noticeably higher (67.6, n=223) compared to the mean (64.0). There was little difference between genders, for people born in Australia or elsewhere, or for people who were studying or not. Notably, people receiving public support (financial) had a lower sense of overall wellbeing (61.3).

In preparing the survey, the research team formed a number of hypotheses about the factors likely to have an impact on wellbeing, including health (pain and reduced function), living circumstances (living alone or with family), community participation and support, remaining/gaining access to the workforce, etc.

Living arrangements had a significant impact on individual wellbeing with those living with a spouse or partner, or with spouse/partner and children, showing a much higher sense of wellbeing than other groups (living alone, living with parents, relatives, friends or housemates). This is likely a reflection of how much informal care and support is provided by a partner. People identifying as living alone with children under 18 (as opposed to living with spouse and children) reported a very low sense of personal wellbeing (50.3, n=7), but the numbers are too small to determine any statistical relevance. This low score is likely to reflect the difficulties of raising children whilst also managing an arthritic condition.

Social and workforce participation is related to personal wellbeing with those in full-time or part-time employment reporting the highest sense of wellbeing (66.2 and 66.5 respectively). Those identifying as neither employed, looking for work, or retired reported a very low sense of wellbeing (53.2, n=88). This group was likely to comprise people on home duties, parents, children, and carers and those on disability support.

Finally, the survey data showed that people who volunteered in some capacity had a stronger sense of wellbeing (68.6, n=265) than people who did not (61.8, n=403).

While still statistically significant, the difference in results for people with arthritis compared to people in the general population was the smallest in the areas of community connectedness and standard of living. This may be because people responding to the survey are already connected within the community (possibly demonstrating survey bias).

Using personal wellbeing as a measure in this survey is useful to provide a context for other elements of the research. The size of the sample of carers means that the data for carers should be understood in the context of the qualitative responses.

5.1.2 Emotional wellbeing

Arthritis was reported by research participants as having a substantial adverse impact on emotional wellbeing, in particular at the time of diagnosis and in managing

pain, and also because of the impact on finances, family and relationships. Some comments from participants include:

> I would have liked some emotional guidance when first diagnosed, I felt very alone despite my caring husband, I was in a very 'dark place' for the first time in my life and quite frankly I was scared.

> I am always in pain. You learn to live every day in pain. And you learn to sleep in pain.

> Arthritis turned my life upside down, back to front and inside out! … It has had financial effects in that I only work part-time now but I spend more money on specialists visits and have various medications to buy now which are a financial burden. It casts a dark shadow over my feeling of general wellbeing. Even though I am doing fairly well at the moment there is always the anxiety that my condition could deteriorate at any time. I may experience medication side effects or systemic effects of my illness. I find I feel annoyed that people do not understand what it is like living with an auto-immune disorder.

> Not being able to be involved in activities with my kids that I would like to and dealing with long-term pain and the psychological effects can bring depression. Reliance on immediate and extended family to help with day-to-day activities, the cost of medication and struggling to study because of pain, not being able to work a full-time or even part-time job at times due to pain. Realising my future will not be as I had hoped and planned, having to make accommodations based on my health. Always having to think ahead to social occasions and holidays as to how I can cope with the pain associated, i.e. bush walking, sitting on uncomfortable chairs at a friend’s house, stairs. Not having the love life with my husband that I would like to.

> My husband is now going into enormous debt to renovate our home so that I can move around easier, get into the shower, go to the toilet, and even, with lower benches and oven, cook again. Psychologically it is terrible as my self-worth has dwindled and depression set in quickly. If I didn't have such a loving family there is no way I could have coped with this. I had goals to finish my MBA, now my goal is to get out of bed each day.

The effects on mental health and emotional wellbeing of living with arthritis were identified across a spectrum from low mood to clinical depression. This was as a result of living with constant pain and fatigue, general debility, limited mobility, and lack of independence because of their arthritis. One person said:

> I think the arthritis caused the depression, partly anyway. And when I am depressed, the pain feels much worse, and I tend to focus on it more.

The emotional wellbeing of carers was also highlighted as a problem. Families caring for parents, partners and children with arthritis all did so in an informal and usually unsupported capacity. In addition, where people with arthritis were also carers their condition limited their ability to provide care, for example lifting a child, supporting a parent, and carrying out daily activities. A carer said:

> While the tasks of daily living such as showering and meals can be managed with my assistance and the assistance of care staff, the emotional impact of severely decreased mobility and independence are more difficult to overcome. I have sought support from a psychiatrist so that I can continue to support my mother who suffers from reactive depression. … Help with coping with a sense of grief about the life that might have been if not severely limited with arthritis would be appreciated. Day to day life is manageable. Emotional wellbeing for the person with arthritis is harder to achieve.

5.2 Health

5.2.1 Diagnosis

Participants in the research highlighted a time delay between the onset of symptoms and diagnosis. This is of concern as early treatment is known to reduce the long-term effects of many types of arthritis (National Collaborating Centre for Chronic Diseases 2009; Kim et al. 2013). For example, for rheumatoid arthritis, early diagnosis and intervention, ideally within 12 weeks of symptom onset, can reduce the severity and disability associated with the condition by one-third (Finckh et al. 2006).

Survey participants were asked to identify what year they first started to experience the symptoms of their arthritis, and in what year it was formally diagnosed and treatment started.

Table 9 below shows that only a third of participants were formally diagnosed shortly after the symptoms appeared (year zero in the table below) and a third were not diagnosed for five or more years.

Table 9: Time between onset of symptoms and diagnosis

Years	n[a]	Per cent
0	222	32.8
1	103	15.2
2	59	8.7

3	42	6.2
4	34	5.0
5	42	6.2
6-10	78	11.5
11-20	58	8.6
21-30	26	3.8
31-50	12	1.8
Total	676	100

Source: Survey, Section C – Your arthritis

The length of delay differed between types of arthritis. For example, for participants only identifying as having one type of arthritis, rheumatoid, psoriatic and other forms of arthritis were identified more quickly (48 per cent, 36 per cent and 50 per cent diagnosed shortly after the symptoms presented), whilst there was a bigger delay in diagnosing ankylosing spondylitis (only 8 per cent shortly after symptoms presented, and for some, up to 30 years after symptoms presented).[9] Only two of the nine survey participants with juvenile idiopathic arthritis were diagnosed within a year of symptom onset.

One person said:

> It took about four years [to get a full bone scan]… I don't know whether it was a matter of them just not believing me or thinking I was complaining.

Often people reached a critical condition before they were correctly diagnosed.

> It even got to the stage when I was that bad, when I was really diagnosed, my parents were looking at getting me a wheelchair because I couldn't do anything, basically, I was that physically, how would you say? Disabled, I guess.

> By the time I was 15, 16 I was having to use a wheelchair, then I saw an orthopaedic surgeon to find out what was going on and my hips were deteriorating very, very rapidly. I could hardly walk, I was in excruciating pain, it was horrific times for me ... By the time I was 18 when I was in hospital to have my hips replaced that's when they thought I better see a rheumatologist.

Participants in this research identified a number of issues concerning diagnosis in addition to the delay between symptoms presenting and diagnosis. Many participants were told nothing could be done and that arthritis was just part of getting old. Young children and teenagers were often dismissed with comments such as:

[9] note that the results are not statistically relevant for this group due to the small sample size

> "Just growing pains", "You've done something", "Your child is just overreacting."

> The GP … was dubious of RA occurring in 'someone so young' (I was 23 at the time). Better education of GPs in this disease might be the difference between effective early treatment and management of symptoms, and trying to control full-blown disease.

Information provided at the time of diagnosis ranged from very little to overwhelming quantities. Many participants felt the information and support provided was mainly targeted to older people and there was a need to develop resources and support for younger people with arthritis.

5.2.2 Management of arthritis

People with arthritis are normally managed by a general practitioner (GP), a rheumatologist or other medical specialist and should also have access to care by other health care providers such as physiotherapists, occupational therapists, exercise physiologists, remedial masseurs, chiropractors, and osteopaths. Inflammatory forms of arthritis such as rheumatoid arthritis normally require specialist care by rheumatologists.

Survey participants gave access to health services the highest satisfaction score (in terms of formal support provided) in the survey (mean score of 6.74 out of 10).[10] Overall, however, the perceived quality of care received from health care providers varied significantly. Many highlighted the need for better access to multidisciplinary care and for better co-ordinated care, including being seen by different members of a multidisciplinary team around the same time (rather than multiple appointments on different days). This was particularly important for children and for people in regional areas travelling long distances for an appointment.

General health care

More than half of survey participants (55 per cent) identified support from general health care providers (including GPs and nurses) as an important source of formal support.[11] Many people commented that there were some excellent medical practitioners who had provided great support and appropriate care but this was not always the case.

> I have a very good GP who gave me all the info that I have subsequently needed. My rheumatologist is also very personable and informative.

[10] Source: Question 27 – level of satisfaction with formal support.
[11] Source: Question 26 – most important sources of formal support.

> In eight minutes GPs can't do anything let alone diagnose complex illnesses or even try, attempt to diagnose one patient to the next … they are not aware of JIA and lots of other stuff …. The consistent problem is, and even with adult arthritis the GP misdiagnoses constantly.

Many participants with inflammatory forms of arthritis reported that they were not referred appropriately to specialist care.

> It was not until I moved to another area and needed to change doctors that I was referred to a specialist rheumatologist [by her GP] and began to receive the care and advice I should have been receiving since the onset of the disease. … By the time my new GP referred me, both hips needed replacing and I could barely walk. I was using crutches to get around and still working fulltime.

> My doctor didn't know anything about this condition … [and despite] blood test and RA present – still didn't offer treatment. I asked for a referral and they told me to find someone and they would refer me. Having more trained doctors in the country areas would help as I travel 800km to see a rheumatologist.

Specialised health care

Just under half of survey participants (46 per cent) identified the support from specialised care providers (e.g. rheumatologists, orthopaedic surgeons) as an important source of formal support.[12]

Timely access to specialist care is important for initiation and continuation of treatment. However, this was often an issue and is of concern because early diagnosis and prompt treatment of inflammatory forms of arthritis which require specialist care can reduce the severity and disability associated with these conditions. Some participants reported that there was a lengthy delay between initial symptoms and referral to a specialist (see Section 5.2.1), and also a delay between the referral and being able to see someone. This was especially an issue in rural areas. The quality of specialist care was also variable:

> When he went on leave this year I got a new specialist. He explains everything, often with pictures, and when I presented with major inflammation in my knees a week after blood tests still showed nothing, he reviewed my medications, with lots of detailed information about what was going on, what the medications were, and how they work.

[12] Source: Question 26 – most important sources of formal support.

Access to services varies across different states and territories, as well as within them depending on proximity to regional centres and the quality of the specialist services. Survey participants said:

> For seven years I used to have to make twice yearly visits to Sydney from a regional centre 450km away to see a rheumatologist. Now a rheumatologist visits the city I live in every fortnight for two days.

> Due to the area that I live in I have to travel a five hour round trip to be able to see my specialist. He has made it easier by Skyping me once a year and I only have to travel once a year now.

To overcome the issue of distance a number of participants cited the benefits of having regional care co-ordinators:

> There needs to be something like an arthritis management specialist nurse consultant in each regional area who could do much of the ongoing management and education for consumers in co-operation with some pain management specialists, psychologists, rheumatologists etc. A sort of Arthritis Clinic - this would reduce costs and time for GPs and improve the quality of treatment and access to information for people entering the arthritis world.

The role of nurses in co-ordinating services for patients with arthritis was raised by many participants as a possible solution.

Allied health care

Many participants sought support from allied health services and remarked on the benefits of working with these practitioners in managing their arthritis. They said:

> I attend a hydrotherapy classes at least once a week and can now move a lot more freely in the water and feel better about being able to do things in the water that cannot do on land. I have a good physiotherapist who I see if I have a flare up of symptoms.

> Since I went to a podiatrist and got orthotics they have really helped reduce the pain.

> My rheumatologist has referred me to a physiotherapist to learn some exercises to strengthen my joints and also a naturopath to figure out if there are certain foods that affect me so that I can eliminate them completely.

> Referral to allied health practitioners by GPs and specialists however was rarely offered and people often had to identify and build their own team, or rely on referral through personal recommendations:

> I feel the treatment of arthritis through the medical system is very drug based in its approach. I had to ASK [their emphasis] my specialist last year for a referral to a good physio when things were getting a bit tough.
>
> I'm determined to go forward, to push ahead and do the best I can with my exercise, however I must add that I was assertive with my GP and insisted on referrals for other advice and a health plan with the physio and podiatrist.
>
> I have to be a bit proactive myself and find people who did want to help me and did want to work a bit harder, I suppose.

The cost of accessing allied health practitioners was problematic

> I also need help from a physiotherapist and a podiatrist quite often but they are expensive.

A number of participants had a Chronic Disease Management Plan which allowed Medicare subsidies for individual allied health services that helped them manage their condition. These plans are initiated by the person's GP and eligible people can claim a maximum of five allied health services per calendar year. Beneficial though the service is the limited number of visits can be a drawback for people with a significant level of disability as a result of their arthritis. Others have sought assistance from private health funds.

Managing the symptoms of arthritis

People used various strategies to manage their arthritis, including consultations with a specialist (rheumatologist) and pain management strategies. In terms of allied health and pain management, services may have been available but research participants were not always aware of them and sometimes came across them by chance. They were not always referred to services by their GP or specialist. Participants said:

> The other thing I was not aware of was that there was a pain management unit alongside the rheumatology clinic, which provided information and assistance that complemented the treatment I was receiving. It took 13 months to get into treatment with them, and I would have pursued that a lot sooner, had I known.
>
> The other thing that we would have appreciated more support on is the role diet and nutrition may play in managing the symptoms of arthritis. … We have also just found out (five years down the track) that our son would have benefitted from seeing an occupational therapist.

Managing fatigue

Many people with arthritis experience the effects of fatigue where their limbs feel heavy and unable to function, they lack energy and experience symptoms similar to flu. These feelings of extreme and intense physical or mental tiredness do not always improve after rest. Fatigue is more common for people with inflammatory, auto-immune conditions including rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, lupus, scleroderma, Sjögren's syndrome, or fibromyalgia.

Many people experience mental fatigue, when they find themselves unable to think straight, and lose concentration or motivation. Other people also experience emotional fatigue which makes them irritable, low in mood or tearful. These attacks of fatigue can occur at any time of the day and may start when people wake up, so they don't feel refreshed from sleep. At other times fatigue may appear when they are busy or concentrating on a task. However for many people, fatigue seems to have no apparent cause and just occurs without warning, with episodes lasting anywhere from an hour to the whole day and in some extreme cases continuing over several days or weeks at a time.

Many factors are likely to contribute to fatigue in arthritis. They include inflammation during active phases of the disease; other long-term co-morbid conditions including diabetes and thyroid problems; the effect of some drugs which are used to treat arthritis related pain; pain itself which is a major feature of most types of arthritis; inactivity due to pain or joint problems which causes muscles to become weak; stress and anxiety; and sleep disturbance. There is probably no single factor which causes fatigue but it is likely to be the result of several factors that combine and interact with one another. One person said:

> Socially, I find it quite hard sometimes to keep up with what everybody else is doing. I get quite tired, quite easily. I think it is a process of having the pain. … I've actually sort of learned … to make my own plans when I feel like making plans and to stay home and enjoy that time if I don't feel like going out.

Many people reported that managing fatigue was often overlooked as part of their treatment.

Managing disease flares

The systemic effects of some types of arthritis also makes some people feel physically unwell. In addition, the episodic nature of arthritis can make life unpredictable. A person said:

> I have had quite an unstable year with flare ups and am now on my third type of medication …. More often than not this year I have been flaring up and unable to move or sleep three out of seven nights… I find the frustration; pain and often depression can really impact you personally

> ... I am hopeful with my next medication I can get it under control and feel normal again.

People experiencing a disease flare need rapid access to specialist advice and health services as prompt and effective management is required to control pain and reduce damage to joints. Timely access to specialist advice, however, is often a problem, especially for people in rural and remote areas.

Emotional support

As noted in Section 5.1.2, arthritis can have a substantial adverse impact on emotional wellbeing, especially at diagnosis and when dealing with pain. Research participants however indicated much lower levels of satisfaction with the formal support they received to help them manage their emotional and mental wellbeing compared to their physical wellbeing (Table 10).

Satisfaction varied by arthritis type, with people with psoriatic arthritis, ankylosing spondylitis and “other” types of arthritis reporting the lowest level of satisfaction with support for their emotional and mental wellbeing. People with these types of arthritis also recorded the lowest level of satisfaction with formal support for their physical wellbeing.

Table 10: Satisfaction with support, by arthritis type (mean score)

	RA n=237	JIA n=10	OA n=456	PA n=55	AS n=45	Other n=138	Total n=676
Emotional and mental wellbeing	4.616	6.200	4.771	3.800	4.067	4.307	4.642
Physical wellbeing	5.149	6.333	5.137	4.556	4.214	4.713	5.112

Source: Survey, Section C – Your arthritis

Notes:
RA = rheumatoid arthritis, JIA = juvenile idiopathic arthritis, OA = osteoarthritis, PA = psoriatic arthritis, AS = ankylosing spondylitis, other as before.
Includes people with more than one type of arthritis.
Based on satisfaction score where 0 is completely dissatisfied and 10 is completely satisfied
Results for JIA are not statistically comparable due to the small number of people identifying as having JIA (n=10).

Many participants indicated they would have benefited from GPs and specialists considering emotional health as part of their treatment. They said:

> It wasn’t until I was able to see a specialist and she said the magic words 'Our aim is to get you back to where you were before' that my mood and sense of wellbeing has improved.

> Having an awareness from the medical profession that the diagnosis could affect me mentally, i.e. possible depression, fear for the future and loss of confidence [would have helped].

Other chronic conditions

Almost half of survey participants (49 per cent) reported that they had other health conditions or disabilities that affected them achieving their goals. Overall people indicated that having arthritis and managing another condition compounded the problems of both conditions, for example people whose fingers were affected by rheumatoid arthritis couldn't manage their blood sugar testing and insulin injections if they had diabetes, or daily injections if they had Multiple Sclerosis.

A number of people stated that they tried hard not to allow their arthritis to have any impact on their other condition but for the majority of people this was outside of their control. People who need to exercise to manage their depression or weight gain (because of the side effects of their arthritis medication) had difficulties exercising because of concerns their body wouldn't cope with the exercise.

Other participants reported that other conditions had been difficult to diagnose because the assumption was the symptoms came from the arthritis. One person said:

> The doctors took 12 months to diagnose the hernia thinking it was arthritis. It could have been very serious if left undiagnosed much longer. The surgeon was shocked and operated in two days.

Other participants reported that their arthritis and other conditions are inter-related stating that when their arthritis was bad then their other conditions were difficult to manage as well, but perversely when their arthritis was stable then their other conditions got worse and deteriorated further.

Some people were experiencing the effects of living with haemochromatosis (n=6), the most common symptoms of which are fatigue, weakness and lethargy and joint pains, leading to osteoarthritis.[13] Other participants reported additional auto-immune conditions or deteriorating neurological conditions which they were trying to manage alongside their arthritis. Sometimes this was a condition associated with their arthritis, including osteoporosis, and for other people the condition was unrelated.

[13] Haemochromatosis is the most common genetic disorder in Australia and about 1 in 200 people of northern European origin have the genetic risk for Haemochromatosis. People with Haemochromatosis absorb too much iron from their diet and the excess iron is stored in the body. Over time this leads to iron overload and the excess iron stored in the organs and joints increases gradually over many years. The liver can become enlarged and damaged, leading to serious diseases such as cirrhosis or liver cancer, but it can also cause other health problems including heart disease, diabetes, endocrine and sexual dysfunction and arthritis. The most common symptoms noticed by people with Haemochromatosis are fatigue, weakness and lethargy and joint pains leading to osteoarthritis. http://haemochromatosis.org.au/symptoms

Arthritis can also complicate treatment and management for other conditions, including conflicts between medications, implications for surgical procedures, including those unrelated to the management of arthritis, and implications for obstetrics (see also Section 5.6.2).

5.2.3 Medication

The management of arthritis through medication appears to fall into two areas. The first is the relief of symptoms, with pain relief being the most significant for people. The second is the modification of the disease process to reduce inflammation, delay disease progression reduce the rate of joint damage and increase mobility. Many people reported using over-the-counter analgesics and NSAIDS (non-steroidal anti-inflammatory drugs).

The survey participants made it clear that different medications worked for different people, and some people experienced side effects from some of the medications that either had to be endured or counteracted by other medication – all adding to the cost of treatment. People also reported benefitting from the development of the biologic disease modifying anti-rheumatic medications. However, one participant reported, '*no guidance was provided on doing your own injections'*.

Others were concerned about side effects, the interaction between medications for their other conditions and the cost of medications.

Some medications are more costly and harder to access as they are only currently subsidised through the PBS for people who fulfil certain specified criteria or have other conditions.

> When my Rheumatologist wanted to put me on [a biologic] she literally had to make me sick to qualify … since then the rules to qualify have changed! I went through numerous medications and the cost of them is unbelievable for a young family. I used to feel so bad that my prescriptions used to cost around the $200 mark a fortnight.

Although many people felt they benefitted from the prescription of a steroid they were unhappy about the side effects. Many participants reported that managing the side effects of a number of medications was a significant issue in the ongoing management of their arthritis. Many participants talked about the variety of medications they ended up taking over time with what they felt was limited information. They wanted to know more about the medications they were given and their potential side effects.

A number of participants indicated they sought specialist help and medications overseas for a number of reasons but for many it was because of the lack of availability of the medication on the PBS.

5.2.4 Surgery

Despite recent advances in the medical management of arthritis leading to a reduction in the need for surgery, there are still significant numbers of people who develop irreversible damage to joints and tendons. Orthopaedic surgery can provide pain relief, restore function, and improve quality of life in some cases. Procedures include joint replacement, arthrodesis and carpel tunnel release. Many people have more than one surgical procedure to repair damage. One person said:

> I've had surgery twice on one foot and once on the other, my right hand has got four new knuckles and I have had a wrist rotation, a tendon transfer as well as the replacement knuckles … the right hand I had done because it was painful and I was always knocking it.

The timing of any surgical intervention depends on the clinical urgency of the problem and how far the damage has progressed. One person said*:*

> The doctors just said "don't have your hips done until you are 60". I would have been in a wheelchair by now (54) and I ached so terribly, couldn't sleep, walk, dance and exercise and was depressed. I just love my new hips and freedom from pain.

5.2.5 Medical costs

Medical costs include medication, ongoing management of the condition (GP and/or specialist), and allied health care. The government provides a range of support mechanisms to meet medical costs. This includes the Pharmaceutical Benefits Scheme (PBS), the Health Care Card, and Medicare.

Many participants reported that the cost of medical services and medications had a substantial negative impact on their finances, especially when they were no longer able to work because of their condition (see Section 5.5.1). Participants also reported meeting most of the substantial costs of managing their arthritis personally.

More than half of survey participants identified medical care and the costs of medication as having the greatest impact on their financial situation. This varied by type of arthritis, with people with psoriatic arthritis being the largest group selecting both medical care and the costs of medication as having the greatest impact on their financial situation. In particular, participants reported that the cost of some medications was prohibitive. Sometimes this was because the medication was not available on the PBS. Often it was the result of people experiencing a reduced income because they were unable to work or had to reduce their working hours because of the effect of their arthritis. Many times it arose from their caring responsibilities which impacted on their opportunity to work and sometimes it was because they were on a retirement income.

There appear to be some anomalies in relation to the availability of some medications on the PBS, depending on the condition for which they are prescribed. For example, some anti-nausea medications to counter the effects of a drug used for both cancer and arthritis are available on the PBS when prescribed for cancer patients, but not for someone with arthritis. One person said:

> At one point I was on anti-nausea medication because the Methotrexate makes me sick 24/7 and it was costing us $200 a week.

Other people found the medication they had been able to access overseas was not yet available in Australia unless as part of a clinical trial, and their participation in that trial was time limited after which they were expected to meet the full costs.

Many participants reported that access to a Health Care Card made a substantial difference to the affordability of medicines and reduced the need to choose between spending money on medication or food and other essentials. A similar difficulty people had was obtaining recompense form their private health cover. A person said:

> I think people should have access to a health care card and also to cheaper prescriptions. I've had to go without prescriptions sometimes, because I can't afford them with other living expenses.

Some people, who felt it was important to continue working rather than apply for the Disability Support Pension, felt they were penalised as this made them ineligible for a Health Care Card and associated benefits despite struggling with the cost of treatments. Someone who was working said:

> It’s a catch 22 – because I work full-time I can’t access many of the fee free or discounted services that I need to be able to continue working full-time.

> I think there should be some form of funding for people with chronic arthritis; because I work I have to pay for all my medical expense and even with [the] Medicare rebate, regular specialist, and GP, physio and medications adds up to a considerable amount.

Medicare is largely a ‘fee for service’ system which has the benefits of simplicity and ease of administration but the simplicity can be a disadvantage for patients with complex conditions such as JIA and other types of arthritis. The standard level B consultation does allow the GP to see the patient for up to 20 minutes but the dominance of the fee for service health service inhibits team work in a primary care setting, particularly between GPs and other health care professionals such as nurses and allied health workers.

5.3 Habilitation and rehabilitation

5.3.1 Daily activities

People raised habilitation and rehabilitation in relation to their daily activities, the role of occupational therapists, and other forms of support. Participants reported that most people and support providers do not recognise arthritis as a disability, so people with arthritis are often not provided with the habilitation and rehabilitation that may be required. Some participants had received services for another reason (e.g. road traffic accident).

Survey participants were asked whether the effects of their arthritis limited their ability to undertake daily activities; 37 per cent answered yes always, 58 per cent answered yes sometimes (indicating the episodic nature of the disease), and 5 per cent answered no. This varied by type of arthritis – see Figure 3 below. People with osteoarthritis and juvenile arthritis were more likely to report that their condition always limited their activities while people with inflammatory forms of arthritis, which are often characterised by disease flares, were more likely to report that they were sometimes limited in their ability to undertake daily activities.

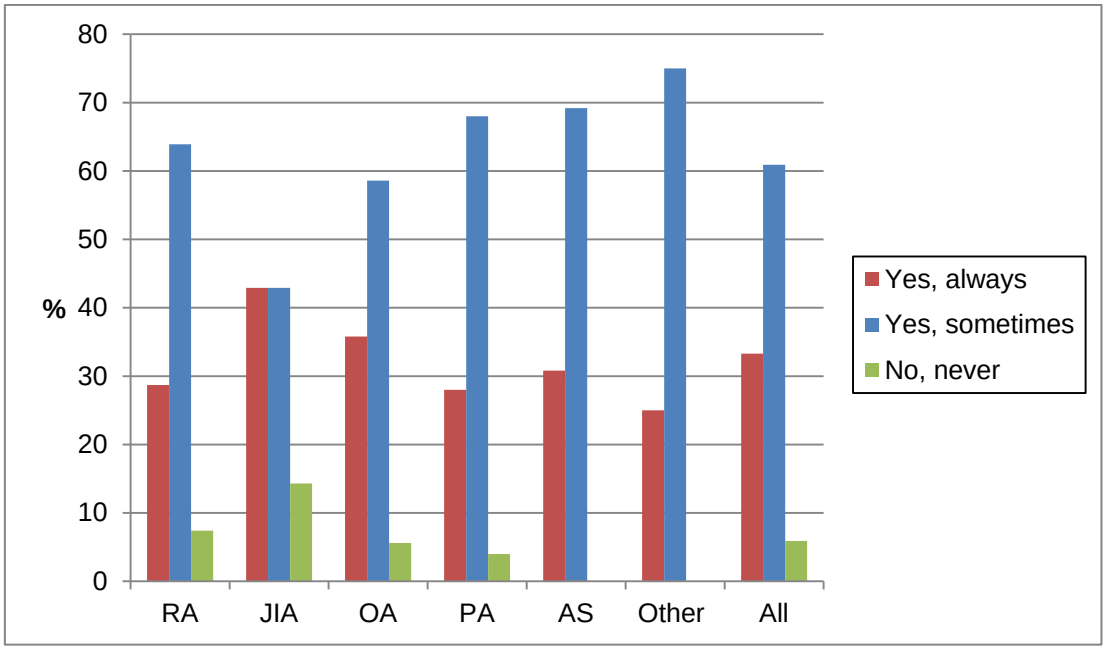

Figure 3: Effects of arthritis limiting ability to undertake daily activities, by arthritis type

Source: Survey, Section D – Daily life

Notes: RA = rheumatoid arthritis, JIA = juvenile idiopathic arthritis, OA = osteoarthritis, PA = psoriatic arthritis.

For participants who indicated that their arthritis limited their ability to undertake daily activities, those that answered yes always or sometimes were asked about the impact their arthritis had on their ability to perform a range of tasks. Responses

ranged from Mild (rarely requiring assistance) to Profound (always requiring assistance) – see Appendix D: Online survey, question 16 for full definition. Daily activities include personal care activities (e.g. showering and dressing) and domestic activities; managing the home and garden; their indoor mobility and their outdoor mobility; their ability to use private and public transport; and participating in community and leisure activities.

The activities that were most affected were managing the home and garden and undertaking domestic activities, with 34 per cent and 22 per cent of participants respectively reporting a severe or profound impact on being able to manage these activities. In addition, 5 per cent of participants reported a severe or profound impact on their ability to undertake personal care (see Figure 4).

One person said:

> But the pain that then you experience after doing things like chopping vegetables or stirring, say, meat in a pan. That really hurts.

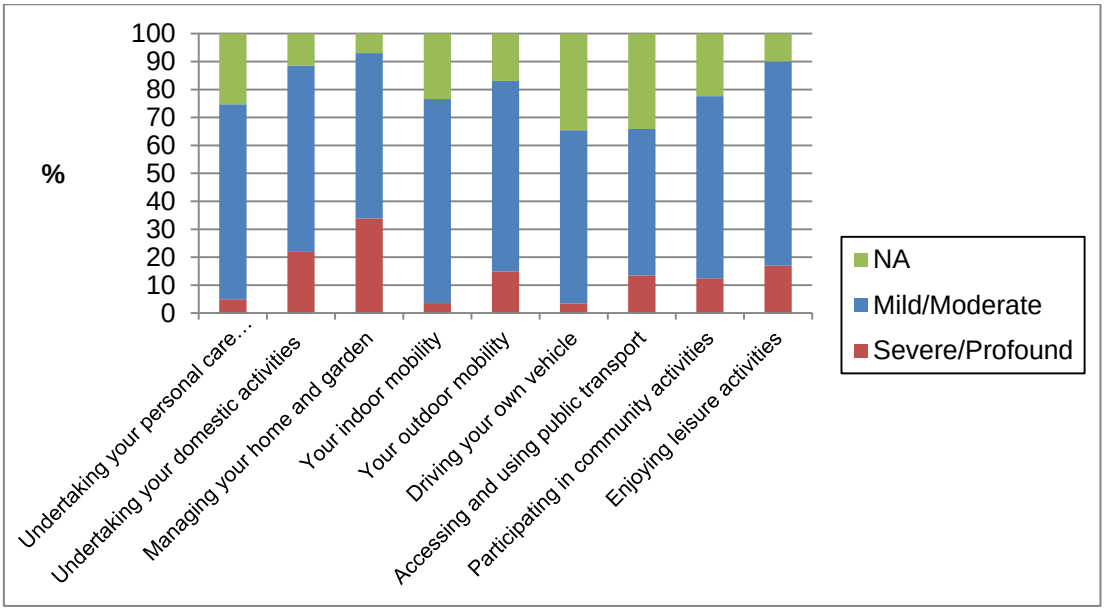

Figure 4: Effects of arthritis limiting ability to undertake daily activities

Note: This group is a subset of those participants who have answered yes always, or yes sometimes, to the question, Do the effects of your arthritis (e.g. pain, stiff joints, fatigue) limit your ability to undertake daily activities.

Source: Survey, Section D – Daily life

5.3.2 Modifications and equipment

Over 60 per cent of survey participants had made modifications to their home or car because of their arthritis. People with juvenile idiopathic arthritis, rheumatoid arthritis

and ‘other’ forms of arthritis were most likely to report making modifications (83 per cent, 74 per cent and 75 per cent respectively).[14] Comparatively, only 56 per cent of people with psoriatic arthritis had made modifications to their home or car. Where survey participants identified as having multiple types of arthritis, the percentage of people making modifications reduced as the number of types of arthritis increased. This seems unusual and may be due to people moving to more accessible accommodation rather than modifying their homes. A carer said:

> My 11yr old son has arthritis. We live in a two storey house and have needed to set up a bedroom downstairs to limit the amount of times that he has to use the stairs, particularly in the morning after waking. We are currently looking at moving to a single storey home.

However, advice on appropriate modifications and assistive devices was not always easily accessible. A person with arthritis said:

> Access to an occupational therapist would be great to help me assess what assistive devices can help me in my home, like hand rails, lowering my cupboards, posture support and if I need major renovations to be carried out on my flat to make mobility easier. These have been difficult to access through the public health system and I have not got the financial means to seek assistance from private practice.

Survey participants were asked to identify up to three costs which had had the greatest impact on their financial situation. Only 10 per cent identified aids and equipment as a significant cost. Aids and equipment may vary considerably in cost, from small basic kitchen gadgets that help open or grip jars and tools that help with buttons and zips, to power wheel chairs. One person said:

> I have had to change things in my house like having flick mixers for taps. Changing door handles as I cannot handle round ones. I have to use grips to open jars. We have put in hand rails in the toilet and shower for those bad days. Having a trolley to put my washing in so I don't have to bend over to get the clothes out and using large pegs that are easier to grip.

5.3.3 Transport

Many participants did not have a car and were reliant on public transport. One person said:

> I couldn't afford car insurance once [the] government stopped covering green slip [general insurance costs have increased].

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[14] Figures based on survey participants identifying one type of arthritis only.

But not all public transport is accessible. A person said:

> We lost our train service in 2004, and now need to catch a bus with no disabled access to the train line. The government needs to recognise the fact that people with mobility issues are regular users of public transport, and trains are much easier to access than buses.

5.4 Study and Work

5.4.1 Impact on work/study capacity

Sixty-seven per cent of all participants reported that arthritis had affected their work or study, now or in the past; 23 per cent reported that they were permanently unable to work or study because of their condition; 68 per cent were restricted in the type of work or study they could do and 65 per cent were restricted in their hours of work or study. In addition, 35 per cent reported that they required workplace modifications while 14 per cent reported that they needed ongoing assistance to participate in work or study.

Sixty-four per cent of research participants were under 65 years of age, therefore were potentially still in the work force or studying. People who were working or studying said:

> [It is difficult] to communicate to management that all of a sudden, even though I did not look sick, that I was now finding it hard to carry out the same tasks as before

> Eventually my hands blew up… I was a district nurse and it was in the days when you had to go visit people to give them their insulin [injections].

> I had to defer university because I just couldn't cope… and ended up finishing it part-time. I've worked when I can and I just had to leave work when I couldn't. I did a lot of contract work for the government… And that made things a lot easier. Starting full-time or part-time work didn't actually happen until after I'd had the chemotherapy trial[15] … So that affected my financial status, it affected my family, because they are the people who picked up the pieces when I was very ill.

> I was not able to complete schooling (I left in year 10) as the effort for me to get to school each day was so tiring I just had no ability to cope

[15] Methotrexate is commonly used to treat rheumatoid arthritis and is also used for cancer treatment. People need to 'trial' methotrexate before they can be eligible for biologic medications under the PBS.

> with the strain and stress of doing the HSC. On top of that there is then the whole issue of bullying because you are different which is not easy for a young girl to deal with!

5.4.2 Level of employment or study

The labour force participation rate for survey participants was just 44 per cent compared to the national participation rate of around 65 per cent.[16] Twenty-two percent of survey participants were employed full-time, 19 per cent were employed part- time, and 43 per cent were retired.

[16] ABS, Labour force, detailed – electronic delivery, March 2014, Cat. no. 6291.0.55.001

Table 11 below shows the breakdown of all survey participants by their participation in the workforce by age. For younger participants, i.e. those aged less than 35 years, labour force participation was similar to the participation rate for their peers in the general population. However, after age 35, labour force participation by survey participants was significantly lower than for the age matched general population. Note that this data should be read with caution as the sample of participants is not nationally representative.

The largest group of participants was those over 65 years old and considered to be of retirement age (n=222), although 30 participants in that age group were either in full-time or part-time work, and one was looking for work. Of the participants who identified as being retired, one-quarter were in the 55–64 year age group – this may include people who have planned to retire early, or those that were forced to retire early due to the arthritis. A woman said:

> I continued to work until I needed a hip replacement, I was a registered nurse, and received no support from my workplace. I continued to struggle to work until I reached the age when I could access my superannuation.

The other data of interest is the number of participants who are neither employed, looking for work or retired. Seventy-five people identified as ‘none of the above’ (13 per cent of participants), nearly all of whom were under 65 years old and 36 per cent of whom were in the 55-64 year age group. This group could include students, people who are out of the workforce to care for young children, or those on disability support.

Table 11: Participation in the workforce, by age of survey participants

		employed ft		employed pt		looking for work		retired		none of the above		Total	
		n	%	n	%	n	%	n	%	n	%	n	%
age	< 25	1	16.7%	2	33.3%	0	0.0%	0	0.0%	3	50.0%	6	100.0%
	25-34	12	46.2%	8	30.8%	0	0.0%	0	0.0%	6	23.1%	26	100.0%
	35-44	21	38.2%	15	27.3%	4	7.3%	0	0.0%	15	27.3%	55	100.0%
	45-54	42	41.6%	28	27.7%	7	6.9%	5	5.0%	19	18.8%	101	100.0%
	55-64	48	25.9%	40	21.6%	8	4.3%	62	33.5%	27	14.6%	185	100.0%
	65-74	10	6.1%	17	10.3%	1	0.6%	132	80.0%	5	3.0%	165	100.0%
	75+	0	0.0%	3	5.3%	0	0.0%	54	94.7%	0	0.0%	57	100.0%
	Total	134	22.5%	113	19.0%	20	3.4%	253	42.5%	75	12.6%	595	100.0%

Source: Survey – question 17a
Notes: ft = full-time, pt = part-time, n = number of participants.
n=595 - total number of respondents lower than 669 as some participants did not provide their age.

Survey participants also identified whether they were studying or volunteering. Twelve people were studying full-time and 50 part-time. A further 231 people were volunteering in some capacity.

Participants who were neither working nor studying were more likely to have rheumatoid arthritis, osteoarthritis, or one of the 'other' forms of arthritis. Also, those not in the workforce experienced disease onset at a much younger age than those who were employed. This may reflect the severity of the younger onset types of arthritis, the progressive nature of these conditions or the difficulty faced in initially engaging in the workforce as opposed to seeking modifications to hours or working practices once in a job.

5.4.3 Changes to employment or study

Survey participants were asked whether their arthritis affected their work or study now or in the past; 74 per cent of people in the workforce and 93 per cent of people not in the workforce said that arthritis had affected their work or study.[17] A substantially higher proportion of people who aren't in the workforce, said that arthritis had affected their past work or study.

Survey participants were then asked to identify how their arthritis had affected their work or study. Table 12 shows the results for participants who were employed (full-time or part-time) against those not in the workforce (participants were able to select more than one response hence the high response rate).

People who were not in the workforce were much more likely to have experienced work/study restrictions compared to those who were employed. Two-thirds of employed participants reported that their arthritis restricted the type

[17] Source: Survey – question 18

of work or study they were able to undertake compared to 79 per cent of those not in the labour force, while 60 per cent of those employed and 72 per cent of those not in the labour force reported restrictions in the hours they could work. Needing to take time off work was also common with 40 per cent of those employed and 51 per cent of those not in the labour force reporting that their condition made them take at least one day a week off work. Of participants who were unemployed or not in the workforce, more than half reported that their arthritis permanently prevented their participation in either work/study.

Table 12: How arthritis has affected work or study (can select more than one)

Type of restriction	Employed		Unemployed/NILF	
	n	%	n	%
Restrict type of work or study	124	64.2	51	78.5
Restrict number of hours work/study	115	59.6	47	72.3
Make it more difficult to change work/study	80	41.5	32	49.2
Make you take at least 1 day off	77	39.9	33	50.8
Need ongoing assistance	15	7.8	16	24.6
Need adjustment or modification	65	33.7	26	40.0
Change type of work/study	68	35.2	29	44.6
Permanently prevent work/study	6	3.1	33	50.8
Partner/family change work/study	23	11.9	17	26.2
Other	27	14.0	5	7.7
Total	193		65	

Source: Survey – Question 19
Note: Percentages and totals are based on participants

> [Working at] a reception of a night with the fitness company, I was standing doing long night-shift fitness hours on reception … they pretty much said I had to leave because I kept sitting down, I couldn't stand constantly for longer than 15 minutes at a time and they didn't like that ... Ever since, I haven't been able to get another job. My income has been much reduced as I have had to resign from my previous employment on the advice of my physician and I am now dependant on a disability pension.

> I would like advocacy with regard to work. I asked even my local arthritis group who offered some support but not really enough in the beginning. I would have liked an officer to help speak to my workplace and offer assistance making a plan with my work.

5.5 Standard of living and social protection

5.5.1 Financial impact

Survey participants were asked what impact arthritis had had on their finances – 66 per cent identified a negative impact on their finances. Five per cent of survey participants said they were much worse off and needed financial support, whilst 16 per cent struggled to meet their expenses.[18] Sixty-six per cent of survey participants had a private source of income, whilst 33 per cent relied on public support (e.g. disability support or aged pension).[19]

The financial implications of arthritis can be split into two categories – the added cost of living with the disease and the loss of income due to reduced capacity to work (see Sections 5.2 and 5.4). The costs identified during the interviews included medical care, the cost of medications, the cost of aids and equipment, home help and maintenance services, personal care and transport. In the survey participants were asked to select up to three costs that had the greatest impact on their financial situation. As Figure 5 shows, the costs of medical care and medication were most commonly reported as the most significant costs. One person said:

> If I developed any health complications that required more expensive treatments or equipment or specialists I simply couldn't afford them ... in fact I couldn't afford to see the specialist in my first month of getting ill AND had no way of getting to the specialists office, as I was too sick to get there myself & had no-one to provide that support.

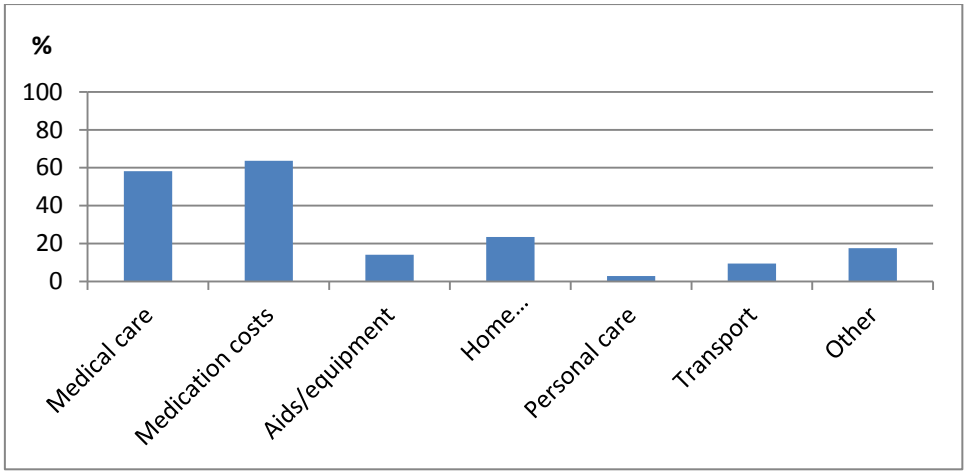

Figure 5: Costs of managing arthritis that had the greatest impact on financial situation (could select up to three responses)

Source: Survey, Section D – Daily life, number of responses 1195

[18] Source: Survey, Section D – Daily life.
[19] Source: Survey, Section F – About you. Private income includes employment, own business, superannuation and family.

The reduced capacity to work included both reduced capacity to participate in the workforce in the long-term and the need to take time off on a regular basis (see Section 5.4 above).

As stated above, 33 per cent of survey participants identified their main source of income as public support. Almost half of participants not in the workforce rely on public support as their main source of income – this is substantially higher than those who are employed (as you would expect given that public support is means tested).

Research participants identified many problems they had with social protection (e.g. financial support and formal care services provided by government):

- Does not recognise arthritis as a cause of disability
- Does not respond to fluctuations of a disease (social protection offered only for disability considered permanent or long-term)
- Is highly complex
- Does not meet the major costs of arthritis – medical care and medication.

One person said:

> Since being diagnosed, I have had to close my business (cafe) and can no longer work. This has led to my husband having to move to the city to get a higher paying job because, according to Centrelink, I am not disabled enough to claim DSP. We have also had to put our house on the market as we can no longer afford to own our own home.

Some people had navigated the social protection system and were able to manage – but without it would struggle. Others needed advice to understand what was available and how to access it. Someone without income support said:

> I do not know what funding or entitlements I am allowed to have, so have never done anything to claim anything back as I don't know where I should go.

The same participant suggested a system which might help newly diagnosed people to determine their possible entitlements:

> A checklist scenario may be a worthwhile thing…to let people know what they can and can't claim and where to go to get such claims.

People who were working found themselves financially penalised for trying to continue to work but still having to manage the costs of their arthritis because they were not entitled to a health care card. Many participants felt the additional costs experienced by people with a long term illness who remain in the work

force should still be recognised so they are provided with access to free or greater subsidy with their medication costs:

> The government is helping people with disabilities but workers who have chronic illness aren't given much assistance apart from 5 visits to allied health per year. The financial impact of Medicare and private health funds and paying for services can be significant.

> Ideally anyone with a chronic illness should automatically be entitled to a health care card, even if on reasonable income. Reasons for this is that you still have the same expenses to pay including mortgage and daily living costs, but in addition have the added stress of medical bills and medication expenses.

5.5.2 Access to formal support services

As seen in Figure 3 and Figure 4, many survey participants experienced problems carrying out some aspect of their daily activities. The activities with which participants struggled the most included doing things around the home and garden, and basic domestic activities. Others needed help with personal care activities.

Participants in both the survey and interviews identified family as their primary source of support, with few people having access to formal support services. For example while 24 per cent were receiving financial support and 4 per cent were accessing community services, 14 per cent or survey participants were accessing privately funded home help. Someone with access to formal support services said:

> That was a by chance thing, just over a year ago I was in hospital and the social worker came to see the elderly lady next to me and was asking how she was at home. I pulled her aside as she was going to leave and she originally went “no, no, no this is for people with disabilities” and I said “well I have got three, which one would you like” I found out then I could get some assistance.

When survey participants were asked about how satisfied they are with their formal support, the lowest scores were given to satisfaction with their financial situation, access to paid work, access to community support services, access to services to support emotional and mental wellbeing, and access to someone who could lobby or advocate on their behalf (5.60, 5.48, 5.48, 5.19, and 5.01 respectively where satisfaction is measured from 0-10) – effectively, all formal support services except health services.[20] When asked what the most important sources of formal support were, only 11 per cent of participants identified community services such as home and community care. This may reflect the level of disability within the participant

[20] Source: Survey – Section E, Your support (formal support)

sample, poor access to community services, or the fact that community services do not automatically service people with arthritis – particularly when people can require intermittent care during flares.

5.6 Family

5.6.1 Impact on family

Family members are the main source of physical and emotional support for people with arthritis and often take on the role of carers at enormous physical, emotional and personal cost. The impact on carers is discussed in more detail in Section 5.7.

The impact on families can vary depending on the life stage at which the person with arthritis is diagnosed. Different issues arise in different life stages whether that is early childhood, education, working life, family and relationships, through to retirement.

The majority of people with arthritis are over 40, but children also have arthritis. As discussed in Section 5.8.2 below, caring for a child with arthritis had a huge impact on family life, not just in terms of the impact on the affected child's growth and development, but also on their parents and siblings. The same can be said for caring for older relatives. Many carers either gave up work or compromised their participation in the workforce in order to be able to care for their child, partner, or parent. Having arthritis can limit a person's ability to fully participate in family life as one young father indicated:

> I am limited what I can do with my young children. Even "horsey rides" can't be done. Can't run with them or teach them sports very easily.

The ability of people to maintain their links with family can be compromised by physical barriers or transport difficulties. A woman said:

> Because of my arthritis and not having a car, I very rarely get to see family, and even when I do I am limited in whose house I can visit. For example my sister's house has lots of steps and I am unable to go to her place. So I have been cut off from family to a large extent.

Some families are not supportive and this may depend on cultural attitudes. A young woman said:

> I was about five or six when I got my arthritis... I was not actually taken to a GP, [in my] culture it is a disgrace to have an abnormal child … I was locked up and beaten, I wasn't treated and I was not medicated at all. It wasn't until many years later this girl intervened … but then it was way too late and I was completely deformed.

Living with arthritis can also have a catastrophic effect on family relationships. A woman said:

> My marriage recently broke up and one of the reasons my husband cited was that he felt 'burdened' by my arthritis. That'll stay with me forever as a change that has happened because of this condition since I was diagnosed with RA at 27[years of age].

5.6.2 Starting a family

Starting a family is a complicated issue for young men and women with inflammatory forms of arthritis because it usually entails coming off their medication to try to conceive and, for women, during pregnancy and breastfeeding. The consequences of this choice are often felt afterwards with prolonged flares which can last for years. A woman said:

> My condition is even more changeable of late, as I have spent months coming off all the medication I have been on for the past decade to try and have a child … This has been quite stressful and I feel this is an area of arthritis support that could perhaps have more attention and support given to it. I … found the information being given conflicting and difficult to understand, and went and saw a number of doctors.

In addition, caring for an infant can be difficult, including playing with, holding and dressing a child and being unable to breastfeed their infants because they had to resume their medication. Mothers said:

> Support for mothers with arthritis is desperately needed. There is nothing out there at all. It's pretty terrible. There is no information or studies on breastfeeding and flares, etc. It's very isolating.

> Everyday life is a huge struggle but most of all the biggest change for me is being a mum with arthritis and having to look at my little girl’s face when she doesn't understand that mummy can't do certain things with her.

Family is often the first and only form of support. The parent without arthritis is often called upon to provide more support, to their partner and their new born child, which then affects their workforce participation, economic situation and standard of living, and ultimately their relationship.

Arthritis can also be a barrier to forming long lasting relationships in the first place. One woman said:

> I was also told at the time that I would probably not be able to have children (or that it would be incredibly difficult to do so) because of my

> RA, and unlike the other information he gave me at the time that has proven to be correct. It has led to a downfall of many relationships as I have never wanted my partner to become my carer so I push people away when I have a flare. I have almost doubled my weight ... This severely affects my self-esteem.

5.7 Social participation

Noreau et al. (2004) found that interpersonal relationships, responsibilities, fitness and recreation were the categories of social participation most associated with quality of life. Many research participants reported that they had to limit their social participation to basic functioning, such as daily activities, school and work. One person said:

> Family picnics are a thing of the past, as I can't get from the car to picnic area without being in more pain than I can cope with. Visiting friends poses similar problems. I often feel useless, I can't find anything that I can do to help the people I love, instead I am a burden on them. I still have a son in primary school and a daughter in high school, they pass up things to be there for me. I find the schools lack understanding with my children or with our situation.

The impact of arthritis on people's ability to participate socially was felt across all stages of life. One person said

> So there has been quite a big change, socially. Obviously, when I first got my rheumatoid as a 20-year-old, everybody is out and about at the pubs and nightclubs and I'm at home being nursed by my parents.

Lack of understanding of the impact of arthritis amongst relatives, friends, the broader community and colleagues also affected social participation. Arthritis is poorly understood as a disease and many of the symptoms are not visible – particularly in terms of pain and fatigue. One person said:

> I have lost a lot of friends … due to my diagnosis. I was unable to attend many events due to chronic fatigue, pain and difficulty when driving due to high inflammatory levels and I don't think a lot of people realise exactly what I was suffering with knowing that I look "normal" on the outside.

Survey participants reported a reasonable level of satisfaction with community connectedness (score of 64.8, see Table 6 above). Some participants found significant benefits of engaging in support groups, whether locally or online, if they could find one that was age appropriate.

Some participants identified that access to strata apartments or public buildings in the wider community continued to challenge people with arthritis, impacting on their participation in the community.

> I have found the Body Corporate very unhelpful. In fact, I had to lodge a complaint with the Anti-Discrimination Board to get them to make the front door comply with the Disability Access as required by the DA for the building.

> I live in a town where many buildings have been built above flood level, and have limited disabled access by ramps or lifts. … The City Hall has a lift which requires the need for an operator, often difficult to find. … It is demeaning for sensible adults to have to locate an escort to use a lift.

5.8 Carers

5.8.1 Carers of adults

People caring for adults with arthritis raised a number of critical issues relating to their ability to care. They highlighted the need for a range of information which would assist them to carry out their caring responsibilities and indicated there was a lack of information about support services which might be available, including respite services (in-home and centre based) and other in-home support services.

Carers reported a lack of facilities for providing in-home and centred-based care and respite for both adults and children. This included a need for help with personal care and domestic activities. For example one carer indicated she would appreciate help with meal preparation which would *'… improve independent living for my mother and reduce my workload and consequent physical input on me'*.

Another carer had retired from work in order to support her mother:

> My mother has severe arthritis in multiple joints and has had most of her joints replaced. … I assist her at times when she has been most needy, for example before and after surgery and during rehabilitation. In order to do this...I retired early from my paid employment. … She has regular 'respite' from her care environment in my home in order to maintain some sense of home life.

Although this carer arranges for her mother to stay with her at times of greatest need, and many people in recognition of their caring responsibilities are in receipt of the Carer's Allowance, other carers highlighted the need for (and lack of) overnight services available for in-home respite or emergency respite. They suggested the use of funding packages so that:

> a carer can have respite from caring, and either the arthritic person (sic) goes on a short holiday or the carer does' or they are able to 'enlist external assistance during absences of me, the principle carer.

Some people didn't apply for the Carer's Pension. A woman with arthritis said:

> She [her mother] applied for it once. But then, now that she's at home and stuff, we just didn't want to do it again because it was too much paperwork …. It was only $40 I think. [Now] she's working from home, it's just easier.

Information about symptoms and treatment options for arthritis was pivotal for carers especially, as one said: '*up to date information on all types of therapies, treatments and medications including holistic treatments'*. Information for ways to reduce or manage the impact of arthritis and the side effects of medication was raised by many people, but some people said they received no information. Other carers said:

> Information and support is getting better but it still has a long way to go … it is important that I have sufficient information available re medical situations, and to have the support of a local doctor and personal support for me the carer as well as her.

> We never received any information on support groups such as Arthritis NSW or family groups. … All medical websites we received were very much focused on the doctor's view. I was missing time to reflect and understand the disease and then having a follow up appointment to talk through treatment options.

The lack of information about the disease process, understanding the treatment and when treatment is contraindicated because of other conditions, was raised by many including this carer who indicated:

> My mother's GP prescribed a drug for the treatment of my mother's osteoarthritis but failed to consider the situation holistically. My mother faithfully took that drug for a significant duration before the renal specialist 'whipped her off it' because it was contra-indicated with her renal failure.

The importance of GPs in disseminating up to date information was highlighted by many participants. A carer said:

> GPs needed to provide information on rheumatoid arthritis and be more aware [of] and able to talk about the importance of treating before it progresses to a stage where ordinary living is no longer possible rather than there being no way to reverse the condition.

A carer said they also needed '*more medical support in terms of being able to question and talk to professionals particularly about medications'*. This is a role taken on by some pharmacists but does not work well if carers are collecting prescriptions on someone else's behalf.

Some people had the capacity or resources to find information themselves. A carer working in community care said:

> I worked for many years in medical social work and have sought out information myself and joined organisations that would provide me with information. I have found detailed information from the pain specialist, rheumatologist and orthopaedic surgeons to be extremely valuable.

Carers said information needed to be targeted at different age groups and needs. One said:

> I have two family members suffering with disabling arthritis. One in young adulthood with a young family, and the other one is geriatric [sic]. The information and support they need are different and distinct.

Being provided with information about the condition and its prognosis, however, was often emotionally challenging for carers, especially for the parents of young adults with arthritis who may have been unaware of what questions to ask a medical specialist or who found it difficult to raise those questions. A mother said:

> My husband and I are constantly learning about new information or services from people in our local community. It is very frustrating and stressful to hear of people who can no longer work and [are] in need of carers.

Carers also wanted information about managing pain for people with arthritis. A carer said they wanted to be:

> Educated on what sort of problems a person with chronic pain can be confronted with, how to help the person in their daily duties. It is important to help the person and not do it all yourself, to show them that it can be done but in a different way.

Carers said the effects of living with someone with constant pain can be significant and ameliorating the stress, anxiety and depression of both people was complex. Carers spoke about how they managed:

> I just try to remain as positive and supporting as possible … mentally it's challenging to be around a mind which is in a state of pain almost constantly. I'm new to this, we have just got married and it has been only of late that my wife's inflammation has being going nuts.

> Since I gave up my job and became a carer, I found that the basic personal counselling has assisted me considerably in handling mum's depression, and also the hostility/verbal aggression that has been directed at me at various times due to the fact that I am "available". … I also try and get mum to go out with me at least once a week to get her out of the house (even if the outing is just for a coffee in a café) - I think that helps both of us feel a bit less isolated.

As described above, many carers are also active participants in the workforce. A carer said:

> My boss was supportive and considerate when I had to juggle my work hours and when I took time off work [to look after her son].

While the ability to work was often restricted in order to fulfil the carer role, maintaining income was critical to meet the additional costs of medication and care and to make up for lost income when a partner of working age could no longer work because of their arthritis or in order to care for a child with arthritis,. A husband said:

> I cannot take a job out of my city and I can only do my casual job if my wife is beside me. I must adjust our way of life to be more efficient due to our reduced income … I spend most of my time looking after her: preparing medicines, taking her to her doctors, hospitals. I must juggle my time to get a small income.

Many people with arthritis are also caring for others and this can make it more difficult to find appropriate support. A woman with arthritis said:

> I am my husband's carer (he has had type 1 diabetes for 33 years) and we find there is no 'home help' package that takes BOTH our health issues seriously, that enables targeted, flexible and ongoing help.

5.8.2 Carers of children

People caring for children with arthritis raised similar issues about caring for their children, including the need for information about support services available to carers, and information about signs, symptoms and treatment options for their child's condition. Carers said:

> There are no successful strategies to manage the impact of caring for someone with arthritis. Having a child with arthritis turns your life upside down.

> We had to personally seek out and educate ourselves with the information about the condition. Information [around] recognising signs

> and symptoms that can reduce flare ups and general information about [systemic] JIA and treatments, future, etc.

Many parents identified the need for more information about the disease and about the long-term implications of the condition. A parent said:

> We were given no information regarding how bad JIA could become. We had no idea that our son may not be able to walk some days or face such extreme pain. We would have appreciated more information on pain management techniques.

Carers of children with arthritis reported struggling with the costs of managing the disease because of the need to take time off work for hospital visits, the cost of petrol, the cost of accommodation to attend medical appointments, and the cost of medications especially when they were not on the Pharmaceutical Benefits Scheme (PBS). A parent said:

> Our finances have been detrimentally affected for many years, [by the cost of] specialists x-rays, ultrasounds, treatments, medications, aids, physiotherapists and lost wages.

Many families found one or other parent would need to reduce their work hours, negotiate flexible working arrangements or had to give up work altogether. Parents said:

> My daughter is six years old and she has JIA. She was only two when we found out that she had JIA. She spent weeks and weeks in hospital with it. My husband had to give up work to care for her.

> I took a demotion and went part-time to ensure that my child was getting the rest she needs before and after school.

Other families developed strategies in order to maintain support for their child.

> [We have] created a reliable support network of friends around us as a backup when hospital visits are required and educated ourselves about the medical condition and effective ways to treat pain, inflammation and febrile temperatures and work with local occupational therapists when required.

Due to the demands of their caring responsibilities carers reported that other relationships within the family became affected. Parents said:

> It has affected our leisure activities and the time we could sometimes spend with our [other child]. Friends and even some family members struggle to understand a chronic disease that often is not visible. …The social isolation has often been the most difficult for our daughter [with

> arthritis] and as she has become a teenager there have been more challenges.
>
> Any spare time… [is used] going to medical appointments, organising medical staff, organising support groups, supporting other people or just looking after them – nothing else.

Arthritis organisations in the states and territories assist families and one family described in the case study below, developed an information kit for other parents of children with JIA. Other carers found their information and support through the internet. A parent said:

> We did a lot of research online and found support networks for our daughter to access in a safe environment and chat to children in similar situations … we were fortunate to have a wonderful community educator working with Arthritis Tasmania. When our daughter was first diagnosed the support, information and assistance that she provided to us and helping to educate her teachers and classmates was invaluable. She also assisted us to attend the national JIA camp which was great. Unfortunately this service is no longer available in the same capacity which is a shame.

Being able to understand the situation was empowering for families. A mother said:

> I built up knowledge: understanding the disease and what my son is going through… understanding the future outlook of living with JIA... understanding treatment and medication…finding complementary treatment and by finding complementary ways to help my son dealing with JIA.

Parents caring for a child with arthritis have to make many physical adjustments to a family's lifestyle. A mother said:

> My 11yr old son has arthritis. I have reduced my work hours … We found that he required more assistance in the afternoon due to fatigue… He also struggles to do homework after school due to fatigue so … after discussing his issues with his teacher it was decided that he would no longer complete homework tasks.

Helping their child to manage the impact of pain and fatigue affects all aspects of the caring process.

> My daughter has JIA and I have continued to try and find new ways of exercising with her to keep her moving even when she is having a bad day… As she has got older I have encouraged her to take responsibility

> for her own management of her condition as she is now 18 years old, but her ongoing fatigue and pain just makes everything harder for her - especially coping with work and study.

As children's facilities are not always available when visiting specialists some children with arthritis, especially those experiencing the effects of uveitis, might find themselves being treated in adult eye clinics which are not necessarily accessible or designed to meet the needs of children. This can be a difficult experience for children and their parents:

> At private eye hospitals they are generally not geared up to deal with kids with eye conditions due to arthritis. So it's pretty scary for them. No toys, no entertainment before the operation, and not many staff who know how to calm them down, etc.

Effective management of juvenile arthritis is complex and requires input from a team of medical and allied health practitioners. Some carers indicated they were now supported by a medical team. However, this was not always the case and many more parents felt that this multidisciplinary team approach was missing and there was little or no co-ordination between services. Some parents said:

> Treatment should be more of a team approach, e.g. doctors, nurses, physio, counselling, OT [occupational therapist] all working together and case conferencing.

> You have appointments but there's no orchestration of them, you have to go whenever the appointments are available or whenever you can afford them, because they are incredibly expensive … so you've got to space them out rather than have a series of appointments together where you can take half a day off and get them all over and done with … I think orchestrated care is more than a multidisciplinary team in name, it is co-ordinated care, genuinely co-ordinated, you have one time that you go, everybody sees the child, they work together.

Parents indicated that more counselling services were needed to help children and teenagers deal with the impact of their arthritis.

> Counselling services are needed to deal with the impact of arthritis on children/teenagers. Counselling services could also work with the family and the child's school to deal with all the problems associated with having a child with arthritis at school, e.g. social isolation, school absence, fatigue, not being able to play sports.

Access to respite or even simply babysitting options can be limited if other people don't know about or understand the condition. Parents with younger children find it difficult to use informal babysitting services. Many participants felt that Home

Care was not flexible enough to meet their needs and wondered whether the NDIS will be better and allow them an opportunity to direct their own support needs as and when they require them. Respite is essential to maintain emotional and physical wellbeing and family dynamics, amongst other things. A carer said:

> Families are under stress, the fracture lines start appearing, it takes far more work and people just haven't got the energy to do it, to maintain relationships, when the financial strain is enormous. You also have parents dealing with this [stress] on their own as well.

Sharing or networking with people in similar situations often helps to reduce isolation. Peer support for parents, children and young people, especially in relation to rare conditions help. A carer said:

> We are on a secret Facebook group where I will literally type out the swearword and nobody judges … you know you could have the worst possible day and put it all in there. And then you could be there for when someone else is going through that sort of thing … some of them are on the other side of the world … we all have this in common.

Raising awareness in the community and schools

Raising awareness in the community and at school was seen as an essential step by parents who thought there was a need to educate teachers, children and other parents about kids and arthritis and the types of issue they and their families face. Parents said:

> 99 per cent of the population know that kids can be diabetic but only about 5 per cent know that kids can suffer from arthritis. If more people in the wider community were aware, it would be much easier for them to be assisted and supported at school and in everything they do.

> [My daughter] has had surgeries on her eyes this year and has missed a lot of school. Perhaps a service that helps them catch up with their studies would be good for school age.

6 What helps people manage their condition?

6.1 Informal support

6.1.1 Family and friends

People with arthritis rely heavily on their immediate family for informal support with 84 per cent of survey participants indicating that immediate family members were their most important source of informal support. (see Table 13 below). One woman said:

> My husband is now going into enormous debt to renovate our home so that I can move around easier, get into the shower, go to the toilet, and even, with lower benches and oven, cook again. Psychologically it is terrible as my self-worth has dwindled and depression set in quickly. If I didn't have such a loving family there is no way I could have coped with this. I had goals to finish my MBA, now my goal is to get out of bed each day.

The pressure of the carer role on relationships and family dynamics is explored in the case study on JIA (see Section 4.4) and in the section on carers (Section 5.8) which highlights the need for external support and respite care to assist family members in their caring role.

The next most important source of informal support was neighbours and friends. Only 11 per cent of participants nominated facilitated support groups as an important source of informal support (see Section 6.3).

Table 13: Most important sources of informal support (could answer select one or more)

Type of informal support	n[a]	Per cent of cases
Immediate family	486	83.8%
Other relatives	66	11.4%
Neighbours/friends	187	32.2%
Facilitated support group	61	10.5%
Self-help group	75	12.9%
Other	55	9.5%
Total	930	160.3%

Source: Survey, Section E – your support (could answer more than one)
Note: The total of percentage cases exceeds more than 100% as participants can tick more than one response.

In terms of the support provided, survey participants selected from a list of activities that were identified by interview participants. Table 14 shows participant response rates, indicating support was most required for domestic activities, managing their arthritis and accessing leisure facilities. Personal care was also a significant area of support highlighting the difficulties in just managing day to day activities; this suggests that people's emotional wellbeing could be affected by having to continually ask their spouse, family member or friend to assist with very intimate activities or having to struggle on themselves.

Table 14: Informal support provided

Type of informal support	n[a]	Per cent of cases
Personal care	119	21.9%
Domestic activities	331	61.0%
Managing arthritis	200	36.8%
Access to employment/voluntary work	27	5.0%
Access to education facilities	21	3.9%
Access to leisure facilities	139	25.6%
Information about services	107	19.7%
Other	85	15.7%

Source: Survey, Section E – your support (could answer more than one)
Note: The total of percentage cases exceeds more than 100% as participants could tick more than one response.

6.1.2 Community

Support is also available in the local community and neighbours and friends were identified by a third of participants as key sources of support.

Other people with arthritis in the community were often a great source of informal support and information sharing. Although many participants expressed satisfaction with the information available from their local medical practitioners, the majority found the information they needed was either not provided or lacking in essential detail to assist them to make informed choices or understand the disease process, its effects and treatment options. As a result, many relied on contact with other people with arthritis to fill in these information gaps and also as a source of emotional support.

Many people were keen to provide support to others with arthritis in the community by sharing information, e.g. through patient information sessions or participating and supporting others in local community groups. They said:

> My doctor and physio have often asked me to have a chat with patients who have been newly diagnosed to reassure them, and to encourage them to see that RA is not the end of the world, and that yes, the possible side effects of the drug treatments are scary, but doctors will monitor the patient closely, and bad outcomes are very rare.

> The [Women's Insights into Rheumatoid] Arthritis' book was helpful, once I searched that out and I wish that was more on hand and given to me once I was diagnosed, it made me feel like I wasn't alone and others go through the same thing.

Many participants found help and support from the broader community in terms of online support groups (including livewire, an online social network for children with illnesses or disability). Participants used forums to source information as well as emotional support, sharing stories and experiences with people all over the world. They said:

> Other people who are sick have either made up groups themselves or they have just joined other groups… and people can join and talk about it. I dare say that's the main frontline of support.

> I have found online support groups invaluable. I use three on Facebook. I felt very alone when first diagnosed as I had never heard of it and didn't know anyone else with it. Through those groups I now have people I can talk to who understand. I think that is very important.

> I have some online friendships (one who has significantly helped me recover through keeping in touch for over three years now) with old school mates, that has been an entirely, unexpected blessing and helped me immeasurably, to maintain my psychological wellbeing.

Many people however remarked that the invisibility of arthritis to others meant that they often felt reluctant to seek assistance or care, or they felt that, when they did, people considered them to be fraudulent. One person said:

> There is a lot of ignorance in the community - if you look healthy, a lot of people assume you are, and think that you are somehow malingering when you struggle to do something, which can be hard.

6.2 Formal support

Formal support identified by participants as helping them to manage their arthritis was concentrated in the area of health services including general health care, allied health services, complementary treatments and pharmaceutical care. Many also commented on the social protection available that helped to support them to meet their high medical costs and to support them when they were unable to work due to ill health.

Survey participants were asked to rate their satisfaction with formal support available to them. Satisfaction with formal support was generally only moderate. Satisfaction levels varied by state and generally correlated with levels of personal

wellbeing (Table 15). Satisfaction with formal support and personal wellbeing were highest in Victoria and lowest in Tasmania.

Table 15: Personal wellbeing and satisfaction with formal support, by state

State	Personal Wellbeing score		Satisfaction with formal support	
	n	mean score	n[a]	mean (scale 0 to 10)
NSW	343	65.0	244	6.95
VIC	65	67.4	39	7.15
Qld	65	65.2	40	6.55
SA	23	63.5	16	6.75
WA	39	61.8	21	6.71
TAS	14	61.1	10	6.20
ACT	46	60.4	-	-

Source: Survey, Section B – your wellbeing, Section E – your support, Section F – About you
Notes: No participants from the Northern Territory so therefore not included.

Satisfaction with formal support services was higher in major cities compared to regional areas (Table 16). Interestingly, people in outer regional Australia consistently showed greater levels of satisfaction with formal support than people in inner regional Australia.

Table 16: Satisfaction with formal support, by remoteness

Remoteness	n[a]	Satisfaction (mean, scale 0 to 10)
Major cities	274	7.03
Inner regional Australia	76	6.37
Outer regional Australia	17	6.71

Source: Survey, Section E – your support, Section F – About you

6.2.1 Health care

Participants highlighted the importance of having supportive and knowledgeable health practitioners to help them manage their arthritis. In particular having a multidisciplinary team of health care providers who communicated with each other was the most satisfactory approach to managing their arthritis. However, a multidisciplinary approach was not always adopted by GPs or specialists and people usually needed to identify and co-ordinate their own multidisciplinary team.

Participants indicated they wanted greater access to allied health practitioners for mobility, diet, exercise, therapy, pain management, modifications and advice, but accessing these services was expensive and there was limited coverage under Medicare or private health insurance. Support for allied health visits under Medicare Chronic Disease Management Items was beneficial but was limited to just five visits a year which many people found to be insufficient.

Participants also highlighted the importance of having a good relationship with a pharmacist to help them when managing multiple medications. Pharmacists understand how different medications may interact and also understand the side effects of different drugs. This is particularly critical when the medication prescribed by a rheumatologist may interact with that prescribed by a GP for other conditions.

Participants noted the benefits of medication being available on the PBS or being accessible under a Health Care Card – both for the direct treatment of arthritis and any medication to manage the side effects.

6.2.2 Social protection (financial support)

With the high cost of medication and the loss of income due to a reduced capacity to work, social protection was considered as crucial in supporting people with arthritis. Participants spoke about the need for information about income support and for concessions to help them manage the costs associated with their condition:

> I really don't know what I am eligible for or how to access it. Some type of government issued booklet would be very helpful.

> My team of health care professionals are all fantastic but apart from my rheumatologist I pay for all of them from my own pocket. If I didn't work this hard, I would certainly go quickly downhill. It wouldn't be long before I would be unable to work and would end up on a disability pension.

> I was granted my disability support pension in 1997 … being on the DSP made it easier to get my public housing, it's certainly not money that you can live off, which is why I've always been glad to be able to work part-time when I can. … there is a mobility allowance that comes along with that now.

> I think people who have a known health condition that can't be improved over time… should have access to a health care card and also to cheaper prescriptions. I've had to go without prescriptions sometimes, because I can't afford them with other living expenses.

Other participants were trying hard to manage their arthritis so they could continue in employment despite the difficulties.

> I feel like I am trying very hard to keep my arthritis under control so that I can be an active member of society - so I can work full-time and forge a career, so I can have an active social life and make a positive contribution to my community. But I also feel that I get little to no official government support in achieving this.

Some participants found they had drawn down on their superannuation to try and meet their day to day costs because their medical expenses were so high. Some of their expenses they were able to claim on their tax bill but participants noted that this benefit was being phased out.

6.2.3 Home care services

Formal home care services were a valuable form of support for those participants who were able to access them. However, most support at home was provided by family either because of the close proximity of the family, the lack of access to a flexible service, or because of a reduced or limited income.

More survey participants privately funded home help and maintenance services than accessed public services. Some participants identified that support was provided by a home care worker, but most identified the need for more formal support to help both inside and outside of their homes.

Only 61 participants (11 per cent) indicated that community based services were helping them achieve their goals. Referrals to community services were inconsistent or services were not able to respond and placed people on long waiting lists. Even when services are in place, it can be difficult if the person needs to increase their services because of a change in their condition or family circumstances.

> I am unable to properly clean my home without the assistance of a home care worker on a weekly basis. I am not able to stand long enough to prepare my meals… I cannot walk unaided around my home so I use a wheelchair, mostly I push it around for support, however when I have really bad days I use the wheelchair to move around the house. I also use the wheelchair as a mobile tray to carry meals etc.
>
> Eventually I got four hours a week and then two years ago I got my own community living package and it's been the best thing.

A few people were fortunate enough to have accessed a self-directed funding package, available from different sources, including Lifetime Care and Attendant Care[21], and as a result were able to direct their own home care. However, many participants were unable to access this support because of their level of disability, their location, and the long waiting lists for services. One person who runs her own business described the success of her support package:

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[21] Lifetime Care is a NSW scheme that provides services to people severely injured in motor vehicle accidents in NSW (see www.lifetimecare.nsw.gov.au). Attendant Care, now the Community Support Program, is a NSW scheme that provides individualised funding to people with physical and/or neurological disability to manage their personal care needs and be as independent as possible (see http://www.adhc.nsw.gov.au/individuals/support/everyday_living_support/community_support_program)

> I get support for personal care every morning because I can't dress and I can't reach my hair and I need help to wash my hair , someone makes my lunch and does the cleaning, _____ does all the cooking and runs me around everywhere in terms of medical … employing my own staff has been the best thing..

In identifying the most important sources of formal support more survey participants privately funded home help and maintenance services than accessed public services.

6.3 Other

A number of not-for profit and community organisations provide support for people with arthritis. Arthritis organisations located in each state and territory provide information, resources, health education and self-management courses to help people to manage their condition. They also facilitate arthritis support groups which provide information, activities and emotional support to members. Some condition-specific organisations and support groups are also available. Other things that help people manage their condition include supportive employers and modifications and equipment.

6.3.1 Arthritis support groups

Survey participants were asked to identify the most important sources of formal support available to them. Arthritis support groups were identified by only 11 per cent of participants as a source of formal support – this is surprising given that the survey was distributed to people likely to be already actively engaged with arthritis support groups, but may also reflect the way the question was asked. However, participants also indicated a low satisfaction with access to someone who can lobby or advocate on their behalf (5.01, the lowest satisfaction score associated with formal support available).

In contrast, the interviews and survey identified the positive aspects of arthritis support groups as well as identifying things they felt could be improved upon. People said:

> The arthritis association supplied a fab information pack and regular newsletters.

> It wasn't until I changed rheumatologists that I was put in touch with Arthritis Qld … Through them, I was able to find more information and support and was put in touch with other sufferers, talking to other people with RA made the biggest change to my life and I wish I had had access to other people as soon as I got diagnosed. This would have meant that I didn't spend that first six months crying.

But existing arthritis support groups do not meet everyone's needs, particularly young people, for example:

> There is no support for the few people who have Stills in this country. Information is limited and even sourcing the right medication is difficult and then paying for it is prohibitive - more than a mortgage! … I think advocacy would be great, but being a twenty something male, my son just gets on with it and does the best he can.

> Much of arthritis support seems to be aimed at the elderly [sic], and I am sure I will be grateful of it when I get there, but more support for the young sufferers would be wonderful. And a better education for the public about what it's all about.

> It would be really helpful if there was a support group/line that could give answers to medical questions. Arthritis NSW is a great team, but they are limited in how much medical advice they can give and doctors often speak in a very technical language that is hard to understand, especially when you receive bad news and need time to cope with it. ... Google is …not always a good solution.

6.3.2 Employers

Supportive employers, flexible work arrangements and workplace modifications can assist people with arthritis and their carers to continue to participate in the workforce, reduce reliance upon social protection, maintain living standards, and meet the cost of medications and other support. Despite formal legislative requirements, however, adjustments in the workplace or working practices are often at the discretion of an employer. Participants who were in the workforce said:

> The thing is, I can do the job, as long as there are some allowances for my bad arthritis days. Lots of days I am fine, but there are days when some tasks I can't manage. A lot of employers in this causal employment environment aren't usually very supportive.

> [My son] told his employer that he would need to start later each day until he could get on top of the flare up because it is hard for him to 'get going' in the morning, and he is exhausted by the end of the day.

> I work two and a half days a week. I haven't changed the type of work. I do change the way I work. I'm taking a lot more care of the ergonomics.

> I found work really hard to overcome barriers in understanding and [to] access adjustment that was appropriate for me. I often feel very aware that I have challenges at work that I shouldn't and continue to face them

6.3.3 Modifications and equipment

Sixty-three per cent of survey participants had made some modifications to their home or car or to the way they approached tasks which allowed them to manage their daily living activities more easily. People under the Department of Veterans Affairs (DVA) had found them very helpful in providing both an occupational therapist to conduct an assessment as well as providing and paying for the necessary equipment or modifications. They said:

> DVA and our GP and OT have made our lives much more bearable.

Many participants indicated they had changed their car from a manual to an automatic model, purchased a higher car to make access and egress easier, and where possible located one without bucket seats or one which offered multiple and motorised ways to change the seating and wheel positions. Many participants reported installing remote controlled garage doors while a limited number of people had purchased a wheelchair hoist for their vehicle. Unlike the Motability Scheme in the UK[22] and other European countries[23] [24] which operate vehicle adaptation schemes for people with a disability, all these adaptations were purchased privately. There are schemes for the provision of aids and equipment for motor vehicle access available in Australia, such as the Vehicle Modifications Subsidy Scheme in Victoria and the Vehicle Options Subsidy Scheme in Queensland, but none of the participants in the survey reported being aware of their existence.

Within the home most people reported they had changed the way they completed their activities of daily living for example sitting to prepare meals or do the ironing. They had also looked at adjusting the height of their chairs, desks and tables, removed their rugs and other trip hazards and purchased a range of small aids and equipment to make their lives easier. This included freestanding rails in the bathroom and around the toilet, jar and can openers, larger handled cutlery, 'helping hands', back supports, slip resistant mats, etc.

A number of people had purchased an electronic bidet which made their personal hygiene much easier to manage while other people had looked at purchasing an electric bed to assist with transferring to and from their bed and changing positions whilst in bed. Other participants had also undertaken or were planning on undertaking minor works of adaptation including replacing their taps with lever handles, installing rails in the bathroom and toilet and alongside stairs and steps and reducing the height of steps.

> My home has been modified with rails in the shower and doors and I have chairs for showering and cooking etc. which I am grateful for.

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[22] http://www.motability.co.uk/
[23] www.autoadapt.se
[24] www.ptu.dk

Some people indicated they had undertaken larger works of adaptation including removing the bath and replacing it with a shower, installing a stair lift, renovating their kitchen to change the height of work benches, cooker tops and other appliances, replacing cupboards with drawers, and installing fixed or temporary ramps to provide access to their home and the garden.

A number of people had either sold their house and moved to, or built a level access property.

> Our home has been completely modified to accommodate my disabilities. A carer showers & dresses me daily - the shower has rails, a chair & the door opens wide. We have an internal lift to the second floor but my bedroom & bathroom are on the lower level. I am fortunate that my husband has been supportive & a devoted companion - he designed the house for my comfort, he does the shopping, cooking & driving (after my neck fusion, I stopped driving)

However, a number of participants indicated that they were unable to make any changes because of financial constraints.

> The Department of Housing has placed rails in the house to help me … The doctor wanted them to put in drawers instead of cupboards as I cannot bend down to them, however the department will not do this saying they would only replace it with cupboards not drawers, that is if they replace it at all. I feel useless and as though I do not matter at all when I cannot even afford to do something as simple as a kitchen replacement.

> Some days I do not leave the house because I have trouble negotiating the five steps at the front of my house and there are times when I worry about not being able to climb the stairs to get back inside. I would really love to be able to buy a stair lift, however these are quite expensive and currently beyond my means, which is a disability support pension.

> Better access to information and advice about appropriate modifications and assistive devices, e.g. from an occupational therapist, as well as better access to financial support to meet the cost of these adaptations, would be of great value.

6.3.4 Information

Information provided at the time of diagnosis or subsequently was considered critical in terms of being able to understand the disease, the implications of the diagnosis, and what people could do to manage and mitigate symptoms.

Error! Reference source not found. below shows the level of satisfaction (on a scale from 0-10) expressed by survey participants about the information provided about their condition and how to manage it, and about health and community care services by arthritis type. People were generally only moderately satisfied with the information provided to them about their condition, with satisfaction levels highest for juvenile idiopathic arthritis and rheumatoid arthritis and lowest for ankylosing spondylitis and osteoarthritis. Satisfaction with the information provided about health and community care services available to them was generally low, with the exception of juvenile idiopathic arthritis.

Table 17: Satisfaction with information, by arthritis type (mean score)

Information:	RA n=237	JIA n=10	OA n=456	PA n=55	AS n=45	Other n=138	Total n=676
Condition	5.869	6.300	5.388	5.600	5.200	5.312	5.518
Health and community care services	4.873	5.600	4.947	4.473	4.289	4.522	4.848

Source: Survey, Section C – Your arthritis

Notes:
RA = rheumatoid arthritis, JIA = juvenile idiopathic arthritis, OA = osteoarthritis, PA = psoriatic arthritis, AS = ankylosing spondylitis, other as before.
Includes people with more than one type of arthritis.
Based on satisfaction score where 0 is completely dissatisfied and 10 is completely satisfied
Results for JIA are not statistically comparable due to the small number of people identifying as having JIA (n=10).

Some people were happy with the limited information provided at the time of diagnosis

> I was told VERY little initially… It is an ongoing process of understanding and acceptance. Initially I thought I should have been told a lot more and felt the amount of information given was inadequate, but I've found out over time and I accept that the way I have come to understand this information as possibly the 'best' it could have been.

For others, the information provided at diagnosis and subsequently was inadequate, but they were able to find information elsewhere. Many people accessed information through informal sources. Access to a list of reliable sources of information was suggested as a helpful measure. A carer said:

> The whole medication issue was quite confronting to us and we did feel we needed to continue our own research to have enough information. 5 or 10 minutes with a specialist (even with a list of questions) never seems to be enough. Probably a list of reliable websites to source information would have been great in the first instance.

7 What could be improved?

Research participants were able to identify many areas of informal, formal and other forms of support that could be improved or developed. Ultimately this could reduce the disability caused by arthritis, maintain or improve people's ability to engage in daily life activities and ultimately lead to a better quality of life. They ranged from basic health care to increasing public understanding and awareness of the disease in all its forms.

7.1 Informal support

7.1.1 Family and friends

Informal support, primarily from family and sometimes friends, was the only form of support available to most of the participants. Whilst this allowed for enormous flexibility and for care to be individualised, it is recognised that this reliance on family to provide support services also affected normal participation in family life and affected relationships between partners, with and between children, and with parents. Family can be either supported or relieved from this caring role, or a combination of the two. This might include:

- Providing information to help carers understand the type of arthritis, how to recognise flares or acute stages of arthritis, and how to manage the symptoms
- Providing information about what physical and emotional support is available
- Establishing peer support groups and other sources of emotional support
- Providing formal care services and on a flexible basis if needed
- Supporting people with arthritis participate in family responsibilities (e.g. caring for children or older relatives)
- Providing access to respite care, ranging from suitable babysitting of children with JIA to periodic respite from caring for a relative
- Providing access to financial support to allow the family to carry out their caring role.

7.1.2 Local community

Some participants suggested that more could be done to educate the local community about the conditions and the impact they have on people, young and old.

That way the local community may be able to provide greater support, whether that was in schools, community groups, or other social domains. The local community could become more supportive to people with arthritis through:

- Building awareness that arthritis conditions are not age specific and not always visible
- Building awareness that the disability associated with arthritis can range from mild to severe
- Building capacity in schools, services and places of employment to accommodate people with arthritis across their life course.

7.1.3 Arthritis organisations and support groups

Eleven per cent of survey participants reported that they were actively engaged with arthritis support groups; this is likely to reflect the way in which participants were recruited for the survey. Many participants offered suggestions on how these groups could be improved, including:

- Recognising the different types of arthritis
- Recognising the different age groups affected and developing more appropriate support services for those groups
- Providing more medical information and providing it in plain English
- Providing information about support available
- Supporting peer groups and exchange of information
- Supporting people with arthritis at work
- Expanding existing educational activities, including self-management programs which help people understand more about arthritis and its management.

Given the number of different types of arthritis and the age groups affected, research participants highlighted the need for appropriate peer support groups to share information and provide each other with emotional support. People in remote areas, as well as regional and metropolitan areas, relied on on-line support groups for information and peer support. This was particularly important to people with less common types of arthritis, and young people, who felt incredibly isolated, uninformed and unsupported (in terms of advocacy). Some of the groups were found by word of mouth, others by searching online. Talking to others helped emotionally and mentally. It was suggested that people with

arthritis, particularly when first diagnosed, could be helped to find appropriate online community groups that would meet their needs by sign-posting people to relevant websites and forums depending on age and type of arthritis.

7.2 Formal support

7.2.1 Health care

Whilst identifying health care as their primary source of support, participants in this research identified a number of areas that could be improved. The most significant issue identified by research participants was the need for a co-ordinated approach to health and social care services rather than the current siloed approach.

People with progressive forms of arthritis would benefit from having access to a named member of a multidisciplinary team who would be able to assist the person to co-ordinate their care. A multidisciplinary team approach would provide the opportunity for regular ongoing assessments of the effects of the disease on a person's life, for example, levels of pain, fatigue, how they are managing everyday activities, their mobility, ability to work or participate in social activities at home and in the community, their overall quality of life, mood, impact on personal relationships and so on. Health care services can also be improved by:

- Educating the community and medical practitioners about the symptoms of the different types of arthritis to speed up diagnosis and minimise any damage between symptom onset and treatment
- Improving access (physical and timely) to specialists, including in remote and regional areas
- Improving access to specialists during flare-ups
- Providing more information to patients at diagnosis and during management, including other sources of care such as physiotherapists and occupational therapists, podiatrists, counsellors and psychologists.
- Encouraging the ongoing monitoring and management of arthritis, including pain management and consideration of how allied health care can help manage or mitigate symptoms
- Enabling, wherever possible, the coordinated care of people with arthritis, for example through a designated health care nurse
- Providing an information line to help understand the condition, treatment options, and the medications available and their cost

- Improving the understanding of arthritis across other specialists and services, for example in obstetrics and the treatment of diabetes.

7.2.2 Medical costs and social protection

The cost of medical care and medications were identified as having the greatest impact on people's financial situation, and over a fifth of participants reported that they were moderately or much worse off financially as a result of their condition. The chronic nature of the disease and the need for constant care and medication means that many people struggle financially – something that may get worse at retirement age depending on retirement income. Participants suggested:

- Including arthritis medication and any medications and supplements to manage their side effects on the PBS (not just for arthritis, but for any chronic illness)

- Increasing the allowances within a care plan for access to subsidised allied health care

- Increasing the Medicare rebates for access to specialists to deal with complex illness

- Providing guidance on how to navigate the social services available – i.e. what is available and how to access it.

- Access to a health care card for people with chronic illness to assist them with their health care costs.

7.2.3 Other services

Better access to home care could help, whether this was on a regular basis, occasionally during acute stages or flare ups, or to provide a family with respite (or support when family were unable to provide support). However, services do not always recognise the disabling impact of arthritis or provide the flexibility in service delivery to provide support during flare ups.

Research participants identified the need for home care services to relieve both the physical, financial and emotional pressure being placed on family members who were providing ongoing care. Some people lived alone and did not have family to rely upon for care and support needs. Home care services should:

- Provide age appropriate support recognising that not everyone with arthritis is an older person

- Recognise that home care may not be required permanently, for example it may be used during disease flares or during a recovery period after an operation
- Support people with arthritis to enable family and social participation
- Include assistance with tasks around the home, including home maintenance and gardening.

7.3 Information

Information needs vary across the different types of arthritis, age groups, life stages, disease stage and individual circumstances. One research participant demonstrated that within one family there were very different and distinct information needs (across generations). The amount of information necessary to support this broad group of people is enormous. However, having better information can directly improve wellbeing and give people better understanding and control in managing their arthritis.

A broad range of recommendations were made about the type of information that could be provided to individuals and their families, and when (both at the time of diagnosis and in ongoing consultations), including age appropriate information about:

- The different types of arthritis (the nature of the disease, its progression, the longevity)
- The different medications available to manage the arthritis (and their costs)
- Options for pain management (including medication and other techniques)
- Support groups (covering different types of arthritis and life stages)
- Alternative techniques to manage and minimise the damage caused by arthritis or manage pain (e.g. exercise, diet, osteopaths, massage therapists)
- Sources of emotional support
- What equipment is available and how to source it
- Navigating social and disability services, including formal care and financial assistance

Information needs to be made available at the time of diagnosis and during the course of management and should be communicated both verbally and in printed

form/available on-line. Information provided at the time of diagnosis could also address the misconceptions that people may have about their condition.

7.4 Public awareness

How arthritis was understood and perceived by others directly affected the health, treatment, employment, and social participation of people with arthritis. Efforts could be made to:

- Raise the profile of the disease and give people who experience the effects of arthritis a sense of belonging – raising public awareness and potentially funds
- Raise awareness that arthritis can affect all people, young and old, male and female
- Raise awareness that impairment arising from extreme pain and fatigue associated with arthritis and other diseases is not always visible.

7.5 Other

7.5.1 Employers

Participants identified a number of issues about gaining and maintaining employment when impaired by their arthritis. This was particularly difficult given the often hidden nature of the disease, the limited understanding of the disease, and also the variation in symptoms over time due to flare ups.

Participants identified the need for assistance in negotiating more actively with their employers the adjustments they would need to be able to remain or return to work. This might include adjustments within the work place, a change to less physically demanding work, and flexible working arrangements. Attention needs to be given to:

- Providing information to workplaces, or for employees to take to their employers, about how to enable people with arthritis to continue working
- Providing assistance to access occupational therapists
- Providing opportunities for retraining.

7.5.2 Modifications and equipment

Modifications and equipment, both in the workplace and at home, enable people with arthritis to participate in day to day activities. This may range from simple implements, such as bottle openers and zip pulls, to power chairs and home/office modifications. A lot of information is spread by word of mouth, but this could be made more accessible by:

- Encouraging the sharing of information about modifications and equipment that help reduce the impairments of arthritis. This may include tips and tricks.

- Providing links to Independent Living Centres, located in all states and territories, to help people develop techniques and strategies for daily living and learn about modifications and equipment that can help them continue living safely at home.

8 Key findings

8.1 Disabling impacts of arthritis

This research identifies that arthritis can be very disabling with more than one-third of participants (37 per cent) reporting that their arthritis always limits their ability to engage in daily activities, while a further 58 per cent reported that it sometimes limits their ability to engage in daily activities.

People with arthritis also report a significantly lower sense of wellbeing compared with the general Australian population (mean score of 64.0 compared with a general population score of 77.6). The most significant adverse impact occurred in the domains of health, employment and finances.

The impairment associated with arthritis varies significantly, depending on the type and severity of the condition, the presence of other health conditions, and the time since diagnosis.

The level of disability experienced by people with arthritis can also vary depending on individual life circumstances, whether people have access to support (informal or formal), access to employment or study, access to adjustments in their study or work, the presence of other health conditions, and their financial circumstances.

The impact of arthritis is not limited to individuals with arthritis but also affects their family in terms of the physical, emotional and financial support they provide. For some, arthritis limits their social participation, or means that they need to be continually cared for by their parents, partners or children; they may be unable to start families of their own, or if they do, their role in bringing up their family is limited by their condition.

The research shows that people with arthritis cannot be treated as one homogenous group. People experience a wide spectrum of disability that may require short-term, long-term or permanent access to formal support (both care and financial support) depending on individual circumstances.

8.2 The impact on social participation

Where arthritis causes disability, people become socially excluded across one or more and sometimes all life domains – study, work, family and social.

In particular, people's ability to participate in work is adversely affected by arthritis with 23 per cent of participants reporting that they were permanently unable to work or study because of their condition, 68 per cent reporting that they were restricted in

the type of work or study they could do and 65 per cent reporting that they were restricted in their hours of work or study.

The extent to which people are affected depends on personal circumstances and the informal support provided at home and in the place of work or study.

Greater formal support both at home and in the place of work or study would improve social participation for this group.

8.3 Financial consequences of arthritis

The financial consequences of arthritis are significant due both to the added costs associated with living with the disease and the loss of income due to reduced capacity to work, and this adversely affects other areas of social participation and wellbeing.

The financial consequences of arthritis include the costs of ongoing medical care, the high and continual cost of medication, and lower earnings due to reduced capacity to work or engage in daily activities.

Two-thirds of participants reported that they suffered financially because of their arthritis, while one in five reported that they struggled to meet their expenses or needed financial support due to the financial impact of their arthritis. Many of the participants reported compromising their ongoing health care and other basic needs (food and utilities) to meet the cost of medication.

Government support for ongoing medical costs was identified as a high priority, particularly given the chronic nature of arthritis and the high cost of medication and treatment.

8.4 Considerations for the NDIS

While some people with arthritis will require an individualised package of support under the NDIS, many others will experience disability warranting other long-term support. If someone with a serious arthritic condition does not qualify for an individualised package of support because they are assessed as Tier 2 participants, it is not yet clear how the NDIS will benefit them. Current indications are that Tier 2 participants will need to rely on existing systems of referral and support, and these are the same systems that currently result in many people not receiving support because their arthritis is not considered to be a disability. An additional concern is that many of the existing programs also appear to have uncertain futures if they are absorbed into the NDIS system.

This report indicates that people with arthritis could benefit from the NDIS reforms and that the NDIS should recognise the severely disabling effects of arthritis. In

addition, people with arthritis and their families should become aware of the NDIS and the provisions that may be available to them in individual packages in Tier 3, referral to other support in Tier 2, and general information in Tier 1.

8.5 Final implications

This report reflects the voices of people with arthritis who are trying to hold down a job, raise a family, and participate in the life of the community, while managing the disabling effects of their condition. They face significant challenges due to the complexity and fragmentation of health services, inflexibility in the social support sector, and limited awareness in the community of the impact of living with arthritis.

The findings of the research have not been prioritised as each individual has their own priority. However, access to financial support, appropriate health care and formal care would appear to reduce the barriers experienced by people with arthritis in their ability to engage in daily life activities.

Research participants requested that follow up interviews be conducted in 12–24 months to track their experiences and to determine what has changed.

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Appendix A: Literature review

A review of national and international literature about current conceptualisation and practice relating to quality of life and the provision of support services for people with arthritis

1. Purpose of the review

The purpose of the literature review is to identify and collate information about current policy, programs, support and service models relevant to arthritis and disability in Australian jurisdictions and internationally.

2. Introduction

The United Nation's Convention on the Rights of Persons with Disabilities (CRPD) was introduced to:

> promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (Article 1, CRPD).

The policy goals of the UN Convention are echoed in Australian policy documents at both the national (the National Disability Strategy) and the state levels. Compliance with the CRPD, for example, is listed first among the NSW Government's commitments in Stronger Together 2011-16 (ADHC, 2010).

Research has shown that arthritis is a significant contributor to disability in Australia and is the second leading cause of disability after mental health (AIHW, 2010; ABS, 2010). However, many people with arthritis, or indeed government policy makers, would not consider arthritis to be a disability. For most people it is a health condition managed by medical intervention. Some people can make changes to minimise the impact of arthritis on their day to day lives, making adjustments at home and in the work place. There are many cases, however, where loss of function means that medical care is no longer enough to maintain a quality of life and care services, that is disability care services, are required to assist people in going about their day to day lives.

The purpose of this literature review is to explore previous research in this area and, in particular, what happens when arthritis becomes more than a medical issue and becomes one of managing a disability. For this reason we have used life domains (health; habilitation and rehabilitation; work and employment; standard of living and

social protection; family participation; and participation) identified in the UN Convention to discuss the literature to identify how those life domains are promoted and protected to ensure full and equal enjoyment of life. In particular, we consider the following objectives of the Convention:

- Right to full inclusion and participation in the community (Article 19)
- Right to the enjoyment of the highest attainable standard of health without discrimination (article 25)
- [Measures to ensure people can] attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life … services and programs should… begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths, … [and are provided] to all aspects of society … including in rural areas (Article 26)
- Right to work, on an equal basis with others (Article 27)
- An adequate standard of living for themselves and their families, including adequate food, clothing and housing, and to the continuous improvement of living conditions (Article 28)

Literature published between 2003 and 2013 in English-language was examined. Procedurally, two steps were followed. First, bibliographic searches of web-based databases (Medline, Web of Knowledge) were conducted. This was then supplemented by “snowball” searches of articles cited in publications already identified, as well as the identification of existing literature known by the authors. Key words for the search were: arthritis, disability, costs, support, policy, and quality of life. The key inclusion criterion for the literature review was the relevance to arthritis management in terms of policy, programs, support and service

3. Findings

3.1 Health

Arthritis is a significant contributor to disability in Australia and is the second leading cause of disability after mental health (ABS, 2010; AIHW, 2010). In 2011-12, arthritis was the leading long-term health condition experienced in Australia where it affected over 3 million people or about 15 per cent of the population (ABS, 2010). There are over 100 types of arthritis, with rheumatoid arthritis and osteoarthritis being the two most common types. It is more prevalent in women than in men and the onset of arthritis usually occurs between the ages of 15 and 64. The prevalence of arthritis increases with age where half of all Australians over the age of 80 have some form of arthritis (Deloitte Access Economics, 2007). While arthritis results in few deaths, it can cause significant pain and distress (AIHW, 2010). Even with good pain management and treatment, fatigue can remain a significant problem (Gignac *et al.*, 2012).

The impact of arthritis on quality of life is significant, as it affects not just a person's functional abilities but can also cause significant psychological distress (AIHW, 2007). In 2011, Arthritis Australia commissioned a national survey to discover the impact of arthritis on Australians. The study found that a large proportion of people with arthritis (79%) also have other chronic health conditions, such as heart disease, high blood pressure, diabetes or depression (Arthritis Australia, 2011). The occurrence of arthritis with another chronic disease can complicate treatment and management plans (AIHW, 2010).

In Australia, arthritis, along with musculoskeletal conditions, was declared a National Health Priority Area in 2002, a collaborative effort between the federal and state and territory governments. The National Centre for Monitoring Arthritis and Musculoskeletal Conditions was established at the Australian Institute of Health and Welfare (AIHW) in 2005 to undertake surveillance and monitoring of arthritis and other musculoskeletal conditions in Australia (AIHW, http://www.aihw.gov.au/). A National Action Plan for Osteoarthritis, Rheumatoid Arthritis and Osteoporosis has been prepared by the National Arthritis and Musculoskeletal Conditions Advisory Group with the goal "To decrease the burden of disease and disability associated with osteoarthritis, rheumatoid arthritis and osteoporosis within Australia and improve health related quality of life" (NAMSCAG, 2004).

However, in the national survey commissioned by Arthritis Australia (2011), the findings indicated that how people felt about their health status was associated more with their perceived standard of care, the information made available to them and associated access, as opposed to the severity of their arthritis (Arthritis Australia, 2011). This indicates a level of dissatisfaction with current access to, and provision of service by, health practitioners in Australia.

Brand et al. (2011) conducted a structured search of government and other key health websites to investigate the extent to which policy about the management of osteoarthritis has been translated into new service models within Australia. The findings indicated that despite the development of national osteoarthritis specific chronic disease management policy, translation into practice had not been implemented by state jurisdictions in a consistent or planned manner. Nor had the few developed service models been comprehensively evaluated for cost-effectiveness with regard to individual health outcomes. The authors argue that despite clinical practice guidelines providing a strong evidence base for effectiveness of specific intervention, there is little to guide the health practitioner in determining cost effective ways to provide care and deliver services. They recommend that in order to achieve positive health outcomes for people with arthritis, a well-planned and coordinated national strategy is required to improve care in a standardised manner. This should be driven by clinician leadership and supported by arthritis specific incentive programs with appropriate performance monitoring at all levels of the health system (Brand *et al.*, 2011).

3.2 Habilitation and rehabilitation

Glazier *et al.* (2003) found in their study of adults aged 55 and over living in Canada, that while almost all the people experiencing hip and knee arthritis symptoms and disability received a recommendation of pharmacotherapy, only half received a recommendation for comprehensive therapy (Glazier *et al.*, 2003). Access to timely appropriate intervention for people with arthritis, particularly to address psychosocial needs and pain management, has been a recurrent theme within the literature. In fact, Geuskens *et al*. (2008) found that health related quality of life among individuals with early arthritis is more strongly associated with demographic and psychosocial characteristics than clinical characteristics. The authors argue that this suggests health practitioners should take psychosocial and demographic factors into account and tailor treatment accordingly so as to achieve the optimal outcomes (Geuskens *et al.*, 2008).

Identifying people with emotional and social stress at an early stage may decrease the negative consequences of the disease. Gafvels *et al*. (2012) conducted a study in Sweden with people newly diagnosed with rheumatoid arthritis between the ages of 18-64 who presented with psychosocial issues. The study found that almost half the people newly diagnosed had psychosocial problems severe enough to merit intervention. The results suggested that these people tended to be in a more vulnerable social and economic situation and were more anxious and depressed than others in the study. It was recommended that people newly diagnosed with arthritis should be screened for emotional and social stress and referred to trained health professionals (social workers, psychologists) for ongoing support. The authors argue that detecting and treating emotional and social problems early in the disease would probably facilitate adaptation and decrease the negative psychosocial consequences of arthritis (Gafvels *et al.*, 2012).

Backman (2006) conducted a review of literature involving psychosocial interventions and pain outcome measurement. The aim was to summarise the psychosocial factors that are associated with arthritis pain and highlight recent evidence for psychosocial approaches to pain management for arthritis. The author argues that pain, along with other symptoms from arthritis, can threaten the ability of people with arthritis to participate in a range of meaningful, obligatory and discretionary activities including work, family life, leisure and social relationships. This in turn may compromise the psychological and social wellbeing of people with arthritis. The findings from the literature review suggest that while psychosocial approaches enhance medical regimes of care, the psychosocial impact of arthritis is not always fully appreciated by health care professionals. However, the current body of evidence regarding psychosocial interventions is not sufficient to be able to draw confident conclusions and hence further research is required. The author argues that further research needs to identify which strategies are most effective based on the pain experience, diagnosis, age, gender, income and vocation of people with arthritis (Backman, 2006).

3.3 Work and employment

Arthritis affects the working age population, and the associated personal and economic costs are high (Escorpizo *et al.*, 2007). Gignac *et al.* (2012) found that people with arthritis do report experiencing positive influences from work, despite it also being a cause of stress. Employment provides resources, it is important in self-identity, enables people to be productive, it supports social interactions, and provides opportunity for physical activity (Gignac *et al.*, 2012). However, people with arthritis are more likely to be not working and have a higher amount of lost time from work compared with the general population (Escorpizo *et al.*, 2007). For people with rheumatoid arthritis, work disability often occurs early in the course of the disease and results in up to a third of people stopping work within 2-3 years after disease onset (Jacobs *et al.*, 2011). This reduced work participation directly affects the quality of life for people with arthritis and their families, and has major financial consequences for both the individual and for society (Wilkie *et al.*, 2012).

Schofield *et al.* (2013) conducted a study aimed at quantifying the economic impact of early retirement due to arthritis in Australia. Using the Health & Wealth MOD, a micro simulation model involving nationally representative information, the study considered factors such as reduced income, reduced personal savings, reduced taxation revenue, increased benefits payments and lost gross domestic product (GDP) due to the early retirement of 45 to 64 year olds with arthritis. From the data it appears that the cost of arthritis to both individuals and government in Australia is considerable, and due largely to loss of participation in the workforce. The authors argue that the data shows that cost savings could be made if disability from arthritis is prevented through primary prevention or improved treatment, and if individuals can remain in the workforce (Schofield *et al.*, 2013).

Given that policies to extend working life have become a central response to ageing populations in developed countries, and that there is a substantial likelihood that people will develop some form of arthritis as they advance in age, it has become increasingly important that people with arthritis remain in, or return to work (Wilkie *et al.*, 2012). Escorpizo *et al.* (2007) argue that recent advances in disease management and work accommodations may enable people with arthritis to stay at work, although perhaps with ongoing difficulties. Based on an extensive literature review and expert discussion, they found that work productivity loss or its remediation need to be viewed in the context of each specific job. Factors such as job demands, pace and flexibility, as well as the demands from life outside of work, such as leisure and family roles, can all influence work outcomes (Escorpizo *et al.*, 2007). These findings are supported by Yen *et al.* (2011), who found that occupational and workplace factors, including a non-supportive work environment, lack of work flexibility (work hours, adaptations to working practice), negative work culture, and lack of support from colleagues and managers are linked to absence and reduced productivity (Yen *et al.*, 2011). The fact that workers with arthritis transition in and out of different levels of disability or productivity and work status

over time adds to the complexity of ensuring positive work outcomes (Escorpizo *et al.*, 2007; Gignac *et al.*, 2012).

Gignac *et al.* (2012) conducted a study aimed at investigating both role perception and the inter-relationship of work with other roles for people with osteoarthritis and inflammatory arthritis. The data for this study was collected through focus groups with forty adults with arthritis living in Canada. Participants identified that having arthritis did affect their identity and impacted on both their work and personal roles. The results were categorised into four types of role balance or imbalance: role overload, which involved the perception of having too few hours to perform all roles adequately; role conflict, where there was a perception that the requirements in one area of life were at odds with other areas; role strain, which was identified as being pervasive and arose from several sources; and role facilitation, which emphasised the positive impact of work and personal life roles on arthritis. Participants identified personal strategies (e.g. positive framing) and contextual factors (e.g. support) as being important in contributing to or ameliorating role balance/imbalance (Gignac *et al.*, 2012).

3.4 Standard of living and social protection

Financial hardship has been identified by people living with chronic illness as a substantial barrier to managing their illness successfully. While Australia provides universal hospital coverage and subsidises many medical and pharmaceutical costs, some out of pocket expenses for medical and social care remain. Costs of medications, transport, medical and other health services, and access to facilities can all impact on the household budget. These additional expenses also often coincide with a decrease in the person's capacity to maintain paid employment, thus creating further financial strain (Yen *et al.*, 2011). Those unable to continue in paid employment can be further disadvantaged by the need to rely on their existing financial resources thereby reducing their savings and accumulated assets. This has long term implications for their ability to cope with financial stress, and reduces income from savings in retirement (Schofield *et al.*, 2013).

There is limited information available on the relationship between socioeconomic status and arthritis. However, there is evidence that socioeconomic factors influence the prevalence of arthritis, with the proportion of Indigenous Australians with arthritis being higher than non-Indigenous Australians, and the proportion of arthritis being higher among low socioeconomic groups (AIHW, 2010). It is recognised that individuals of lower economic status have a lifestyle that is less protective of arthritis. This includes reduced levels of physical activity, higher levels of obesity, and a greater likelihood of smoking. A person's occupation is also an influencing factor, with those working in physically demanding occupation being more at risk of developing arthritis in their joints, particularly in their knees (Brennan *et al.*, 2012).

Geuskens *et al.* (2008) found that health related aspects of quality of life among individuals with early arthritis were more strongly associated with demographic and

psychosocial characteristics than clinical characteristics. They conducted a cross-sectional study with people in the Netherlands who had experienced inflammatory joint complaints for less than twelve months and collected measures such as demographic information, comorbidities, psychosocial factors, and length of time between onset of inflammatory joint complaint and medical examination. The authors argue that there is currently insufficient research into the associations between these characteristics and health among the various diagnostic groups and that a better understanding of the associations could influence the choice of treatment for people with arthritis. The findings suggest that physicians should take psychosocial and demographic factors into account and tailor treatment accordingly so as to achieve the optimal outcomes for individuals (Geuskens *et al.*, 2008).

Brennan and Turrell (2012) used longitudinal data from a population-based cross-sectional study to examine the relationship between individual and neighbourhood level disadvantage upon arthritis in Australia. The results from the study indicated that individuals from disadvantaged neighbourhoods were more likely to report arthritis compared to individuals residing in less disadvantaged neighbourhoods, independent of education, occupation and household income. As this was the first study to examine the association between social disadvantage and arthritis using a multilevel analysis, and being a cross-sectional study, it was impossible for the authors to draw any causal relationships between social disadvantage and arthritis. However, they did provide some speculative discussion particularly focusing on the role of social capital. The authors argue that the data suggests the importance of focusing on both people and places for disease intervention, and further research is required into examining the association, as without which it will be difficult to reduce the prevalence of arthritis and to identify potential target groups for preventative health programs (Brennan *et al.*, 2012).

3.5 Family participation

People, along with their families, experience the impact of chronic illness in many areas of their lives (Yen *et al.*, 2011). Gignac *et al.* (2012) found that people identified that having arthritis did affect their identity and impacted on their work and personal roles. In their study investigating the experience of role balance/imbalance among individuals with arthritis, two strategies were frequently discussed that were aimed at managing role overload: increasing instrumental support and making trade-offs. These strategies were reported to be used only occasionally at work; however, they were often used in relation to household management and leisure. Many people reported that they were unable to sustain involvement in all roles and reported role loss in their personal lives, especially in socialising and leisure. The authors argue that personal life role loss could be a potential early warning indicator of later employment difficulties (Gignac *et al.*, 2012).

Gavfels *et al.* (2012) found that being affected by rheumatoid arthritis at a young age was associated with psychosocial problems. The authors surmised that younger people were more likely to have children living at home, and that the effects of

arthritis would make the economic pressures on the family greater. In addition, they also found that those having psychosocial problems were also less often living with a partner. The authors concluded that social support can be used predictor of depression and anxiety, with high social support likely to buffer distress in early rheumatoid arthritis (Gafvels *et al.*, 2012).

Yen *et al.* (2011) used survey data collected from 4574 members (response rate of 45.7%) of National Seniors Australia (NSA) to explore the support needs of people with chronic illness, including arthritis, in terms of assistance with household tasks and personal care. The results suggested that people with chronic illness had a greater need for assistance in their day to day life, with five times as many requiring help with shopping and ten times as many requiring help with housework. The study found that the majority of this assistance was provided by partners. Hence, the authors argue that partners themselves need to be adequately supported to carry out this care giving role (Yen *et al.*, 2011).

3.6 Participation

Participation, in social inclusion terms, includes connecting with people, using local services, and participating in local, cultural, civic and recreational activities (Australian Government, 2012). For most people, engaging and connecting with people is part of everyday life and requires little effort. However, for some people engaging and connecting with people can be a massive achievement due to the physical, financial and social barriers that must be overcome.

Geuskens *et al.* (2007) conducted a review of current literature to investigate performance in social role for people with rheumatoid arthritis. The review identified employment as the most frequently studied social role in outcome and intervention studies, followed by socialising (a subset of leisure). Other domains, including domestic life, and interpersonal interactions and relationships, were found to be seldom studied. The authors argue that further studies are required to gain insight into which social roles are of most interest during different stages of life for people with rheumatoid arthritis, and how these social roles can be measured (Geuskens *et al.*, 2007).

Martin *et al.* (2011) conducted a study aimed at providing formative understanding of the use of community resources by adults with osteoarthritis. The authors argued that while previous research has provided information regarding the use of community resources by the general older population, little is known about which specific community resources are used for osteoarthritis self-management. Participants identified: medical providers, religious organisations and social networks as important for medically managing their osteoarthritis; community aquatic centres, senior centres, shopping centres and recreational facilities as resources for physical activity and behavioural management of osteoarthritis; and social networks as an important resource for emotional management of

osteoarthritis. Participants also identified environmental characteristics that either facilitated or hindered their use of community resources including lighting, footpaths, surfaces, parking, access to facilities (e.g. shops), distance to recreational facilities, and fees associated with certain activities (e.g. aquatic exercise) (Martin *et al.*, 2012).

4. Conclusions

This literature review focused on policy, programs, support and service models relevant to arthritis and disability within the life domains identified in the UN Convention on the Rights of Persons with Disabilities. It investigated both Australian and international literature for information on the support needs of people with arthritis need to maximise their quality of life and participation. Two gaps that were identified in the literature review process are the impact of arthritis in life areas aside from work (the impact of arthritis on the workforce is well documented) and the impact of juvenile idiopathic arthritis (beyond treatment options) – both warrant further more detailed investigation in the future.

The literature has identified evidence that there may be barriers for people with arthritis to exercise their fundamental human rights. For this reason, each of these themes will be explored in the rest of the research, including the consumer roundtable, interviews and survey. In particular, the research will explore:

- People's experience of accessing quality, appropriate health care (both physical, emotional and psychosocial), from initial diagnosis to ongoing care, and the identification of any barriers and facilitators
- People's experience of accessing and maintaining employment and the identification of any barriers and facilitators
- Access to habilitation and rehabilitation as a facilitator to their life and enjoyment of these human rights
- The implications of people's lived experience of arthritis in terms of being able to attain and maintain adequate standards of living for themselves and for their family
- People's experience of being included and participating in family and society and the identification of any barriers and facilitators.

Appendix B: Summary of roundtable

Introduction

The group met on 3 June 2013 in Sydney, NSW. The group was asked to discuss the lived experience of Arthritis in the context of the core objectives of the *UN Convention on the Rights of Persons with Disabilities* (the Convention), particularly health, habilitation and rehabilitation, work and employment, standard of living and social protection, and participation (social and family). The discussion was facilitated by Rosemary Kayess of SPRC. This report summarises the key points raised during the group discussion. A summary of participants is presented in Table A1 below.

Table A1: Summary of roundtable participants

Demographics of participants (n=13)		
Gender	Female	11
	Male	2
People with arthritis/other	Arthritis	11
	Carer	1
	Educator	1
By state	ACT	1
	NSW	8
	NT	0
	QLD	1
	SA	1
	TAS	1
	VIC	0
	WA	1
People identifying as CALD or ATSI	CALD	1
	ATSI	0
Condition (may have one or more)	RA	7
	JIA	2
	PA	1
	OA	2
	Ankylosing spondylitis	1
	Sjögren's syndrome	1
	Fibromyalgia	1
	SLE	1

Notes:
CALD – Culturally and Linguistically Diverse, ATSI – Aboriginal and Torres Strait Islander
RA – rheumatoid arthritis, JIA – juvenile idiopathic arthritis, PA – psoriatic arthritis, OA – osteoarthritis, SLE - systemic lupus erythematosus

General comments on research

- The label of 'arthritis' is not working, the term is misunderstood by health practitioners and society perceives it as an older person's disease'. This has impacts across all of the life domains.
- Need to improve the understanding of arthritis for medical practitioners, employers and the general public.

Health

- Diagnosis – benefits from early diagnosis, but as the disease is not well understood, diagnosis can be made late or incorrectly
- Affects the whole body – not necessarily localised to joints, muscles and tendons, but also impacts on levels of fatigue, lungs, eyes, adrenals, etc. Requires allied health care and has impacts on other health care and treatment
- Care and treatment – hidden symptoms, with new medications, symptoms are less visible – can't see pain and requires person to vocalise symptoms
- Management – it is an unpredictable disease, symptoms vary person to person, day to day – don't know why flare ups happen
- Mental and emotional health – takes time to accept disease (because of stigma) and needs support through the adjustment process (pressure on family)
- Perception of the disease – people see it as an 'older person's disease' which can make people downplay their condition and lead to difficulties mentally/emotionally
- Not recognised as a disability – should be: people at the meeting were comfortable with that label now but may have been uncomfortable at the time of diagnosis

Potential solutions

- Educate health professionals – clinical education
- Provide whole patient care – mental health support should be provided on diagnosis and ongoing support should be provided
- Consider impact of arthritis on other areas of health, e.g. pregnancy
- Encourage prevention through education
- Education to lead to earlier diagnosis and better management
- Better support through transition through life stages
- Better peer support and promotion of peer support and support groups – has helped already
- Promoting support groups and other resources – thinking about form, type and timing of resources
- Perhaps put onus on Arthritis Australia to contact people newly diagnosed?
- Not just diagnosis, need management plan (diet, medication, pain control, managing fatigue etc.)
- Empower people to take control of their care
- More financial support for medical care and encourage allied health and proactive health care

Other issues

- More assistance for co-morbidities, such as diabetes
- Quantify costs of not providing services, pension vs working
- Costs associated with arthritis aren't clear

- Not enough quantitative data to support legislative or policy arguments – but so broad, how do you identify all of them?

Work

- How to explain to employer that you can't come to work all of the time
- Sometimes people are in the wrong type of employment so need to retrain or retire
- Workplace not supportive, lack of understanding and support and willingness to adjust
- Arthritis undermines your capacity to work and leads to individuals being marginalised
- Not recognised as a disability in the workplace
- Need to be realistic about what you can manage, and difficult to make that choice
- Hard to come to terms with restrictions on employment
- Need resources available to support people working with a disability
- Employer should ask what you need, rather than require each person to fight for basic needs
- Lack of understanding and basic awareness (Article 8 of the Convention)
- Self-employment prevalent; flexibility allows time to recover when needed

Community

- Participating in community is limited by fatigue
- Eventually friends stop asking you out and you become socially isolated
- Need to socialise with supportive people
- Arthritis affects every aspect of life and every decision – removes any spontaneity and people end up over-planning everything and making calculated decisions at every step
- Support services have let people down – lack of basic social services have led to one person becoming homeless in one example
- People had received verbal abuse for the use of a disability parking permit as their disability was not visible – to the point that some limped to avoid abuse: should not have to justify disability to the community

Standard of living

- Reduced earning potential, increased medical costs, less disposable income, lower standard of living to life before/without arthritis
- Choices to be made about whether to employ a cleaner vs other basic expenditure
- Need to ensure long-term financial planning
- Can't get income protection or life insurance
- Have to exhaust all savings before Centrelink will assist
- If more pain medication required, cut back on food/socialising

Family/home life

- Puts pressure on partner to earn more/compensate for loss of earnings
- Children are asked to assist or provide support where they would not otherwise
- Dynamics of family change, less spontaneous, less disposable income

Appendix C: Summary of interviews

A total of 28 interviews were conducted by telephone with people identified by Arthritis Australia and state and territory arthritis organisations. All interviewees provided consent in writing to participate and were reimbursed for their time. All interviews were transcribed and then analysed against the same themes used in the roundtable.

The interviewees included participants from all States and Territories except the Northern Territory. Only two were from a culturally and linguistically diverse (CALD) background and there was no representation from anyone who identified as being from an Aboriginal and Torres Strait Islander (ATSI) background, despite the literature suggesting that the proportion of Indigenous people with arthritis is higher than non-Indigenous people (Australian Institute of Health and Welfare, 2010). The majority of the participants were female (24). People were interviewed across the age groups, with 46 per cent younger than 44 years old, 36 per cent between 45 and 64 year age group, and 18 per cent 65 years or older. A high proportion of the women in this age group were in a parenting role and/or in paid work. The preponderance of female participants may be due to the way they were identified through Arthritis Australia or their partner organisations, but is also reflective of the higher proportion of women who will experience the effects of arthritis.

Each interview, organised at the convenience of the participants, took between 30 to 60 minutes. A number of interviews went up to 90 minutes and this often reflected the difficulties being experienced by the person or their family because of the effects of their arthritis. Each participant was invited to send any additional thoughts via email if they remembered something at a later date, and three people took up this opportunity.

The participants reflected their experiences of living with the most common forms of arthritis including rheumatoid arthritis, ankylosing spondylitis, juvenile idiopathic arthritis, psoriatic arthritis, osteoarthritis, scleroderma, Sjögren's syndrome and spondyloarthropathy. Two people were managing additional health issues over and above their arthritis, and three participants were using a wheelchair as a result of the effects of their arthritis. One person appeared to be relatively unaffected by her arthritis, while a second person experienced greater problems as a result of a disability which was additional to his arthritis.

The main themes emerging from the interviews include the significance of informal support, limited knowledge about and difficulties accessing formal support, an apparent low level of public awareness about the nature of arthritis and its effect on individuals, the absence of information at the time of diagnosis, a lack of age appropriate support groups, a lack of co-ordination between different health services, and problems accessing health services in a timely manner. The extracts included in this report illustrate the main findings from the 28 interviews. The

extracts come from interviewees across the demographics identified in Table 2 of the main report, and unless otherwise stated come from people with arthritis.

Informal support: support from a family member appeared to be the main form of support accessed by people with arthritis.

> My partner does most of that – he does the vacuuming and hanging the washing out and anything that's heavy and then, depending on how I am, I do what I can manage and he does the rest (female parent with arthritis).

> The cooking is difficult. My husband [will] go before 6am and gets back after 6 o'clock. I try sometimes to do a slow cooked meal. I get help with preparing that during the day if I do it on the one day that the community care are here and then the other days we hope that my husband can do it or we get take away or something (parent with arthritis).

Only two people were receiving regular support from Home Care[25]:

> I have Home Care, I couldn't manage without Home Care ... they come for 45 minutes, twice a day, seven days a week ... and it costs very little (female retired teacher with arthritis).

Although it was not always an obvious service.

Three people were managing their own packages and the rest were relying on family and friends to assist with personal and domestic assistance.:

Formal support: a number of people were in receipt of a disability support pension (DSP) and their experiences of being able to access this service from Centrelink varied from person to person.

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[25] http://health.gov.au/hacc Commonwealth Home and Community Care provides services that support older people to stay at home and be more independent in the community
HACC ACT http://health.act.gov.au provides support services to assist people live in their own home, prevent premature admission to residential care or carers.
HACC NSW http://www.adhc.nsw.gov.au helps older people and with disability to remain at home and prevent their inappropriate and premature admission to residential care
HACC SA http://www.sa.gov.au provide a comprehensive, coordinated and integrated range of basic maintenance and support services for frail older people, people with a disability and their carers
HACC TAS http://www.dhhs.tas.gov.au provides funding for basic community care services that support persons who are under 65 years or Aboriginal and Torres Strait Islander people aged less than 50 years of age living with disabling conditions and their carers. Services are targeted towards people who live in the community and whose capacity for independent living is at risk, or who are at risk of premature or inappropriate admission to long term residential care.
HACC VIC http://www.health.vic.gov.au funds services that support frail aged people, younger people with disabilities, and carers.
HACC WA http://www.health.wa.gov.au provides basic support services to some older people, people with a disability and their carers to assist them to continue living independently at home.

> Being on the DSP made it easier to get my public housing (female with arthritis of working age now on disability support pension).

> It would be good if the government would not just think of means testing everything ... it makes it awkward for people when someone's on a better of wage. They've actually knocked my DSP down eleven and a half thousand three years ago, they're not only making it harder now for people to join it but they also knocked the threshold down (male with arthritis of working age now on disability support pension).

> Originally I tried to get the Austudy because I didn't even know I could go on the pension. … They just wouldn't give Austudy at all. I was in shock. And I went to the CRS[26] which try to help you get jobs and that and they couldn't even help me get a form of studying. They said why don't you try disability … a lot of the people aren't entitled to it depending on how severe your arthritis is (female with arthritis recently returned to study).

> Had I known I could claim this [DSP], I probably would have claimed it from the moment I stopped working ... But the government doesn't tell you these things are out there until you ask (female parent with arthritis).

The associated entitlement to a health care support card was of great benefit, particularly due to the high cost of medication and pain relief.

> It's a very expensive illness. You've got nothing to cover it, nothing – out of pocket expenses you're not covered, your specialists aren't covered, you either pay over and above for the GP, you have got to pay for the medication, it's a very expensive illness (female business owner and parent with arthritis).

However, for people who were married or in a cohabiting relationship the problem came when their spouse or partner increased their earnings to try and make up for any shortfall in their income due to their reduced capacity to work. This then took them above the income threshold for a disability support pension, but most difficult was the loss of their Health Care Card and the financial assistance with health care costs, e.g. for prescriptions.

> I have had conversations with the people from Centrelink and they've actually said we'd possibly be better financially if my husband quit his job and we became totally dependent on the government. … but it still wouldn't actually add up for me because I need so many surgeries and

[26] CRS Commonwealth Rehabilitation Services

> joint replacements and going on waiting lists for things when you're [young] they don't see it as a high priority (parent with arthritis).

> Two years ago my wife got a pay raise and that put me over the limit or put her over the limit-- and I lost my health care concession card. … I was only getting a small pension because of my wife's wages.... [my medicine is] $36.10 [per script] (male with arthritis of working age now on disability support pension).

> I'm fortunate in one way, because I'm legally blind I'm entitled to get a pension and the blind pension is not means tested, so I get a Health Care Card, which is really good because I've got a friend in Melbourne who doesn't have one because her husband works and she pays for all her medication, I've got [another] friend who has chosen not to live with her partner so she can continue to get the pension (female professional with arthritis).

> When the spouse's income goes up and then suddenly not only do you lose the disability support but you lose all the other entitlements. It's mainly the health care card, you know. That is the biggest killer of the lot, you know. You've got to start paying -- the big money for these tablets and all that you're on. And you know, I've got no option but to be on them (male with arthritis of working age now on disability support pension).

Many participants complained about the lack of equity when paying for medicines to counter the side effects of their arthritis treatments, which are not available on the Pharmaceutical Benefits Scheme (PBS) for people with arthritis but are available on the PBS for people with cancer receiving the same medication.

> I was originally on a disability pension, but they cancelled that in 2010 because my husband's income went up ... At one point I was on anti-nausea medication because the methotrexate makes me sick 24/7, but it was costing us $200 a week. ...the anti-emetic drug is covered by PBS for treatment if you're having methotrexate for the treatment of cancer but not for the treatment of rheumatoid arthritis. Same drugs, same side effects but they won't cover it. (female business owner and parent with arthritis).

A number of participants had been offered a Medicare-subsidised chronic disease management plan (formerly the Enhanced Primary Care plan) by their GP. Under these care plans, eligible people have access to five subsidised allied health visits each year for services such as physiotherapy, podiatry, counselling, etc., but others were unaware of their eligibility and were trying to meet the costs of ancillary services themselves. However, those with care plans felt that the number of subsidised visits available was inadequate.

> I have just gone and got one so I can get three visits for a podiatrist and a couple of physios. … It's five in total. But if you want to see a podiatrist, for example, and a physio, you split the five between them. If I could have five physio visits and five podiatry visits then that might be a bit more worthwhile. (female business owner and parent with arthritis).

The variable and episodic nature of many types of arthritis, which may feature sudden and unpredictable flares, during which the symptoms of the condition worsen substantially, also creates problems when accessing and using disability supports. Some participants indicated they would like to have applied for a parking permit for use when experiencing a flare-up (an acute activity or relapse in the condition) of their condition, but because of the variability or contrast in their condition when in remission they had been reluctant to do so. This was also related to the difficulties they experienced by having what some participants saw as a 'silent disability' and the public reaction to them because their disability was not always visible.

> When I have in the past used my disability parking pass I have copped written and verbal abuse, especially when getting my daughter out of her car seat and into the pram (survey)

Public awareness: the majority of participants talked about the need for greater public awareness of the condition and the fact that people commonly assume arthritis is related to old age and wear and tear on the joints as part of the ageing process and as a result dismissed the real impact of the condition. They felt there was a significant need for an awareness raising campaign to shift some of the preconceived notions of what it means to live with arthritis. A number of people indicated the need for a high profile figure to increase the chances of making a significant impact and the McGrath Foundation was cited as a good example of how a public figure could increase awareness of a health condition.

> We're trying to provide more understanding of what arthritis is ... people believe arthritis is an old people's disease, but it's very much a silent disease. Because you can look at somebody and not know that they actually have it ... it's also more difficult because it's not being treated properly (female business owner and parent with arthritis).

Information dissemination: One of the most striking findings to come from the majority of the interviewees was their reporting of the paucity of information available to people who had just been diagnosed, and participants indicated almost unanimously about the lack of information available from their GP and their rheumatologist when they learned of their condition. Many people sought information by looking on the internet but the majority would have liked someone to have provided them with an information pack up front which they could take home and discuss with their family and then discuss with others at a later date.

> What surprised me is when I went to the rheumatologist, he had nothing, no leaflet, nothing was given to me … [for] people being newly diagnosed it would be so fantastic for them to have information from Arthritis Association [sic] (female working part-time).

> There's no consistent information so we developed an information kit because we were spending vast amounts of time trying to find out what resources there are and what the prognosis was (working parents of child with arthritis[27]).

Support groups: many of the younger participants indicated they had used the internet to find age appropriate support groups and a number of participants were using international sites.

> You have to find the ways you can get by – to me talking to a psychiatrist or a clinical psychologist doesn't work because basically they're mirroring back to you what you've just said to them. So I just don't see the point, other than to speak to other parents. We're on several different secret Facebook groups, there's no judgment because all the parents know exactly what you're going through… and, you could be there for someone else is going through that sort of thing. I'm friends with people in the US, in France, in England on these Facebook pages and, you know, we all have this in common that we have these sick kids (working parents of child with arthritis).

Some people had completed the 6-week self-management course on rheumatoid arthritis run by their local arthritis organisation and found it very helpful:

> I also found out that they had a course called ‘Healthy Living’, or ‘Living with Long-Term Chronic Pain and Self-Management’. That was a six week course. It was fantastic. Because we didn’t all just have rheumatoid arthritis, I learned so much more, I was feeling more in control and the more I learned the better it seemed to get (female retiree with arthritis).

However, because of the lack of contacts of a similar age, or work and family commitments, they had drifted away from the people they had met while taking the course. Online support groups, including Facebook, seem to offer an opportunity to look at other ways of engaging younger people experiencing the effects of living with arthritis.

[27] Joint interview

> A lot of support groups are online. I belong to a couple of them. The new ones which have started – they are online but then they meet up in the area (female business owner and parent with arthritis).

Co-ordination of health services: families with children with juvenile idiopathic arthritis (JIA) are finding it particularly difficult to negotiate the health services in a way which provides a positive outcome for their child. One of the issues they raised in the interviews is the lack of co-ordination between services. One family talked about driving to the hospital one day to see the paediatrician or the rheumatologist, and then having to return on another day to see the physiotherapist or the occupational therapist, rather than having a co-ordinated series of visits.

> We've had to make a lot of connections with allied health ourselves. We've had to get our own hydrotherapy because we just pushed for it and then we couldn't afford the time to take him the number of times he really needed to go. Information is important, but everything is institutional or business based, so as a result you have appointments but there's no orchestration of them, and, because they can be incredibly expensive, you've got to space them out rather than have a series of appointments together (working parents of child with arthritis).

Access to health services: many people talked about the problems of being able to access their specialist in a timely manner and having to wait weeks or months before they can be seen. Two of the interviewees actually ended up in the emergency department as it was the only way to access their specialist.

> We couldn't get in touch with the rheumatologist here. Eventually we did get in contact with the rheumatologist who basically said she didn't know what to do … so then we contacted the paediatric rheumatologist and by the time he managed to reply he said it was too late to do anything (working parents of child with arthritis).

In another state a participant indicated:

> It's still hard for them to get me an appointment even here in [State capital]. I can't get into a GP it takes you two weeks or three weeks to get into a GP [but] I might not be sick in three weeks. …I explained that I was a managed patient. What I needed was a specialist to be able to provide me with my medication because I can't get it except for seeing a specialist. I just could not believe I could not get in as a managed patient to see a specialist – it took six weeks (female business owner and parent with arthritis).

Appendix D: Online survey

1. Are you living in Australia? Yes/No (if no – thank you for your interest in the survey)

2. Do you have arthritis or a related chronic musculoskeletal pain (from now on referred to as arthritis)? Yes/No (if yes – go to question 4, if no (for example you are a carer – go to question 3)

3. Do you care for someone with arthritis or chronic musculoskeletal pain? Yes/No (if yes go to question **?**, if no – thank you for your interest in this survey)

Section A: The impact of arthritis

This is the most important part of the survey and we appreciate you taking the time to answer this section in detail.

This is the most important part of the survey and we appreciate you taking the time to answer this section in detail.

We want to learn about what changes you have made to your life because of your arthritis. This can include any effects on your day to day activities, your family and friends, your work or study, your finances, your home, your feelings, your goals and aspirations, and your general approach to life.

4. What are the main changes in your life due to having arthritis?

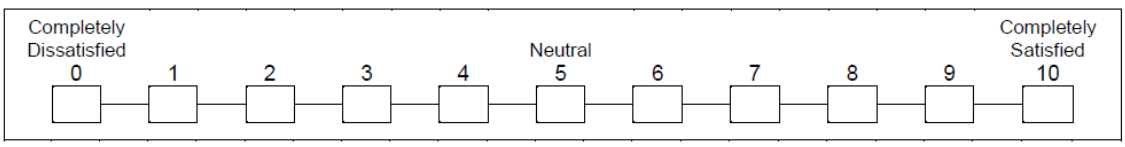
5. What have you done that has successfully managed or reduced the impact of your arthritis? Think about something you achieved, think about what you did, what you were feeling, what made it great. Feel free to use more than one example.

6. Thinking about future goals, what support or services could help you achieve your goals and help you in your day to day life?

Section B: Your wellbeing

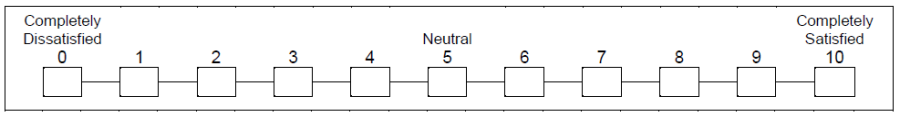
These questions come from a standard well respected survey. This will allow us to compare your results to the general population to see how your wellbeing is affected by your arthritis. For this reason, please answer every part of this question.

7. Thinking about your own life circumstances, how satisfied are you with <u>your life as a whole</u>?

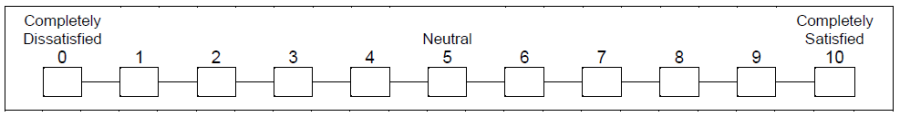


8. How satisfied are you with:

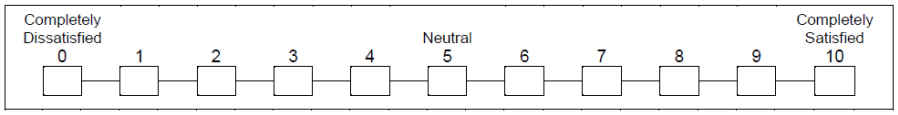
Your standard of living?



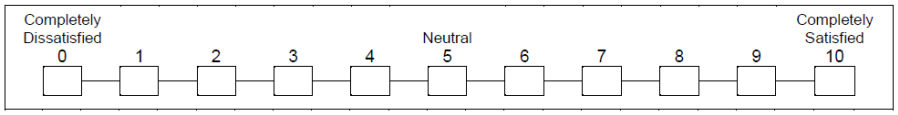
Your health?



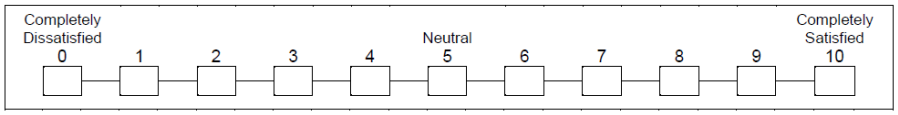
What you are achieving in life?



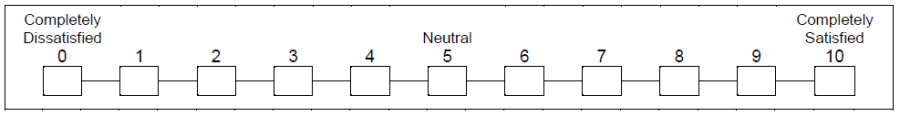
Your personal relationships ?



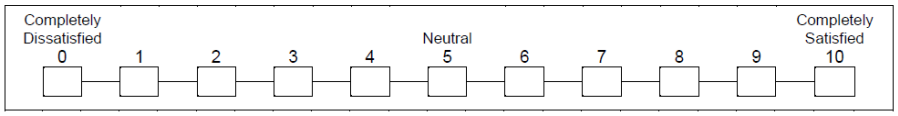
How safe you feel?



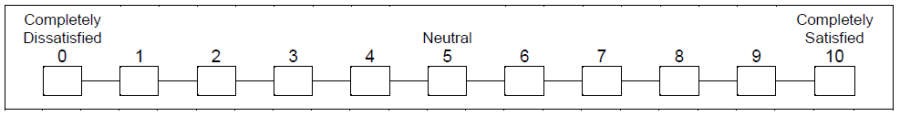
Feeling part of your community?



Your future community?



Your spirituality or religion?



Section C: Your arthritis

This section focuses on your arthritis.

9. What type of arthritis do you have? Please select from the list below and tick all which apply

- rheumatoid arthritis (RA)
- juvenile idiopathic arthritis (JIA)
- osteoarthritis (OA)
- psoriatic arthritis
- Sjögren's syndrome
- ankylosing spondylitis
- spondyloarthropathy
- fibromyalgia
- systemic lupus erythematosus (SLE)
- other form of arthritis or musculoskeletal disorders (specify)

10. In what year did you first start experiencing the symptoms of your arthritis? (four figure box)

11. In what year was your arthritis formally diagnosed and treatment started? (four figure box)

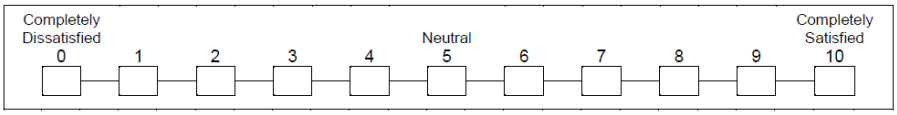
12. Do you have any other health conditions or disabilities that affect you achieving your goals? [yes / no – if yes, please specify]

13. What impact does your arthritis have on your ability to manage these other conditions or disabilities?

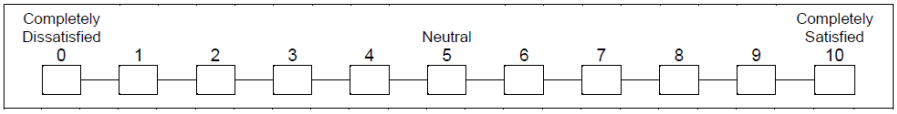
This question is about the information and support available to you for your emotional and physical wellbeing when you first knew you have arthritis.

14. How satisfied were you with:

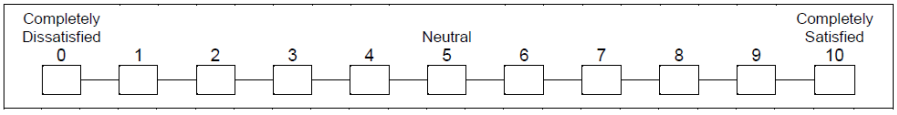
(a)The quality of information provided to you about your condition and how to manage it?



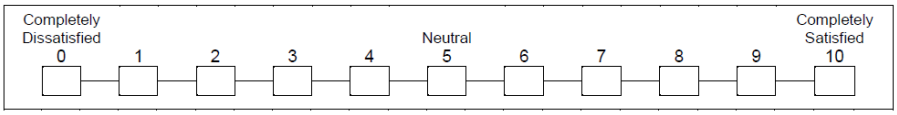
(b) The quality of information provided to you about on-going health and community care services?



(c) The quality of support provided for your emotional and mental well-being?



(d) The quality of support provided for your physical well-being?



15. Please note any information or advice that would have been of use to you when you first knew you have arthritis that you didn't receive at the time.

Section D: Your daily life

This question is about the effects your arthritis has on your capacity to undertake daily living activities. We realise this may vary from day to day but please answer in a way which reflects your more difficult days.

16. Do the effects of your arthritis (e.g. pain, stiff joints, fatigue) limit your ability to undertake daily activities?

- Yes, always
- Yes, sometimes
- No, never (skip to next question)

a. If you have answered always or sometimes, please look at the table below. Thinking about daily activities, and using the scale mild-moderate-severe-profound and not applicable, tick the box which most resembles your ability to manage these activities, where:

- Mild = I **rarely** require assistance to carry out activities
- Moderate -= I **sometimes** require assistance to carry out **some** activities
- Severe = I **always** require assistance to carry out **most** activities
- Profound = I **always** require assistance to carry out **all** activities
- Not Applicable = I **never** require assistance to carry out these activities

	Mild	**Moderate**	**Severe**	**Profound**	**N/A**
Undertaking your personal care activities e.g. showering, dressing					
Undertaking your domestic activities e.g. vacuuming, laundry, cooking					
Managing your home and garden					
Your indoor mobility					
Your outdoor mobility					
Driving your own vehicle					
Accessing and using public transport					
Participating in community activities					
Enjoying leisure activities					

In the following questions we would like to know what impact your arthritis has had on your ability to work or study

17. Are you:

a.

- Employed – full-time?
- Employed – part-time?
- Looking for work
- Retired
- None of the above

b.

- Studying – full-time
- Studying – part-time
- None of the above

c.

- volunteering? (y/n)

18. Has your arthritis affect your work or study, now or in the past?
Yes
No
Not applicable
If no /not applicable go to question 19

19. In relation to your work or study, now or in the past, does (or did) your arthritis: (pick all that apply)

a. restrict the type of work or study you do
b. restrict the number of hours you can work or study
c. make it more difficult to change your work or study
d. make you take at least 1 day a week off work or study (when the arthritis flares)
e. mean that you need ongoing assistance at your place of work or study
f. mean that you need adjustments or modifications or additional special equipment in your place of work or study
g. mean that you have had to change the type of work or study you do
h. permanently prevent you from working or studying
i. mean that your partner or a family member had to change their work arrangements to help support you
j. other (please describe)

20. Have you needed to make any modifications to your home or car because of your arthritis (y/n)
If yes please specify

21. What impact has arthritis had on your finances?

Little or no effect
Slightly worse off, I can manage at the moment
Moderately worse off, I struggle to meet expenses
Much worse off, I need financial support

22. What costs have had the greatest impact on your financial situation?

a. Medical care
b. Medication costs
c. Aids and equipment
d. Home help and maintenance services
e. Personal care
f. Transport
g. Other (please specify in the box below)

Section E: Your support

Your informal support

*The following questions are about your level of satisfaction with the **support** you have from people who help you achieve your goals. We would like to learn more about what informal support you receive that helps you achieve your goals on a daily basis.*

*When we say **informal support** we mean support from your family, friends and relatives. When we say **support** we mean the emotional and physical aspects of that informal support and any information that may have assisted you.*

23. Who are the most important sources of **informal support** for helping you to achieve your goals? Please select all that apply.

a) Your immediate family
b) Your other relatives
c) Your neighbours or friends
d) Local support group
e) Internet support group
f) Other, please specify in the text box below

24. What informal support do they give you? Please select all which apply.

a) Support with personal care
b) Support with domestic activities
c) Support with managing your arthritis
d) Support with access to employment or voluntary work
e) Support with access to educational facilities
f) Support with access to leisure activities
g) Information about services
h) Other (Please specify in the box below)

25. Is there anything that could help or assist **the people who give you informal support** or that may have helped them in the past?

Your formal support

*The following questions are about your level of satisfaction with the **formal support** you have from organisations or paid people who help you to achieve your goals. We would like to learn more about what **formal support** you receive to help you achieve your goals on a daily basis.*

*When we say **formal support** we mean services provided by local, state or federal government services or non-government organisations or paid workers such as health, disability, housing, income support and education.*

*When we say **support** we mean the emotional and physical aspects of that formal support including funding, direct services and information that may have assisted you.*

26. What are the most important sources of formal support you receive for achieving your goals? Please select all that apply.

a) Financial support, e.g. income support, DSP, Health Care Card, insurance

b) General health care, e.g. GP, nurse

c) Specialised health care, e.g. rheumatologist, orthopaedic surgeon

d) Other health care, e.g. physiotherapist, occupational therapist

e) Other community services, e.g. Home and Community Care, Home Modifications, equipment

f) Privately funded home help and maintenance services

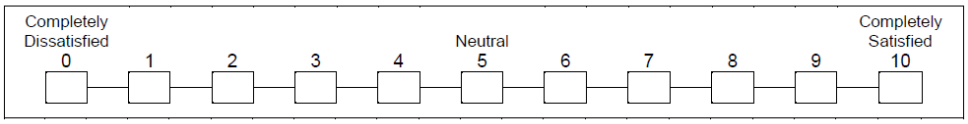
g) Arthritis support organisations, e.g. Arthritis Australia, State or local arthritis organisation

h) Disability Services

i) Other (please specify in the text box below)

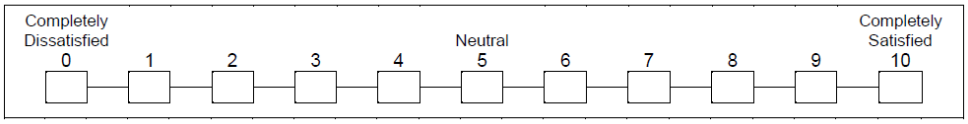
27. Thinking about your daily life, how satisfied are you with your **formal support** for the following areas: Please pick a number between 0 and 10 to indicate how satisfied you are with:

Your financial situation



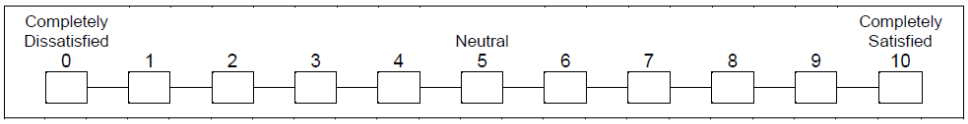
N/A

Your access to paid work



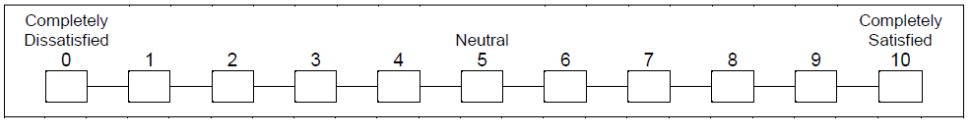
N/A

Your access to voluntary work



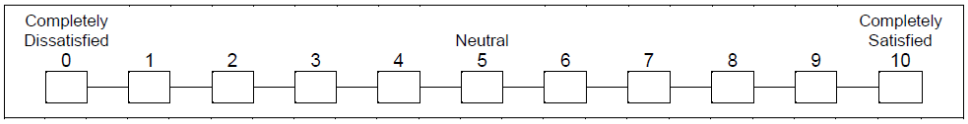
N/A

Your access to education



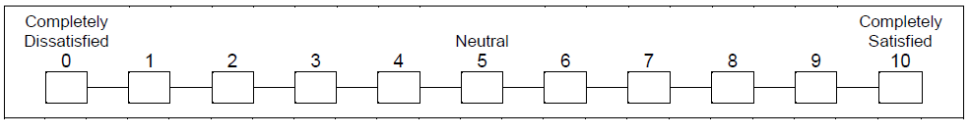
N/A

Your access to health services



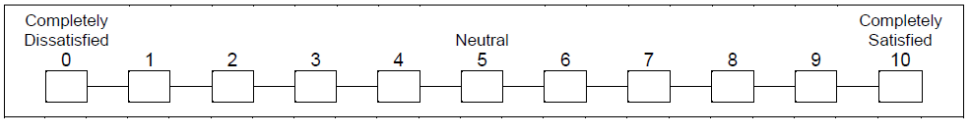
N/A

Your access to community support services



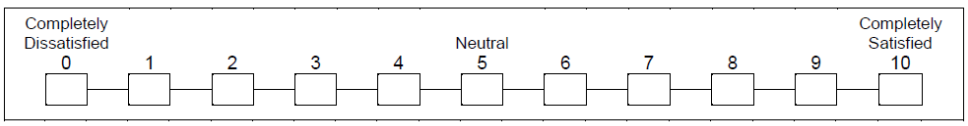
N/A

Your access to services which support your emotional and mental well-being



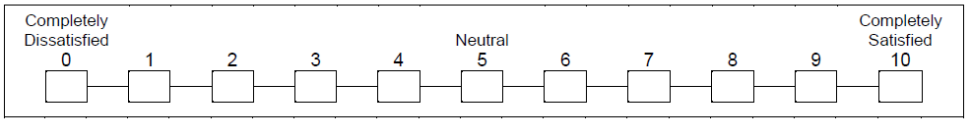
N/A

Your access to medical supplies & daily living equipment



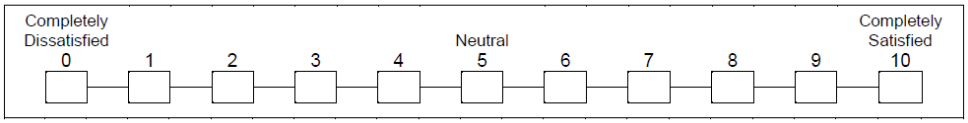
N/A

Your access to suitable housing options



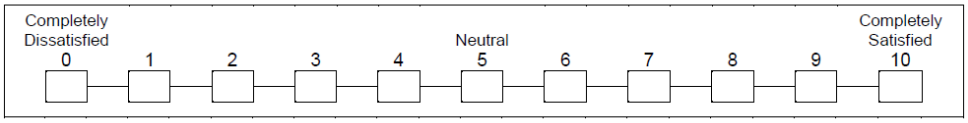
N/A

Your access to accessible transport options



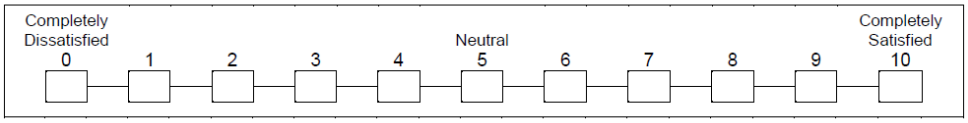
N/A

Your access to public places



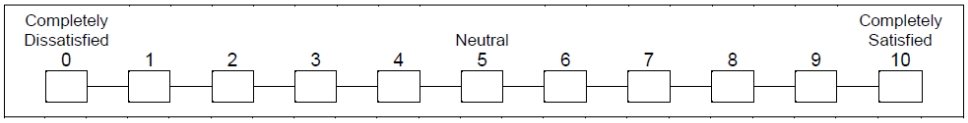
N/A

Your opportunities to engage socially



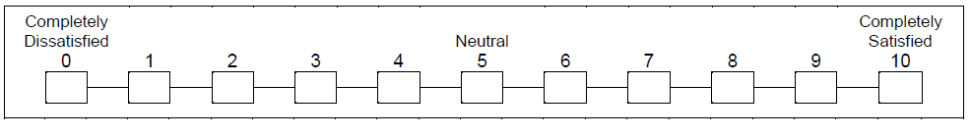
N/A

Your opportunities to participate in your community



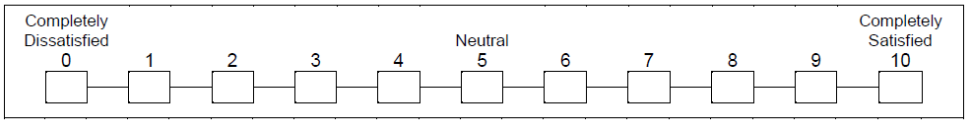
N/A

Your access to someone who can lobby or advocate on your behalf



N/A

Your access to information



N/A

28. Do you have any other comments?

29. Is there other formal support that could help you achieve your goals now or in the future?

Section F: About you

Everyone's circumstances and needs are different. For that reason we would like to know a little more about you that will help us understand the context of your answers.

About you

30. What year were you born (four figure field)

31. What is your gender? (male, female, prefer not to say)

32. Were you born in Australia? (y/n)

33. Do you identify as an Aboriginal or Torres Strait Islander? (y/n)

34. Do you identify as being from a culturally and linguistically diverse background? (y/n)

35. Which of these best describes your current living circumstances? (Please select relevant option)

- Live alone
- Live with spouse/partner
- Live with spouse/partner and children
- Live with children under 18 years only
- Live with parent/s
- Live with other relative or friend
- Live with housemate
- Live in residential facility
- other (please specify in the text box below)

36. Which of these BEST describes your main source of income?

a. private income, e.g. job, own business, superannuation, family
b. public support, e.g. disability support pension, aged pension, Austudy, NewStart or other
c. other income support payment, e.g. insurance; or other

37. What is your postcode? 4 digit field

Section G: Conclusion

38. Is there anything that you would like to add, for example any gaps in support or services?

Section H: Your contact details

39. To go into the draw to win a $200 Coles Myer voucher and/or receive a copy of the summary of the research, please enter your email address here:

40. Please let us know if you would be happy to be contacted to provide further information [yes/no]

Appendix E: Overview of arthritis types

The following descriptors of the main conditions have been have been developed from the information sheets available on the website of www.arthritisaustralia.com.au and www.arthritisresearchuk.org. These sheets are available from both organisations for the benefit of people with arthritis, their families and advocates.

Rheumatoid arthritis

Rheumatoid arthritis is the second most common form of arthritis in the Australia and in 2010 was estimated to affect around 428,000 people in Australia[28]. It can affect adults at any age, but most commonly starts between the ages of 40 and 50 and about three times as many women as men are affected.

Rheumatoid arthritis is the severest form of arthritis[29] and is an autoimmune disease in which the immune system attacks the body's own tissues, causing inflammation in the synovium (the inner layer of the joint capsule which produces synovial fluid) of joints. The trigger for RA is currently unknown but there is some evidence that lifestyle factors may affect a person's risk of developing the condition. The result is red, hot, swollen and painful joints. The pain arises from the nerve endings which are irritated by the chemicals produced by the inflammation and the joint capsule being stretched by the swelling in the joint. When the inflammation goes down, the capsule remains stretched and unable to hold the joint in its proper position, making the joint unstable and with a tendency to move into unusual or deformed positions.

Symptoms of rheumatoid arthritis tend to come and go and people will have flare-ups when their symptoms become worse than normal. Common symptoms of rheumatoid arthritis include joint pain and swelling, stiffness, tiredness (fatigue), depression, irritability, anaemia, flu-like symptoms, such as feeling generally ill, feeling hot and sweating. Other less common symptoms include weight loss, inflammation in the eyes, rheumatoid nodules, inflammation of other body parts, for example lungs and blood vessels and the membrane around the heart, but this is rarer.

Rheumatoid arthritis varies from one person to another but it usually starts quite slowly affecting a few joints typically the fingers, wrists or the balls of the feet which become uncomfortable and may swell, often intermittently. People also feel stiff when they wake up in the morning.

For about 1 in 5 of those with rheumatoid arthritis the condition develops very rapidly, with pain and swelling in a lot of joints, severe morning stiffness and great

[28] A snapshot of arthritis in Australia 2010: National Centre for Monitoring Arthritis and Musculoskeletal Conditions (2010) AIHW
[29] ibid

difficulty doing everyday tasks. Research shows that the sooner you start treatment for rheumatoid arthritis, the more effective it's likely to be, so early diagnosis is important.

There is a genetic component which may increase a person's chances of developing rheumatoid arthritis, but genetic factors alone do not cause it and even if family members have RA the severity can be very different from person to person.

Juvenile idiopathic arthritis

There are several different types of juvenile idiopathic arthritis (JIA), some of which are milder than others and the impact and treatment will depend on the type.

Oligoarthritis is the most common type of JIA and affects about two-thirds of children and young people with arthritis and most commonly affects one or both knees. This form of arthritis is often mild and is the most likely to go away and leave little or no damage to the joints. However this type of arthritis has the highest chance of developing chronic anterior uveitis (inflammation of the eye), so children will need regular eye checks with an ophthalmologist. This eye inflammation doesn't cause a red or painful eye but can still cause reduced vision if it isn't treated, which is why regular checks are important.

Polyarthritis JIA is the second most common type of JIA and tends to cause painful swelling in fingers, toes, wrists, ankles, hips, knees, and the neck and jaw. It may come on suddenly or can steadily involve more joints over a period of months. The child may feel unwell and tired and occasionally develop a slight fever. The symptoms may continue into adult life but it can go into remission where all the symptoms disappear. A blood test will show whether a marker called rheumatoid factor is present in the blood.

Extended oligoarthritis presents as oligoarthritis in the first 6 months and then involves other joints (5 or more) after that. This type of JIA can cause damage to the joints and early treatment with drugs like methotrexate can keep this damage to a minimum.

Enthesitis-related JIA is a form of JIA which affects the places where tendons attach to the bone causing inflammation and often affecting the joints of the leg and spine. In contrast to the uveitis seen with the other types of JIA, this type of JIA is associated with a red painful eye – acute uveitis. Those affected may develop stiffness in the neck and lower back in their teens or as a young adult. There may be a family history of ankylosing spondylitis or inflammatory bowel disease because of a particular genetic marker called HLA-B27.

Systemic-onset JIA is the rarest type of JIA with joint pain appearing as part of a general illness involving fever, tiredness, rash, loss of appetite and weight loss. The child will experience enlarged glands in their neck, under their arms and around their groin area. The spleen and liver may appear enlarged, and very occasionally, the

covering of the heart is inflamed (pericarditis). In the first few weeks there may be no sign of swollen joints, and the diagnosis may be uncertain. If a child or young person has clinical features which do not fit neatly into the above groups they are classified as having undifferentiated arthritis.

Psoriatic arthritis

Psoriatic arthritis causes painful inflammation in and around the joints and usually affects people who already have psoriasis. Psoriasis is a skin condition that causes a red, scaly rash, especially on the elbows, knees, back, buttocks and scalp. However, some people develop the arthritic symptoms before the psoriasis, while others will never develop the skin condition.

Psoriasis can affect people of any age, both male and female, but psoriatic arthritis usually only affects adults.

Osteoarthritis

Osteoarthritis is estimated to affect 1.9 million Australians and almost two-thirds of them are female (Arthritis and Osteoporosis Victoria 2013). The prevalence of osteoarthritis rises with age especially after the age of 45 years.[30]

Osteoarthritis is a condition that affects the surfaces within joints which become damaged so the joint doesn't move as smoothly as it should. Although often referred to as "wear and tear" arthritis, osteoarthritis is a disease and not an inevitable part of the ageing process.

When a joint develops osteoarthritis, some of the cartilage covering the ends of the bones gradually roughens and becomes thin and the bone underneath thickens. All the tissues within the joint become more active than normal and the bone at the edge of the joint grows outwards, forming bony spurs called osteophytes. The synovium (the inner layer of the joint capsule which produces synovial fluid) may thicken and make extra fluid causing the joint to swell. The capsule and ligaments which are the tough bands that hold the joint together slowly thicken and contract as if trying to make the joint more stable.

Sometimes the changes inside the joint won't cause pain or problems, but in severe osteoarthritis, the cartilage can become so thin that it doesn't cover the ends of the bones which rub against each other and start to wear away. The loss of cartilage, the wearing of bone and the bony spurs can change the shape of the joint, forcing the bones out of their normal position.

The main symptoms of osteoarthritis are pain which tends to be worse when the joint is moved or at the end of the day. In severe osteoarthritis, pain is felt more often. Stiffness is common after the joints have been resting but usually improves as

[30] A snapshot of arthritis in Australia 2010: National Centre for Monitoring Arthritis and Musculoskeletal Conditions (2010) AIHW

a person moves. The joint may creak or crunch as it moves (crepitus). Joints will also be swollen and the swelling may be hard (caused by osteophytes) or soft (caused by synovial thickening and extra fluid), and the muscles around the joint may look thin or wasted. The joint may not move as freely or as far as normal and sometimes it may give way because the muscles have weakened or the joint has become less stable. Exercises to strengthen the muscles around the joint can help to prevent this.

An individual's symptoms will often vary for no clear reason and some people find that changes in the weather make the pain worse, especially damp weather along with falling atmospheric pressure. Others find the pain varies depending on how active they've been. In more severe cases, the pain might not go away which may stop people sleeping and cause difficulties in their daily activities for example, osteoarthritis of the knee or hip can make it difficult to climb stairs or get up from a chair.

Osteoarthritis usually starts from the late 40s onwards and it is not fully understood why it's more common in older people, but it might be due to the weakening of muscles and the body being less able to heal itself, or the joint slowly wearing out over time. For most joints, especially the knees and hands, osteoarthritis is more common and more severe in women. A major injury or operation on a joint may lead to osteoarthritis in that joint later in life. Normal activity and exercise don't cause osteoarthritis, but doing very hard activities over and over or physically demanding jobs can increase the risk. Being overweight is an important factor in causing osteoarthritis, especially in the knee. It also increases the chances of osteoarthritis becoming worse.

People who experienced a joint injury or joint abnormality may find it can lead to earlier and more severe osteoarthritis than usual, for example Perthes' disease. .

Genetic factors appear to play a part in osteoarthritis of the hand and, to a lesser extent, of the hip and knee.

Ankylosing spondylitis

Ankylosing spondylitis is an inflammatory condition that affects the joints in the spine. As the inflammation settles, calcium is laid down where the ligaments attach to the vertebrae. This makes the back less flexible. Eventually the individual bones of the spine may link up or fuse and this is called ankylosis. Spondylitis simply means inflammation of the spine.

Ankylosing spondylitis (AS) affects 2–3 times as many men as women and it's most likely to start in their 20s or 30s. The genes people inherit may make them more likely to develop AS, but the condition isn't passed on directly. Most people with AS have a gene called HLA-B27, which can be detected by a blood test, but having this

gene doesn't mean they will get AS. Even in families where somebody has AS, a brother or sister may have the HLA-B27 gene and never get the condition

The severity of ankylosing spondylitis varies from person to person and a person's symptoms might be so mild that they almost forget they have the condition, but if they're more serious it can have a significant impact on their quality of life.

Ankylosing spondylitis is a type of arthritis called a 'spondyloarthritis' and is one of a group of conditions that share many of the same symptoms. These conditions include undifferentiated spondyloarthritis, psoriatic arthritis, spondyloarthritis associated with inflammatory bowel disease (or enteropathic arthritis), reactive arthritis, and enthesitis-related juvenile idiopathic arthritis (JIA).

In the early stages, ankylosing spondylitis is likely to cause stiffness, pain in the buttocks and backs of the thighs and the symptoms may first be noticed after a muscle strain, so the condition is often mistaken for common backache. Pain in the neck, shoulders, hips or thighs may follow and some people also have pain, stiffness and swelling in their knees or ankles, or in the smaller joints of their hands and feet. For some people, especially children, the first signs may be in their hip or leg rather than their back. Other possible symptoms include tenderness in the heel bone, making it uncomfortable for them to stand on a hard floor, tenderness at the base of their pelvis making sitting uncomfortable, pain and swelling in a finger or toe, chest pain or a 'strapped-in' feeling if their spine is affected at chest level, which makes it difficult for people to take a deep breath, an inflamed iris (uveitis or iritis), tiredness and anaemia. The condition may also be associated with depression and frustration and bowel problems such as inflammatory bowel disease (IBD) or colitis.

Sjögren's syndrome is a condition that mainly causes a dry mouth and eyes, though it can also cause a range of other symptoms including joint pain and fatigue. There are 2 types of Sjögren's syndrome, primary when it occurs on its own and secondary, when it occurs in association with another disease such as rheumatoid arthritis, lupus or scleroderma.

Women aged between 40 and 60 are most likely to be diagnosed with Sjögren's syndrome. Only about 1 in 10 Sjögren's syndrome patients are men, and the condition only rarely occurs in childhood. While there may be a genetic component to Sjögren's syndrome it's unusual for children to inherit the condition from their mother or father.

The most common symptoms of Sjögren's syndrome are dry eyes and/or mouth and feeling tired and achy. Many people don't have any other symptoms, but the range and severity of symptoms can vary a great deal from person to person. Some people find strong lights can be uncomfortable, while others find their eyes become sticky with mucus. Their mouth may become dry and they may have mouth ulcers, which can sometimes cause a sticky feeling in their mouth or throat. It may be difficult to swallow and their sense of taste may be altered. Their voice may be

hoarse or weak, and some people have a dry cough. Occasionally a very dry mouth can lead to other problems such as fungal infections (e.g. thrush), an unpleasant taste in their mouth and increased dental decay. The salivary glands may also become painful and/or swollen.

Fatigue (extreme tiredness) is one of the most common symptoms, and as a result some people may also feel down or depressed. The joints may be painful and swollen due to inflammation, while some people have a general achy feeling or tenderness at various points around their body. Joint problems are usually less severe than in conditions such as rheumatoid arthritis.

Other parts of the body may also be drier than normal, for example the digestive passage, making it difficult to swallow food; the bowel, causing symptoms similar to irritable bowel syndrome (e.g. abdominal pain), the skin, which may also be itchy or unusually sensitive to strong sunlight and the air passages, making people more sensitive to irritants such as smoke or dust.

Other problems and complications that can sometimes be associated with Sjögren's syndrome include fever, cold, blue fingers or Raynaud's phenomenon, migraine-like headaches, swollen lymph glands in the neck, armpits or groin, problems with weakness or numbness, inflamed blood vessels (known as vasculitis), chest pain (caused by pleurisy) or breathlessness, liver or kidney problems.

Systemic lupus erythematous (SLE)

Systemic lupus erythematous (SLE) often known just as lupus, is an autoimmune disease where the immune system produces antibodies that attack the body's own tissues, causing inflammation.

Lupus is about 9 times as common in women as in men, more common in younger women – only about 1 in 15 cases begin after the age of 50, when it tends to be less severe – more common in women of Chinese, African or Caribbean origin. Lupus can also affect children, usually only over the age of 5, but this is rare. Lupus is not inherited directly from parents, but if there is a close relative with lupus there is an increased risk of developing it. If a person has lupus there's about a 1 in 100 chance of their child developing it

Lupus usually affects the skin and joints, but it may also involve the heart or kidneys, when the effects can be severe. Lupus can affect many different parts of the body and if the heart, brain or kidneys are affected, it can be much more serious, but most people will only have one or a few of the following symptoms: a rash over parts of the body that are exposed to the sun; the fingers changing colour in cold weather, going first very pale, then blue and finally red (this is called Raynaud's phenomenon);groups of mouth ulcers, which may come back repeatedly; Sjögren's syndrome, which affects around 1 in 8 people with lupus and causes a dry mouth and eyes and hair loss. Many people will find that the symptoms come and go.

Joint pain is common, especially in the small joints of the hands and feet. The pain tends to move from joint to joint and is often described as flitting. Lupus doesn't usually cause joints to become permanently damaged or deformed. About 1 in 20 people with lupus develop more severe joint problems. Less than 1 in 20 have hypermobile joints or a form of arthritis called Jaccoud's arthropathy, which can change the shape of the joints. Around 1 in 3 people with lupus have significant inflammation of their kidneys, and kidney damage can sometimes occur. Most people with inflammation can be successfully treated if it's spotted early through regular tests. Other symptoms may include high blood pressure, particularly if the kidneys are involved, a rise in the cholesterol level, anaemia and a reduction in the number of platelets and/or white blood cells (which tend to be more common in children), blood clots in the veins or arteries, usually caused by anti-phospholipid antibodies – some of these autoantibodies can also affect pregnancy, causing an increased risk of miscarriage.

Steroid tablets which are often used to treat lupus, can also cause an increase in blood pressure. Other symptoms may include migraines which affects 1 in 3 people, anxiety or depression, dizziness, memory loss or confusion, seizures (similar to epilepsy) or feelings of paranoia. A small number of people may experience inflammation in the lining tissues around the heart (pericarditis) and lungs (pleurisy), both of which cause breathlessness and sharp chest pains Large amounts of fluid developing in these lining layers, causes severe breathlessness, but this is rare. Other symptoms include narrowing of the blood vessels, leading to an increased risk of angina, heart attacks and strokes, swelling of the lymph glands, abdominal pain, caused by effects on the gut, pancreas, liver or spleen, a painful red eye or changes in your eyesight, an autoimmune disease that affects the thyroid gland, in particular the type which makes the gland underactive (affects fewer than 1 in 10 people), rheumatoid arthritis or inflammation of the muscles (myositis) which is rare.

Fibromyalgia

Fibromyalgia is a fairly common long-term (chronic) condition that causes widespread muscular pain. It's thought that as many as 1 person in every 25 may experience symptoms. More women than men are affected and the condition varies a great deal from one person to another and from day to day. The symptoms of fibromyalgia are often very similar to the symptoms of myalgic encephalomyelitis (ME), or chronic fatigue syndrome.

Fibromyalgia isn't inflammatory or degenerative so it won't cause permanent damage to the muscles, bones or joints. It can have a major impact on the quality of life, but it's not life threatening or progressive. The most common symptoms of fibromyalgia are widespread pain in the muscles, tiredness (fatigue) and sleep disturbance.

The severity of symptoms varies from person to person and from day to day. Many people have flare-ups from time to time when their symptoms become suddenly

worse. Fibromyalgia doesn't usually have any outward signs, so people with the condition may look well even when they are in a lot of pain. As a result, other people may not appreciate the pain and tiredness being experienced.

The pain may affect the whole body, or it may be particularly bad in just a few areas. Some people find that their pain feels worse in very hot, cold or damp weather. People with fibromyalgia often say that the fatigue is the worst aspect of the condition. Less frequent symptoms of fibromyalgia include poor circulation – tingling, numbness or swelling in your hands and feet, headaches, irritability or feeling a bit down, forgetfulness or poor concentration, feeling an urgent need to urinate, especially at night, irritable or uncomfortable bowels (diarrhoea or constipation and abdominal pain).

Fibromyalgia is often difficult to diagnose as the symptoms vary considerably and could have other causes. They can be similar to the symptoms of other conditions, for example an underactive thyroid gland (hypothyroidism). Blood tests are required to rule out other conditions. A diagnosis of fibromyalgia is made if a person has specific tender points in certain areas of their body. These areas can be tender even when they're pressed very gently. While tenderness can occur at individual sites in other conditions, for example tennis elbow, if a person has fibromyalgia they will have tenderness in many different parts of their body – usually 11 or more sites.

The exact causes of fibromyalgia are unknown but research suggests that there's an interaction between physical, mental and psychological factors. Many people with fibromyalgia report that their symptoms started after a viral infection, a physical or mental trauma (like a car accident or bereavement) or following a period of stress and anxiety, for example in a relationship. The pain doesn't have a physical cause but is something to do with the way the brain processes pain. This doesn't mean that the feeling of pain is any less real, but because there's no physical reason, fibromyalgia doesn't cause any permanent damage to the joints.

People with fibromyalgia are more sensitive to physical pressure. This means that what would be a relatively minor knock for most people could be extremely painful for someone with fibromyalgia. It's thought that this increased sensitivity could be related to chemical changes in the pain pathways in the body. Sleep disturbance may also contribute to this increased sensitivity. A number of things may lead to sleep disturbance, such as pain from an injury or another condition such as arthritis, stress at work or strain in personal relationships, depression brought on by illness or unhappy events.

Some people who have fibromyalgia also report being affected by chronic tiredness, headaches, joint pain in various parts of their body, restless leg syndrome, which causes spasms in either one or both legs and a few people report having spasms in the arms as well. Other symptoms include irritable bowel syndrome (IBS) and temporo-mandibular joint disorder (TMJD), which causes problems with the joint connecting the jawbone to their skull, resulting in pain in their jaw and areas nearby.