

# THE VOICE OF ARTHRITIS

A SOCIAL IMPACT  
STUDY OF ARTHRITIS  
IN AUSTRALIA  
2004

# THE VOICE OF ARTHRITIS

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Arthritis Australia would like to thank those people who took the time to complete our questionnaire and for sharing their personal and often intimate experiences. This information gives us a better understanding of how arthritis affects sufferers, their families, their carers and their workplaces.

Along with our State & Territory Affiliates we will be using the research outcomes for reviewing and developing our support services, educational and awareness programs, and advocacy strategies.

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2004



The Leadership Factor is an international research agency which focuses on understanding needs and perceptions of customers and the population generally. The company is at the forefront of this type of research and conducts more than 200 studies for some of the world's leading organisations.

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# 1. EXECUTIVE SUMMARY

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## 1.1 OBJECTIVES OF THE SOCIAL IMPACT STUDY

- To establish and confirm Arthritis Australia's understanding of all aspects of the disease of arthritis and how it impacts on sufferers, their families/carers and their workplaces, enabling Arthritis Australia to prioritise effort and investment in raising awareness of arthritis throughout Australia.
- To help support the economic findings as outlined in the Access Economics Research Paper (March 2001) on "The Prevalence, Cost and Disease Burden of Arthritis in Australia".
- To generate both qualitative and quantitative feedback from sufferers, their families, and the work environment.
- To assist Arthritis Australia in lobbying both government and business for increased research funding and to provide media information that will become the "Voice of Arthritis".

## 1.2 METHODOLOGY AND SAMPLING

The Leadership Factor designed a questionnaire in conjunction with Arthritis Australia using previous research conducted by Arthritis Australia and in-depth interviews with health educators to understand what is most important to those people who have arthritis and are involved with arthritis.

The survey was a paper based self completion questionnaire and was mailed in March 2004 to 3000 people with arthritis by each State Arthritis office from their database.

A response of 1,016 was received prior to the survey close date representing a response rate of 34%, typical of this type of survey. The data provides a high degree of statistical confidence (95% confidence +/- 0.1), which is good, and consistent with major research studies of this type.

## 1.3 SAMPLE DETAILS – AGE AND GENDER

As would be expected and representative of the population with arthritis, the sample was heavily biased to those in the 60+ years age bracket (76% of sample) and females (61% of sample).

Over eighty percent of respondents are either retired or on a pension and own their own home. Only eight percent are in full time employment.

In terms of arthritis type, sixty-eight percent of responses are from people who have osteoarthritis, with twenty-eight percent having rheumatoid arthritis. Of those with osteoarthritis, sixty-six percent are in the chronic stage and forty-seven percent of people with rheumatoid arthritis are in the acute phase.

## 2. SATISFACTION

Respondents were asked to score their satisfaction or dissatisfaction using a five-point verbal scale across a range of measures relating to:

- Medication and therapy
- Information available
- Physical health
- Economic issues
- Education
- Relationships
- Lifestyle
- Work/Employment

### A) BY GENDER

Both male and female respondents recorded the same four issues as those which produced the highest levels of satisfaction which are regarding personal support and issues regarding medication and availability of medical assistance:

- The level of support received from family and carers (82% male - 78% female satisfied)
- The ease of purchasing medication (84% m – 86% f)
- The ease of locating accredited medical and allied health professionals (78% m – 81% f)
- The availability of suitable medications (75% m – 78% f) with 55% very satisfied.

The highest level of dissatisfaction for both males and females was with regard to economic and physical issues.

- Financial impact (49% male - 65% female dissatisfied)
- Your fitness to do the things that you want to do (57% m – 63% f)
- Physical impact on your life (56% m – 60% f)

### B) BY AGE GROUPS

#### Age less than 24 years

Among the youngest age group, the following issues produced the highest levels of satisfaction:

- The level of support received from family and carers (75% satisfied)
- Eating habits (75%)
- Ease of purchasing medication (75%)

The highest levels of dissatisfaction are with a range of issues but all centred around lifestyle changes, physical, career and financial:

- Physical impact on your life (100% dissatisfied)
- Financial impact (100%)
- Employment opportunities (100%)
- Ease of access to public transport (100%)
- Career advancement opportunities (100%)
- Ease of integration into workplace (100%)

\*\*\* (Please note that this age group only had 8 responses) \*\*\*

## 2. SATISFACTION (CONT'D)

### Age between 25 and 44 years

Among the 25 – 44 year age group, the issues which produced the highest levels of satisfaction were:

- Access to information by the internet (77% satisfied)
- Level of support received from family and carers (70%) with 42% very satisfied
- The ease of locating accredited medical and allied health professionals (64%)

The highest level of dissatisfaction is associated with physical and emotional issues.

- Your energy level (79% dissatisfied) with almost 40% being very dissatisfied
- The effect stress and depression may have caused in your personal relationships (78%)
- Your fitness to do the things that you want to do (75%)
- Physical impact on your life (74%)

### Age between 45 to 59 years

Among the 45 to 59 year age group, the issues which produced the highest levels of satisfaction were varied.

- The ease of locating accredited medical and allied health professionals (74%)
- Access to information by the internet (68%)
- The level of support received from family and carers (68%)
- Availability of suitable medications (68%)

The highest level of dissatisfaction was with physical issues.

- Physical impact on your life (74%)
- Your fitness to do things that you want to do (73%)
- Your energy levels (64%)

### Age of 60 years and above

The oldest group of respondents recorded the following issues as those which produced the highest levels of satisfaction. They mostly related to medication and the cost involved.

- The ease of purchasing medication (89% satisfied) with 70% being very satisfied
- The level of support received from family and carers (84%) – 65% very satisfied
- Availability of suitable medications (82%)

The highest level of dissatisfaction was with physical aspects of their lives such as:

- Your fitness to do the things that you want to do (56%)
- Physical impact on your life (53%)
- Your energy levels (45%).

## 2. SATISFACTION (CONT'D)

### C) BY ARTHRITIS TYPE

Amongst those people with osteoarthritis, medical issues and family support produced the greatest levels of satisfaction.

- The ease of purchasing medication (87% - with 66% being very satisfied)
- The ease of locating accredited medical and allied health professionals (81%)
- The level of support received from family and carers (81%)
- The availability of suitable medications (79%)

The highest level of dissatisfaction was based on both physical and financial issues.

- Your fitness to do the things that you want to do (61%)
- Physical impact on your life (59%)
- Financial impact (56% - with 42% very dissatisfied)

People with rheumatoid arthritis were most satisfied with issues related to medication and their medical practitioner.

- The ease of purchasing medication (85% - with 64% very satisfied)
- The ease of locating accredited medical and allied health professionals (81%)
- The availability of suitable medications (78%)
- Ease of getting an appointment with medical and allied professionals (78%)
- Access to relevant information on medication and treatment (77%)

The highest level of dissatisfaction was with both physical and financial matters.

- Your fitness to do the things that you want to do (64%) with 23 % very dissatisfied
- Physical impact on your life (61%)
- Financial impact (55%)
- Energy level (52%)

## 3. THE IMPACT OF ARTHRITIS

Respondents were asked to score the overall impact using a five-point verbal scale across a range of measures relating to:

- Personal Life
- Economic Impact
- Physical Impact
- Impact on Family and Carers
- Social Impact
- Employment/Career

The top issues that respondents classified that had the greatest positive and the greatest negative impact are summarised below.

### A) BY GENDER

The highest level of negative impact for both males and females is with regard to their physical capabilities with day to day life.

- Movement restrictions (83% males and females)
- Exercise restrictions (81% m – 82% f)
- Impact of disability (82% m – 80% f)
- Overall physical impact on your life (81% both)

Both males and females indicated that relationships as well as impact of surgery provided some positive impact

- Your relationship with family (27% m – 30% f)
- Your relationship with friends (23% m – 30% f)
- Impact of surgery (26% m – 35% f)

### B) BY AGE GROUPS

#### Age less than 24 years

Among the youngest age group, the majority of issues scored 100% negative impact due to the small sample size (n=8). It is clear that certainly for younger people, having any form arthritis has a negative impact and for those who responded, it was significantly negative. The following issues produced the highest levels of positive impact. They were:

- Your relationship with your colleagues (50%)
- Relationship with carer (50%)
- Overall impact on your contribution to society (50%)

*(Please note that this age group only had 8 responses)*

#### Age between 25 and 44 years

Among the 25 – 44 year age group, the issues which produced the highest levels of negative impact were based around physical and financial factors:

- Overall physical impact on your life (93%)
- Cost of treatments (90%)
- Movement restrictions (90%)
- Limitations to day to day life (90%)

## 3. THE IMPACT OF ARTHRITIS (CONT'D)

Relationship issues produced the highest level of positive impact across all sectors:

- Your relationship with your family (21%)
- Pain tolerance (21%)
- Your relationship with fellow employees (16%)
- Your relationship with your partner (13%)
- Your relationship with your friends (12%)

### Age between 45 to 59 years

Among the 45 to 59 year age group, the main issues which produced the highest levels of negative impact were only related to physical factors:

- Overall physical impact on your life (93%)
- Exercise restrictions (92%)
- Limitations to day to day life (92%)
- Movement restrictions (91%)

The issues which produced the highest levels of positive impact were once again based around relationships.

- Your relationship with your friends (18%)
- Your relationship with your family (17%)
- Your relationship with your colleagues (16%)

### Age of 60 years and above

The oldest group of respondents recorded that physical limitations were those factors that were having the highest negative impact. The main issues were:

- Movement restrictions (80%)
- Impact of disability (78%)
- Exercise restrictions (78%)
- Overall physical impact on your life (77%)
- Limitations in day to day life (74%)

Relationships were the main factor producing the highest levels of positive impact as well as how required surgery and pain tolerance.

- Impact of surgery required (37%)
- Your relationship with your family (32%)
- Your relationship with your friends (31%)
- Pain tolerance (28%)
- Your relationship with your colleagues (26%)

## 3. THE IMPACT OF ARTHRITIS (CONT'D)

### C) BY ARTHRITIS TYPE

Amongst those people with osteoarthritis, the top issues that produced the highest levels of negative impact were all physically related.

- Movement restrictions (83%)
- Impact of disability (81%)
- Exercise restrictions (80%)
- Overall physical impact on your life (79%)
- Limitations in day to day life (78%)

Surgery and relationships produced the greatest levels of positive impact.

- Impact of surgery required (34%)
- Your relationship with your friends (29%)
- Your relationship with your family (28%)
- Pain tolerance (26%)
- Your relationship with your colleagues (24%)

People with rheumatoid arthritis recorded that physical issues produced the highest levels of negative impact. The main issues were:

- Movement restrictions (84%)
- Overall physical impact on your life (82%)
- Exercise restrictions (82%)
- Impact of disability (79%)
- Limitations in day to day life (78%)

Surgery and relationships were the main factors recorded with the highest positive impact for people with rheumatoid arthritis. They were:

- Your relationship with your friends (30%)
- Your relationship with your family (29%)
- Impact of surgery required (29%)
- Your relationship with your colleagues (27%)

# 1. INTRODUCTION

## 1.1 BACKGROUND INFORMATION

Arthritis Australia is the national body responsible for raising the profile of those people suffering from arthritis and its related diseases. All states and territories have their own independent organisational structures.

Arthritis Australia focusses on raising financial support from both government and business as well as raising the profile of arthritis through the media.

The mission of Arthritis Australia is to improve the quality of life of people by reducing and preventing the effects of arthritis. In accomplishing this aim, Arthritis Australia is clearly focussed on assisting all people in Australia who have arthritis, those who care for these people, as well as people at risk of developing arthritis.

Arthritis is Australia's major cause of disability and chronic pain.

- 60.4% of all people with arthritis are women
- 60% of all people with arthritis are of working age (15-64yrs)
- Arthritis affects approximately 11% of the workforce

Arthritis has a significant economic impact on Australia. The overall financial cost of arthritis to business is around \$9 billion annually. It is responsible for nearly 1.8 million days of reduced activity and about 213,000 days off work or school each year in Australia.

Arthritis has become one of the seven national health priorities alongside cardiovascular health and stroke, cancer control, diabetes, asthma, mental health and injury prevention and control. This will mean greater collaboration between Federal, State and Territory governments and will draw on the expertise of clinical, non-government and consumer groups to address significant areas of health burden, in this case, arthritis.

## 1.2 THE VOICE OF ARTHRITIS PROJECT

Arthritis Australia is focussed on gaining a greater understanding of both the social and economic impacts of arthritis and its related diseases on the Australian community.

This research study was designed and commissioned to explore in greater detail how the effects of arthritis impact;

- The individual afflicted by the disease
- Their family or carer
- Their workplace

The study also explored respondents' level of satisfaction or dissatisfaction across a number of criteria:

- Medication and therapy
- Information available
- Physical health
- Economic issues
- Education
- Relationships
- Lifestyle
- Work/Employment

The study was conducted by The Leadership Factor, an international research agency specialising in this type of work and who has conducted similar studies for the Royal National Institute for the Blind and United Cerebral Palsy.

## 2. OBJECTIVES OF THE SOCIAL IMPACT STUDY

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- To establish and confirm Arthritis Australia's understanding of all aspects of the disease of arthritis and how it impacts on sufferers, their families/carers and their workplaces, enabling Arthritis Australia to prioritise effort and investment in raising awareness of arthritis throughout Australia.
- To help support the economic findings as outlined in the Access Economics Research Paper (Mar 2001) on "The Prevalence, Cost and Disease Burden of Arthritis in Australia".
- To generate both qualitative and quantitative feedback from sufferers, their families and the work environment.
- To assist Arthritis Australia in lobbying both government and business for increased research funding and to provide media information that will become The Voice of Arthritis.

## 3. METHODOLOGY AND SAMPLING

The Leadership Factor designed a questionnaire in conjunction with Arthritis Australia.

Previous research conducted by Arthritis Australia with health educators to understand what is most important to those people who have arthritis and are involved with arthritis, was used as the basis of the questionnaire design. In addition to a review of previous research, five in-depth telephone interviews were conducted with health educators to further qualify requirements and issues most often raised by those who have arthritis.

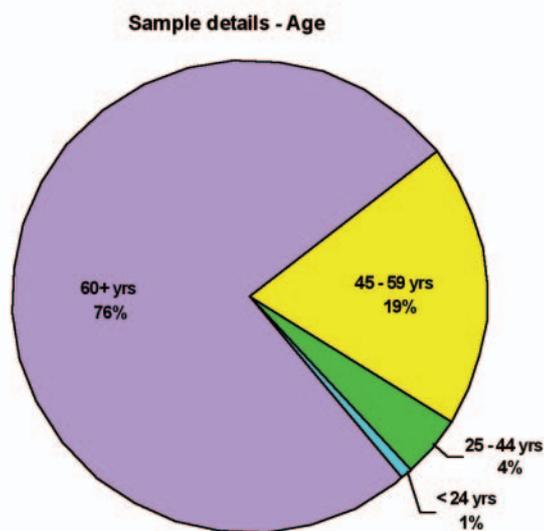
The survey was a paper based self completion questionnaire and was mailed to 3000 people with arthritis by each State Arthritis office using their existing database.

To ensure those respondents who may have had difficulty in filling in a paper based survey, the questionnaire was designed to make it user friendly, by pre-coding as many sections as possible. This allowed those people who have difficulty in filling in a document to only mark a cross where applicable, or alternatively ask a carer to fill in the questionnaire for them.

A response of 1,016 was received prior to the survey close date representing a response rate of 34%, typical of this type of survey. An additional 90 surveys were received after the survey close date and have not been included in this report. The data provides a high degree of statistical confidence (95% confidence +/- 0.1), which is good, and consistent with major research studies of this type.

### 3.1 SAMPLE DETAILS – AGE

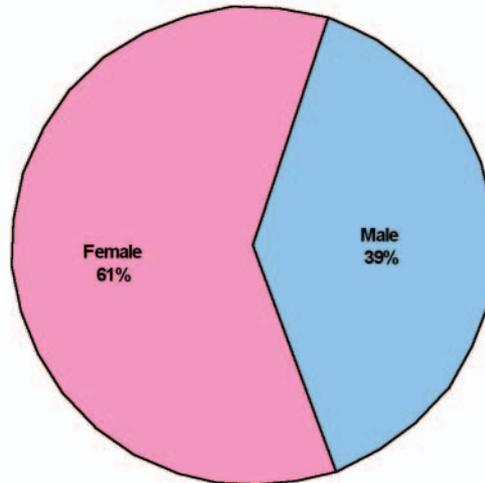
	Base Size	<24 yrs	25 - 44 yrs	45 - 59 yrs	60+ yrs
Total	1014	8 0.8%	44 4.3%	195 19.2%	767 75.6%
By Gender					
Female	615	6 1.0%	33 5.4%	127 20.7%	449 73.0%
Male	399	2 0.5%	11 2.8%	68 17.0%	318 79.7%
By State					
NSW	289	3 1.0%	8 2.8%	57 19.7%	221 76.5%
Qld	191	1 0.5%	8 4.2%	38 19.9%	144 75.4%
Vic	149	2 1.3%	9 6.0%	30 20.1%	108 72.5%
SA	59	0 0.0%	3 5.1%	15 25.4%	41 69.5%
WA	43	0 0.0%	2 4.7%	10 23.3%	31 72.1%
ACT	22	0 0.0%	1 4.5%	4 18.2%	17 77.3%
Tas	20	0 0.0%	2 10.0%	2 10.0%	16 80.0%
NT	4	0 0.0%	1 25.0%	0 0.0%	3 75.0%
By Arthritis Type					
Osteoarthritis	693	1 0.0%	7 1.0%	109 15.7%	576 83.1%
Rheumatoid Arthritis	279	4 1.4%	25 9.0%	62 22.2%	188 67.4%
Other	197	3 1.5%	20 10.2%	65 33.0%	109 55.3%
Don't Know	22	0 0.0%	0 0.0%	3 13.6%	19 86.4%



## 3. METHODOLOGY AND SAMPLING (CONT'D)

### 3.2 SAMPLE DETAILS – GENDER

Sample details - Gender

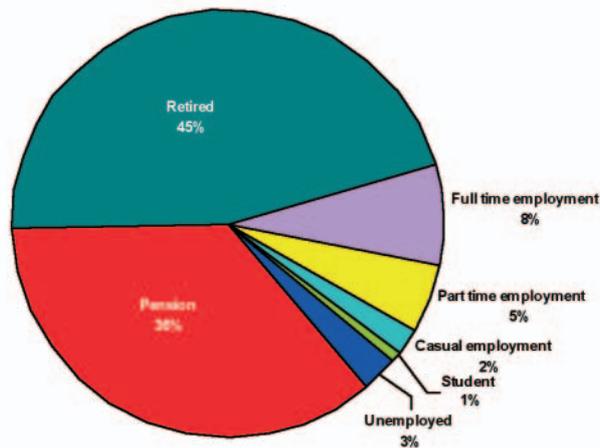


	Base Size	Male	Female
Total	1014	399 39.3%	615 60.7%
By Age			
<24yrs	8	2 25.0%	6 75.0%
25 - 44 yrs	44	11 25.0%	33 75.0%
45 - 59 yrs	195	68 34.9%	127 65.1%
60+ yrs	767	318 41.5%	449 58.5%
By State			
NSW	289	123 42.6%	166 57.4%
Qld	191	81 42.4%	110 57.6%
Vic	149	61 40.9%	88 59.1%
SA	59	20 33.9%	39 66.1%
WA	43	14 32.6%	29 67.4%
ACT	22	12 54.5%	10 45.5%
Tas	20	8 40.0%	12 60.0%
NT	4	0 0.0%	4 100.0%
By Arthritis Type			
Osteoarthritis	693	256 36.9%	437 63.1%
Rheumatoid Arthritis	280	107 38.2%	173 61.8%
Other	197	74 37.6%	123 62.4%
Don't Know	22	12 54.5%	10 44.5%

## 3. METHODOLOGY AND SAMPLING (CONT'D)

### 3.3 SAMPLE DETAILS – EMPLOYMENT STATUS

Sample details - Employment status

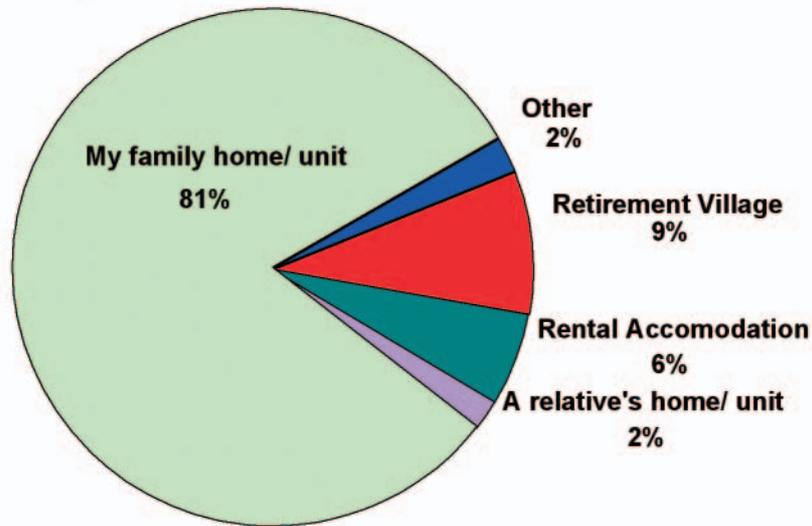


	Base Size	Student	Casual employment	Parttime employment	Full time employment	Retired	Pension	Unemployed
Total	760	7 0.9%	13 1.7%	40 5.3%	60 7.9%	361 47.5%	258 33.9%	21 2.8%
By Age								
< 24 yrs	7	2 28.6%	2 28.6%	1 14.3%	0 0.0%	0 0.0%	2 28.6%	0 0.0%
25 - 44 yrs	42	3 7.1%	3 7.1%	8 19.0%	17 40.5%	0 0.0%	5 11.9%	6 14.3%
45 - 59 yrs	187	0 0.0%	10 5.3%	26 13.9%	39 20.9%	40 21.4%	56 29.9%	16 8.6%
60+ yrs	758	3 0.4%	5 0.7%	16 2.1%	19 2.5%	417 55.0%	291 38.4%	7 0.9%
By Gender								
Male	397	1 0.3%	7 1.8%	17 4.3%	46 11.6%	209 52.6%	110 27.7%	7 1.8%
Female	598	7 1.2%	13 2.2%	34 5.7%	29 4.8%	249 41.6%	244 40.8%	22 3.7%
By State								
NSW	283	1 0.4%	3 1.1%	14 4.9%	26 9.2%	141 49.8%	92 32.5%	6 2.1%
Qld	189	2 1.1%	4 2.1%	6 3.2%	16 8.5%	85 45.0%	70 37.0%	6 3.2%
Vic	142	2 1.4%	5 3.5%	7 4.9%	7 4.9%	69 48.6%	49 34.5%	3 2.1%
SA	59	0 0.0%	0 0.0%	8 13.6%	8 13.6%	25 42.4%	15 25.4%	3 5.1%
WA	42	2 4.8%	0 0.0%	3 7.1%	1 2.4%	18 42.9%	15 35.7%	3 7.1%
ACT	22	0 0.0%	1 4.5%	1 4.5%	1 4.5%	9 40.9%	10 45.5%	0 0.0%
Tas	19	0 0.0%	0 0.0%	1 5.3%	0 0.0%	13 68.4%	5 26.3%	0 0.0%
NT	4	0 0.0%	0 0.0%	0 0.0%	1 25.0%	1 25.0%	2 50.0%	0 0.0%
By Arthritis Type								
Osteoarthritis	680	2 0.3%	7 1.0%	25 3.7%	33 4.9%	345 50.7%	256 37.6%	12 1.8%
Rheumatoid Arthritis	275	3 1.1%	7 2.5%	17 6.2%	26 9.5%	114 41.5%	94 34.2%	14 5.1%
Other	190	5 2.6%	9 4.7%	13 6.8%	19 10.0%	64 33.7%	70 36.8%	10 5.3%
Don't Know	22	0 0.0%	1 4.5%	1 4.5%	1 4.5%	13 59.1%	6 27.3%	0 0.0%

## 3. METHODOLOGY AND SAMPLING (CONT'D)

### 3.4 SAMPLE DETAILS – RESIDENTIAL STATUS

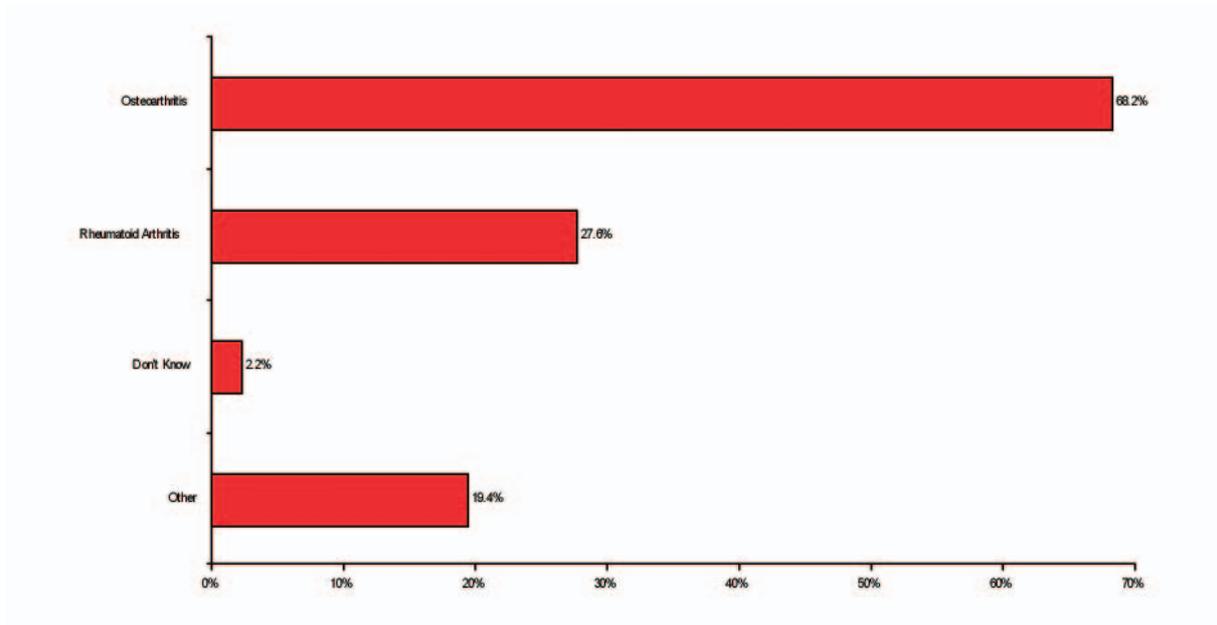
**Sample details - Residential status**



	Base Size	My family home/unit	A relative's home/unit	Rental Accommodation	Retirement Village	Other
<b>Total</b>	989	802 81.10%	18 1.80%	58 5.90%	88 8.90%	22 2.20%
<b>By Age</b>						
< 24 yrs	8	6 75.0%	1 12.5%	1 12.5%	0 0.0%	0 0.0%
25 - 44 yrs	43	34 79.0%	0 0.0%	9 20.9%	0 0.0%	0 0.0%
45 - 59 yrs	191	170 89.0%	4 2.1%	12 6.3%	1 0.5%	4 2.1%
60+ yrs	746	591 79.2%	13 1.7%	36 4.8%	87 11.7%	18 2.4%
<b>By Gender</b>						
Male	392	331 84.4%	9 2.3%	20 5.1%	24 6.1%	7 1.8%
Female	597	471 78.9%	9 1.5%	38 6.4%	64 10.7%	15 2.5%
<b>By State</b>						
NSW	277	227 81.9%	6 2.2%	18 6.5%	22 7.9%	4 1.4%
Qld	188	154 81.9%	4 2.1%	10 5.3%	17 9.0%	3 1.6%
Vic	146	117 80.1%	2 1.4%	10 6.8%	15 10.3%	2 1.4%
SA	57	43 75.4%	0 0.0%	4 7.0%	10 17.5%	0 0.0%
WA	42	35 83.3%	0 0.0%	1 2.4%	2 4.8%	4 9.5%
ACT	22	19 86.4%	1 4.5%	0 0.0%	1 4.5%	0 0.0%
Tas	20	16 80.0%	1 5.0%	1 5.0%	2 10.0%	0 0.0%
NT	4	3 75.0%	0 0.0%	1 25.0%	0 0.0%	0 0.0%
<b>By Arthritis Type</b>						
Osteoarthritis	671	541 80.6%	13 1.9%	36 5.4%	67 10.0%	14 2.1%
Rheumatoid Arthritis	273	214 78.4%	7 2.6%	20 7.3%	21 7.7%	11 4.0%
Other	195	164 84.1%	4 2.1%	13 6.7%	10 5.1%	4 2.1%
Don't Know	21	18 85.7%	0 0.0%	1 4.8%	2 9.5%	0 0.0%

## 3. METHODOLOGY AND SAMPLING (CONT'D)

### 3.5 SAMPLE DETAILS – ARTHRITIS TYPE



	Base Size	Osteoarthritis	Rheumatoid Arthritis	Other	Don't Know
<b>Total</b>	1014	693	280	197	22
<b>By Age</b>					
<24yrs	8 0.8%	1 0.01%	4 1.4%	3 1.5%	0 0.0%
25 - 44 yrs	44 4.3%	7 1.0%	25 8.9%	20 10.2%	0 0.0%
45 - 59 yrs	195 19.2%	109 15.7%	62 22.1%	65 33.0%	3 13.6%
60+ yrs	767 75.6%	576 83.1%	188 67.1%	109 55.3%	19 86.4%
<b>By Gender</b>					
Male	399 39.3%	256 36.9%	107 38.2%	74 37.6%	10 45.5%
Female	616 60.7%	437 63.1%	173 61.8%	123 62.4%	12 55.5%
<b>By State</b>					
NSW	289 28.50%	214 30.90%	72 25.70%	50 25.4%	6 27.3%
Qld	191 18.80%	119 17.20%	58 20.70%	46 23.4%	5 22.7%
Vic	149 14.70%	91 13.10%	45 16.10%	34 17.3%	3 13.6%
SA	59 5.80%	41 5.90%	11 3.90%	8 4.1%	3 13.6%
WA	43 4.20%	25 3.60%	13 4.60%	11 5.6%	1 4.5%
ACT	22 2.20%	15 2.20%	5 1.80%	7 3.6%	0 0.0%
Tas	20 2%	15 2.20%	7 2.50%	5 2.5%	0 0.0%
NT	4 0.40%	3 0.40%	1 0.30%	0 0.0%	0 0.0%

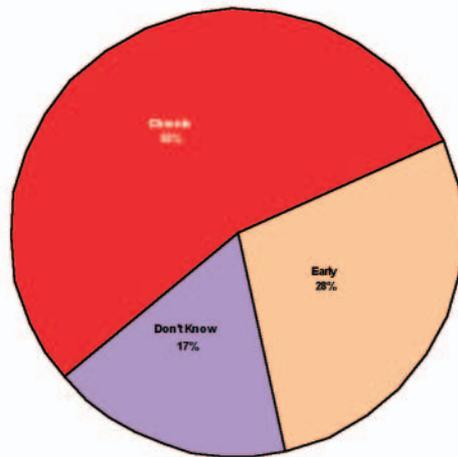
\* - Column percentages

## 3. METHODOLOGY AND SAMPLING (CONT'D)

### 3.6 SAMPLE DETAILS – ARTHRITIS STAGE

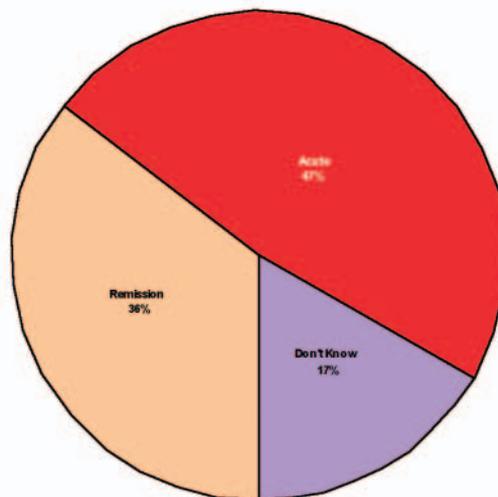
Sample details - Arthritis Stage

*Osteoarthritis Sufferers*



Sample details - Arthritis Stage

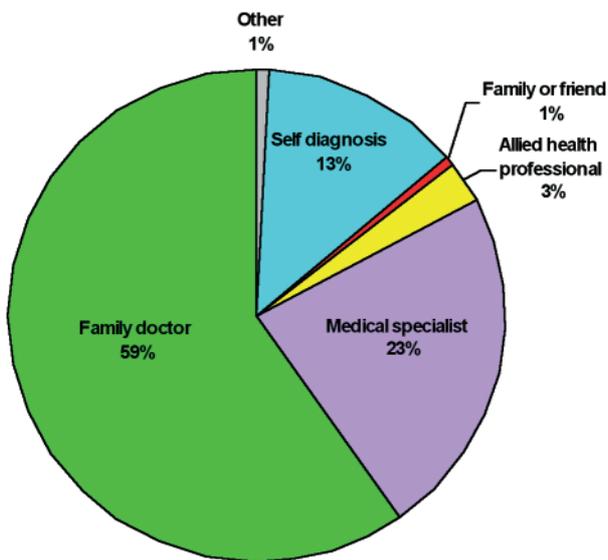
*Rheumatoid Arthritis Sufferers*



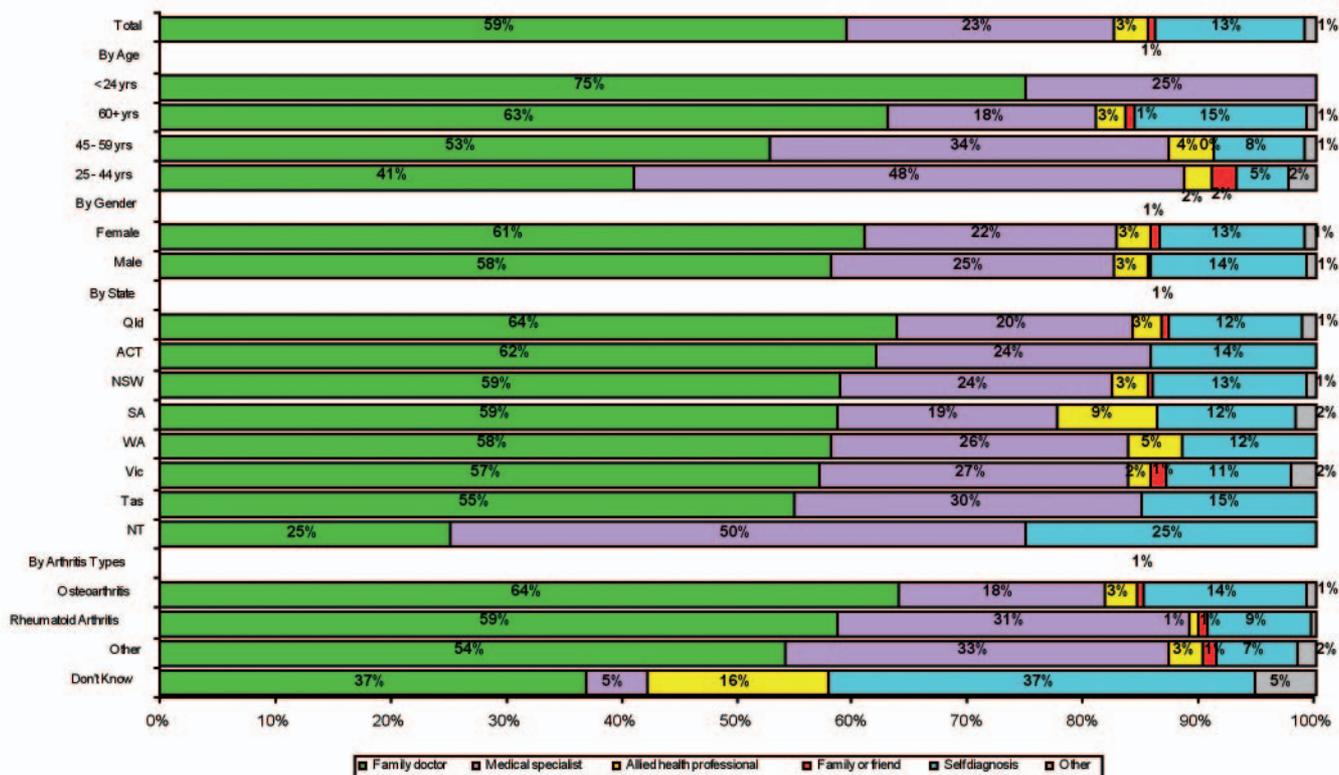
# 4. THE DIAGNOSIS OF ARTHRITIS

## 4.1 HOW DID YOU DISCOVER THAT YOU HAD ARTHRITIS?

How did you first discover you had arthritis?



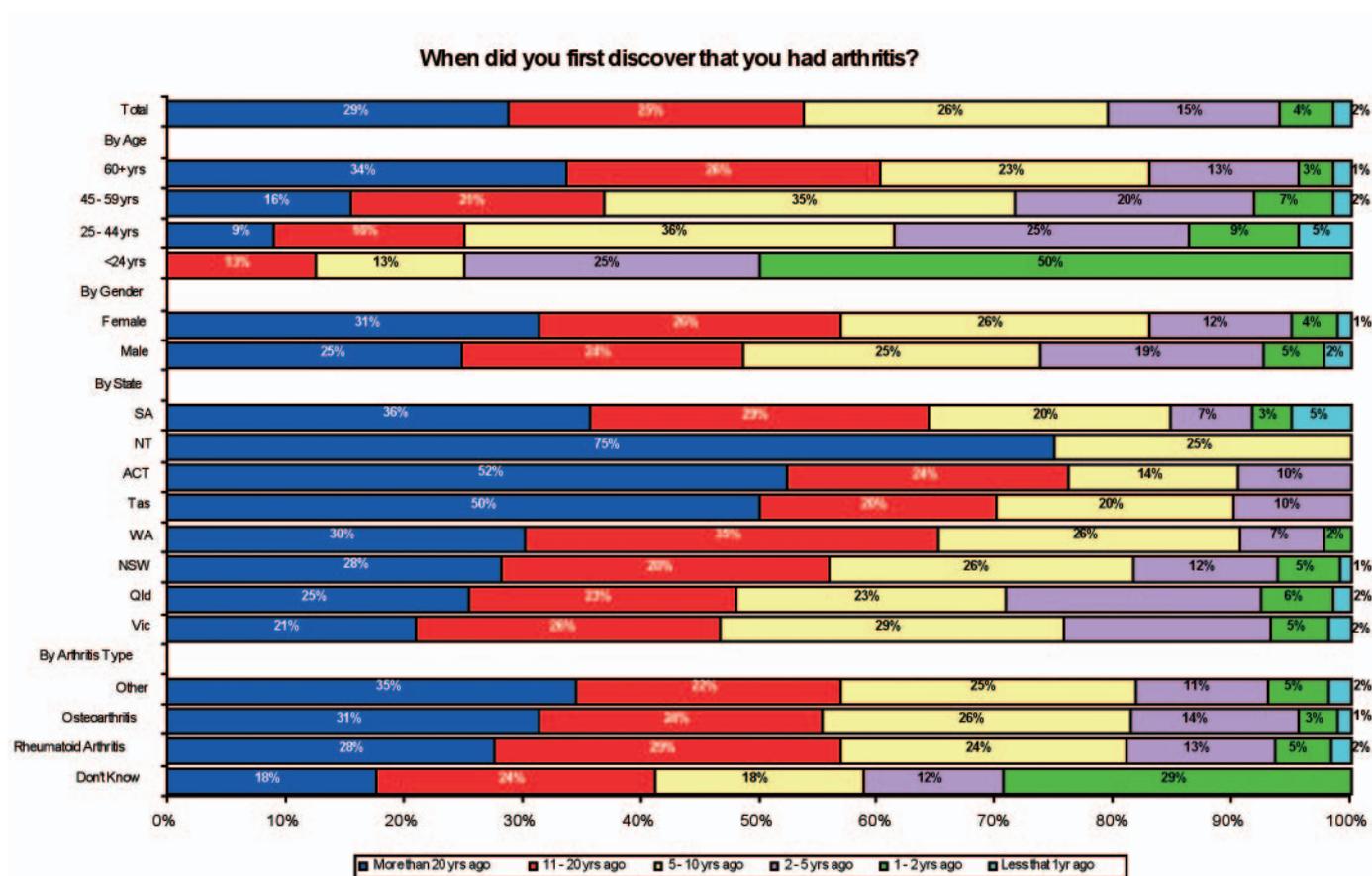
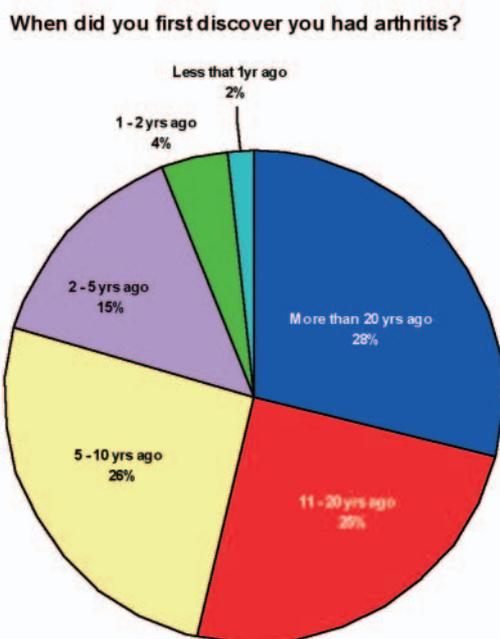
How did you first discover that you had arthritis?



## 4. THE DIAGNOSIS OF ARTHRITIS (CONT'D)

### 4.2 WHEN DID YOU DISCOVER THAT YOU HAD ARTHRITIS?

Seventy-nine percent of respondents discovered they had arthritis more than five years ago.

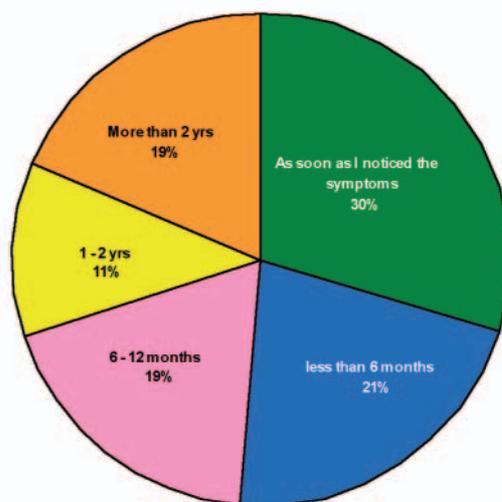


## 4. THE DIAGNOSIS OF ARTHRITIS (CONT'D)

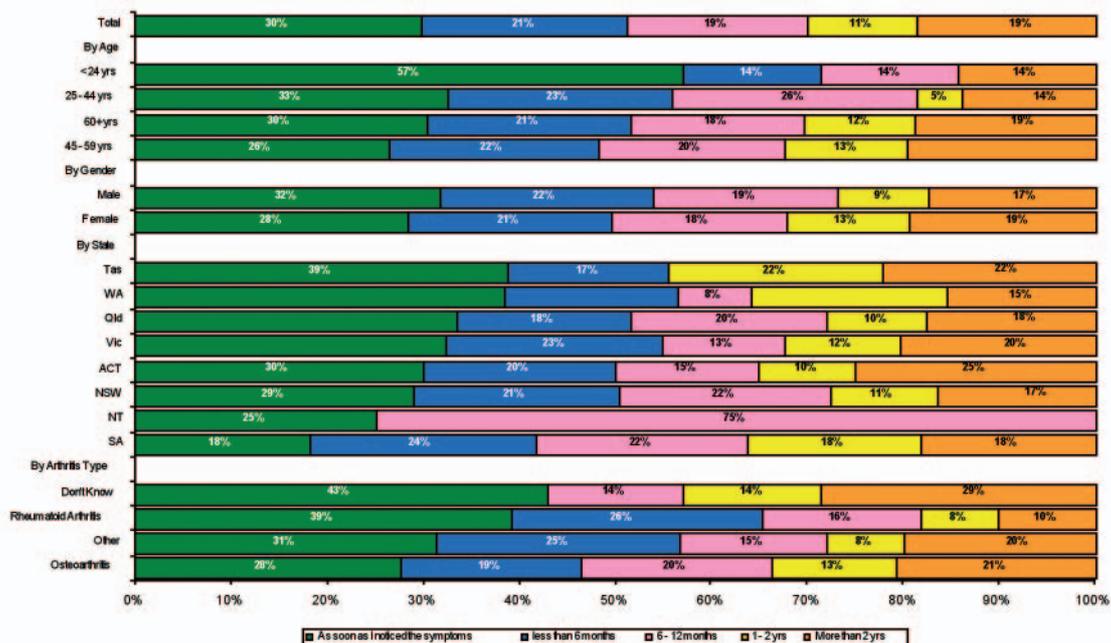
### 4.3 HOW LONG AFTER EXPERIENCING SYMPTOMS DID YOU VISIT THE DOCTOR FOR A DIAGNOSIS?

Just over half of respondents visited their doctor for a diagnosis within six months of noticing the symptoms of arthritis while only nineteen percent did not get a diagnosis for more than two years.

Approximately how long after you first felt the symptoms of arthritis was it before you visited a doctor for diagnosis?

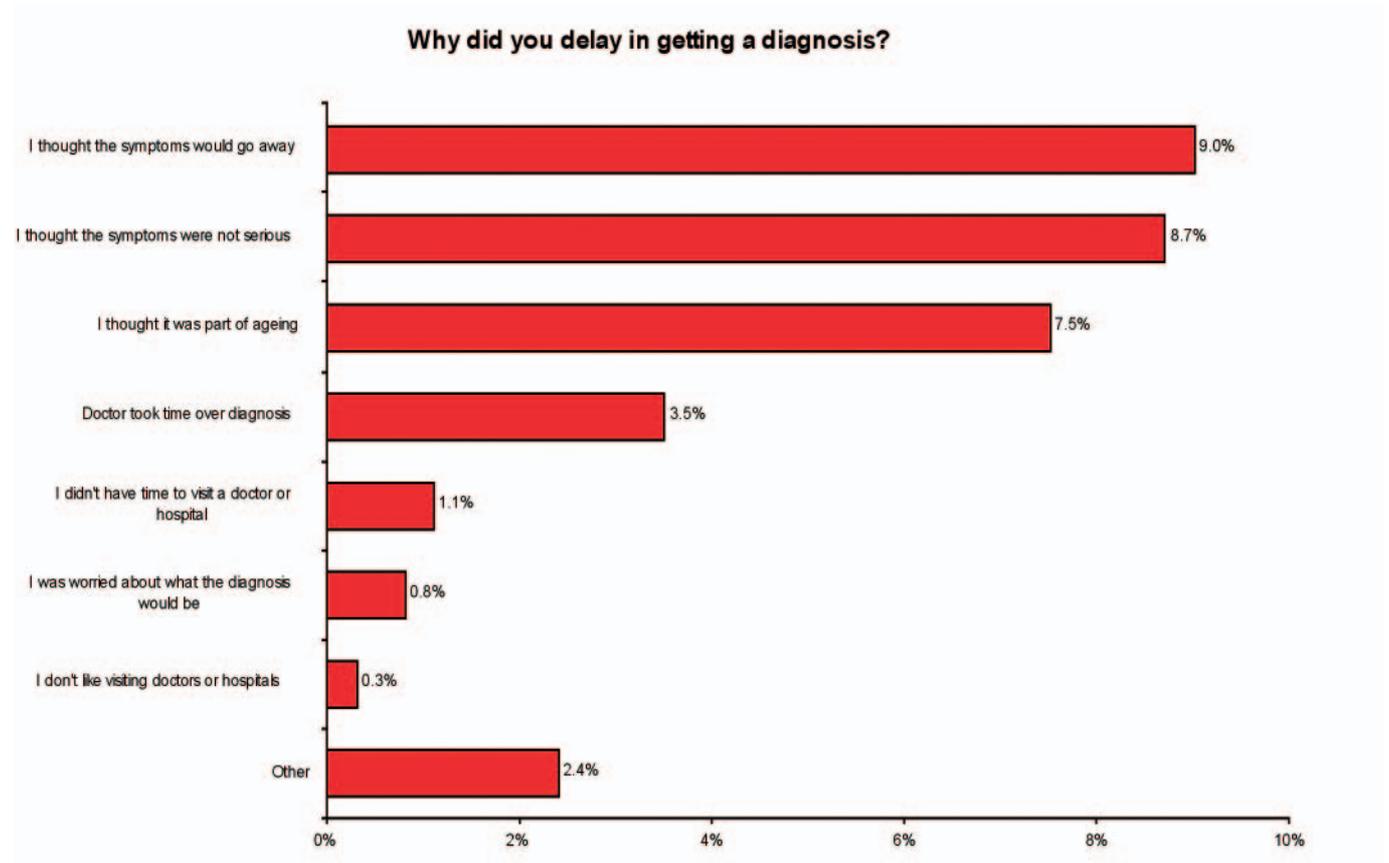


When did you first discover that you had arthritis?



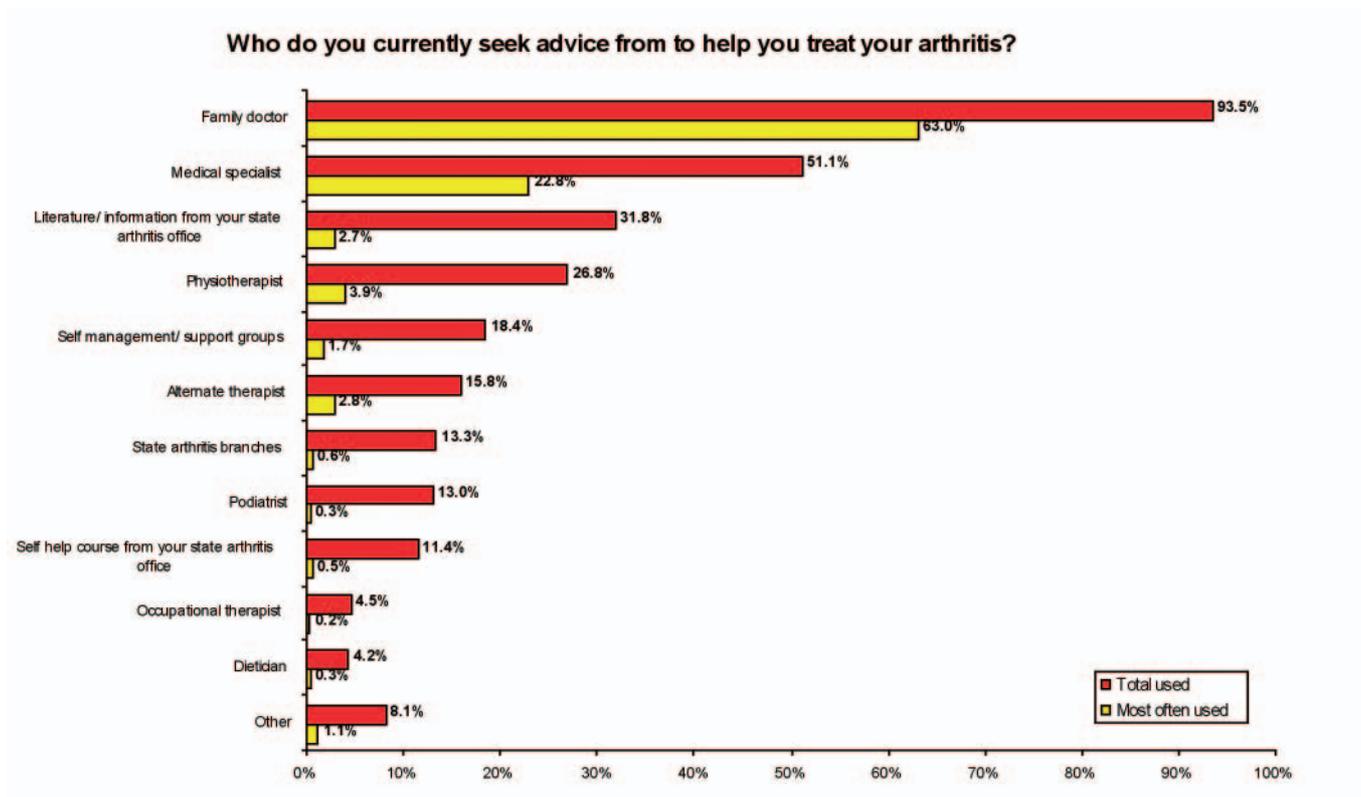
## 4. THE DIAGNOSIS OF ARTHRITIS (CONT'D)

### 4.4 WHY DID YOU DELAY IN GETTING A DIAGNOSIS?



# 5. THE TREATMENT OF ARTHRITIS

## 5.1 WHO DO YOU SEEK ADVICE FROM TO TREAT YOUR ARTHRITIS?

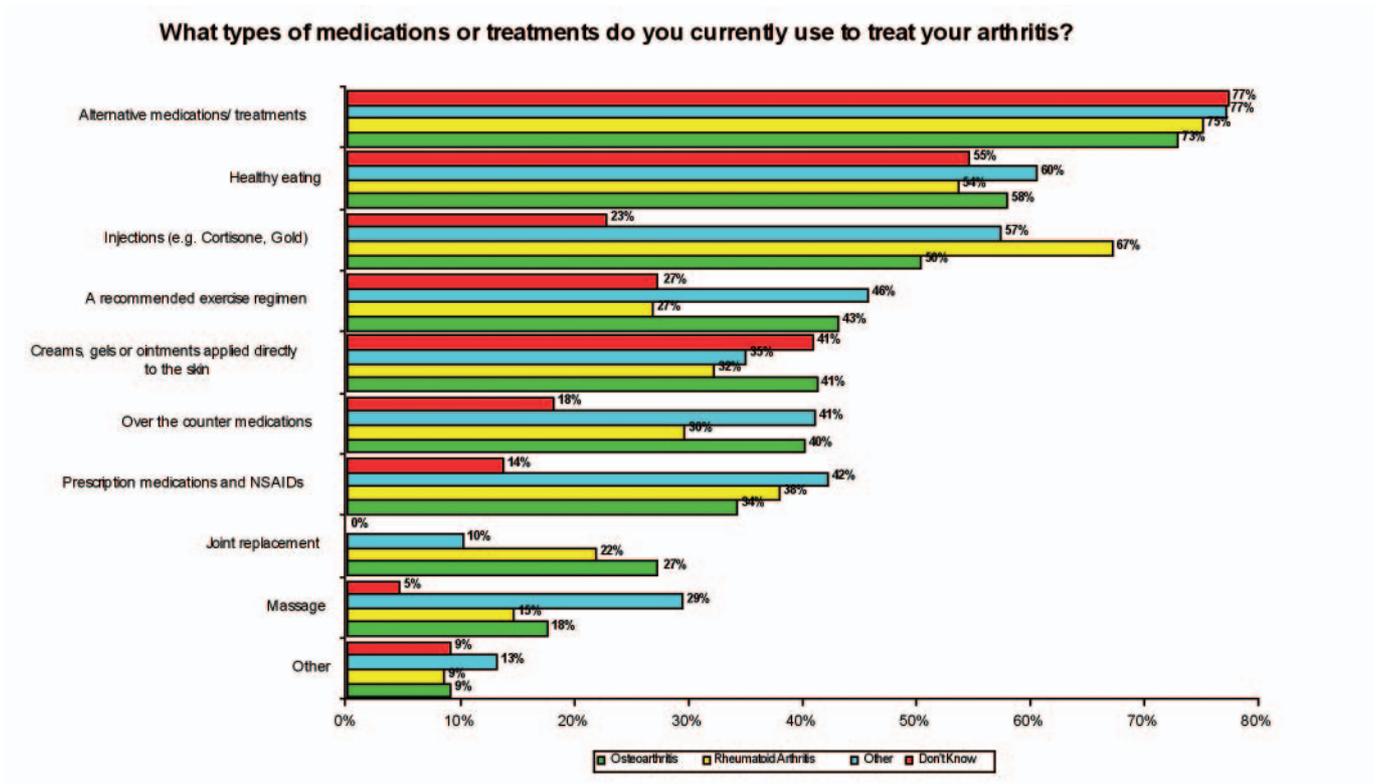
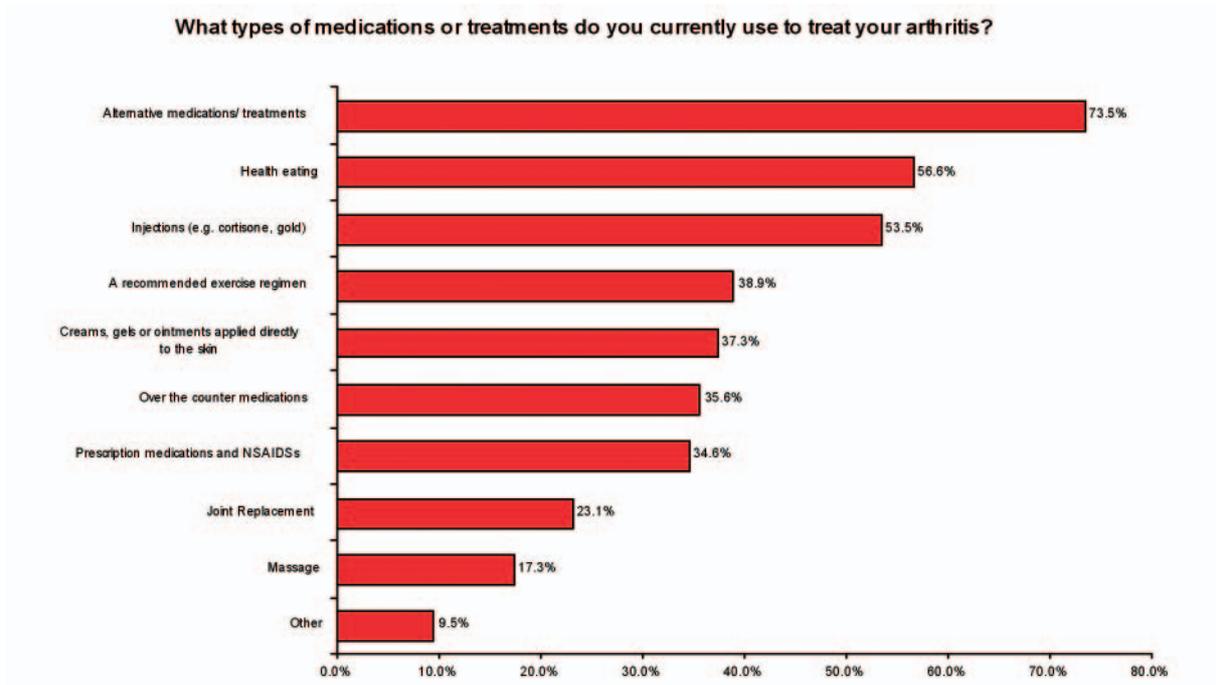


	Osteoarthritis		Rheumatoid Arthritis		Other		Don't Know	
	Most often	Total	Most Often	Total	Most Often	Total	Most Often	Total
Family doctor	67.0%	94.1%	43.2%	83.2%	56.3%	87.3%	40.9%	68.2%
Medical specialist	12.4%	39.8%	42.9%	78.9%	22.8%	52.8%	4.5%	27.3%
Literature/ information from your state arthritis office	2.6%	32.5%	1.4%	29.3%	2.0%	35.5%	4.5%	31.8%
Physiotherapist	4.3%	30.4%	0.7%	17.1%	4.6%	29.4%	9.1%	31.8%
Self management/ support groups	1.4%	20.3%	1.4%	15.4%	2.5%	23.4%	9.1%	18.2%
Alternate therapist	2.2%	15.2%	2.5%	12.1%	5.1%	26.9%	0.0%	9.1%
Podiatrist	0.1%	13.3%	0.7%	15.7%	0.0%	14.2%	0.0%	4.5%
State arthritis branches	0.4%	15.0%	0.7%	8.9%	0.5%	12.7%	0.0%	9.1%
Self help courses from your state arthritis office	0.7%	12.7%	0.0%	11.4%	0.5%	11.7%	0.0%	0.0%
Occupational therapist	0.3%	4.2%	0.0%	4.3%	0.0%	4.6%	0.0%	4.5%
Dietician	0.4%	4.2%	0.0%	3.9%	0.0%	4.6%	0.0%	0.0%
Other	1.2%	7.6%	0.0%	6.4%	2.0%	11.2%	0.0%	13.6%

# 5. THE TREATMENT OF ARTHRITIS (CONT'D)

## 5.2 WHAT TYPE OF MEDICATION/TREATMENT DO YOU CURRENTLY USE TO TREAT YOUR ARTHRITIS?

Interestingly, almost three quarters of respondents report using alternative medications and treatments and over half choose healthy eating compared to just over a third who use prescription medications. Just over a half of respondents use injections as their treatment for arthritis and less than twenty percent undertake massage therapy.

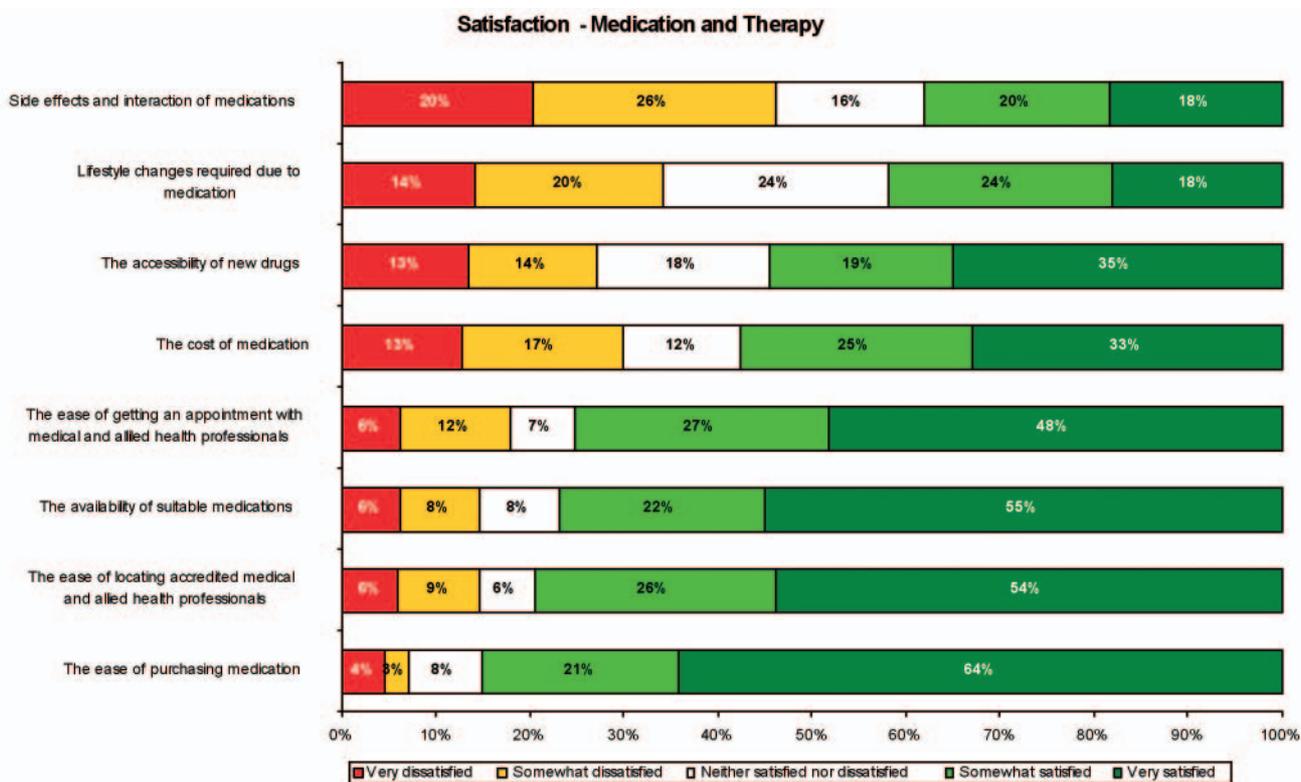


## 6. SATISFACTION

Respondents were asked to score their satisfaction or dissatisfaction using a five-point verbal scale across a range of measures relating to:

- Medication and therapy
- Information available
- Physical health
- Economic issues
- Education
- Relationships
- Lifestyle
- Work/Employment

### 6.1 MEDICATION AND THERAPY



Across most measures in Medication and therapy, the older age group, 60+, including those on a pension or retired, indicated higher levels of satisfaction than other age groups.

The younger age groups tended to more dissatisfied particularly with lifestyle changes. Students and the unemployed are more dissatisfied than those in some form of employment.

There is minimal variance in satisfaction between males and females across all measures although females tend to be more dissatisfied with side effects and lifestyle changes.

Those in rental accommodation are more dissatisfied with medication and therapy than residential status.

There is very little variance in satisfaction between arthritis types although those who have acute rheumatoid arthritis are less satisfied with the accessibility of new drugs, side effects and interaction of medication and lifestyle changes due to medication.

## 6. SATISFACTION (CONT'D)

Respondents indicated a large degree of satisfaction with:

- The ease of purchasing medication (85% satisfied – 64% very satisfied)
- The ease of locating accredited medical and allied health professionals (80% satisfied – 54% very satisfied)
- The availability of suitable medications (77% satisfied – 55% very satisfied)
- The ease of getting an appointment with medical or allied health professionals (75% satisfied – 48% very satisfied)

The highest level of dissatisfaction was with 'side effects and interaction of medications', with a broad spread of opinion (38% satisfied; 46% dissatisfied).

The lowest satisfaction was for 'lifestyle changes due to medication' (42% satisfied; 34% dissatisfied).

54% of respondents indicated satisfaction with 'the accessibility of new drugs' and 58% are satisfied with 'the cost of medication' (30% dissatisfied).

### a) Ease of locating accredited medical and allied health professionals

80% of respondents indicated some level of satisfaction with this requirement while only 6% indicated they are dissatisfied. There was no variance in opinion between males and females, however, 25-44 year-olds had the lowest level of satisfaction (64% satisfied - 33% very satisfied) while the 60+ age group indicated the highest level of satisfaction (82% satisfied).

Dissatisfaction also appears to be low in comparison in Queensland and ACT and, among students and the unemployed.

### b) Ease of getting an appointment with medical and allied health professionals

75% of respondents indicated satisfaction with the highest level of satisfaction recorded for Northern Territory respondents (100%) and the lowest with 25-44 year olds, students and the unemployed.

### c) The availability of suitable medications

77% of respondents indicated satisfaction with the highest level of satisfaction among 60+ years and those who reside in the Northern Territory, South Australia, ACT, those living in a retirement village on a pension or retired.

The highest level of dissatisfaction was among the unemployed (26% dissatisfied) and living in rental accommodation.

### d) The ease of purchasing medication

85% of respondents indicated satisfaction with high levels of satisfaction among all groups with the exception of 25-44 year olds (59% satisfied) and students (43% satisfied).

### e) Accessibility of new drugs

This was the third lowest level of satisfaction among respondents in Medication and Therapy (54% satisfied). 60+ years tend to be more satisfied, particularly those living in NT, Victoria and WA retired on a pension, residing in a retirement village, a relative's home or other accommodation.

Those who indicated high levels of dissatisfaction were 25-44 year olds (57% dissatisfied; 20% satisfied), less than 24 year olds (40% dissatisfied: 20% satisfied), those who live in Tasmania (40% dissatisfied: 46% satisfied), students, those in some form of employment and those who live in rental accommodation.

### f) Cost of medication

A wide of spread of opinion with 58% satisfied and 40% dissatisfied. The highest levels of satisfaction were achieved by 60+ years, retired or on a pension, those less than 24 years, those living in the ACT, residing in a retirement village or other accommodation and those who do not know the stage of their arthritis (rheumatoid or osteoarthritis).

The highest levels of dissatisfaction were indicated by 25-44 year olds (51% dissatisfied), 45-59 year olds (49% dissatisfied), those who live in rental accommodation (46% dissatisfied), those unemployed, casual employment or full time employment:

## 6. SATISFACTION (CONT'D)

### g) Side effects and interaction of medication

While opinion overall was evenly spread, 'side effects and interaction of medication' has the lowest level of satisfaction among respondents regarding Medication and Therapy (38% satisfied; 46% dissatisfied). Females (50% dissatisfied) are more dissatisfied than males (40% dissatisfied) but the highest level of dissatisfaction is among NT (100% dissatisfied), unemployed (66% dissatisfied), Tasmanian residents (61% dissatisfied) and the 25-44 year old group (61% dissatisfied).

### h) Lifestyle changes required due to medication

Overall there is a wide spread opinion of satisfaction (42%) and dissatisfaction (34%). Females (37% dissatisfied) are slightly more dissatisfied than males (30% dissatisfied) although their level of satisfaction is identical (43% satisfied).

Although a small sample, respondents under the age of 24 years expressed the highest level of dissatisfaction (83% dissatisfied). Low levels of satisfaction were also indicated by the 25-44 year old and 45-59 year old age groups, 25% and 28% satisfied respectively.

By state, ACT residents (55% dissatisfied) are the most dissatisfied whereas West Australians are the most satisfied (61% satisfied).

Those in casual employment (58% dissatisfied) and the unemployed (53% dissatisfied) are more dissatisfied than other forms of employment, particularly compared to those on a pension or retired.

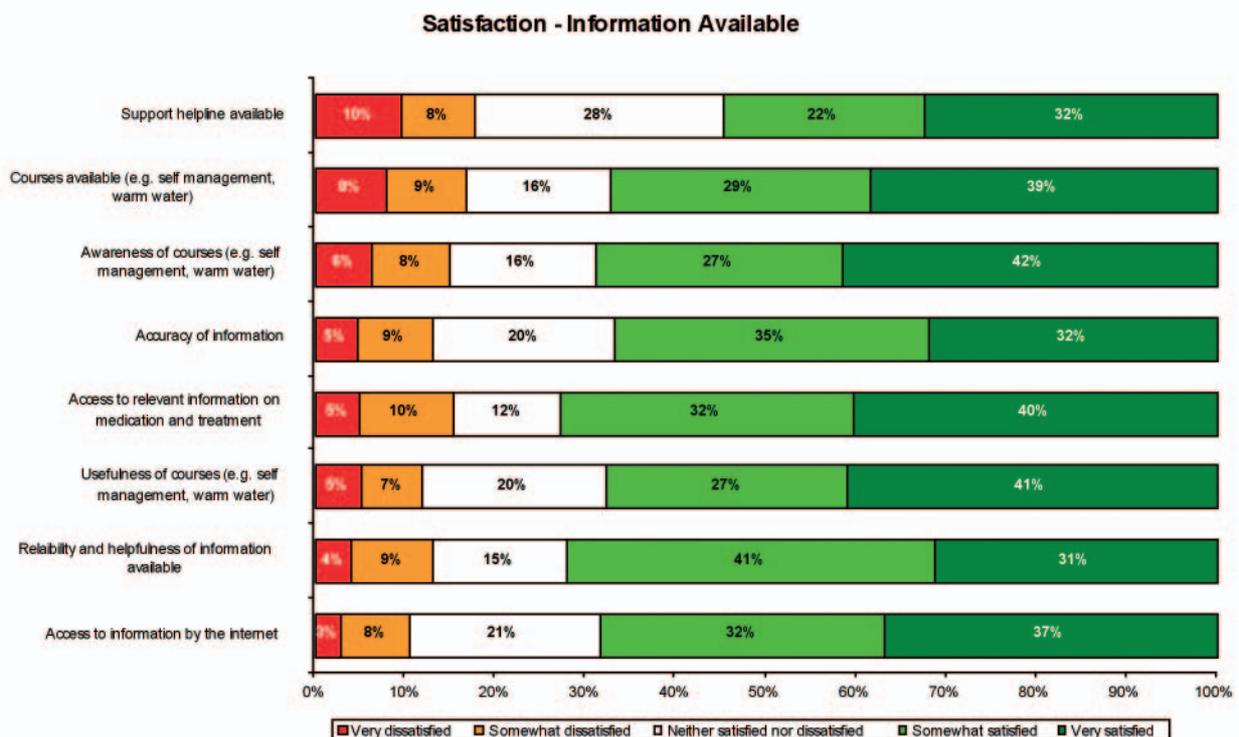
Those who live in other forms of accommodation (60% dissatisfied) and rental accommodation (47% dissatisfied) are more dissatisfied than other residential types, whereas those who live in a relatives home indicated the highest satisfaction (57% satisfaction).

Those who do not know their type of arthritis are the most dissatisfied (100% dissatisfied) and in terms of arthritis type, those with rheumatoid arthritis in the acute stage are more dissatisfied than others (47% dissatisfied)

*"In some instances the side effects of rheumatoid arthritis medication is more potentially harmful than the disease."*

*"It's very difficult not knowing if a medication is going to help the disease when you are not under the correct criteria for the availability for that drug, unless you can afford it."*

## 6.2 INFORMATION AVAILABLE



## 6. SATISFACTION (CONT'D)

A higher level of satisfaction was indicated across all areas in regard to Information Available, though there is some dissatisfaction with the availability of the Support Line. This is most evident in NSW and SA.

There is a small amount of variance in satisfaction between males and females across most measures with males tending to be more dissatisfied with availability and usefulness of courses.

There was a high degree of satisfaction with information access by the internet across all states and across all age groups. However 18 -24 year olds were less satisfied with the reliability and helpfulness of the information available.

Respondents indicated a large degree of satisfaction with:

- Access to relevant information on medication and treatment (72% satisfied – 40% very satisfied)
- Reliability and helpfulness of information available (72% satisfied – 31% very satisfied)
- Awareness of courses (69% satisfied – 42% very satisfied)
- Usefulness of courses (69% satisfied – 41% very satisfied)

The highest level of dissatisfaction was with "Support helpline available", which also recorded the lowest satisfaction. (54% satisfied; 18% dissatisfied)

### a) Access to relevant information on medication and treatment

72% of respondents indicated some level of satisfaction with this requirement while only 15% indicated they are dissatisfied. There was little variance in opinion between males and females with males being less satisfied, however 25-44 year-olds had the lowest level of satisfaction (59% satisfied - 19% very satisfied) while the 60+ age group indicated the highest level of satisfaction (77% satisfied).

### b) Access to information by the internet

69% of respondents indicated satisfaction with the highest level of satisfaction recorded for ACT respondents (100%) and the lowest with SA residents and <24 year olds. 83% of students were satisfied with the access. Females had greater levels of satisfaction than males (70% as compared to 66%)

### c) Reliability and helpfulness of information available

72% of respondents indicated satisfaction with the highest level of satisfaction among 60+ years (76%), those who reside in the South Australia and Western Australia, and those retired or on a pension.

The highest level of dissatisfaction was among Tasmanian residents (19%) the unemployed (27% dissatisfied) and living in rental accommodation. There was little difference amongst the various arthritis disease groups.

### d) Accuracy of information

67% of respondents indicated satisfaction with high levels of satisfaction among all groups with the exception of 25-44 years olds (51% satisfied). Tasmanians were most dissatisfied at 31% followed by NT and NSW.

### e) Courses available

69% of respondents were satisfied with courses available with the 60+ age group at 73%. Those living in SA and Qld had the greatest levels of dissatisfaction at 21% and 20% respectively, as well as those in full time employment (28%) and the unemployed (23%).

Females were more satisfied than males (72% compared to 58%).

### f) Awareness of courses

67% of respondents were satisfied, with only 14% dissatisfied. The highest levels of satisfaction were achieved by females, 60+ years, retired or a student, those less than 24 years, those living in the ACT and WA and those residing in a retirement village or other accommodation.

The highest levels of dissatisfaction were indicated by <22 year olds (33% dissatisfied), those unemployed or full time employment.

## 6. SATISFACTION (CONT'D)

### g) Usefulness of courses

68% were satisfied with the usefulness of the courses available with only 12% dissatisfied. Females (73% satisfied) are far more satisfied than males (58% satisfied) but the highest level of dissatisfaction is among Tasmanians (25% dissatisfied), unemployed (16% dissatisfied), and the 25-44 year old group (60% dissatisfied).

### h) Support help available

Only 54% of respondents were satisfied with support helpline available with 18% being dissatisfied. Females (20% dissatisfied) are slightly more dissatisfied than males (15% dissatisfied).

High levels of satisfaction were indicated by the 25-44 year old and 60+ age groups, 63% and 59% satisfied respectively.

By state, Tasmanian residents (28% dissatisfied) are the most dissatisfied whereas Victorians are the most satisfied (64% satisfied).

Those in full time employment are least satisfied with only 38% as compared to 67% of students and 62% of those on a pension who are satisfied with the support lines.

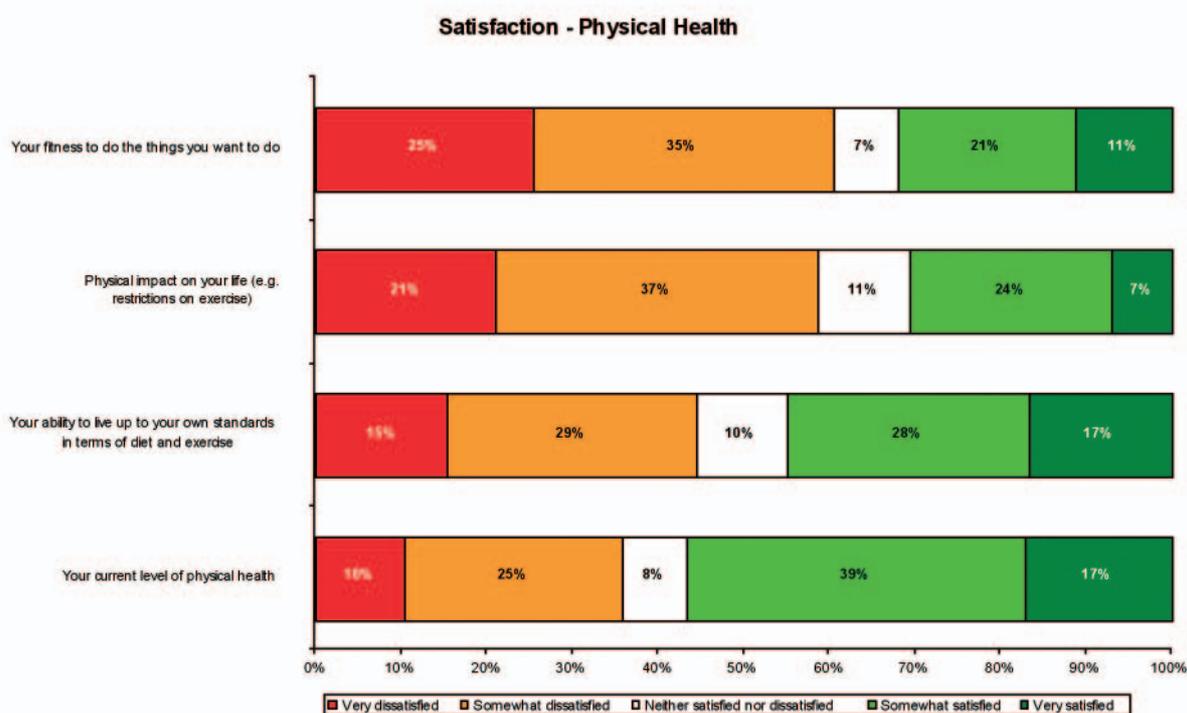
62% of rheumatoid arthritis respondents compared to only 56% of those with osteoarthritis and 53% of other types of arthritis.

*"When I was first diagnosed with arthritis I was extremely grateful to the Arthritis Foundation for just taking the time to explain things and also send me relevant information."*

*"You have to be pretty careful about what you read on the internet. I discuss with the doctor what I am not sure about."*

*"When told I had osteoarthritis I asked what I could do to help my situation. I was told "keep moving". No mention was made of courses that were available or of any support groups. I found out by sheer accident!"*

## 6.3 PHYSICAL HEALTH



56% of all respondents were satisfied with their current level of physical health with the older age group, 60+, students, and those from ACT indicated higher levels of satisfaction than other age groups. However 35% of respondents were clearly dissatisfied with their current level of health especially in the younger age groups. The unemployed (52%) are more dissatisfied than those in some form of employment as well as those in rental accommodation (49%).

## 6. SATISFACTION (CONT'D)

60% of males were more satisfied as compared to females at 54%. There is very little variance in satisfaction between arthritis types although those who are in the remission phase of rheumatoid arthritis are more satisfied (67%) with their health as against those who are in acute (39% satisfied).

Respondents indicated a greater degree of satisfaction with:

- Your current level of physical health (56% satisfied – 11% very satisfied)
- Your ability to live up to your own standards in terms of diet and exercise (45% satisfied – 17% very satisfied)

The highest level of dissatisfaction was with 'Your fitness to do the things you want to do', (60% dissatisfied).

'Physical impact on your life' recorded a level of dissatisfaction of 58% with only 31% being satisfied.

### a) Your current level of physical health

56% of respondents indicated some level of satisfaction with this requirement with 35% indicated they were dissatisfied. Males were more satisfied with their health than females with the 60+ age group being most satisfied (61%) with <24 year group being the least (28%). Those respondents with rheumatoid arthritis but in remission recorded a high level of satisfaction at 67%.

Dissatisfaction also appears to be low in comparison in Victoria and Queensland, among rental accommodation users and those living with a relative plus the unemployed and casually employed.

### b) Physical impact on your life

Only 31% of those surveyed felt satisfied with the physical impact on their lives and how it impacts on restrictions to exercise. The NT, ACT and Tasmanian respondents were most satisfied. There was minimal difference between males and females in regards to satisfaction.

Dissatisfaction was most evident among 25-44 year olds and 45-59 year olds at 74% with residents of NSW at 65% dissatisfied.

83% of causally employed respondents were dissatisfied, as well as students (86%). There was no real difference between those with osteoarthritis and rheumatoid arthritis.

### c) Your ability to live up to your own standards in terms of diet and exercise

Overall there was minimal variance between those satisfied (45%) and those dissatisfied (44%). The highest level of satisfaction was amongst the 60+ age group and those who reside in Tasmania and the ACT, those living in a retirement village on a pension or retired.

The highest level of dissatisfaction was among the 25-44 year olds (69%) and among students and the casually employed. There was no real difference between those with osteoarthritis and rheumatoid arthritis.

### d) Your fitness to do things you want to do

60% of respondents indicated dissatisfaction with high levels of dissatisfaction among all groups especially 24 year olds at 88%. Females were more dissatisfied than males with Queensland, Victoria and the ACT showing 66%, 64% and 67% respectively. Those most satisfied were found in WA (42%).

Those in casual employment (90% dissatisfied) and students (76% dissatisfied) are more dissatisfied than other forms of employment, particularly compared to those on a pension or retired.

Those who live in rental accommodation (73% dissatisfied) are more dissatisfied than other residential types.

Those who do not know their type of arthritis are the most satisfied (58%) and in terms of arthritis type, those with other types of arthritis are more dissatisfied than others (71% dissatisfied)

*"In the past I have always been an extremely fit person. My arthritis has forced me to give up sports like surfing and left me in a position where exercise is more of a necessity to keep going rather than pleasurable."*

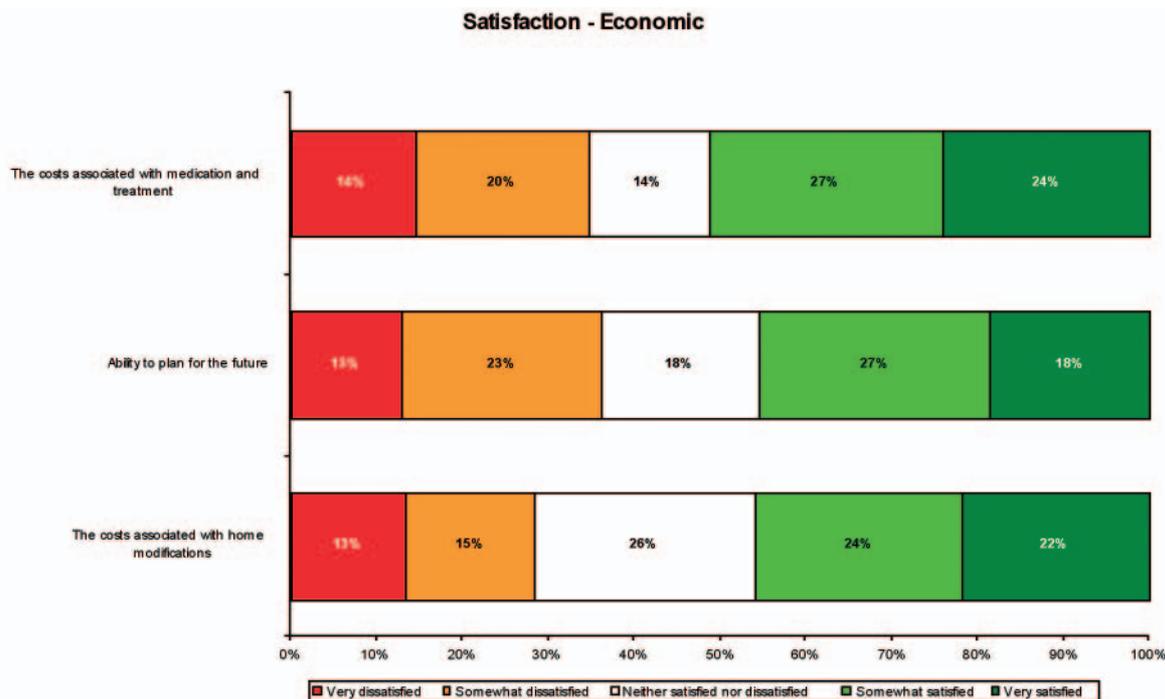
*"I have been a fitness fanatic all my life, at 91 I am the oldest living Wallaby - I am most anxious to regain my fitness and prepared to follow any exercise program recommended."*

*"Have lived with rheumatoid arthritis for seventy years, one realises that certain activities are no longer appropriate. In my teens with football, in my 20's golf, tennis - one learns to accept and live with rheumatoid arthritis"*

*"My current health is fairly good and I am able to live a fairly normal life. Exercising and doing most things without difficulty, taking care with appropriate diet."*

## 6. SATISFACTION (CONT'D)

### 6.4 ECONOMIC



Across the segments in Economic, respondents indicated higher levels of satisfaction with those on a pension or retired or a student than other age groups.

The younger age groups tended to more satisfied with the economic impact for planning for the future, but the 60+ group are clearly more satisfied with the costs associated with both home modifications and medication and treatment.

Students and the unemployed are more dissatisfied than those in some form of employment.

There is minimal variance in satisfaction between males and females across all measures although females tend to be more dissatisfied with side effects and lifestyle changes.

Those in retirement villages were most satisfied than other residential status.

There appears to be more satisfaction for those with OA than other types of arthritis.

Respondents indicated a greater degree of satisfaction with:

- Costs associated with medication and treatment (51% satisfied – 24% very satisfied)
- Costs associated with home modifications (46% satisfied – 22% very satisfied)
- Ability to plan for the future (45% satisfied – 18% very satisfied)

The highest level of dissatisfaction was also with 'Ability to plan for the future', with a broad spread of opinion (45% satisfied; 36% dissatisfied).

#### a) Costs associated with medication and treatment

51% of respondents indicated some level of satisfaction with this requirement while 34% indicated they are dissatisfied. There was little variance in opinion between males and females however, 25-44 year-olds had the lowest level of satisfaction (21%) while the 60+ age group indicated the highest level of satisfaction (59% satisfied), plus those living in a relative's home (79%).

Dissatisfaction also appears to be low in comparison in NSW and, among those casually employed as well as the unemployed.

#### b) Ability to plan for the future

Only 45% of respondents indicated satisfaction with the highest level of satisfaction being recorded for ACT residents (67%) and the 60+ age group (55%) The lowest levels of satisfaction are with 25-44 year olds, casually employed and the unemployed.

## 6. SATISFACTION (CONT'D)

### c) Costs associated with home modifications

46% of respondents indicated a level of satisfaction with the highest being among 60+ age group and < 24 year old as well as those who reside in the WA and Tasmania and those living in a retirement village on a pension or retired.

The highest level of dissatisfaction was among the casually employed (63% dissatisfied).

By state, SA residents (35% dissatisfied) are the most dissatisfied whereas West Australians are the most satisfied (69% satisfied).

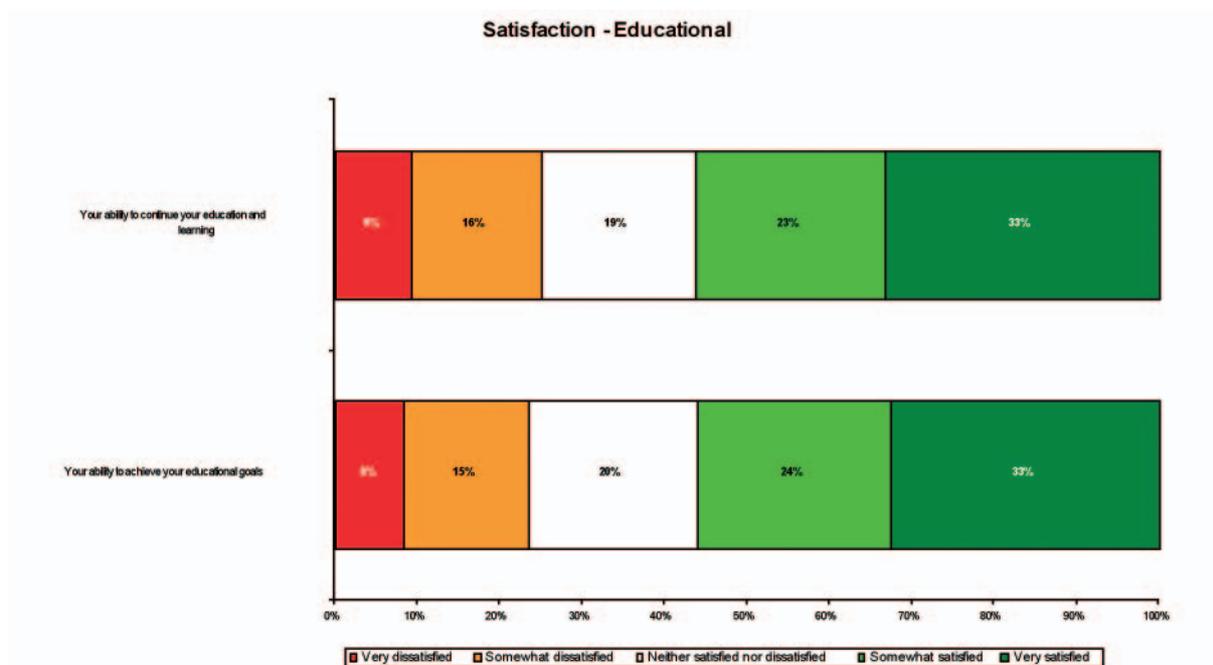
Those in casual employment (63% dissatisfied) are more dissatisfied than other forms of employment, particularly compared to those who are employed full time or retired.

Those with osteoarthritis are the most satisfied (49% dissatisfied) and in terms of arthritis type, those who do not know the type of arthritis they have are more dissatisfied than others (50% dissatisfied).

*"I don't work anymore, on a disability pension and struggle with daily living essentials. There are so many things out there to help with independence and pain but I can't afford anything. If I didn't have loving parents, I wouldn't survive."*

*"Ongoing medication costs for 45 years, operations and home modifications have cost me a small fortune."*

### 6.5 EDUCATIONAL



Across educational requirements, there was a greater level of satisfaction recorded. (57%), mainly from the 24 year old and the older age group, 60+, including those employed both full time and those retired as well as students.

The younger age groups tended to more dissatisfied particularly with the ability to continue education and learning.

There is a greater satisfaction in SA and WA with higher levels of dissatisfaction recorded in both Tasmania and Victoria.

There is very little variance in satisfaction between arthritis types.

Respondents indicated a large degree of satisfaction with:

- Your ability to continue education and learning (56% satisfied – 33% very satisfied)
- Your ability to achieve educational goals (57% satisfied – 33% very satisfied)

### a) Your ability to achieve your educational goals

57% of respondents indicated some level of satisfaction with this requirement while 23% indicated they are dissatisfied. 58% of males were satisfied as against only 54% of females however, 45-59 year-olds had the lowest level

## 6. SATISFACTION (CONT'D)

of satisfaction (64% satisfied - 33% very satisfied) while the 60+ age group and the <24 year olds indicated the highest level of satisfaction (64% and 67% respectively).

Dissatisfaction also appears to be low in comparison in ACT among casually employed and the unemployed.

There was little variation between people with osteoarthritis and rheumatoid arthritis.

### b) Your ability to continue education and learning

56% of respondents indicated satisfaction with the highest level of satisfaction recorded for 60+ year group (64%) and the lowest with 45-59 year olds, from Victoria and Tasmania, those on the pension and the unemployed.

By state, Tasmanian residents (60% dissatisfied) are the most dissatisfied whereas West Australians are the most satisfied (67% satisfied).

Those unemployed (56% dissatisfied) are more dissatisfied than other forms of employment, particularly compared to those employed full time.

Those who live in other forms of accommodation (60% dissatisfied) are more dissatisfied than other residential types, whereas those who live in a relatives home indicated the highest satisfaction (67% satisfaction).

There is little variation between those respondents who have rheumatoid arthritis, osteoarthritis and who are not aware of the type of arthritis they have.

*"I started university and achieved outstanding results however, my health made it impossible to finish."*

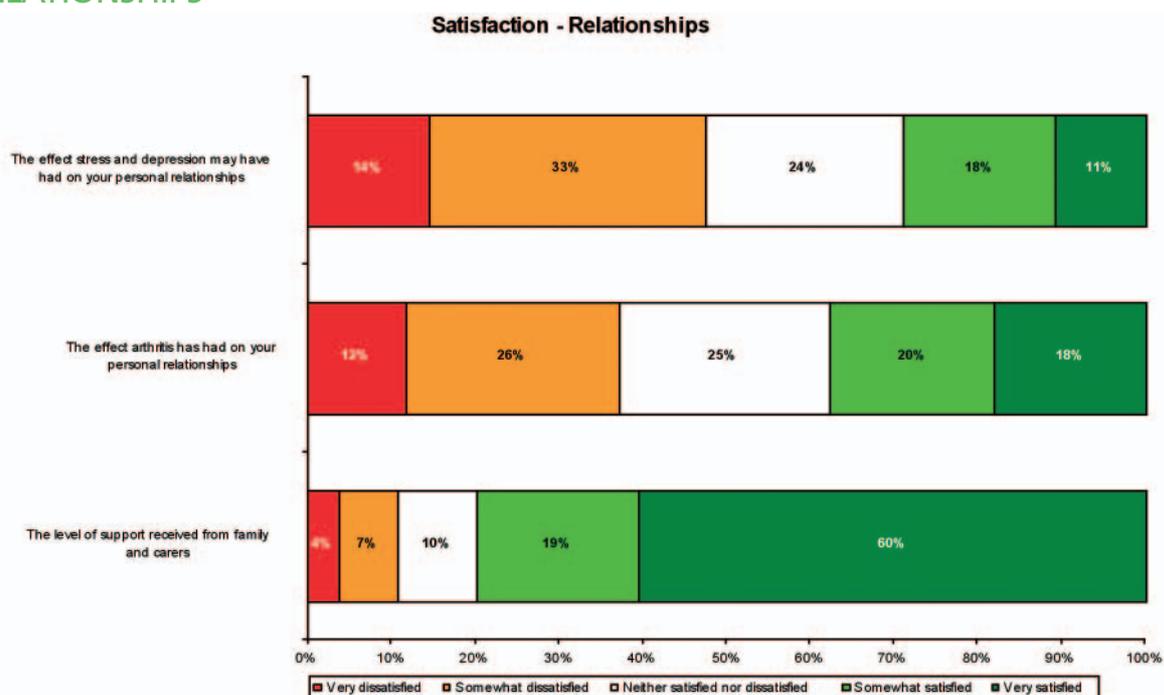
*"Although I have now been retired for 16 years, I still have the ability to learn new educational methods."*

*"Some "brain fog" from Fibromyalgia reduces ability to focus, read or study for any length of time. I used to take a number of classes at "Continuing Education Centre". Physical fatigue and pain contributes too."*

*"As a nurse, education is an ongoing thing. However, I would find it difficult to do large courses i.e. Uni. Fortunately I have completed my degree before rheumatoid arthritis, now I select smaller educational opportunities."*

*"Fatigue is a big part of my life. The energy it takes to continue my ability for education and learning are greatly affected. This is very frustrating. Being discriminated against because you have a disability makes achieving your goals even harder."*

## 6.6 RELATIONSHIPS



Across relationships, there is significant satisfaction with the level of support from family and carers (79%) especially from 24 year olds and the 60+ age group, however overall there is only 29% satisfaction regarding the effect that stress and depression have on the relationship.

## 6. SATISFACTION (CONT'D)

The younger age groups tended to more dissatisfied particularly with the effect that arthritis has had on personal relationships with 78% of 25-44 year olds being dissatisfied.

There is minimal variance in satisfaction between males and females across all measures although females tend to be more satisfied with the level of support from family and carers.

Those in rental accommodation are more dissatisfied with the effect on personal relationships than other residential status.

There is very little variance in satisfaction between arthritis types.

Most respondents indicated a large degree of satisfaction with:

- The level of support received from family and carers (75% satisfied – 60% very satisfied)

The highest level of dissatisfaction was with 'The effect stress and depression may have had on your personal relationship'. (29% satisfied; 47% dissatisfied).

Respondents were split on the effect that arthritis has had on your personal relationship. (38% satisfaction, 38% dissatisfaction).

### a) The effect arthritis has had on your personal relationship

Opinion was split with 38% of respondents being either satisfied or dissatisfied. There was little variance in opinion between males and females, however, 25-44 year-olds had the lowest level of dissatisfaction (73%) while the 60+ age group indicated the highest level of satisfaction (44% satisfied).

There was higher satisfaction in ACT, and Tasmania than in other states. Dissatisfaction was higher in those who are casually employed and in rental accommodation. Among the types of arthritis, those who do not know their type were very dissatisfied (84%) with 30% of those with other types of arthritis showing the lowest level of satisfaction.

### b) The effect stress and depression may have caused in your personal relationship

Only 29% of respondents were satisfied with the level of stress and depression that has been caused. Both 25-44 year olds and <20 year old showed high levels of dissatisfaction at 78% and 60% respectively. Only 40% of the 60+ age group were dissatisfied. Highest levels of satisfaction recorded for Queensland respondents (32%) but all states had higher levels of dissatisfaction with ACT having the greatest (53%) -44 year olds, students and the unemployed. Students and those living in rental accommodation had the highest levels of dissatisfaction.

### c) Level of support received from family and carers

79% of respondents indicated satisfaction with 60% being very satisfied, with the highest level of satisfaction among 60+ years and those who reside in the ACT, WA and Queensland, those living in a retirement village or in a relative's home and those or retired.

The highest level of dissatisfaction was among the 22-44 year olds (21%), students (38%) and those living in rental accommodation (20%). Those who have another type of arthritis were least satisfied still at 75% with the highest level of satisfaction being osteoarthritis at 81%.

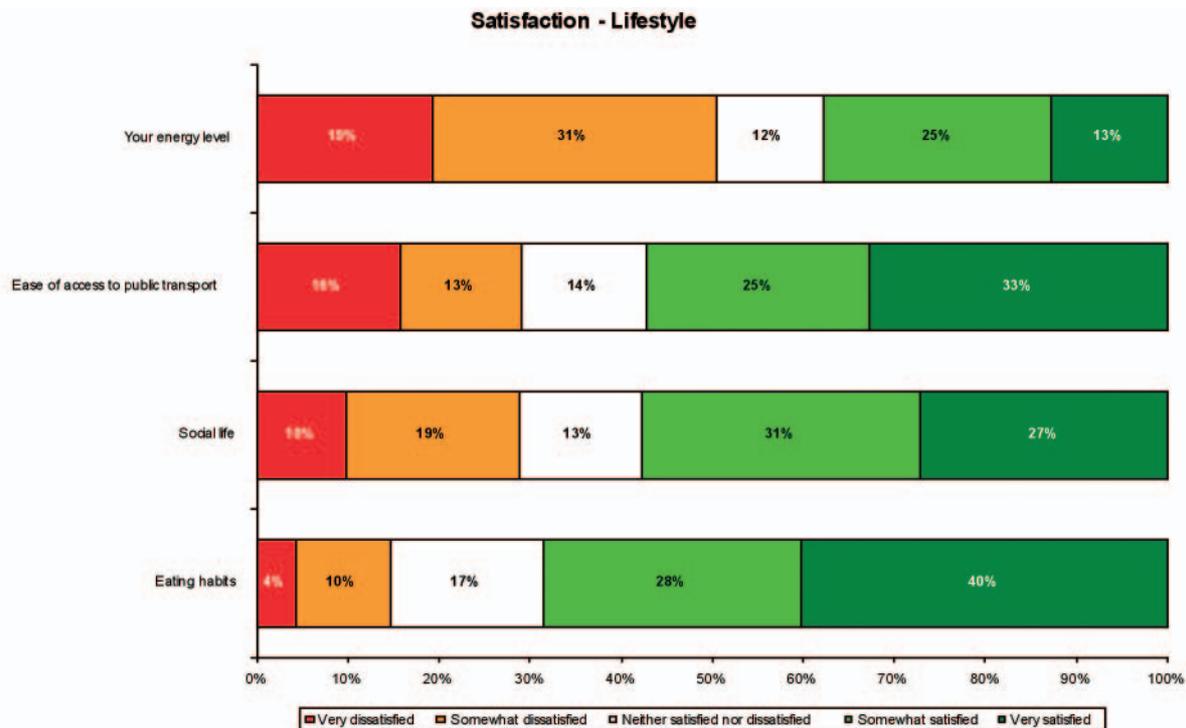
*"It is a lifestyle with lots of rearranging and understanding over time."*

*"Friends and family are very ignorant about rheumatoid arthritis. They think its part of ageing or it would go away soon, or it's all in the mind."*

*"I have a very supportive husband, family, friends and work colleagues. I have days where I am down, due to not being able to do simple things. If they were not supportive, I hate to think how I would be."*

## 6. SATISFACTION (CONT'D)

### 6.7 LIFESTYLE



Across most measures in 'Lifestyle', the older age group, 60+, including those retired, indicated higher levels of satisfaction than other age groups apart from ease of access to public transport where only 34% of this age group were satisfied.

The younger age groups tended to more dissatisfied particularly with energy levels and the effect on their social life. The unemployed are more dissatisfied than those in some form of employment when comparing energy levels and social life.

There is very little variance in satisfaction between the main arthritis types although those who are unsure of their type of arthritis are more satisfied with their energy levels than osteoarthritis and rheumatoid arthritis.

Respondents indicated a greater of satisfaction with:

- Eating habits (68% satisfied – 40% very satisfied)
- Social life (58% satisfied – 27% very satisfied)
- Ease of access to public transport (58% satisfied – 33% very satisfied)

The highest level of dissatisfaction was with 'Your energy levels', with only 38% satisfied but with over 50% dissatisfied.

#### a) Ease of access to public transport

58% of respondents indicated some level of satisfaction with this requirement while 29% indicated they are dissatisfied. Males were more satisfied than females (62% and 55% respectively) with the 60+ age group most satisfied. (70%) The lowest level of satisfaction was the 25-44 year olds with only 34%.

In the states, Victoria had the highest satisfaction at 65% with ACT and Tasmania showing the highest dissatisfaction results. There is no real variation among the different types of arthritis.

By residential status, most respondents in retirement villages were satisfied (62%) with public transport access.

#### b) Your energy levels

Only 38% of respondents indicated satisfaction regarding energy levels with the highest level of satisfaction recorded in Tasmania (39%), those retired and living in a relative's home.

High levels of dissatisfaction were recorded in the lower age groups (78% for 25-44 year olds), those casually

## 6. SATISFACTION (CONT'D)

employed and the unemployed. Among those who have other types of arthritis, dissatisfaction with energy levels was 66% and those with acute rheumatoid arthritis were also highly dissatisfied. (68%)

### c) Eating habits

68% of respondents indicated satisfaction with the highest level of satisfaction among 60+ year olds and those who reside in the ACT and SA, those living in a retirement village and retired, and who have other types of arthritis.

The highest level of dissatisfaction was among the 25 -44 year olds, unemployed (26% dissatisfied) and living in rental accommodation.

### d) Social life

58% of respondents indicated satisfaction with high levels of satisfaction among the 60+ age group (64% satisfied) and those retired (66% satisfied).

By state, WA residents (40% dissatisfied) are the most dissatisfied whereas South Australians are the most satisfied (62% satisfied).

Those unemployed (47% dissatisfied) are more dissatisfied than other forms of employment, particularly compared to those retired.

Those who live in rental accommodation (44% dissatisfied) are more dissatisfied than other residential types, whereas those who live in a relatives home indicated the highest satisfaction (69% satisfaction).

Those who have other types of arthritis are the most dissatisfied (38% dissatisfied) and in terms of arthritis type, those with osteoarthritis are more satisfied than others (58%).

*"Your energy level falls dramatically as you are handicapped. You are not invited to functions as often as before. Could be caused by inability to mingle and your mood at times is not as happy and friendly as before."*

*"I only have my parents in my life. I no longer have friends (not one). I am very restricted as well due to pain levels and my mobility is very poor. The Government doesn't see companionship as an importance, to pay for a carer."*

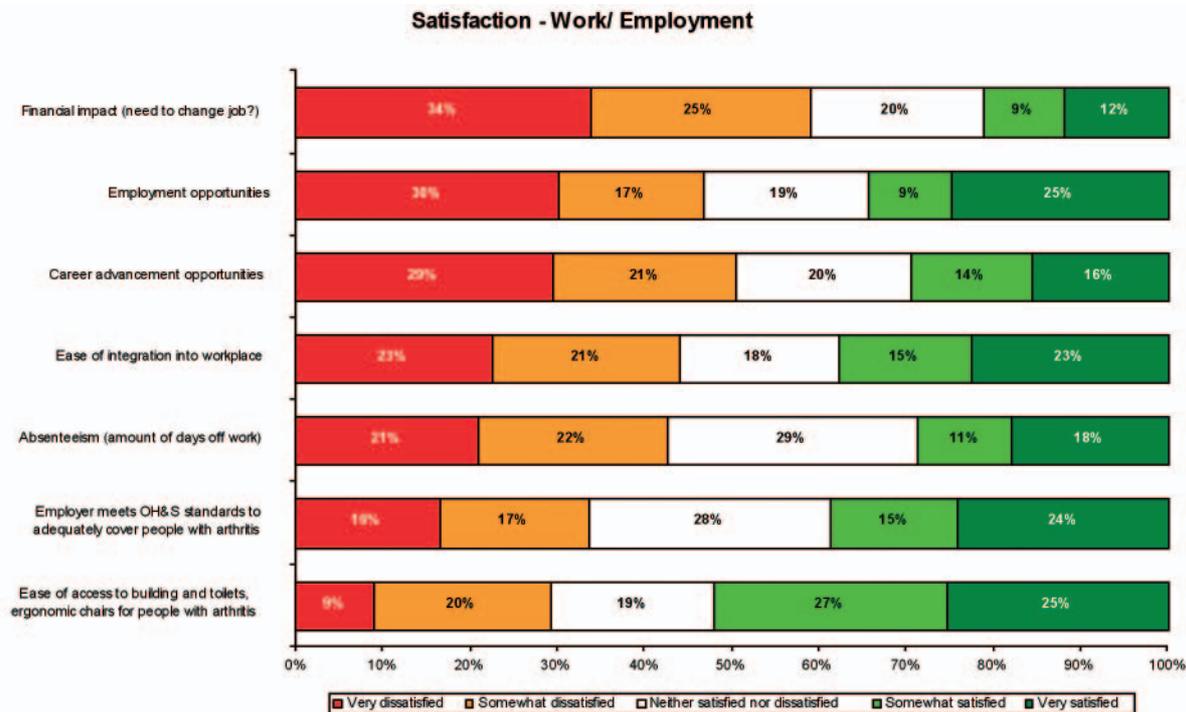
*"What social life? Cannot afford activities I used to enjoy and am usually too tired or in too much pain to enjoy going out."*

*"I live in an area that does not have access to public transport. I try to keep busy and ignore persistent arthritic symptoms."*

*"No thought has been given to public transport for the disabled. We are unable to travel by train or bus - the steps are too high and the driver often leaves before one is seated, hence it requires using taxis at great expense or hopefully an offer by a kindly friend to drive one to a doctor's appointment."*

## 6. SATISFACTION (CONT'D)

### 6.8 WORK/EMPLOYMENT



Across the measures in Work/Employment, the younger age groups (24 and 25-44) showed higher levels of dissatisfaction regarding employment opportunities and career advancement, including those casually employed and of course the unemployed. Financial impact was also a main cause of dissatisfaction among all age groups.

Those respondents who were fully employed had the highest levels of career advancement (59%). The 60+ age group were more satisfied with employment opportunities at around 40% which was also supported by ease of integration into the workplace.

Absenteeism was evenly split with older age groups more satisfied with the amount of time off work (around 40%) The younger age groups especially the 25-44 year olds tended to more dissatisfied (55%). Students and those casually employed are more dissatisfied than those in some form of employment.

Full time employees were more satisfied (57%) than other groups with regard to the employers meeting OH&S standards in the workplace. They were also more satisfied regarding access to buildings, toilets, etc (64%), with males being more satisfied than females (59% to 47% respectively). There is variance in satisfaction between males and females across all measures although females tend to be more dissatisfied with employment opportunities, career advancement and absenteeism.

Respondents indicated a large degree of satisfaction with:

- Ease of access to buildings, toilets, etc for people with arthritis. (52% satisfied – 25% very satisfied)
- Employer meets OH&S standards to cover people with arthritis. (39% satisfied – 24% very satisfied)

The highest level of dissatisfaction was with 'Financial impact – need to change jobs' at 59% and the lowest level of satisfaction at 21%.

50% of respondents also indicated dissatisfaction with 'career advancement opportunities'.

#### a) Employment opportunities

Only 34% of respondents indicated some level of satisfaction with this requirement while 59% indicated they are dissatisfied. Males were more satisfied than females (45% as compared to 28%) however, <24 year olds were 100% dissatisfied while the 60+ age group indicated the highest level of satisfaction (43% satisfied).

Full time employees showed the highest levels of satisfaction at 66% and own their own home. Dissatisfaction also appears to be high in comparison in Victoria and, among those casually employed and the unemployed. There was little variance between osteoarthritis and rheumatoid arthritis; however those with acute rheumatoid arthritis were more dissatisfied (67%).

## 6. SATISFACTION (CONT'D)

### b) Career advancement opportunities

50% of respondents indicated dissatisfaction with the highest level of dissatisfaction recorded for 24 year olds (100%), from Victoria (79%), students (100%) and the casually unemployed (82%).

High levels of satisfaction were indicated by those employed full time (59%), in Queensland and NT. Males were more satisfied than females and those with rheumatoid arthritis over other types of arthritis.

### c) Ease of integration into workplace

Most respondents were evenly split on this group with 38% satisfied and 44% dissatisfied. The highest level of satisfaction was among 60+ years at 46%, full time employees (65%) and living in Queensland (43%).

The highest level of dissatisfaction was among those living in WA (72%) and Tasmania (67%), students, casually unemployed and the unemployed and living in other accommodation. Males were more satisfied than females (46%:32%)

### d) The ease of access to buildings, toilets etc

52% of respondents indicated satisfaction with a high level of satisfaction among full-time employees (64%), the 60+ age group with the exception of 25-44 year olds (only 31% satisfied) and part-time employees (39% satisfied). Those in Queensland at 61% were more satisfied than Tasmanians at only 27%. Males were also more satisfied with access to buildings/toilets etc at 59% compared to females at only 47%. There was little variance between osteoarthritis and rheumatoid arthritis respondents.

### e) Employer meets OH&S standards

Overall only 39% of respondents were satisfied, mainly from full-time employees (57%), the 60+ age group, particularly those living in Queensland and NSW. SA respondents had the highest level of dissatisfaction at 46%.

### f) Financial impact

59% of respondents showed a high level of dissatisfaction with the financial impact requiring them to change a job. This was most evident among 24 year olds (100%), 25-44 year olds (73%), female (65%) those casually employed or students (both 100%), residing in rental accommodation.

The highest levels of dissatisfaction by state occurred in Victoria, Queensland and SA with residents in WA showing the highest level of satisfaction at 40% (NT has 50% satisfaction but is based on small sample)

66% of those people who do not know which type of arthritis they have showed a high level of dissatisfaction (66%). rheumatoid arthritis recorded 55%, osteoarthritis was 56% and other types of arthritis being 74% dissatisfied.

### g) Absenteeism

43% of respondents were dissatisfied with the amount of time taken off work while only 29% were satisfied. Females (47% dissatisfied) are more dissatisfied than males (35% dissatisfied) but the highest level of dissatisfaction is among Queensland residents (63% dissatisfied), students, those casually unemployed (66% dissatisfied) and the 25-44 year old group (55% dissatisfied).

By state, SA residents (59%) are the most satisfied. Full time employees are more satisfied than other forms of employment at 51%, particularly compared to those casually employed and those living in rental accommodation (72% dissatisfied).

Those respondents with other forms of arthritis are the most dissatisfied (55% dissatisfied) and in terms of arthritis type, those with osteoarthritis are more satisfied than others.

*"Not having a visible disability is extremely difficult. Many people and employers forget you have arthritis and consider you slow or even lazy."*

*"I was able to work as a teacher with the education department for 41 years - term holidays were a chance to build up for the next term. At times I used up reasonable amounts of sick leave."*

*"I had to give up work completely due to my condition. Thankfully my husband is able to support the family without me working."*

*"Employer gives enough assistance when I'm limited with mobility but if I look 'normal' assistance vanishes."*

*"My employer is very supportive and has provided aids recommended by OH&S advisers. Approval was also given for me to participate in a self management course during business hours."*

# 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE

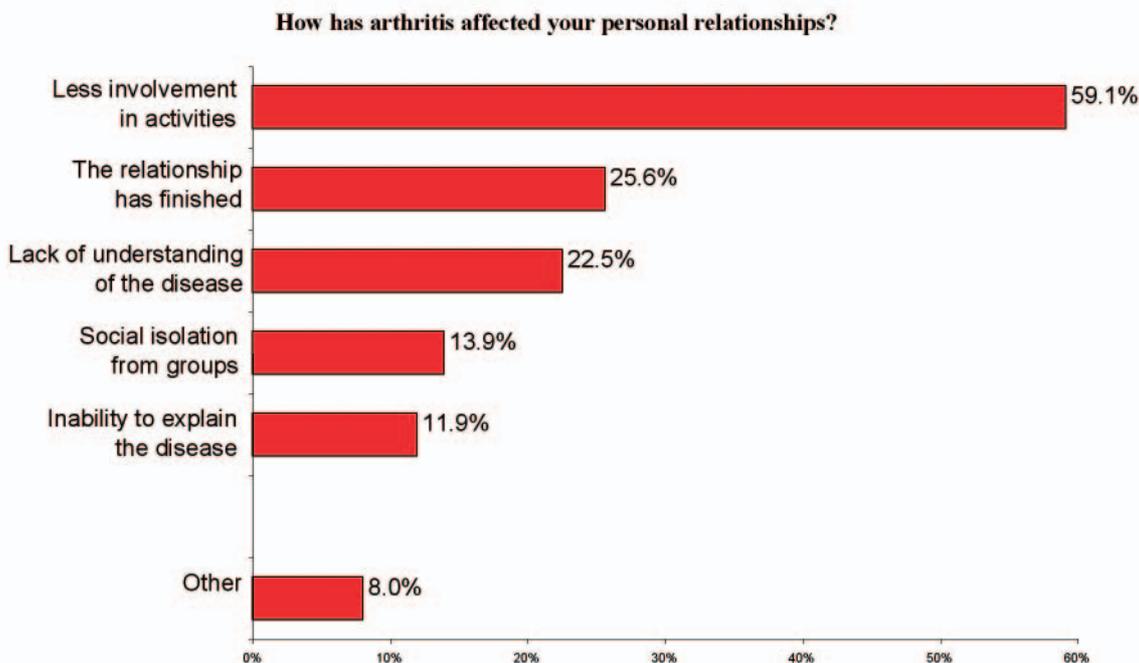
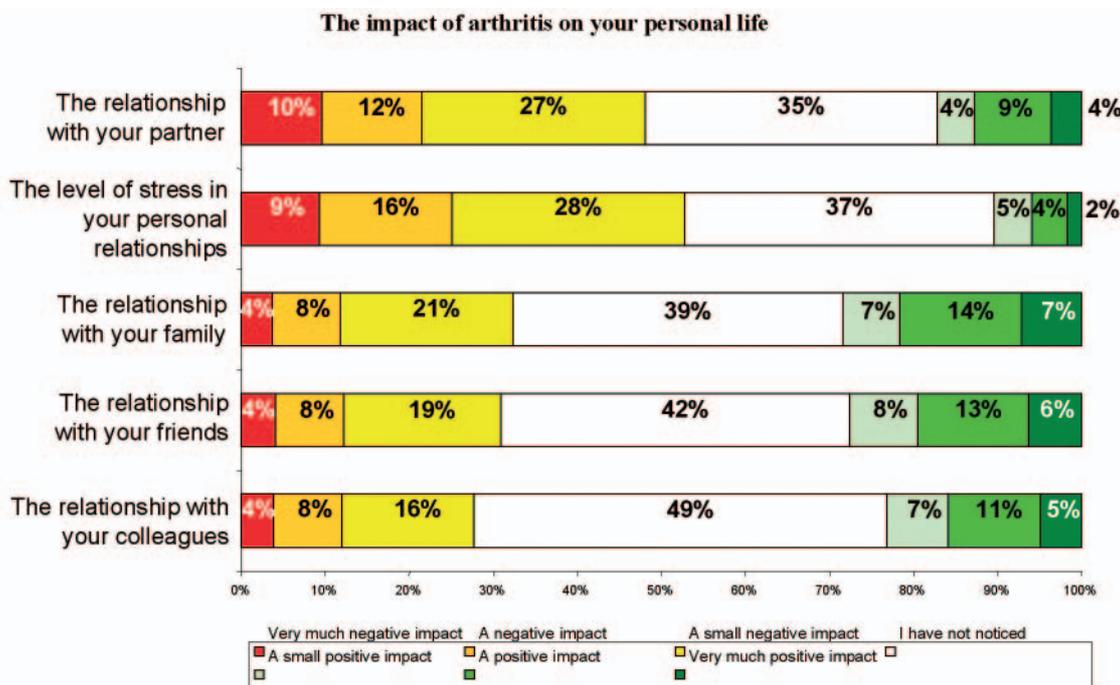
## 7.1 PERSONAL RELATIONSHIPS

The major impact of arthritis on respondents' personal life is the stress it places on their personal relationships and with their partner. The major reason given for this impact is 'their involvement in less activities' due to arthritis and the inability to do everyday tasks as before.

Over a quarter of respondents indicated their relationship with their partner had finished, which was heavily biased to 60+ years (75%) with osteoarthritis (61%) living in Queensland (51.4%). While there is no direct link to the ending of their relationship due to arthritis, the perceived impact of stress on the relationship, involvement in less activities and inability to do everyday tasks as before, would be expected to have had some effect.

In all measures of relationships, a large proportion (over 30%) had not noticed any difference particularly with colleagues (49%).

The lowest level of impact on relationships overall was with colleagues, friends and families. Any negative impact on the relationships with these groups could also be linked to their involvement in less activities, a lack of understanding of the disease and reported social isolation from some groups.



## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### a) Relationship with partner

Almost half of the respondents (49%) have noticed a negative effect to some degree in their relationship with their partner due to arthritis and over a quarter (25.6%) indicated the relationship had finished. In terms of the degree of severity of impact, a slight majority indicated arthritis had a small negative impact only while 35% had not noticed any difference. Only seventeen percent of respondents have noticed a positive effect on their relationship with their partner.

While the impact of arthritis on the relationship with the partner is heavily biased toward a negative impact, about one-third of respondents across the majority of measures indicated they had noticed no difference.

The severity of negative impact diminishes with age with only forty-three percent of the 60+ years age group indicating negative impact compared to seventy-eight percent of 25-44 years.

Females indicate slightly more negative impact than males (50%:46%).

Those who reside in Tasmania perceive more negative impact (63%) than other states whereas ACT residents report almost as much positive impact as negative impact (46% negative impact: 38% positive impact).

Those who are casual employees (60% negative impact) or part-time employees (59% negative impact) perceive more negative impact particularly compared to those retired (45% negative impact) and those in full-time employment (44% negative impact).

In terms of residential status, it would appear those who live in a relative's home or unit experience much greater negative impact than any other form of accommodation particularly those in 'other accommodation' where perception of impact is equally divided between positive and negative.

Those with osteoarthritis perceive significantly less negative impact than 'other arthritis' and rheumatoid arthritis. Those who do not know the rheumatoid arthritis stage or in the acute stage perceive significantly more negative impact than those in remission. Similarly those in the chronic stage of osteoarthritis perceive more negative impact than those in the early stage or do not know.

### b) Relationship with the family

Overall, respondents' perception of impact of arthritis on their relationship with their family is evenly spread. While thirty-four percent of respondents have noticed a negative effect to some degree in their relationship with their family due to arthritis, thirty-one percent perceive a positive impact and one-third or more of respondents across most segments indicated they have not noticed any difference in the relationship they have with their family.

There is much higher negative impact among the 25-44 years (52%) and 45-59 years age group (46%) than others particularly compared to the under 24 years group, where just over half of the respondents indicated a positive impact.

There is an insignificant difference between males and females perception of impact. In terms of state variations, South Australian residents perceive much lower negative impact (21%) and higher positive impact (36%) than others.

Students perceive much higher positive impact than other employment segments (53%) whereas those unemployed, part time or casual employees perceive higher negative impact.

Only those who reside in rental accommodation or their own family home/unit perceive more negative impact than positive and it is quite clear that those who live in a relative's home/unit experience a higher degree of positive impact.

Those with Rheumatoid arthritis, particularly in the acute stage and those with 'other' arthritis perceive more negative impact than other types or stages.

The unemployed registered the highest incidence of severity of negative impact compared to all segments ('very much so and yes' - 33%).

### c) Relationship with friends

The largest proportion of respondents (42%) perceive no difference in the relationship with their friends. Of those who have noticed an impact it is fairly evenly spread but slightly biased toward a negative impact (31% negative: 27% positive).

The 25-44 years (56% negative impact) perceive the greatest negative impact on their relationship with friends and it diminishes with age.

Males perceive slightly higher negative impact compared to females and there tends to be more negative impact in the

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

eastern states with the exception of ACT residents who perceive the highest positive impact (42% positive impact) and NT residents (low sample) who perceive no negative impact at all.

Casual employees and the unemployed perceive more negative impact than other employment status whereas students perceive more positive impact than negative impact.

Those who live in rental accommodation perceive more negative impact than any other type of accommodation, particularly those in a retirement village who perceive the least negative impact.

There is minimal difference between those with osteoarthritis or rheumatoid arthritis, with the exception of those in the acute stage of the latter who perceive much greater negative impact.

### d) The relationship with colleagues

Almost half of respondents indicated no change in their relationship with colleagues however there were slightly more who perceived a negative impact than positive impact.

The highest incidence of negative impact on the relationship with friends is among the following groups:

- 25-44 years (53% negative impact)
- Casual employment (50% negative impact)
- <24 years (50% negative impact)
- Acute rheumatoid arthritis (45% negative impact)
- Don't know type of arthritis (44% negative impact)
- Unemployed (42% negative impact)

The incidence of high severity of impact was small among all groups.

### e) The level of stress in your personal relationships

The level of stress arthritis places on relationships is extremely negative with all age groups except 60+, where it is less so. What can be seen from the results is as people age the negative impact of stress on their personal relationships reduces:

- <24 years = 100% negative impact
- 25-44 years = 81% negative impact
- 45-59 years = 66% negative impact
- 60+ years = 44% negative impact

The negative impact of stress on the relationship is higher among females (56%) than males (48%) and exceeds fifty percent negative impact in all states except ACT (45%).

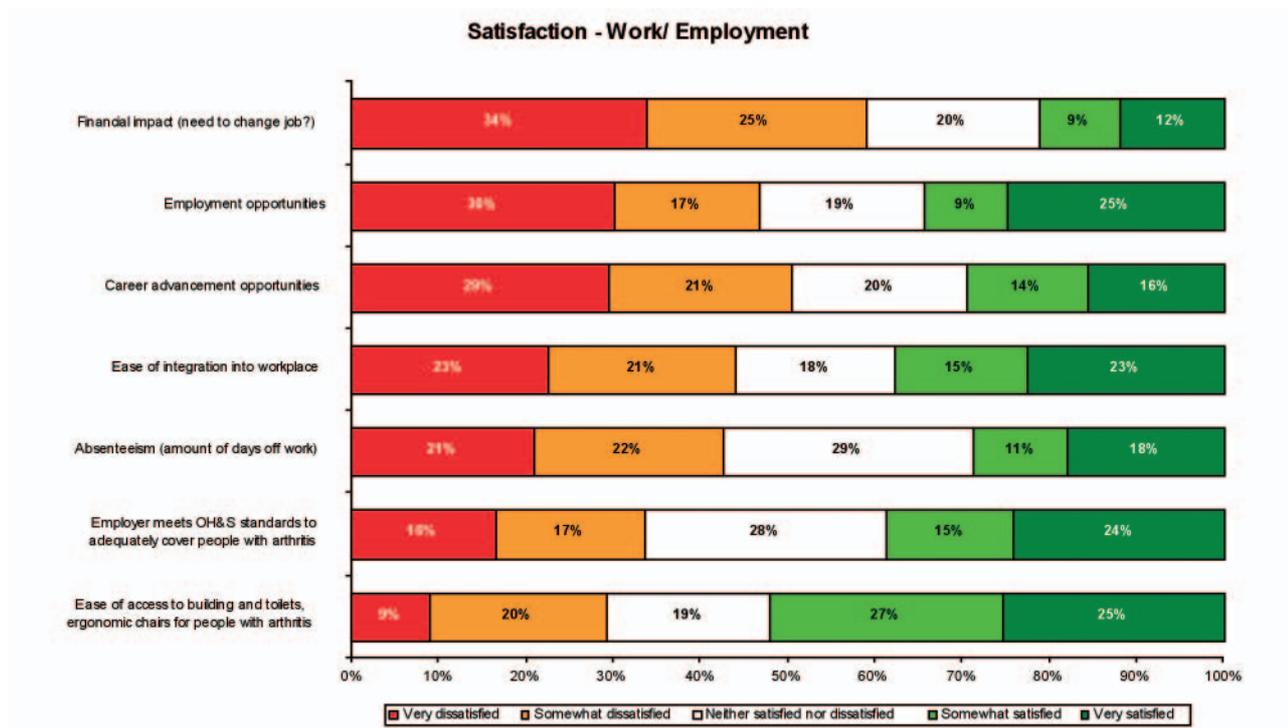
Casual employees, part time employees, the unemployed and those on a pension experience greater negative impact from stress on their relationship than those retired or in full time employment.

Those who reside in a relative's home/unit tend to experience a greater degree of stress than other types of residence, whereas those who live in 'other accommodation' experience the lowest impact of stress on relationship and the highest positive impact. Interestingly, those who reside in a relative's home/unit also report the second highest incidence of positive impact across all segments.

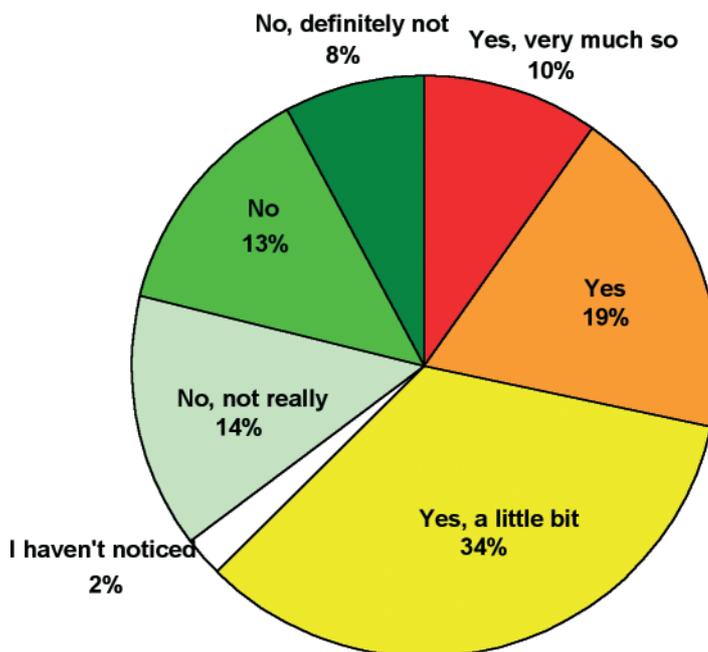
In terms of arthritis type, the impact of stress on the relationship is evenly spread with the exception of osteoarthritis where there is slightly less negative impact, however, those with acute rheumatoid arthritis or do not know its stage experience a higher level of stress than others.

The major issues regarding stress on personal relationships is the inability to do everyday tasks as before (54.1%) and inability to participate in many activities.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)



### Do you feel depressed regarding your arthritis?



Sixty-three percent of respondents indicated they have felt depressed to some degree regarding their arthritis with the majority, 34%, indicating to a small degree.

The incidence of depression and in terms of severity, was much higher among younger age groups, particularly those aged below 24 years and 25-44 year olds.

Females (66%) tend to experience more depression than males (56%). Those living in Victoria had the highest incidence of depression compared to South Australia, Northern Territory and Tasmania, who had the lowest.

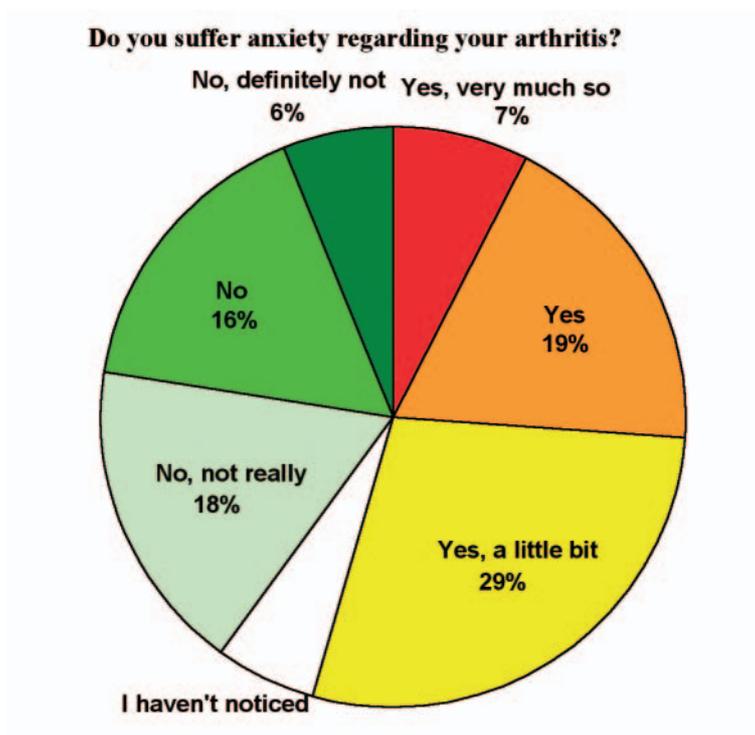
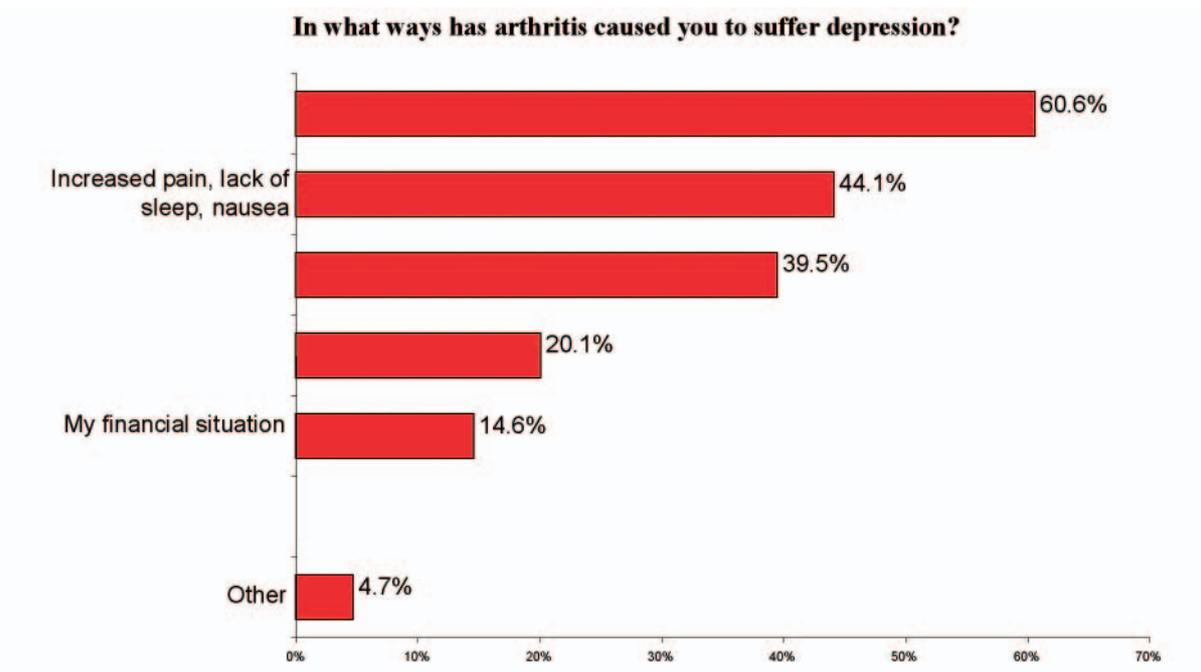
Those who are unemployed experienced the highest incidence of depression of all groups, closely followed by those in casual employment, whereas those who are retired, experienced the lowest incidence of depression in terms of employment status.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Those living in rental accommodation and other accommodation have a greater incidence of depression than other forms of accommodation, whereas those who live with relatives have the least incidence of depression and the highest percentage (excluding NT) of all groups with no depression.

In terms of type of arthritis, those with 'other types of arthritis' experience a greater incidence of depression than rheumatoid, osteoarthritis or 'don't know' categories. There is very little difference overall between rheumatoid and osteoarthritis with the exception of those with acute rRheumatoid arthritis, indicating a very high incidence of depression (81%).

The greatest issue regarding depression among those who experience it, is the inability to do what they used to be able to do (60%), increased pain, lack of sleep and nausea (44%) and the inability to do spontaneous activities (40%).



## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Fifty-five percent of respondents indicated they have suffered some anxiety as a result of their arthritis with the majority, 29%, indicating to a small degree. The major reason given for anxiety is a fear of what the future holds (50%).

The incidence of anxiety and in terms of severity, was much higher among the younger age group, those aged below 24 years, The unemployed, students and those aged 25-44 also reported high incidence of anxiety however those in rental accommodation reported the second highest incidence of severity of anxiety.

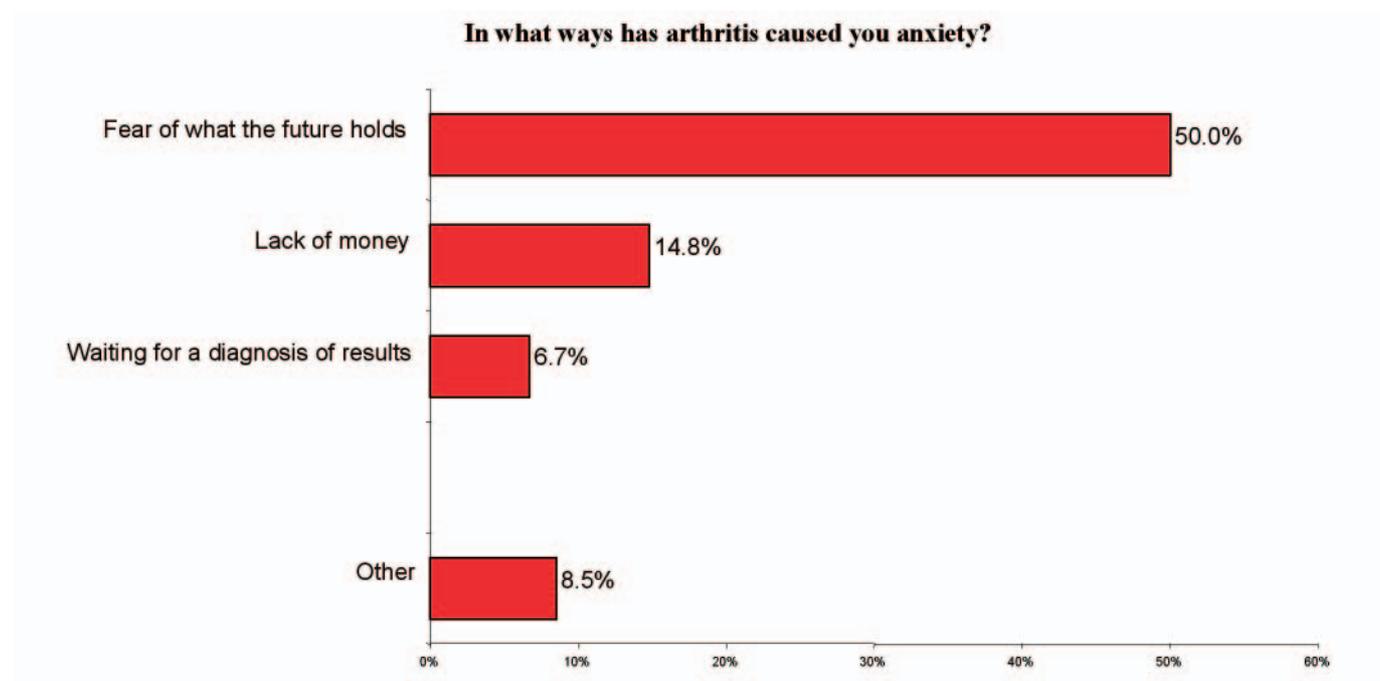
Females (58%) tend to experience more depression than males (49%). Those living in Victoria had the highest incidence of anxiety compared to Northern Territory, South Australia and Queensland who had the lowest.

Those who are unemployed or casual employees experienced the highest incidence of anxiety of employment groups, whereas those who are retired experienced the lowest incidence of anxiety in terms of employment status.

Those living in rental accommodation have a greater incidence of anxiety than other forms of accommodation, whereas those who live with relatives have the least incidence of anxiety of all groups measured and the highest percentage (excluding NT) of all groups with no anxiety.

In terms of type of arthritis, those with 'other types of arthritis' experience a greater incidence of anxiety than rheumatoid, osteoarthritis or 'don't know' categories. Those with acute rheumatoid arthritis (72%) experience the highest level of anxiety than all others stages of arthritis.

The greatest issue regarding anxiety among those who experience it, is the fear of what the future holds.



### h) Counselling advice on your personal relationships

The vast majority have never received any form of counselling advice on their personal relationships. The younger age groups tended to be more open to counselling than the 60+ years group. This may be related to the incidence of negative stress placed on the relationship:

Age	Incidence of negative impact of stress	Has received counselling
<24 years	100%	50%
25-44 years	81%	41%
45-59 years	66%	35%
60+ years	44%	15%

Females are more likely to seek counselling than males and those who live in the ACT (35%) have the highest incidence of counselling while WA has the lowest (10%). As would be expected because of the age incidence of

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

counselling, those who are retired (15%) are least likely to have had counselling while those in part time employment are more likely to.

Those who live in other accommodation or rental accommodation are much more likely to have had counselling than other forms of accommodation.

Those who have 'other type of arthritis' are more likely to have counselling while those who do not the type of arthritis they have are the least likely.

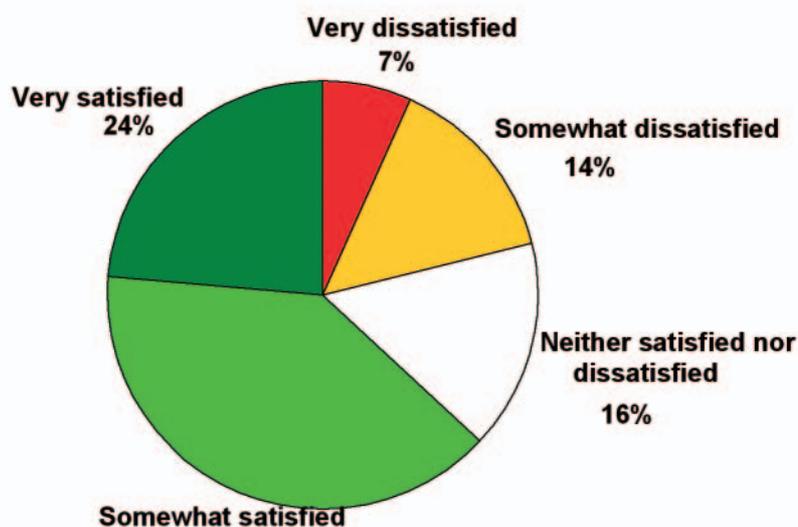
**Have you ever received any counselling advice on your personal life?**



### i) Satisfaction with counselling

Of those (20%) who have received counselling for their personal relationships, just under two-thirds were satisfied with the counselling they received and only twenty-one percent dissatisfied.

**How satisfied or dissatisfied with the counselling that you received?**



All age groups indicated low levels of dissatisfaction with counselling with the highest level of satisfaction among <24 years and 60+. Females tend to be more satisfied than males although males tend to have a lower incidence of dissatisfaction and higher level of ambivalence.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

The lowest level of satisfaction for counselling by state is in Tasmania (low sample), South Australia and ACT with the latter indicating the highest level of dissatisfaction (33%). NT and WA residents have the highest level of counselling satisfaction with 100%.

Those who are retired or on a pension tend to be more satisfied with counselling than part-time employees, who recorded the lowest level of satisfaction (38%) among all segments.

Those who live in a retirement home indicated lower satisfaction than other residential status while those with osteoarthritis indicated higher satisfaction than those with other types of arthritis.

### 7.2 ECONOMIC IMPACT

Aside from cost of transport, respondents indicated a high degree of negative economic impact particularly, in terms of severity, 'loss of wages'. This was explained by just under a quarter of respondents indicating they had to decrease or stop working.

The cost of medication and treatment has also caused a negative economic impact on respondents with overall quarter believing the high cost of alternative medication and their inability to afford new drug treatments or aids.

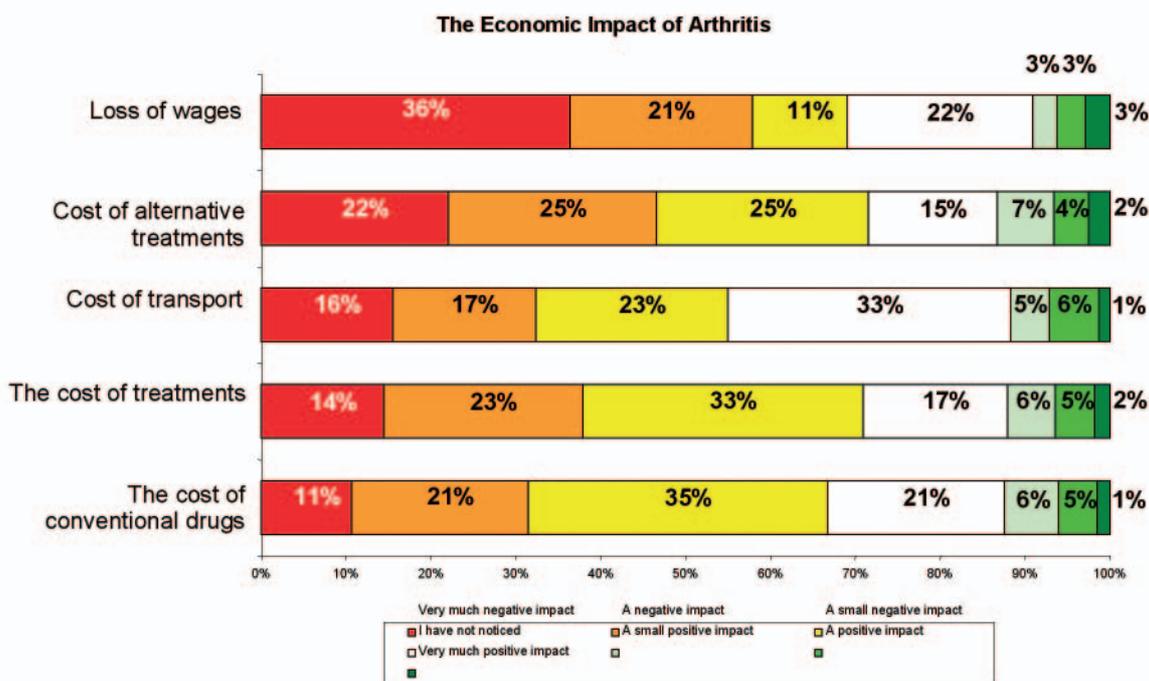
The incidence of economic impact tends to decrease with age and females tend to experience greater economic than males.

WA residents appear to experience slightly more economic impact than other states however, ACT, NT, Qld and Victorian residents experience a higher of severity of economic impact.

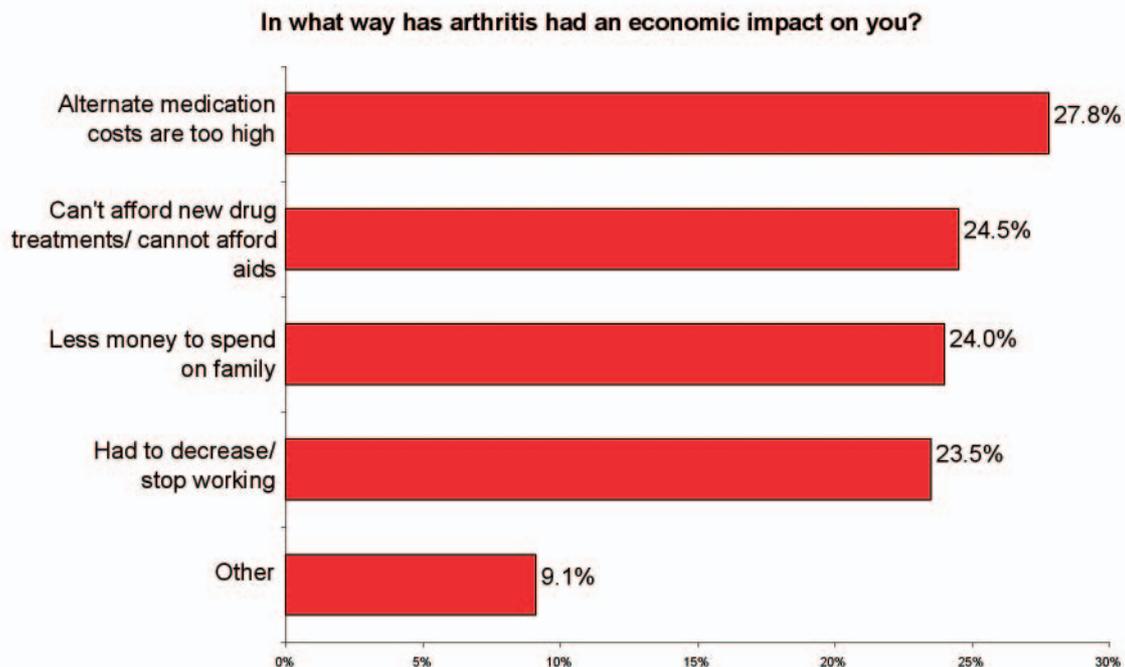
In terms of employment status, as would be expected, casual employees, the unemployed and those on a pension experience the highest economic impact with full-time employees experiencing the lowest level of impact (40% negative impact).

Those who live in a retirement village (88% negative impact) experience greater economic impact than other residential status, particularly compared to those who live in their own home/unit (68% negative impact).

Those with rheumatoid arthritis, particularly in the acute stage, or 'other arthritis' experience a greater economic impact than other types of arthritis. Those with chronic osteoarthritis experience the greatest severity of economic impact compared to other types of arthritis.



## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)



### a) Cost of conventional drugs

The cost of conventional drugs has a major economic impact with over half of the respondents in each segment except those with smaller samples.

The 25-44 years and 45-59 years experience much higher negative impact than other age groups while aside from being slightly more severe impact there is no discernible difference in the negative impact on males and females.

Those living in WA and Victoria indicated more negative impact than other states particularly Queensland and ACT who indicated the lowest. NT residents, while a small sample, indicated the greatest severity of impact.

The incidence of negative impact is much greater among those less than 60 years, particularly 25-44 years (84% negative impact), however, while there is a difference in perception by age, there is minimal difference in opinion between males and females.

In terms of state variations, opinion is fairly evenly spread among the major states with WA recording the highest negative impact (79%) and Queensland the lowest (63%) while Tasmania, with a small sample, recorded the lowest negative impact overall (33%).

Part-time, casual employees and the unemployed perceive much higher negative impact than those retired or in full-time employment.

There is minimal variation between types of arthritis and the different stages with the exception of those who do not know their arthritis type, who perceive less negative impact.

### b) The cost of treatments

The cost of treatments has a major economic impact on all groups except some of those with small samples.

The highest incidence of negative economic impact is among the 25-44 years (90% negative impact) and the unemployed (88% negative impact). Females perceive slightly more negative impact than males and those who reside in Victoria and WA perceive significantly more negative impact than other states, particularly Tasmania and SA.

Those unemployed or in part-time or casual employment perceive more negative impact than other employment groups but there is minimal variation in opinion of impact among accommodation types except for severity of impact which is greater among rental accommodation.

Those who have 'other type of arthritis' or rheumatoid arthritis perceive higher negative impact than those who do not know their arthritis type or with osteoarthritis. There is minimal difference between the different stages of arthritis.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### c) Loss of wages

The majority of respondents (68%) indicated negative impact from loss of wages due to arthritis, with over one-third indicating to a severe degree.

Those living in a retirement village appear to have experienced the greatest impact with eighty-seven percent indicating negative impact for loss of wages although of a less severe nature than other residential types.

Less than 24 years (low sample) perceive the greatest impact in terms of severity and probably related to their future career path. The 25-59 age group also perceive a severe impact of loss of wages (78% negative impact – 45% very much so). As with other economic impact measures, the overall negative impact and severity diminishes with age.

Females indicated a slightly higher degree of negative impact than males while WA, Tasmanian and Victorian residents dominate negative impact in comparison to others states, however ACT residents report the highest severity compared to Tasmania who indicated the lowest severity.

Those in casual employment and the unemployed have experienced more negative impact compared to other employment status groups and particularly compared to full-time employment who reported the lowest negative impact (40%).

Those with 'other type of arthritis' and rheumatoid arthritis experience slightly more negative impact than those with osteoarthritis and much more than those who do not know their arthritis condition.

As would be expected, those with acute rheumatoid arthritis and osteoarthritis in its early or chronic stage have experienced greater negative impact than arthritis in any other stage.

The highest incidence of negative economic impact is among the following:

### d) Cost of transport

In terms of economic impact, cost of transport has the lowest impact with just over half (56%) of respondents indicated a negative impact. in the cost of transport due to arthritis. There is little difference between age, however females indicate greater negative impact than males and those who live in a relative's home or unit (80% negative impact) perceive the greatest impact of all groups closely followed by those who live in 'other' accommodation.

NSW residents perceive greater impact than other states while Tasmanian residents perceive the highest positive impact.

Of employment groups, those unemployed (69%) or on a pension (65%) perceive greater impact than others.

There is no difference in perceived negative impact from arthritis among the arthritis types with the exception of 'don't know' (small sample), however, those who have chronic osteoarthritis (63% negative impact) and those who do not know the stage of their rheumatoid arthritis (62%) perceive greater impact than other stages of arthritis.

### e) The cost of alternative treatments

As with cost of treatments, cost of alternative treatments has the greatest perceived negative economic impact on people with arthritis, particularly among those less than 60 years.

Females perceive greater negative impact than males and NSW residents perceive slightly greater impact than other states, while SA residents perceive significantly the lowest impact (59%).

Of employment groups, those unemployed (69%) or on a pension (65%) perceive greater impact than others.

Those who live in their own family home/unit or in 'Other' accommodation perceive less negative impact than other accommodation types.

There is no difference in perceived negative impact from arthritis among the arthritis types with the exception of 'Don't know' (small sample), however those who have chronic osteoarthritis (63% negative impact) and those do not know the stage of their rheumatoid arthritis (62%) perceive greater impact than other stages of arthritis.

## 7.3 PHYSICAL IMPACT

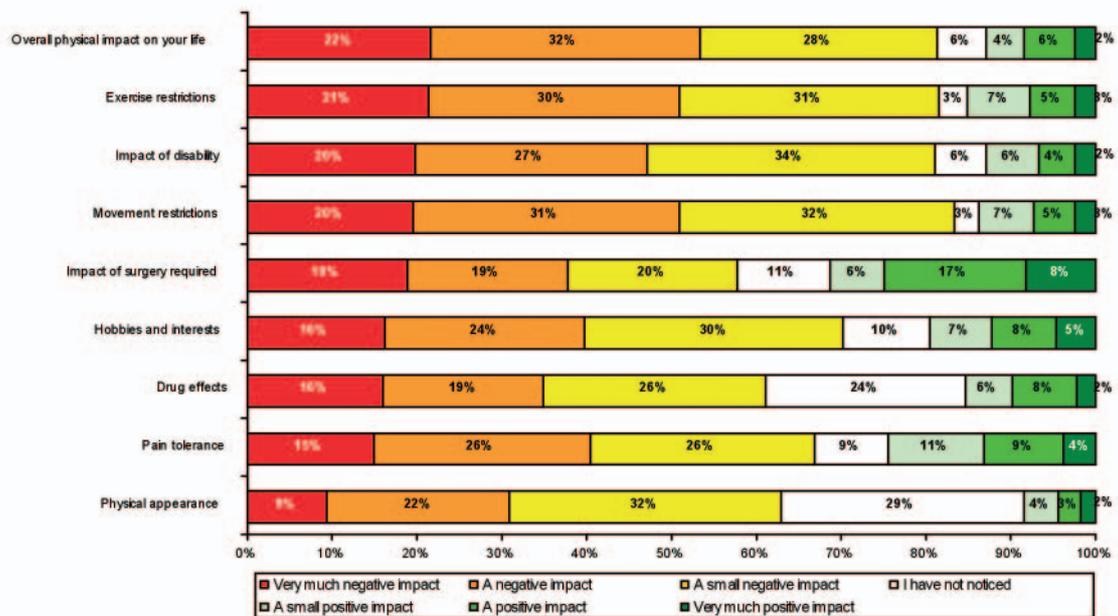
Overall eighty-two percent of respondents indicate arthritis has had a negative physical impact on their life to varying degrees. The major physical impact is with restricted movement, exercise restrictions and the overall impact of the disability. This is extremely prevalent among those less than sixty years of age where ninety to one hundred percent of respondents indicate a negative impact.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

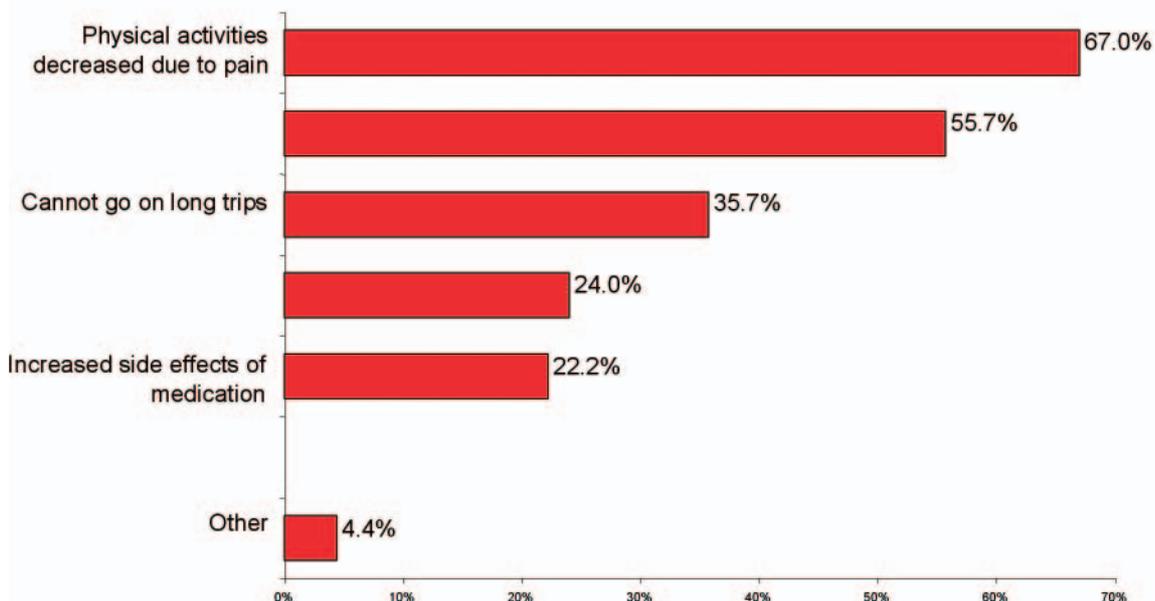
The major reason for dissatisfaction is the decrease of physical activities due to pain and more time required to rest. Over a third indicated they can no longer go on long trips while just under a quarter of respondents suggested decreased sexual activity as a major reason for dissatisfaction with the physical impact of arthritis.

The impact of surgery required has the most positive effect with thirty-one percent of respondents indicating satisfaction to some degree and the lowest level of dissatisfaction (58%).

**Has arthritis had a positive or negative physical impact on your life?**



**In what ways has arthritis had an effect on the physical aspects of your life?**



## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### a) Overall physical impact on your life

Overall negative impact of arthritis on respondents physical life is much more prevalent among respondents less than 60 years and to an extreme negative degree with younger age groups (<60 years) particularly under 24 years. There is no significant difference between males and females but in terms of state, NSW and Victoria indicate slightly more negative impact compared to others.

Those in casual employment indicated a negative impact for all respondents while full-time or part-time employment indicated a greater incidence of negative impact compared to other forms of employment.

In terms of accommodation, those living in retirement villages indicated slightly more negative impact than other forms of accommodation while those living in a relative's home or unit indicated the highest positive impact across all measures.

As would be expected, those with acute rheumatoid arthritis and chronic osteoarthritis experience greater negative physical impact on their life than other stages.

### b) Physical appearance

Sixty-three percent of respondents indicated negative impact from arthritis on their physical appearance and this is most prevalent among younger age groups, up to 44 years.

Females indicated more negative impact on their physical appearance than males.

There is negligible difference between states, however Tasmania and NT residents have a diverse opinion with both the highest negative and positive impacts, but biased toward negative.

Those in casual employment indicate the greatest negative impact by a large margin, relative to other forms of employment, while the retired indicated the lowest negative impact.

In terms of accommodation, those in rental accommodation or a retirement village tend to experience more negative impact whereas those living in a relative's home/unit experience the least.

There is little difference in negative impact between arthritis types in terms of negative impact, however those who do not know their arthritis type and those in the acute or chronic stage of their arthritis experience much greater impact than other stages.

### c) Impact of surgery required

The impact of surgery has the lowest physical impact on respondents (58%) and is perceived to have a positive impact by over thirty percent of respondents.

The impact of surgery required diminished with age with the highest negative impact of surgery in the <24 years (100%) and the 45-59 years age group (72%) although the severity of impact is highest among 25-44 years.

There is minimal difference between males and females

There is a diverse spread of opinion across states. Those who live in WA, ACT and Victoria indicated slightly more negative impact than NSW and Qld, however SA and Tasmanian residents indicated very low levels of impact and very high levels of positive impact.

Those who live in rental accommodation of their own home/unit indicated the highest level of impact in terms of accommodation although in 'other' accommodation it appears to be more severe. Those who live in a relative's home/unit indicated more positive impact than negative impact.

There is minimal difference between arthritis types except 'Other' who indicated no negative impact while those in the chronic or acute stages naturally have a higher incidence of negative impact.

### d) Impact of disability

The negative impact of the disability is very high (81%) particularly with under 24 years (100% negative impact – 50% very much so), 45 – 59 years (90%) and those living in the ACT (88%).

There is minimal difference between 25-44 years and 60+ years and males indicate slightly higher levels of negative impact than females.

NT, Tasmania and South Australian residents recorded much lower levels of negative impact than other states.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Casual employee respondents indicated they all have experienced negative impact from arthritis while students, although a small sample, indicated the most extreme negative impact and the lowest overall negative impact (66%). The severity of impact was lowest among the full-time employed.

In terms of accommodation, 'Other accommodation', although the highest negative extreme of impact, recorded the lowest overall negative impact. Aside from 'other', those who live in rental accommodation experience more extreme negative impact than other accommodation types.

Those who do not know their arthritis type and those with rheumatoid arthritis experience less negative impact than osteoarthritis or other arthritis types and although those with rheumatoid arthritis in the acute stage or who do not know the stage indicate a higher severity of impact, those in the chronic stage of osteoarthritis indicate a slightly higher level of negative impact overall.

### e) Exercise restrictions

Exercise restrictions have a high level of negative impact (82%) among those with arthritis, particularly those under 24 years and casual employees who all indicated negative impact and the majority to an extreme.

45-59 years experience more negative impact than 25-44 years while 60+ years experience comparatively lower levels of negative impact.

There is no difference between males and females although it would appear to be slightly more severe negative impact among females.

Although a small sample there was a diverse spread of opinion among NT residents with the severity of impact either extreme positive or extreme negative. Of the other states, Victoria and ACT residents indicated the highest levels of negative impact whereas SA and Tasmania indicated the lowest.

The unemployed (93% negative impact) also indicated very high negative impact. The lowest level of negative impact is among students, those on a pension and retirees.

Those who live in 'Other' accommodation or a relative's home/unit experience less negative impact.

There is minimal difference between arthritis types with the exception of 'Don't know', who indicated more negative impact and those who do not know the stage of osteoarthritis and rheumatoid arthritis indicated less negative impact.

### f) Movement restrictions

Movement restrictions are also very high in their negative impact (83%) among those with arthritis and as with 'Exercise restrictions', particularly those under 24 years and casual employees, who all indicated negative impact, the majority to an extreme.

The 60+ years experience less negative impact than other age groups and females tend to experience slightly more severe negative impact than males.

In terms of states, ACT indicated the highest negative impact with NT and SA residents lower negative impact.

Aside from casual employees who all indicated negative impact, part-time employees and the unemployed indicated higher levels of negative impact while students and those on a pension indicated the lowest.

There is minimal difference between arthritis type and stage.

### g) Drug effects

Sixty-one percent of respondents indicated negative impact of drugs on their physical life and there is a diverse spread of opinion across all segments.

Those less than sixty years, particularly under 24 years, part-time employees and casual employees indicated higher levels of negative impact than other segments while 60+ years, retirees, those living in a retirement village, those residing in Tasmania and those with osteoarthritis indicated lower levels of negative impact.

Males indicated discernibly lower negative impact from drugs than females.

ACT residents indicated much higher negative impact than other states.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### h) Pain tolerance

Just over two-thirds of respondents indicated a negative impact on their physical life from pain tolerance with the highest incidence of negative impact among 45-60 years, ACT residents and part-time employees.

<24 years and 60+ years indicated lower negative impact than other age groups and females indicated slightly higher negative impact than males.

While ACT and NSW residents indicated the highest negative impact among states, SA residents had an almost even spread of opinion between positive and negative effect.

Those who live in a retirement village appear to experience more negative impact particularly compared to those who live in a relative's home or unit.

There is negligible difference between arthritis types.

### i) Hobbies and interests

Seventy-percent of respondents indicated a negative impact from arthritis on their hobbies and interests and much more so among the 45-54 years age group and the unemployed and less so in the 60+ years group.

There is no difference between males and females and states although the impact appears slightly more severe in the eastern states.

Those who live in a retirement village indicated more negative impact than any other accommodation type and as would be expected those with acute rheumatoid arthritis experience more negative impact than those in remission.

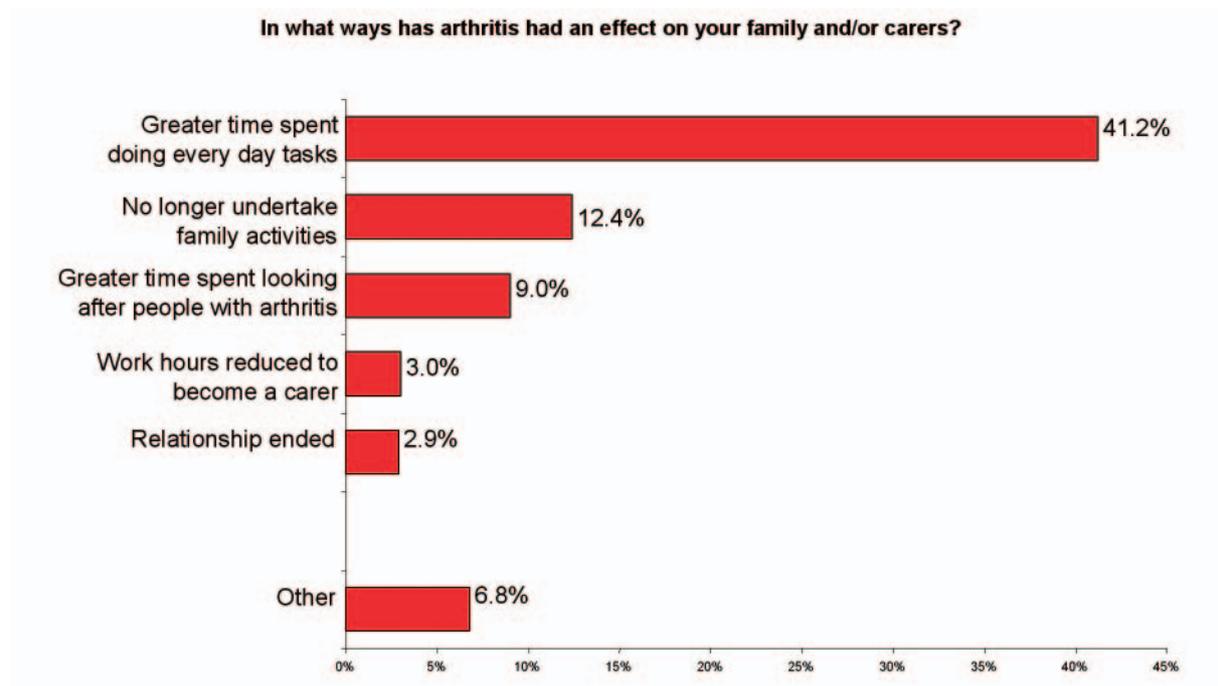
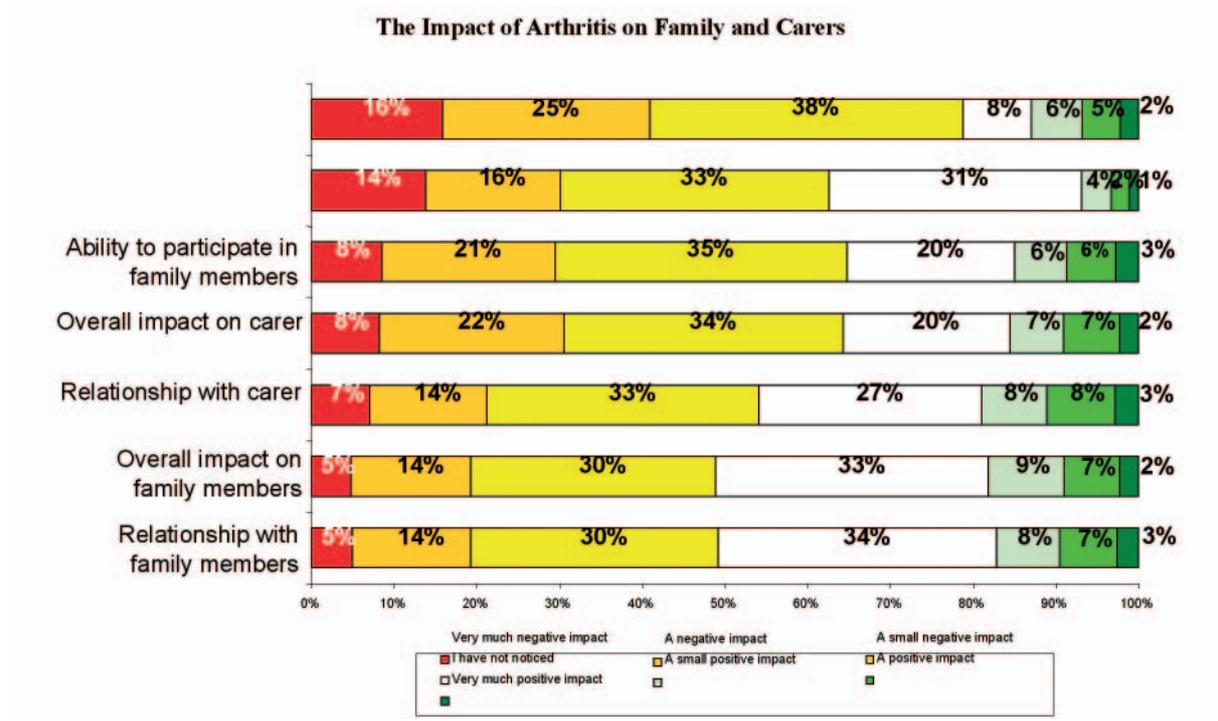
## 7.4 IMPACT ON FAMILY AND CARERS

The negative impact of arthritis on family and carers is quite variable with respondents indicating high negative impact (79%) for the limitations in everyday life compared to relatively low negative impact for the relationship with their family members and overall negative impact on their family members (each 49%). The extreme of negative impact is also low with thirty-eight percent indicating a 'small negative impact'. In terms of measures regarding their family, economic burdens on the family and their ability to participate in family activities registered the highest incidence of negative impact (63% and 64% respectively). This may indicate that respondents feel they are somewhat of a burden for their family although the relationship has not deteriorated.

The overall negative impact on the carer (64%) is much higher than negative impact on the same measure for their family indicating it is the carer who bears most of the workload in assisting them and as a result there is a higher negative impact on the relationship with the carer. It may also indicate the carer is someone outside the family or just one person in the family resulting in lower negative impact on the family overall.

The major reason (41.2%) for negative impact given by respondents is 'greater time spent doing every day tasks'. Only twelve percent of respondents indicated they can no longer participate in family activities.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)



### a) Overall impact on carer

Sixty-four percent of respondents indicate negative overall impact on their carer with those 60+ years perceiving much lower negative impact than other age groups while the 45-59 age group perceive more severe negative impact than others. There is no difference between males and females.

In terms of states, WA (87%) and Tasmanian (84%) residents perceive far greater negative impact than others. Casual employees (76%) and the unemployed particularly (93%) perceive higher negative impact than other employment status.

Those with osteoarthritis (58%) perceive lower negative impact especially compared to those with 'other types' who perceive much higher negative impact (79%). Those with acute rheumatoid arthritis perceive slightly higher negative impact than those in remission while those who do not know their stage indicated the highest negative impact (80%).

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

This is the complete inverse of those with osteoarthritis where those in the early stage perceive the highest negative impact (69%) and those who do not know their stage, the lowest (53%).

### b) Relationship with carer

While the overall negative impact on the carer is perceived at sixty-four percent, respondents indicated a lower level of negative impact (54%) on their relationship with this person. Those living in WA (94%), the unemployed (80%) and the 25-44 years age group (79%) perceive the greatest negative impact. Those living in NT (no impact – low sample), those in 'other accommodation (no negative impact), ACT residents (34%), Tasmania residents (34%), those who live in a retirement village (42%) and those with rheumatoid arthritis in remission (43%) indicated the lowest negative impact.

Females (57%) indicated slightly higher negative impact than males (51%).

Aside from those with extremes of impact, as indicated above, there is minimal difference between other states and employment status.

There is diverse opinion among accommodation status with relatively high negative impact for those who live in rental accommodation (67%) and those living in a relative's home/unit (63%) perceiving higher negative impact than alternative accommodation types especially 'other accommodation' and retirement village.

Those with 'other type of arthritis' indicate much higher negative impact (67%) than the alternatives.

### c) Overall impact on family members

Less than half of respondents indicated negative overall impact on family members while eighteen percent perceive positive impact.

Negative impact diminishes with age with the highest negative impact among 25-44 years (77%) and the lowest 60+ years (42%). Females (51%) perceive slightly more negative impact than males (46%), however they also perceive more positive impact than males (19%:15%).

Aside from those living in the ACT (20% negative impact: 45% positive impact) there is no discernible difference between states.

Those who are unemployed perceive much greater negative impact (78%) than other employment status, particularly those who are retired (40%) and those in full time employment (45%) who achieved the lowest incidence of negative impact.

Those with rheumatoid arthritis, particularly those in the acute stage perceive greater negative impact than those with osteoarthritis. Those with 'other type' of arthritis indicated the highest negative impact (62%) and those who do not know their arthritis type, the lowest (40%).

### d) Relationship with family members

Less than half of respondents indicated arthritis has had a negative impact on their relationship with their family and eighteen percent indicated a positive impact.

The incidence of negative impact is highest with those 25-44 years and the unemployed (75% each) and lowest among those who live in ACT (26%), NT (33% - low sample), those who do not know their osteoarthritis stage (32%) and those with rheumatoid arthritis in remission (35%).

The 60+ age group indicated much lower negative impact (41%) than other age groups while females indicated higher negative impact (53%) than males (44%).

WA residents perceive slightly higher negative impact (58%) than other states and aside from ACT and NT where the incidence of negative impact is lowest, there is no discernible difference between the other states.

Those on a pension, retired or in full-time employment indicated much lower negative impact than other types of employment.

Those with 'other' type of arthritis indicated much more negative impact (64%) than any other type of arthritis and those with rheumatoid arthritis, particularly those in the acute stage, experience more negative impact than those with osteoarthritis.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### e) Ability to participate in family activities

As with the economic burdens on the family, just under two-thirds of respondents indicated negative impact on their ability to participate in family activities and it is much higher among those less than 60 years particularly less than 24 years (100%).

There is minimal difference between males and females but in terms of states, WA residents perceive much greater impact (80%) compared to others while NT (33% - small sample), ACT (42%) and Tasmanian (50%) perceive lower levels of negative impact.

Casual employees, the unemployed and students perceive higher negative impact relative to other employment status.

There is no difference between arthritis types although those with acute Rheumatoid arthritis and chronic Osteoarthritis perceive higher negative impact compared to remission and early stages. Those who do not know their stage recorded the lowest incidence of impact among both arthritis types.

### f) Limitations in day to day life

Limitations on day to day life had the highest incidence of negative impact (79%) and unlike most measures, only a small percentage (8%) had not noticed any change.

The younger age groups, less than 60 years, particularly less than 24 years (100%), experience much higher negative impact than 60+ years and females (82%) is higher than males (64%).

WA (88%) and SA (86%) residents have a much higher incidence than other states while NT residents (50% - small sample) and ACT residents (69%) recorded the lowest negative impact.

In terms of employment, students (100%), casual employees (95%) and the unemployed (92%) indicated higher incidence of negative impact than others.

The negative impact on residential status is evenly spread however 'Other' accommodation had the highest incidence of severity of negative impact (40%).

There is no difference in negative impact between rheumatoid arthritis and osteoarthritis while 'other' types of arthritis had the highest incidence of negative impact (84%) and those who don't know the type of arthritis, the lowest. There is marginal difference between the different stages of arthritis, with the exception of 'don't know' respondents who indicated lower incidence of negative impact.

### g) Economic burdens on the family

Just under two-thirds of respondents indicated negative impact for the economic burdens on their family with the incidence diminishing with age (students – 100%: 60+ years – 52%) and females perceive much higher negative impact (79%) compared to males (55%). As would be expected, only seven percent indicated positive impact.

The incidence of negative impact is highest with ACT (77%) and Tasmanian (76%) residents and much lower with Victorian (59%), Queensland (56%) and NT (50% - small sample) residents.

Retirees (44% negative impact) indicated much lower negative impact than other employment status, particularly the unemployed (76%). This response is also reflected in accommodation status with those who live in a retirement village with an even spread of opinion in terms of positive and negative impact (42% negative impact). This would indicate that retirees who live in a retirement village perceive they are more self supportive economically than other groups and less of a burden.

Those who live in rental accommodation (67%) or a relative's home/unit (63%) indicated higher incidence of negative impact than any other accommodation type particularly 'other accommodation' respondents who indicated no negative impact.

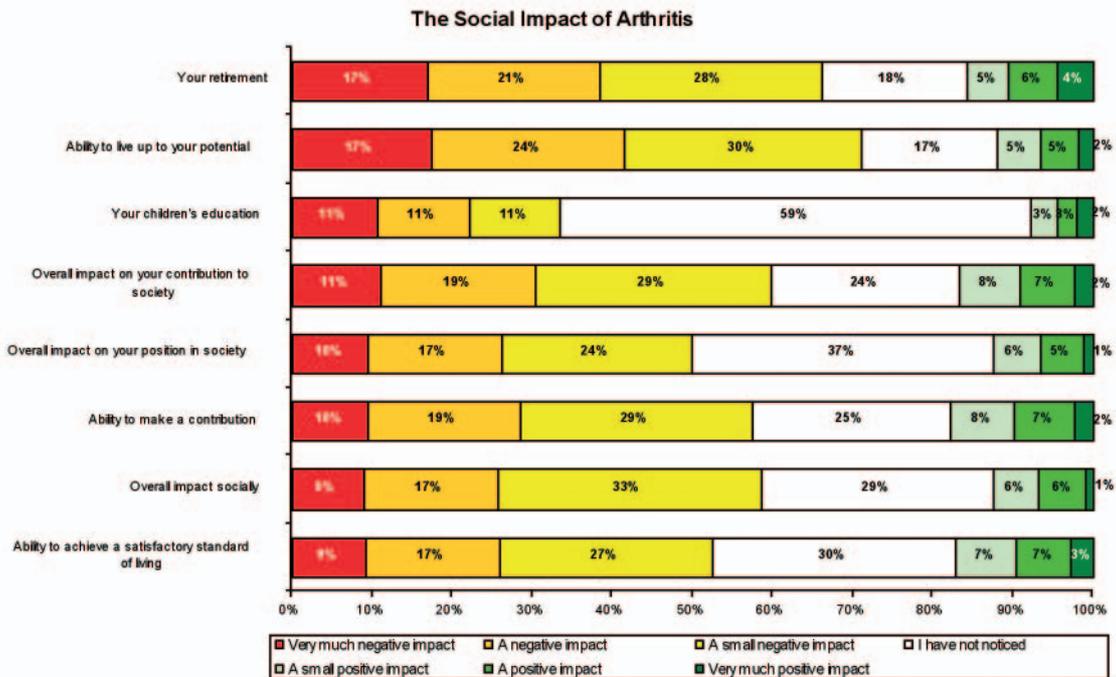
There is no real difference in negative impact between rheumatoid arthritis and osteoarthritis (52% and 51% respectively) however, those with other types of arthritis perceive much higher negative impact ((67%).

In terms of stage of their arthritis, those with rheumatoid arthritis in remission indicate much lower negative impact (44%) compared to other stages compared to those in the early stage of osteoarthritis which is slightly higher (54%) negative impact than other osteoarthritis stages.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### 7.5 SOCIAL IMPACT

The social impact of arthritis has affected respondents to varying degrees across the range of measures from a relatively high negative impact for their ability to live up to their potential (71%) to extremely low negative impact on their children's education (33%).



There are two major reasons given for the negative social impact of arthritis on respondents' life:

- Quality of life has decreased (44.6%)
- No longer in the workplace (39.1%)

There is no doubt respondents' quality of life decreases as a result of arthritis due to responses to other impact measures:

- activities due to pain
- The inability or greater time required to do everyday day tasks
- Movement restrictions
- The need for more rest

Respondents indicated that negative impact diminishes with age across all social impact measures with the exception of their ability to make a contribution where those less than 24 years perceive less negative impact than others.

The negative impact for males and females is almost identical across all measures with the exception of the impact on their position in society and their children's education where females perceive or have experienced more negative impact.

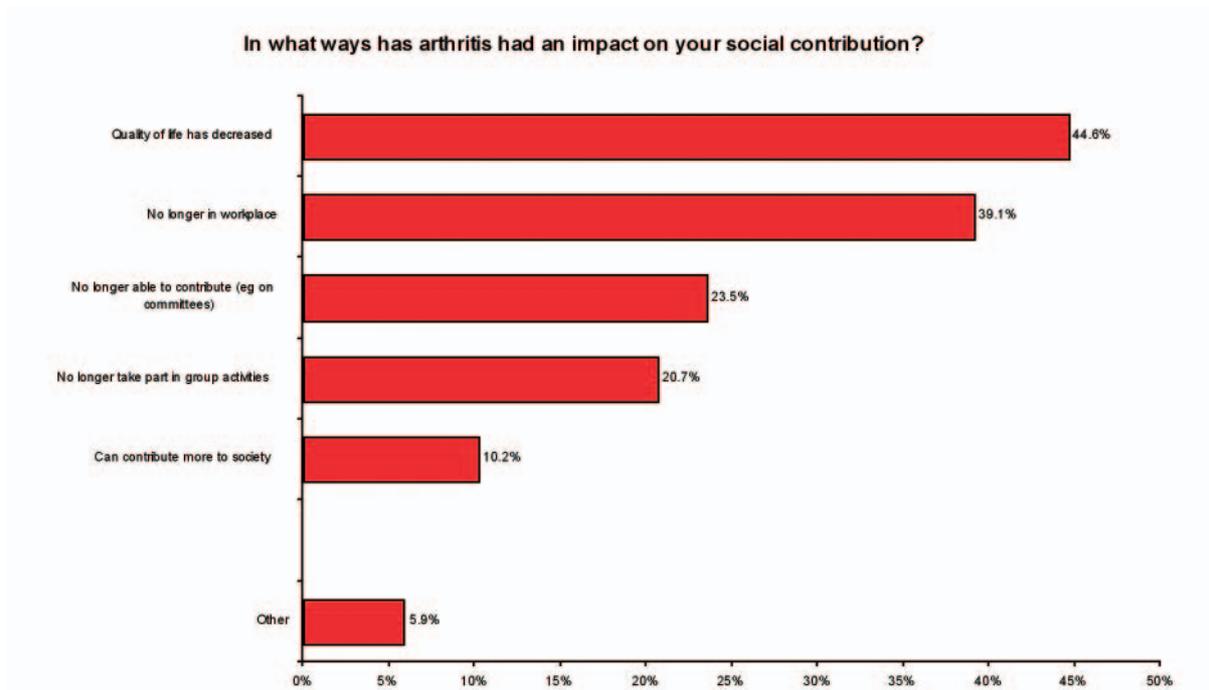
In terms of states, the incidence of negative impact would appear skewed to the eastern states, particularly Victoria which recorded the highest impact for all measures except their ability to achieve a satisfactory standard of living where ACT residents perceive more negative impact. There is no state in which respondents consistently indicate relatively lower negative impact.

Those unemployed perceive more negative impact for social impact than other forms of employment, while retirees and full time employees perceive the lowest negative impact.

Those living in a relative's home/unit ore a retirement village consistently indicate higher negative social impact with the exception of respondents' ability to achieve a satisfactory standard of living and their retirement for which those in rental accommodation perceive greatest negative impact.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Those with other types of arthritis perceive more negative impact while those with rheumatoid arthritis perceive more negative impact than those with osteoarthritis. Those in the acute or chronic stages of the latter two perceive much greater negative impact than those in the early or remission stages.



### a) Overall impact on your contribution to society

Just over half (51%) of respondents indicated a negative impact on their contribution to society with those less than 24 years (small sample) indicating the highest and most severe incidence of impact (67% very much negative impact: 33% negative impact) whereas other age groups and gender are of similar opinion (males 61%: females 59%) except for positive impact where females scored higher (20%) than males (13%).

The incidence of negative impact is skewed to the eastern states, particularly Victorian residents who perceive higher negative impact than others. This compares to Tasmanian residents who perceive more positive impact (45%) than negative impact (27%). ACT residents also indicated a high level of positive impact relative to others (39%) although the majority perceive negative impact (61%).

The unemployed and those on a pension perceive the highest negative impact on the ability to contribute to society whereas those in employment perceive the lowest negative impact.

Those residing in a relative's home or a retirement village perceive much higher negative impact than others and with the exception of those in the acute or chronic stage of arthritis, there is no difference between type of arthritis.

### b) Overall impact on your position in society

Relative to other measures of arthritis impact on their lives, the negative impact of their position in society is much lower with forty-one percent indicating negative impact.

There are varying degrees of opinion regarding the negative impact across all segments, however it is higher among the younger age groups and in particular students (72%), the unemployed (68%), those living in a relative's home/unit (66%), those in the acute stage of rheumatoid arthritis (64%), Victorian residents (62%) and those living in a retirement village (62%).

Females (53%) perceive higher negative impact than males (47%) and while Victorian residents indicate higher negative impact than other states, ACT (28%), NT (33% - low sample), South Australia (38%) and Tasmania (40%) perceive the lowest negative impact, with the latter indicating the highest positive impact (30%).

Those in employment or retired perceive lower negative impact as with those who live in their own family home.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Those with other types of arthritis and rheumatoid arthritis perceive more negative impact than osteoarthritis.

Those in the acute stage of rheumatoid arthritis perceive much greater negative impact than those in remission whereas those in the early and chronic stages of osteoarthritis perceive the same negative impact although the early stage to less severity.

### c) Overall impact socially

Fifty-nine percent of respondents indicated arthritis has a negative impact on their social lives particularly the 25-44 years age group (77%) whereas the less than 24 years age group perceives equal positive and negative impact.

There is minimal variance between males and females perception of negative impact although males perceive less positive impact.

Negative impact is skewed to the eastern states particularly Victoria (67%) whereas WA (48%) and Tasmanian residents (50%) perceive less negative impact.

There is a slight variance of opinion among employment status segments with the exception of students (72%) perceiving higher negative impact.

Those living in their family home/unit or other accommodation perceive lower negative impact particularly compared to those living in a retirement village where the incidence of negative impact is highest (73%).

A significant difference exists for those in the acute stage of rheumatoid arthritis (71% negative impact) compared to those in remission (47% negative impact).

### d) Ability to live up to your potential

In terms of social impact, respondents indicated the highest negative impact is with their ability to live up to their potential (71% negative impact). Negative impact is more prevalent among those less than 60 years, particularly in severity and the negative impact diminishes with age, with those under 44 years perceiving the highest negative impact. There is no significant difference between males and females in genitive impact.

Those living in the ACT and Tasmania perceive much lower negative impact than other states.

Students and the unemployed perceive much higher negative impact than those employed, on a pension or retired and those living in a relative's home (90% negative impact) perceive much greater negative impact than others.

There is minimal difference between arthritis types, however those in the acute or chronic stages of arthritis perceive greater negative impact than other stages.

### e) Ability to achieve a satisfactory standard of living

Just over half (53%) of respondents indicated a negative impact in their ability to achieve a satisfactory standard of living. Negative impact is more prevalent among those less than 60 years, particularly in severity and the negative impact diminishes with age with less than 24 years age group indicating the highest negative impact (83%).

Females perceive slightly higher negative impact than males and ACT residents perceive the highest negative impact (65%) compared to those who reside in other states, particularly Tasmanian residents where arthritis is perceived to have had a more positive effect (42% positive effect: 25% negative effect).

In terms of employment, those unemployed, casual employees and part-time employees perceive higher negative impact.

Those with rheumatoid arthritis, particularly in the acute stage and those with other types of arthritis perceive much higher negative impact than those with osteoarthritis.

### f) Ability to make a contribution

Fifty-seven percent of respondents perceive arthritis has had a negative impact on their ability to make a contribution with those 25-59 years perceiving higher negative impact. There is minimal difference between males and females with the exception of females perceiving more positive impact than males.

Those residing in the eastern states perceive higher negative impact than other states particularly Tasmania where they perceive more positive impact than negative impact (45% positive: 36% negative).

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Those on a pension or unemployed perceive much higher negative impact than casual employees or full time employees.

There is minimal difference between arthritis types with the exception of those in the acute or chronic stage who indicate much higher negative impact.

### g) Your children's education

Only thirty-three percent of respondents indicated negative impact from arthritis on their children's education and as would be expected this is heavily skewed by age and with the greatest concern among those less than 24 years where it perceived to have a severe negative impact by all.

Females perceive much higher negative impact (44%) compared to males (19%) and in terms of where they reside, those in Victoria indicate exceptionally higher incidence of negative impact (66%) relative to other states, particularly NSW (26%).

Those unemployed or on a pension perceive much higher negative impact than other employment status.

Those with other types of arthritis and rheumatoid arthritis perceive slightly higher negative impact than osteoarthritis whereas those who do not know their type of arthritis perceive no negative effect at all.

Those who are in the acute stage or do not know the stage of their rheumatoid arthritis perceive much greater negative impact compared to those in remission whereas there is minimal difference between the stages of osteoarthritis.

### h) Your retirement

Two thirds of respondents indicated negative impact from arthritis on their retirement and it is skewed by age with greater negative impact for those less than 60 years particularly less than 24 years where it perceived to have a severe negative impact by all and those who are getting close to retirement age (78% negative impact).

There is minimal difference between males and females and in terms of state variations, Victoria and WA residents perceive higher negative impact than others.

Casual employees (80% negative impact: 50% very much so) and the unemployed (82% negative impact) perceive much higher negative impact than other employment status, particularly those with full time employment (57% negative impact).

Those living in rental accommodation or 'other' accommodation perceive slightly higher negative impact.

Those with 'other' types of arthritis perceive slightly higher negative impact and those in the acute or chronic stages perceive higher negative impact than other stages of arthritis.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### 7.6 IMPACT ON EMPLOYMENT/ CAREER

Overall, respondents indicated a high degree of negative impact on their employment and career paths apart from the actual relationship they have with both their employer and fellow employees

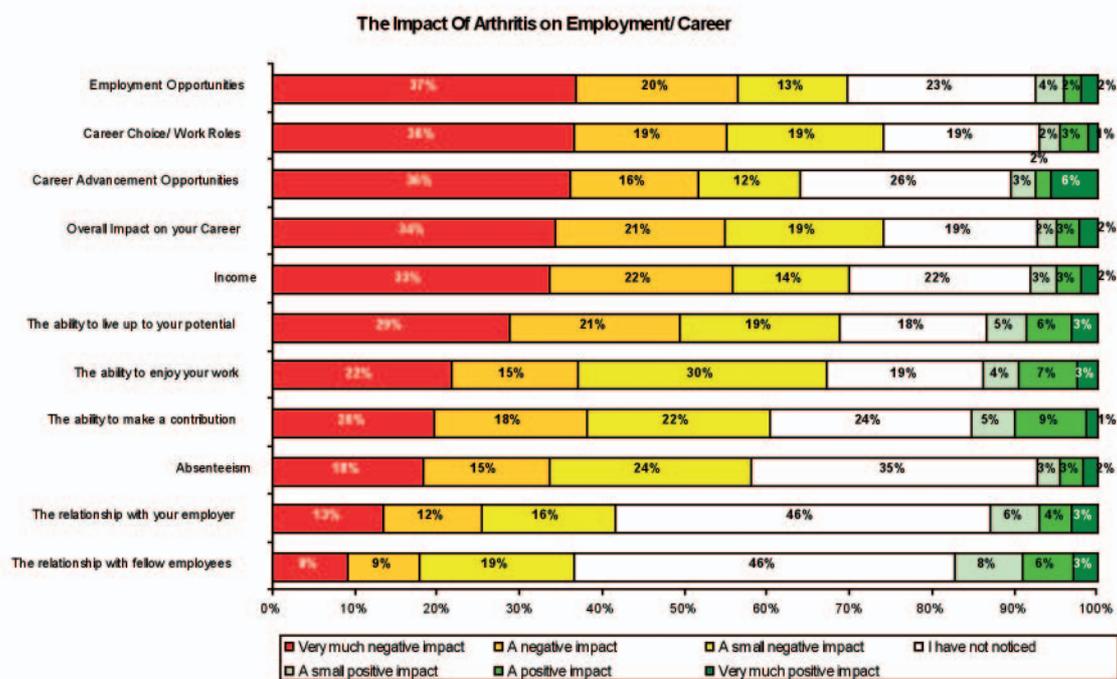
The highest areas of negative impact were with career choice/work roles and overall impact (74%) with over 30% of respondents indicating a very much negative impact on these groups. This was closely followed by employment opportunities and career opportunities. Having to retire was the most common way that arthritis impacted on respondents.

The incidence of impact on employment and career tended to decrease with increasing age with females being impacted more than males.

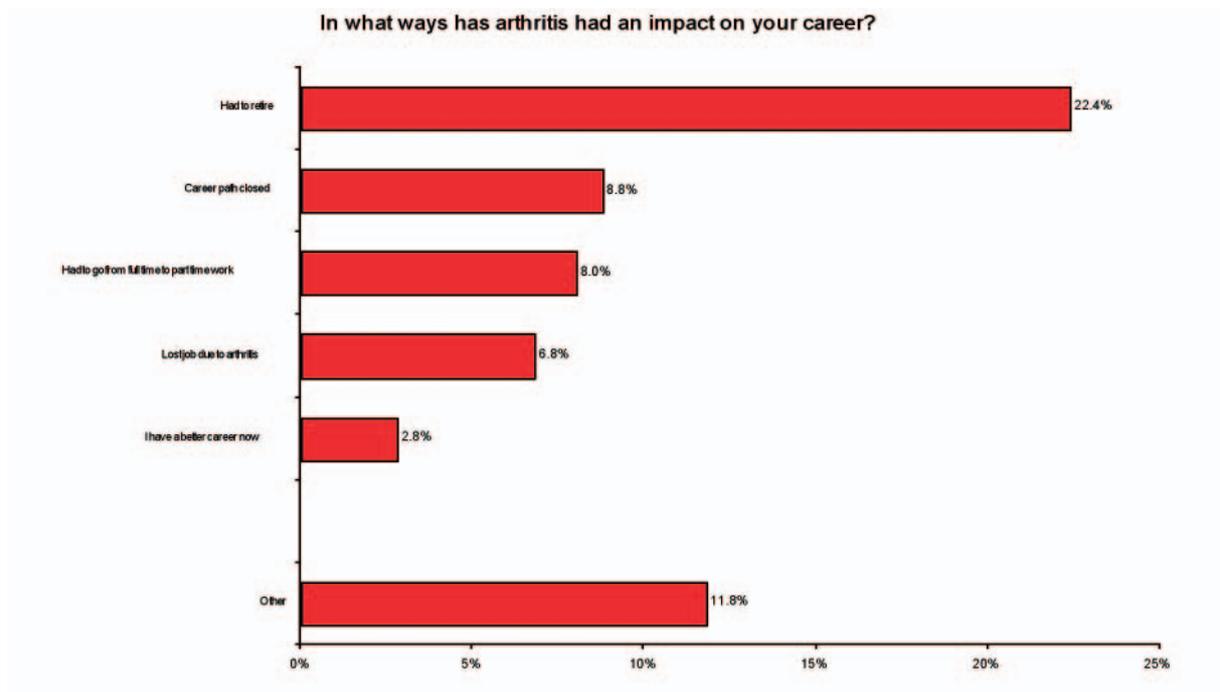
Overall ACT residents and Victorians seem more affected by arthritis when it comes to employment and career with SA having least impact (NT reported no impact, but only a small sample was received).

Income also has a high level of negative impact with reduction of salary the major cause.

The area with least impact was the relationship with fellow employees which only 37% negatively impacted, but 17% of respondents recording a positive impact on their relationship. This appears mainly in Queensland with those suffering with rheumatoid arthritis.



## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)



### a) Overall impact on your career

74% of respondents recorded a negative impact on their career, with 34% having a very much negative impact. This was very evident in the younger age groups especially with the 25-44 year olds who had an 83% negative impact and 24 year olds (100%).

Females were more negatively impacted than males and by state, Victoria and the ACT were worst affected. SA and NT were least affected (note small sample in NT).

The highest severity of impact with regard to employment status was with those who no longer have a career, students, and casually and part-time employed people. Those retired and on a pension also recorded high negative impact as they may have had to retire early and go onto a pension.

Respondents with negative impact also tend to living in rented accommodation (75%), a relative's home (100%) or in a retirement village (84%).

82% of respondents affected with other types of arthritis recorded a negative impact with 43% being severe. 95% of those respondents who had rheumatoid arthritis and were in the acute phase indicated a negative impact with 50% being severe.

### b) Relationship with your employer

Only 41% of respondents indicated a negative impact in the relationship with their employer with 13% indicating a positive impact being mainly students and <24 year olds.

Females indicated a higher level of negative impact than males whilst Victoria and Tasmania dominate negative impact compared to other states.

Of those respondents employed, casually employed indicated the highest level of negative impact, with 33% of students having a positive impact on their relationship.

People living in rental accommodation felt a greater negative impact (42%) than those who owned their house or unit.

Those with other types of arthritis experienced slightly more negative impact, but as would be expected, those with acute rheumatoid arthritis and those with osteoarthritis in the chronic phase have experienced a far greater negative impact than arthritis in any other stage.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

### c) Relationship with fellow employees

Of all the criteria measured, relationships with fellow employees indicated the least amount of negative impact (37%) and the highest positive impact (17%) overall.

The younger age groups indicated higher levels of negative impact than the 60+ age group, with females indicating slightly higher levels as well.

By state, there was a clear issue from Victoria with 64% recording negative impact with 14% recording severe impact. Queensland residents on the other hand experienced the highest level of positive impact at 24%.

Looking at the various employment types casually employed those now unemployed and on the pension indicated the larger levels of negative impact than other types, with full time employees showing 23% of a positive impact.

Those respondents who live in a retirement village or other type of accommodation indicated the greatest levels of negative impact.

Finally, those with other types of arthritis at 43% experienced greater negative impact than those with osteoarthritis or rheumatoid arthritis. But as shown before, those people in the acute phase of rheumatoid arthritis and the chronic phase of osteoarthritis have recorded much higher levels of negative impact than other types of people with arthritis.

### d) Employment opportunities

Overall, the majority of respondents (70%) indicated negative impact with employment opportunities, with over one third indicating this to a severe level.

Less than 24 years old (low sample) indicated 100% negative impact while 45-59 year olds also showed 75% negative impact perceiving the poor employment opportunities on offer.

Females indicated a slightly higher level of negative impact than males and this was more apparent in those living in rental accommodation than for any other accommodation type. Those people who are unemployed or casually employed recorded very high levels of negative impact with both groups indicating >50% with severe impact.

Victorian residents indicated a very high level of negative impact at 90% (with 53% recorded as severe) as did Tasmanians at 100%. Only WA residents had an impact less than 60%.

Over 80% of people with other types of arthritis experienced negative impact, and as expected those in the acute phase of rheumatoid arthritis recorded a severe impact of over 50%.

### e) Income

69% of respondents indicated a negative impact with 'Income'.

The younger age groups indicated higher levels of negative impact with 78% of the 25-44 year olds indicating negative impact with 43% considering it to be severe. Females also experienced higher levels of negative impact than males with a clear indication from Victoria with over 88% having some form of negative impact. ACT residents also experienced negative impact at 77%.

Looking at the various employment types, naturally those people unemployed were impacted most 93% and those on the pension (84%) recording larger negative impacts than other types.

Those respondents who live in other types of accommodation indicated the greatest levels of negative impact at 78%, but over 50% indicated the severe nature of the impact.

Finally, those with other types of arthritis at 75% experienced slightly greater negative impact than those with osteoarthritis or rheumatoid arthritis. Those people in the acute phase of rheumatoid arthritis (86%) have recorded much higher levels of negative impact than other types of people with arthritis.

### f) Career advancement opportunities

64% of respondents recorded a negative impact on their career advancement opportunities, with 36% having a very much negative impact. This was very evident in the younger age groups especially with the 45-59 year olds who had a 70% negative impact (with 43% considering it be severe) and the <24 year olds at 100% (small sample).

Females were more impacted than males and by state Victoria responses were the most significant with 93% having a negative impact with a significant 61% considering it to be severe. These results were much higher than other states

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

apart from ACT which was 83%.

The highest severity of impact with regard to employment status was with those who no longer have a career, and casually employed people. Those retired and on a pension also recorded high negative impact as they may have had to retire early and go onto a pension as their career opportunities closed.

Respondents with negative impact also tend to be living in other accommodation or in a retirement village (both 67%). 75% of respondents affected with other types of arthritis recorded a negative impact with 43% being severe. 84% of those respondents who had rheumatoid arthritis and were in the acute phase indicated a negative impact with 46% being severe.

### g) Career choice/work roles

The choice of career or work role indicated high levels of negative impact at 74% overall with only 6% indicating some sort of positive impact.

This was very evident in the younger age groups with 25-44 year olds experiencing 83% negative impact. There was only slight variance between females and males with females indicating a greater negative impact.

By state, there was a clear issues in three states who all recorded close to on exactly 100% negative impact; Victoria, ACT and Tasmania. Queensland residents on the other hand experienced the highest level of positive impact at 12%.

Those respondents casually employed, on the pension or retired indicated the larger levels of negative impact than other types, with full-time employees showing the least negative impact at 55%. Those on a pension or retired may be as a result from their work role being closed or the career choice was removed.

Those respondents who live in other types of accommodation or rental accommodation indicated the greatest levels of negative impact.

Those with other types of arthritis at 82% experienced greater negative impact than those with osteoarthritis or rheumatoid arthritis. However, those people in the acute phase of rheumatoid arthritis (89%) and the chronic phase of osteoarthritis (76%) have recorded much higher levels of negative impact than other types of people with arthritis.

### h) Absenteeism

Overall, the majority of respondents (57%) indicated negative impact with the amount of time taken from work due to arthritis with only 8% indicating some sort of positive impact.

This was clearly shown in the younger age groups with 25-44 year olds indicating negative impact of 69%.

Once again, females indicated a higher level of negative impact than males (62% to 51%) and this was also evident in those living in rental accommodation and other types of accommodation. Those people who are unemployed or students recorded very high levels of negative impact, and full-time employees experienced the smallest negative impact of 44%.

Tasmanian residents indicated a very high level of negative impact at 100% (with 50% recorded as severe) with Victorians experiencing 77% negative impact. Only WA residents had a smaller impact of 33%.

64% of people with rheumatoid arthritis indicated a negative impact, however this escalated to 80% if they were in the acute phase with 23% indicating a severe impact.

With regard to time off work, 54% of respondents identified that they had to take a week or less time off work per year due to arthritis. However only a small number of respondents (104) answered the question, mainly due to the high percentage of 60+ age group of the overall sample.

### i) Ability to enjoy your work

67% of respondents recorded a negative impact on their ability to enjoy their work, with 22% having a very much negative impact. This was very evident in the 45-59 age group especially who had an 81% negative impact.

There was marginal difference between females and males and by state, Victoria and Queensland were worst affected with 80% and 70% respectively. The ACT had the highest positive impact of 20%.

The highest level of impact with regard to employment status was evenly spread across all groups, though it should be noted that 62% of full-time employees recorded a negative impact with 38% being only a small negative impact.

## 7. THE IMPACT OF ARTHRITIS ON PERSONAL LIFE (CONT'D)

Respondents with negative impact also tend to be living in other types of accommodation (76%) or in a retirement village (90%).

77% of respondents affected with other types of arthritis recorded a negative impact with 27% being severe. 81% of those respondents who had rheumatoid arthritis and were in the acute phase indicated a negative impact with 34% being severe.

### j) Ability to make a contribution

60% of respondents indicated a negative impact with their ability to make a contribution with 15% feeling there was a positive impact.

The 60+ age group recorded a 22% positive impact whereas the younger age groups indicated higher levels of negative impact with 69% of the 25-44 year olds indicating negative impact. There was very little variation between females and males.

State wise, Victoria experienced a negative impact of 73% which was greater than the other states. Tasmanians however recorded a significant 43% positive impact on their ability to make a contribution.

Looking at the various employment types, naturally those people unemployed were negatively impacted the most (100%) as well as students (80%) and those on the pension (72%). Those respondents who live in other types of accommodation indicated the greatest levels of negative impact at 77%, with almost 50% indicating the severe nature of the impact.

Finally, those with other types of arthritis at 67% experienced slightly greater negative impact than those with rheumatoid arthritis and then those with osteoarthritis. However, those people in the acute phase of rheumatoid arthritis (79%) have recorded much higher levels of negative impact than other types of people with arthritis.

### k) Ability to live up to your potential

Overall, the majority of respondents (69%) indicated negative impact with the ability to live up to their potential, with only 14% indicating a positive impact.

Less than 24 year olds (low sample) indicated 100% negative impact while 25-44 year olds also showed 79% negative impact with 34% recording a severe negative impact.

Females indicated a higher level of negative impact than males at 72% and this was more apparent in those living in other types of accommodation than for any other accommodation type. Those people who are unemployed or casually employed recorded very high levels of negative impact with both groups indicating >50% with severe impact.

Victorian residents indicated a very high level of negative impact at 82% (with 38% recorded as severe). Only Tasmanian residents had a significant low negative impact of 38% and a high positive impact also of 38%.

Over 74% of people with other types of arthritis experienced negative impact, and as expected those in the acute phase of rheumatoid arthritis recorded a high negative impact of 82% with 42% being severe.