CONSUMER RESEARCH ACTIVITIES

2018 - 2019

Arthritis
AUSTRALIA

May 2020

Arthritis Australia

CONSUMER RESEARCH ACTIVITIES

2018 - 2019

Contents

1. Introduction

People with arthritis are at the centre of Arthritis Australia's mission and activities and consumer-based research underpins our policy development and advocacy.

In 2018-19, the major focus of our consumer research related to identifying consumer issues and action priorities for the development of the *National Strategic Action Plan for Arthritis*. In addition, consumer research was undertaken to inform Arthritis Australia's responses to government consultations and inquiries.

2. Consumer Research for the *National Strategic Action Plan for Arthritis*

Consumer research to inform the development of the *National Strategic Action Plan for Arthritis* included initial consultations with consumers to identify key issues of concerns, and a public consultation on the *Draft Action Plan*.

2.1. Initial Consultations

Initial consumer consultations included discussions with consumer representative groups and an online consumer survey. Participants were invited to identify key issues and potential solutions relating to their experience of receiving care for their arthritis.

Discussion groups

A focus group was held with Arthritis Australia's National Arthritis Consumer Reference Group. This group includes 10 members, with representatives from across Australia. Most members are linked to consumer networks within their local state or territory, so they were able to draw from both their own personal experience, as well as the experiences reported within their broader consumer networks.

In addition, a consultation was held with representatives of other arthritis consumer organisations including Creaky Joints Australia, Psoriatic Arthritis Australia and Ankylosing Spondylitis Victoria.

A further consultation was held with a group of six consumers with osteoarthritis, including those consumers who were participating in working groups for the development of the *National Osteoarthritis Strategy*.

Online survey

An online consumer survey was conducted from 10 July – 17 August 2018. The survey was promoted through arthritis consumer organisation networks and social media.

The survey asked open-ended questions about people's experience of the care they received for their arthritis. These questions asked how satisfied people were with their care, the reasons for their satisfaction/dissatisfaction, their perceptions of barriers to care, and their ideas for what could be done to improve care in the future.

Respondents

There were 446 respondents to the survey including people of all ages, from all states and territories (Figure 1), and with a range of different types of arthritis (Figure 2). There was a higher response rate from the ACT and a lower response rate from NSW relative to their populations. There was also a higher response rate, compared to the overall population with arthritis, from people with rheumatoid arthritis (34% compared to 13%) and from younger people (22% compared to 10% aged 25 years or less). Two thirds of respondents (66%) were based in a major metropolitan centre, 21% in a regional centre and the remainder in smaller rural centres.

Figure 1: Proportion of consumer survey respondents, by state and territory

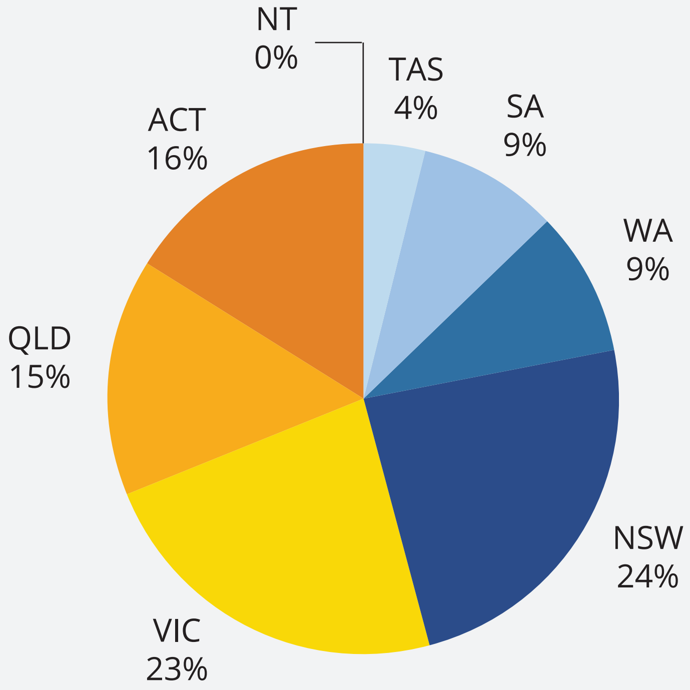
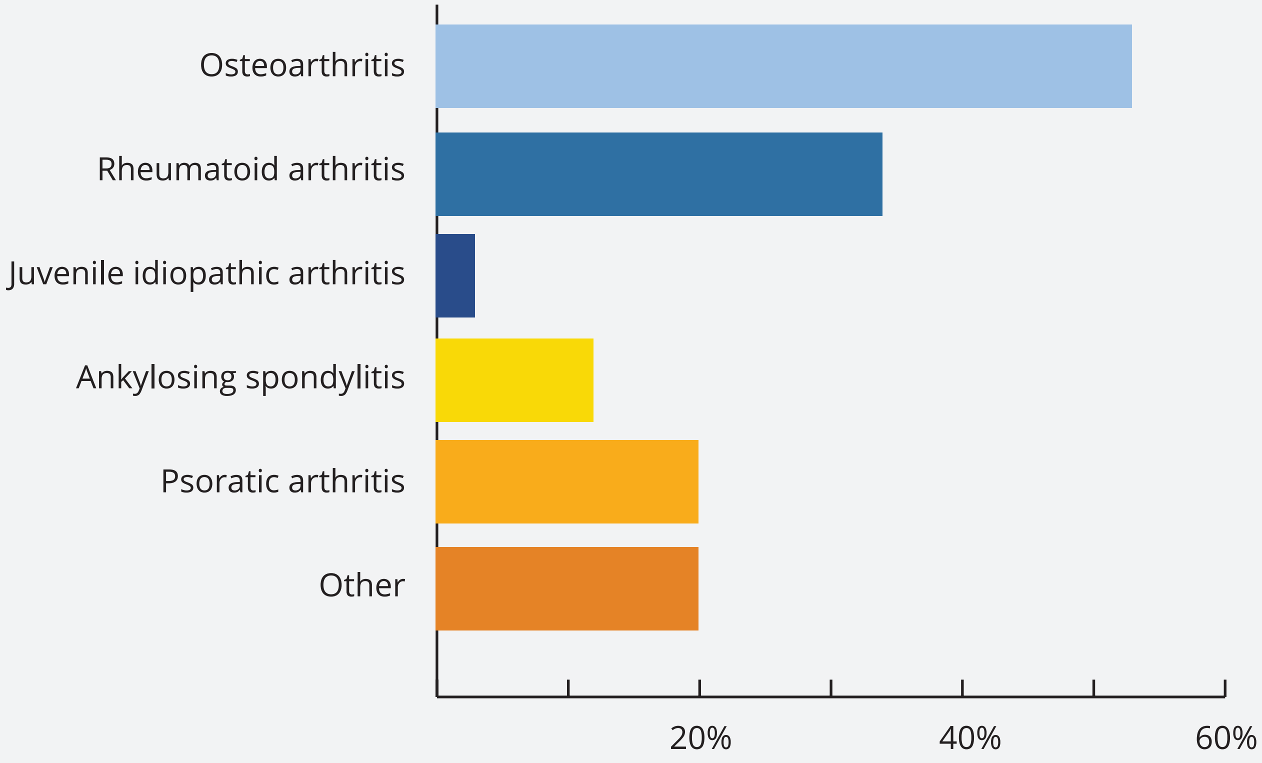


Figure 2: Consumer survey respondents - conditions



2.1.1. Key Themes

The key themes relating to arthritis care raised in the discussion groups and by participants in the online survey were similar and are summarised below.

High out-of-pocket costs

Consumers reported that they faced high out-of-pocket costs for their care, which was mostly undertaken in the private sector. In particular, people reported that the cumulative costs associated with private specialist visits, imaging, allied health professional services (especially for exercise therapy), medicines and surgery were prohibitive.

The high cost of accessing care was the most commonly cited concern among survey respondents, mentioned by one in three people.

Lack of information and support

Consumers highlighted that they received no information or support at diagnosis to help them learn to cope with or manage their condition. In particular, they had no ‘orientation’ to help them adjust to and plan for a life with a chronic condition, and no indication of what to expect in the future. Many reported feelings of confusion, denial and fear for the future.

Participants also reported that they received limited advice about self-management strategies such as exercise, which other health professionals might be of assistance, or where to go for more information or support. Consumers with osteoarthritis in particular often reported receiving no management advice from their doctor and being told to ‘just put up with it’.

Concern about medications and treatment

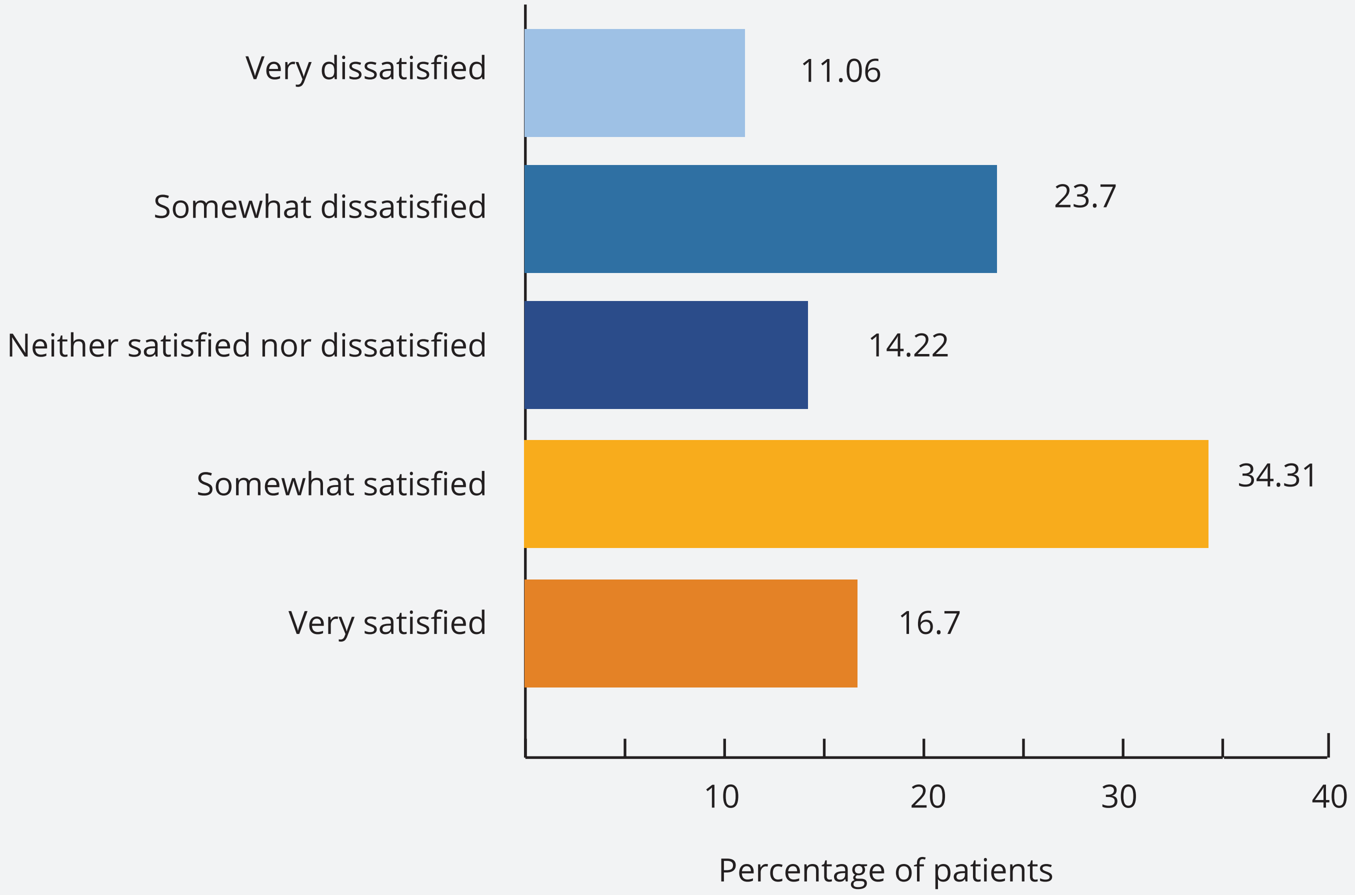
One in four survey respondents expressed dissatisfaction with the medications and treatments available for their condition, with dissatisfaction most commonly expressed by people with osteoarthritis.

For people with inflammatory forms of arthritis, the most common concerns expressed were the difficulties associated with finding and accessing the right treatments, fear of certain medications (e.g. methotrexate) and medication side-effects.

Dissatisfaction with medical care

While around half of survey respondents were satisfied with their care, one in three reported that they were somewhat or very dissatisfied with their care (Figure 3). Satisfaction differed by diagnosis, with more than 40% of people with osteoarthritis and with less common types of arthritis expressing dissatisfaction with their care.

Figure 3: Consumer survey respondents - satisfaction with care



Interestingly, many people who reported satisfaction with their care went on to highlight similar issues to those who reported dissatisfaction with their care. These issues included:

- Lack of health professional knowledge about arthritis and its treatment. This was reported by people with all types of arthritis. In particular, many highlighted that neither GPs nor specialists understood the impact of arthritis on people's lives.
- Diagnostic delays especially for inflammatory forms of arthritis.
- Over-reliance on medications and surgery for management and limited advice about non-pharmacological management strategies, including exercise.
- Poor pain management and limited support for emotional wellbeing.
- Nihilism around management of osteoarthritis and being told to 'just put up with it'.
- Long waiting times for appointments and rushed appointments, especially for specialist visits.
- Lack of holistic care, fragmented care and poor care coordination. Respondents who reported good care coordination were more likely to report satisfaction with their care.
- Poor communication between health professionals and limited use of care plans.
- Travel distance, inconvenience and costs of accessing specialist care, especially for rural respondents.

Survey respondents who reported satisfaction with their care were more likely to report that they had a care plan and that their health professional was proactive and a good communicator who took time to listen to, and work with them, to plan their care.

Limited access to public services

Participants reported limited and inequitable access to public services. This included long waiting times and limited access to public services such as rheumatology, paediatric rheumatology, allied health, pain management and elective surgery. Access was a particular issue in rural and regional areas, but also in some underserviced metropolitan areas.

Limited access to multidisciplinary care

Although multidisciplinary care is recommended for people with all types of arthritis, few people are able to access team-based care. Barriers to accessing multidisciplinary care included:

- Lack of referral or advice from their treating doctor about which allied health professionals could be helpful.
- Difficulty identifying appropriately skilled allied health professionals (especially for inflammatory arthritis).
- The prohibitive cost of accessing allied health services due to limited Medicare or private health insurance rebates.

2.1.2. Suggested Solutions

Survey respondents were asked to identify what things could be done to help them receive the right care in future. The most common suggestions were:

- Improve consumer information, education and support, especially at diagnosis (suggested by one in three respondents).
- Improve multidisciplinary care and care coordination (suggested by 16% of respondents).
- Increase funding for health services (e.g. through Medicare and increased public services) to improve access, reduce waiting lists and reduce out-of-pocket costs (15% of respondents). A common suggestion was to increase the number of Medicare subsidised services available under chronic disease management plans.
- Improve arthritis education for health professionals, especially GPs (10% of respondents) and allied health professionals.
- Raise public understanding and awareness of arthritis and of symptoms that require prompt medical attention.

2.2. Public Consultation on *Draft Action Plan*

The *Draft National Strategic Action Plan for Arthritis* (the *Draft Action Plan*) was made available for an online public consultation from 15 November to 7 December 2018.

Submissions on the *Draft Action Plan* were invited using a variety of channels. These channels included direct email invitation to identified stakeholder organisations and individuals, promotion via the websites and newsletters of Arthritis Australia and other arthritis consumer organisations, and promotion via social media.

Submissions were invited from individual consumers and clinicians as well as more than 100 stakeholder organisations, including arthritis consumer organisations. Respondents were asked to provide their views on the vision, priority areas, objectives and actions outlined in the *Draft Action Plan*. They were also asked to rate the actions within each objective in terms of priority for implementation.

Respondents

In total 221 responses to the consultation were received, of which 164 (74%) were people with arthritis and 15 (7%) were family members or carers for someone with arthritis.

Reponses were generally geographically representative across all states and territories and across metropolitan and regional centres.

Respondents identified that they were interested in a range of arthritis types, most commonly osteoarthritis (62%), chronic pain (52%), and rheumatoid arthritis (50%).

Twenty-five respondents identified as being from a culturally and linguistically diverse background and three respondents identified as Aboriginal and Torres Strait Islanders.

Outcomes

Respondents were asked to rank the objectives and actions outlined in the *Draft Action Plan* on a scale of one to five, with one being the most important and five being the least important. The results were averaged to identify the most highly ranked objectives and actions.

Across the nine objectives of the Action Plan, the following were the three top-ranked objectives, based on a simple average of rankings across all respondents:

1. Empower people with arthritis with information, education and support to effectively self-manage their condition.
2. Improve affordable and timely access to appropriate health care and services.
3. Increase community awareness and understanding of arthritis, its risk factors and opportunities for prevention and improved management.

Sub-group analyses were undertaken for the major respondent groups, namely consumers/carers, health care professionals and stakeholder organisations to identify if there were any differences in priorities across these respondents.

Empowering people with arthritis to self-manage their condition was ranked as the top priority by consumers and health professionals and the third highest priority by organisations.

Improving access to services was the second highest priority objective identified by consumers and the third highest identified by health care professionals but was only ranked sixth by organisation respondents.

Sub-group analyses of the 10 most highly-ranked actions revealed significant differences between consumers and health professionals in their most highly-ranked actions. Consumers rated actions which increased their access to services and support programs more highly than did health professionals. These actions included: affordable access to specialist services; early diagnosis and intervention; affordable access to interdisciplinary team care; consumer support programs; and access to lifestyle interventions.

On the other hand, health professionals ranked actions which would support them in the delivery of arthritis care more highly than did consumers. Many of the actions ranked most highly by health professionals were not included in the 10 most highly-ranked actions overall. The most highly ranked actions for health professionals included: support tools and systems to assist health professionals deliver arthritis care; workforce education and training; treatment guidelines; development of a national data strategy and expanded service delivery in rural areas.

3. Consumer Research for Consultations and Inquiries

Arthritis Australia regularly makes submissions to government inquiries and consultations and undertakes consumer research to inform our responses.

3.1. Proposal to Up-Schedule Modified-Release Paracetamol

In October 2018, the Therapeutic Goods Administration (TGA) held a consultation on the proposal to up-schedule modified release (MR) paracetamol to a 'pharmacist only' medicine. This meant that the product would still be available without a script but would be held behind the counter by pharmacists. This proposal had been developed to address risks associated with overdose related to the MR formulation due to its unpredictable pharmacokinetic profile. The MR release product is primarily targeted to people with arthritis, particularly osteoarthritis.

To develop a response, members of Arthritis Australia's National Arthritis Consumer Reference Group (NACRG), state and territory arthritis organisations, the Consumers Health Forum and PainAustralia were invited to provide their views on the proposed upscheduling and the impact that this proposal would have on people with arthritis. NACRG members, a number of whom are connected to arthritis consumer networks in their States and Territories, were also asked to consult with other consumers in those networks.

Ten people responded to the invitation to provide feedback on the proposed up-scheduling. Of these, the majority (n=7) supported the proposed up-scheduling, one was neutral and two were opposed. Reasons provided for supporting the proposal included:

- Growing evidence suggested that paracetamol was ineffective for osteoarthritis.

- Making the MR product a ‘pharmacist only’ product was a relatively minor inconvenience and would increase consumer interactions with the pharmacist that were likely to support the quality use of both MR paracetamol and other medications.
- Non-MR paracetamol was still freely available.
- Concerns regarding the safety issues highlighted by the TGA, namely the increasing use of MR paracetamol for suicide attempts by young women and the difficulties of effectively managing overdoses associated with this product.

Reasons provided for not supporting the proposal were that it would make it more difficult to use simple medications on an ongoing basis; that it implied that regular users of the product were unable to manage their own medications; and concern that the move might result in cost increases for the product.

A number of respondents highlighted the importance of providing better health system support and funding to increase the uptake of non-pharmacological strategies, such as exercise, for arthritis pain management.

These responses were incorporated into Arthritis Australia’s submission to the TGA.

3.2. Opioid Use for Arthritis

Arthritis Australia was invited to participate in a consultation forum held by NPS MedicineWise to inform the development of a consumer and health professional education program on the use of opioids for chronic non-cancer pain. The aim of this program was to reduce the harms of opioids while ensuring adequate pain management and quality of life.

To inform Arthritis Australia’s participation in this forum, we undertook a scan of medical research and grey literature relating to the use and misuse of opioids for chronic pain management in arthritis, and on consumers’ knowledge, attitudes and beliefs relating to opioid use for their pain.

The key findings from the literature scan were:

- Musculoskeletal conditions are the leading cause of chronic non-cancer pain and are the leading health problems for which opioids are prescribed in primary care.
- There is limited evidence to support longer-term opioid use in osteoarthritis or in chronic back pain, with the small to moderate benefits in pain and function outweighed by the risk of adverse events.
- Weak opioids may be effective in short-term management of pain associated with rheumatoid arthritis, but there are concerns that adverse events may outweigh these benefits and there is limited evidence relating to the impacts of longer term use.
- One the other hand, some evidence suggested that some people with chronic non-cancer pain experience clinically significant pain relief with opioids, with only minor adverse events.

To supplement the information from the literature scan, consultations were held with members of the NACRG and, through them, with wider arthritis consumer networks. These consultations found that many people with arthritis reported that opioid medications helped them to manage their pain during periods when they were experiencing an aggravation of their condition. In addition, many people reported that, as a result of the focus on opioid misuse and measures being implemented to reduce opioid prescribing by doctors, they were being made to feel like criminals for requesting these medications to help them relieve their pain. This was especially difficult when they were not offered any effective alternatives, either pharmacological or non-pharmacological, to assist with pain relief.

These views were conveyed to the consultation forum and helped inform the development of the opioid program which can be found at the NPS MedicineWise website.

Arthritis
AUSTRALIA

Address	Level 2, 255 Broadway, Glebe NSW 2037
Phone	(02) 9518 4441
Free Call	1800 011 041
Website	www.arthritisaustralia.com.au
Email	info@arthritisaustralia.com.au