CONSULTATION SUMMARY FOR THE NATIONAL STRATEGIC ACTION PLAN FOR ARTHRITIS

Arthritis Australia 2019

About arthritis

Arthritis is an umbrella term for more than 100 different conditions that affect the joints. Most of these conditions fall into one of two categories: degenerative arthritis, such as osteoarthritis, or inflammatory arthritis, such as rheumatoid arthritis.

Many inflammatory forms of arthritis are autoimmune conditions in which the immune system, which normally works to fight off infections, attacks a person's own healthy tissues. Inflammatory forms of arthritis include rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, juvenile idiopathic arthritis and systemic lupus erythematosus (lupus) among others.

Contents

Executive Summary

A comprehensive series of consultations was undertaken to inform the development of the *National Strategic Action Plan for Arthritis.* The consultation processes included:

- An Arthritis Roundtable involving key stakeholders to identify priority actions and interventions.
- The establishment of a representative Steering Committee as a consultative group to guide the development of the Action Plan. This committee met on two occasions.
- A series of targeted initial consultations in the form of one-on-one interviews with consumers, health professionals, non-government organisations, state and territory departments of health and Primary Health Networks. The aim of this series of consultations was to ensure a broad range of information and perspectives was taken into consideration in the development of the Action Plan.
- A consumer survey and consumer focus groups.
- An online public consultation on the *Draft National Strategic Action Plan for Arthritis.*

In addition, many of the recommendation in the Action Plan were informed by the *National Osteoarthritis Strategy 2018* which was being developed at the same time and which was also the subject of extensive stakeholder consultations.

The consultations identified a number of issues and potential solutions relating to arthritis care, which informed the development of the *National Strategic Action Plan for Arthritis*.

1 Arthritis Roundtable

The Commonwealth Department of Health, in partnership with Arthritis Australia, hosted an Arthritis Roundtable involving key stakeholders on 8 December 2017. The purpose of the Roundtable was to inform the development of the *National Strategic Action Plan for Arthritis* by developing a list of priority actions and interventions to improve arthritis care in Australia.

Roundtable participants included consumers, health professionals, researchers and health services providers. Participants in the Roundtable are listed in *Appendix A.*

The Roundtable discussion was guided by four themes:

- Awareness, prevention and health promotion
- Early diagnosis, better treatment and care
- Consumer information, education and support
- Research.

Roundtable participants identified the following key actions or interventions.

1.1 Consumer resources

- Build targeted, online tools that respond to individual circumstances, such as age, disease, stage of arthritis etc, and provide peer support (very highly ranked).
- Develop resources for provision of information and support for people at time of diagnosis.
- Deliver 'arthritis boot camps' or similar (language to be appropriate to target group) across Australia; supported by advice of a case manager.

1.2 Better treatment and care

- Roll out the NSW Osteoarthritis Chronic Care Program, as well as models of care for paediatric, inflammatory arthritis and rheumatoid arthritis nationally (most highly ranked).
- Develop and improve the information within, and adoption of, HealthPathways for arthritis through Commonwealth support to encourage prioritisation at the Primary Health Network level (highly ranked).
- Fund a pilot program to develop enhanced multidisciplinary care and care-coordination, including flexible funding, more allied health visits and group sessions.

1.3 Prevention and awareness

- Deliver a broad-based arthritis awareness raising campaign, including social media.
- Include messaging about arthritis in Commonwealth Government health promotion programs and partner with other organisations active in obesity, smoking and chronic disease prevention and health promotion to support arthritis prevention and management.
- Include joint injury prevention as a priority through the Australian Sports Commission and across all government funded sports programs.

1.4 Research

- Increase funding for arthritis research to:

    - Build long-term capacity and support retention of researchers through funding for targeted calls for research in the field
    - Improve outcomes for people with arthritis.

1.5 Workforce capacity

- Fund scholarships each year for formal professional development of specialist nurses and allied health professionals.
- Fund nurse educators and rheumatology nurses eg through Medicare
- Fund the promotion of ongoing professional development upskilling/education programs for health care professionals.
- Develop a business case to show cost-savings that can be generated over the longer term through better access to allied health (through expansion of access to Medicare funding for allied health services).
- Arthritis non-government organisations (including specialty groups) to collaborate to advocate to universities to inform revised/updated course curriculum.

2 Steering Committee

A representative Steering Committee was established as a consultative group to guide the development of the *National Strategic Action Plan for Arthritis*. The Steering Committee included representatives of key stakeholder organisations involved in the delivery of care and support for children and adults with arthritis, as well as consumers. Key stakeholder organisations were contacted in writing and invited to nominate a representative to participate in the Steering Committee. A list of Steering Committee members is provided at *Appendix B*.

The Steering Committee met face-to-face on two occasions. The first meeting, held in May 2018, focussed on:

- Discussing key issues identified at the Arthritis Roundtable in December 2017
- Reviewing evidence and information about key issues relating to arthritis prevention and care, and
- Identifying potential interventions to include in the Draft Action Plan.

The second meeting reviewed and provided further advice on the Draft Action Plan.

3 Initial consultations

Initial targeted consultations were undertaken from May to September 2018. The aim of these consultations was to ensure a broad range of information and perspectives was taken into consideration in the development of the Action Plan.

Participants included consumers, health professionals, non-government organisations, state and territory departments of health and Primary Health Networks. A list of participants in these consultations is provided in *Appendix C*.

Consultations were predominantly conducted via telephone or face-to-face interviews, although some organisations and individuals chose to provide input in writing. Contacts for state and territory departments of health were suggested by the Australian Government Department of Health and input from Primary Health Networks was invited through the Primary Health Network Cooperative. Individuals and organisations for consultation were identified to capture perspectives across geographic areas, arthritis conditions, health care settings, service providers, health professionals and population groups.

3.1 Consumer consultations

3.1.1 Method

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 CreakyJoints 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 from people of all ages, from all states and territories (*Figure 1*), with a range of different types of arthritis (*see Figure 2*). There was a higher response rate from the ACT and a lower response rate from New South Wales 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

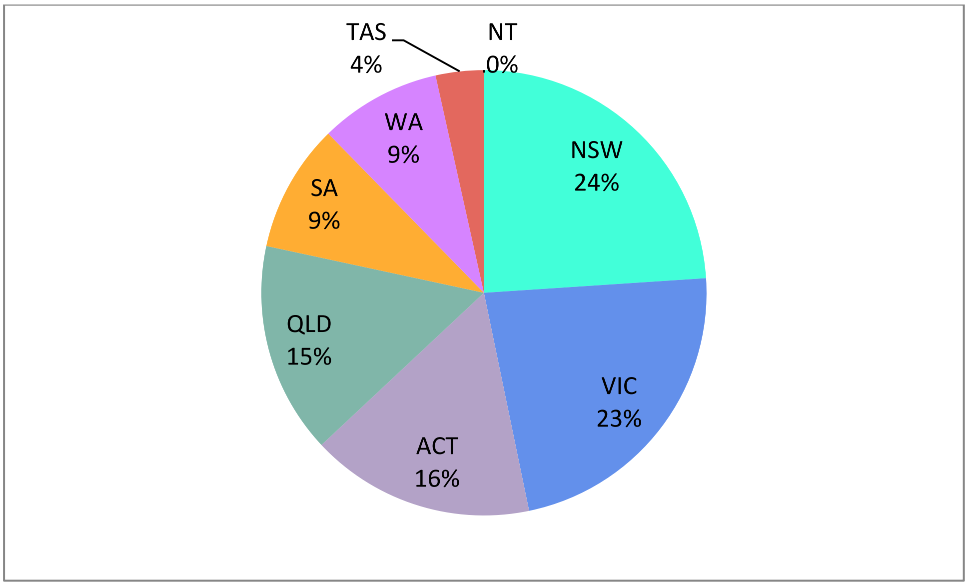
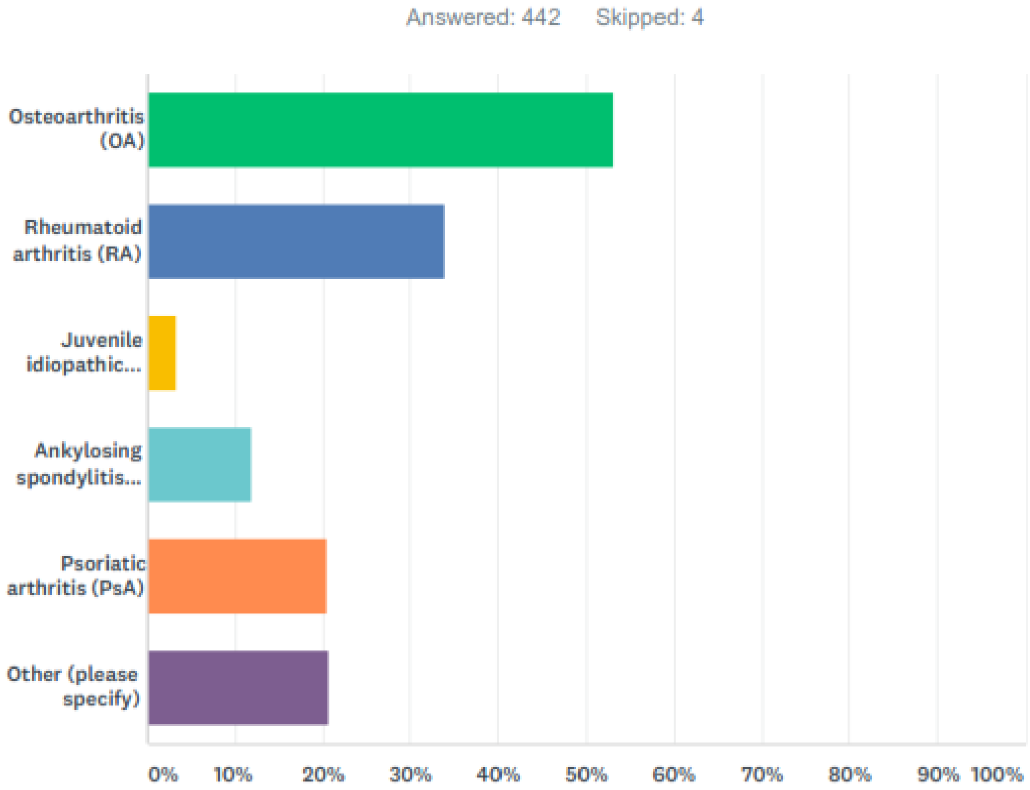


Figure 2: Consumer survey respondents - conditions



3.1.2 Key themes

The key themes relating to arthritis care raised in the discussion group 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

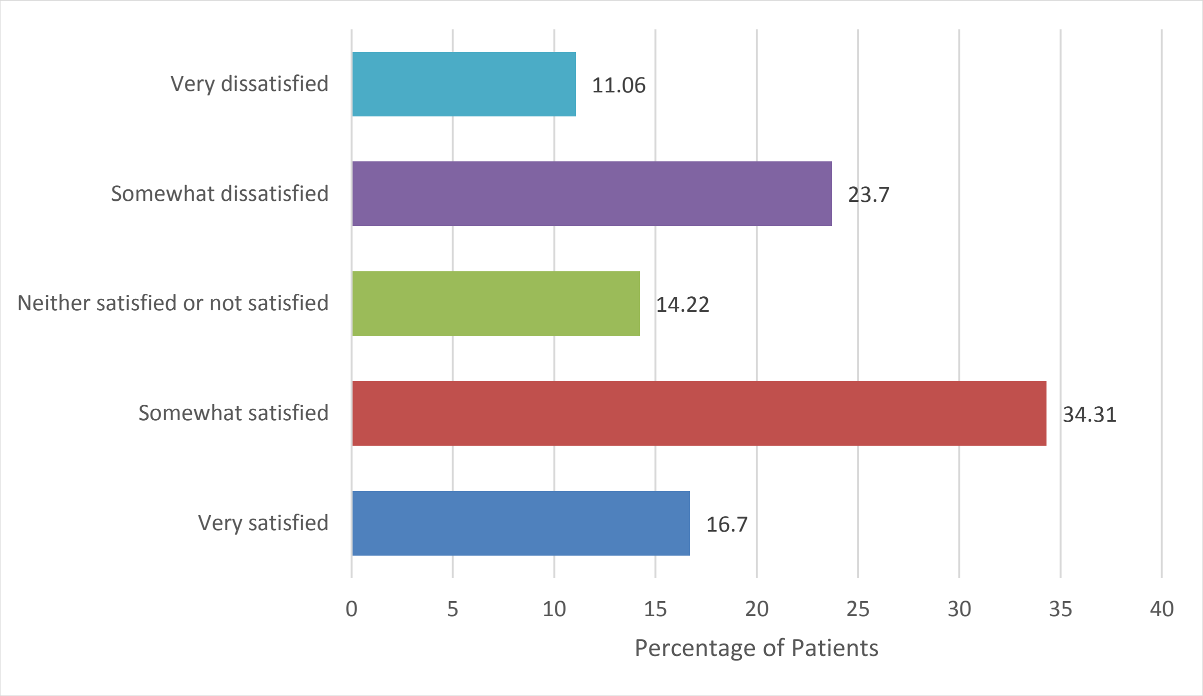
One in four survey respondents expressed dissatisfaction with the medications and treatments available for their condition, with dissatisfaction most commonly expressed by people with osteoarthritis.

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 (see *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.

3.1.3 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.

3.2 Other stakeholders

3.2.1 Method

Relevant stakeholder organisations were contacted by email to request a contact for the consultation. In addition, a number of individuals were nominated by professional associations, such as the Australian Rheumatology Association, or by the Australian Government Department of Health. A list of participants in these consultations is provided at *Appendix C.* Those consulted included 46 individuals and representatives of the following organisations and disciplines:

- 8 arthritis organisations
- 6 state and territory health department representatives

- 5 Primary Health Networks
- 5 health professional associations
- 2 Medical colleges
- 8 individual rheumatologists, including 3 in rural practice
- 4 allied health professionals
- 1 orthopaedic surgeon
- 1 Aboriginal health organisation
- 2 culturally and linguistically diverse organisations
- 4 researchers.

Interviews were semi-structured and participants were asked a series of open-ended questions about their views on key priorities and actions for the Action Plan; barriers and enablers for implementation and; existing activities and initiatives that could potentially be implemented more widely.

3.2.2 Key themes

The key themes raised during these initial stakeholder consultations are summarised below.

Multidisciplinary care

A major concern raised by those consulted (59%) was limited patient access to multidisciplinary care in both the public and the private sector.

The cost to patients of accessing allied health professionals was identified as a major barrier to improving arthritis management. In the private community sector, only five subsidised allied health visits are available to consumers with a chronic condition under Medicare chronic disease management items. Typically, however, a series of allied health visits is required to achieve improvement or behaviour change. Even for people with private health insurance, the cost of visiting allied health professionals is only partially covered.

Inadequate access to psychological support was identified as a major concern given the prevalence of anxiety and depression among people with arthritis and the association of poor mental health with poorer arthritis outcomes.

In addition to cost, identifying appropriately skilled allied health professionals was raised as a barrier to providing appropriate multidisciplinary care, especially for people with inflammatory forms of arthritis or complex needs.

Skilled workforce

More than half of those consulted (57%) identified the need to upskill health professionals in providing appropriate care for people with arthritis and musculoskeletal conditions, with many identifying that medical curricula provided only limited exposure to managing these conditions.

Models and standards of care

More than half of those consulted (54%) highlighted that models of care to support best-practice, evidence-based, high value care for people with arthritis and musculoskeletal conditions had been developed in various jurisdictions but that funding to implement them effectively was often lacking.

Access to services

Limited and inequitable access to specialists and to public services, were highlighted as a major issue by 50% of those consulted. Limited access resulted in long delays and waiting lists to access specialist care including rheumatology and pain management services and surgery, particularly in the public sector.

Patient access to appropriate services was identified as a major issue for people living in rural and remote areas, as well as for people living in underserviced metropolitan areas. Limited funding and support for rural rheumatology outreach services and for outreach by allied health professionals, were identified as major barriers to improving access in these areas.

A particular issue raised was the limited access to paediatric rheumatologists due to workforce shortages and the lack of dedicated funding for training positions in the specialty.

Other themes

Other common themes included:

- Limited patient education and support (35%)
- Limited access to nurses, especially rheumatology nurses (30%)
- The need to improve access to and affordability of exercise programs (30%)
- The need to improve pain management (28%)
- Lack of holistic, person-centred care and limited utilization of management plans (26%)
- Inadequate funding models to support best-practice care (26%).

3.2.3 Suggested solutions

A range of solutions was proposed by those consulted to address the issues they identified. These are summarised below.

Multidisciplinary care

- Increase funding for multidisciplinary services for people with arthritis in the public sector.
- Increase the number of allied health visits subsidised by Medicare for people with arthritis under chronic disease management plans.
- Provide Medicare rebates for group exercise sessions led by allied health professionals.
- Increase support for advanced practice roles for allied health professionals.
- Develop training, certification or credentialing pathways to support allied health professionals to advance their skills, and to allow other health professionals and consumers to identify appropriately skilled practitioners.

- Support more flexible and expanded roles for appropriately skilled allied health professionals (e.g. for patient education, triage, or post-arthroplasty review) to reduce pressure on limited specialist services.

Skilled workforce

- Provide information, training and education for GPs, nurses, and allied health professionals to support improved care for people with arthritis, including the importance of prompt referral to specialist care of children and adults with symptoms of inflammatory arthritis.
- Support more flexible training and education and roles for a range of health professionals in the delivery of appropriate arthritis care using a skills and competency based approach.
- Increase content relating to care of people with arthritis and musculoskeletal conditions in medical curricula.
- Develop tools and checklists to support health professionals in the delivery of appropriate care (e.g sample management plans).

Models of care

- Provide funding to implement existing models of arthritis care across the country (appropriately adapted to local systems and resources).
- Improve referral pathways and triage services from primary care through to surgery to improve timely access to appropriate care.
- Increase utilisation of appropriately skilled nurses and allied health professionals to deliver elements of arthritis care such as patient education and support and triage services.

Access to services

- Increase funding to train specialists to address shortages and maldistribution of the rheumatology workforce, including the paediatric rheumatology workforce.
- Increase funding for public rheumatology services to improve timely and affordable access to appropriate care.
- Increase funding for outreach and telehealth services for specialists and allied health professionals to improve access to appropriate care for people living in rural and remote areas.
- Support dual training of rural specialists and flexible training and roles for a range of health professionals to support appropriate arthritis care in underserviced areas.

Other

- Provide funding for health educators to improve patient education and support.
- Fund rheumatology nurses to provide patient education and support and to assist in the management of people with arthritis.
- Develop and trial new funding models to support best-practice care.
- Improve affordable access to appropriate exercise programs to help people to manage their arthritis.

4 National Osteoarthritis Strategy

The *National Osteoarthritis Strategy (2018)* was developed in parallel with the *National Strategic Action Plan for Arthritis* and informed the recommendations of the Action Plan that relate to osteoarthritis.

The development of the *National Osteoarthritis Strategy* was the subject of extensive consultations including:

- A leadership group, working groups and an implementation advisory committee, including a range of experts to assist in the development of the recommendations of the strategy. In total, these groups included 60 consumers and experts across a range of disciplines.
- Discussion of the draft strategy at a National Osteoarthritis Summit held in Canberra in November 2018, attended by more than 100 stakeholder groups and individuals.
- A public consultation on the draft strategy which received 176 submissions.

Further information is available at University of Sydney
http://sydney.edu.au/medicine/ibjr/events/National_OA_Strategy_PostSummit.pdf

5 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. A copy of the survey questions used for the consultation is provided at *Appendix D.*

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 member and stakeholder 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
- Health professional colleges, associations and peak bodies
- Sporting and fitness professionals
- State and territory Departments of Health
- Primary Health Networks
- Aboriginal Community Controlled Health Organisations
- Culturally and linguistically diverse groups
- Research organisations and academics.

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.

The responses provided were analysed and constructive comments were incorporated into the final *National Strategic Action Plan for Arthritis* wherever feasible and appropriate.

5.1 Respondents

In total 221 responses to the consultation were received. Of these, 205 were provided through the online survey and 16 were mailed or emailed directly to Arthritis Australia.

Of the responses, 185 were provided by individuals and 36 were provided on behalf of organisations. The responding organisations were:

- Allied Health Professions Australia
- Arthritis and Osteoporosis Tasmania
- Arthritis and Osteoporosis Northern Territory
- Arthritis Queensland
- Ankylosing Spondylitis Victoria
- Australian and New Zealand Musculoskeletal (ANZMUSC) Clinical Trials Network
- Australian and New Zealand Society for Geriatric Medicine
- Australian College of Nurse Practitioners
- Australian College of Sport and Exercise Physicians
- Australian Government Department of Health
- Australian Hand Therapy Association
- Australian Healthcare and Hospitals Association
- Australian Medical Association
- Australian Medical Laser Association
- Australian Orthopaedic Association
- Australian Paediatric Rheumatology Group
- Australian Self Medication Industry
- Blacktown Hospital, New South Wales
- Charles Sturt University and Melbourne Stem Cell Centre
- Chiropractic Australia
- CreakyJoints Australia
- Dietitians Association of Australia
- GlaxoSmithKline Consumer Healthcare
- Medibank Better Health Fund
- Medicines Australia
- Musculoskeletal Australia jointly with the MSK Consumer Advisory Council
- National Rural Health Alliance
- North Western Melbourne Primary Health Network
- Northern Sydney Local Health District
- NPS MedicineWise
- OPAL Rheumatology Ltd
- PainAustralia
- Psoriatic Arthritis Australia
- Queensland Health
- Rehabilitation Medicine Society of Australia and New Zealand
- Western Australian Department of Health

Most respondents (74 per cent) were people with arthritis, followed by health professionals (24%), and family members or carers for someone with arthritis (7%).

Reponses were generally geographically representative across all states and territories (*Figure 4*) and across metropolitan and regional centres (*Figure 5*).

Respondents identified that they were interested in a range of arthritis types, most commonly osteoarthritis (62%), chronic pain (52%), and rheumatoid arthritis (50%) (*Figure 6*).

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

Figure 4: Public consultation responses – distribution by State and Territory

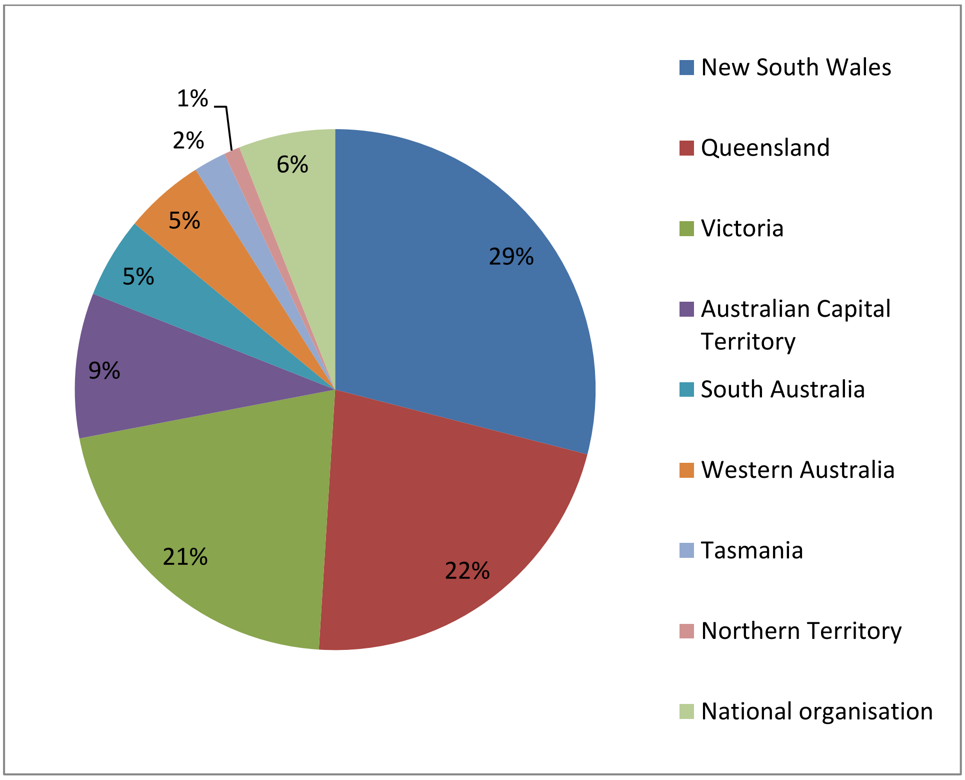


Figure 5: Public consultation respondents – distribution by geographic region

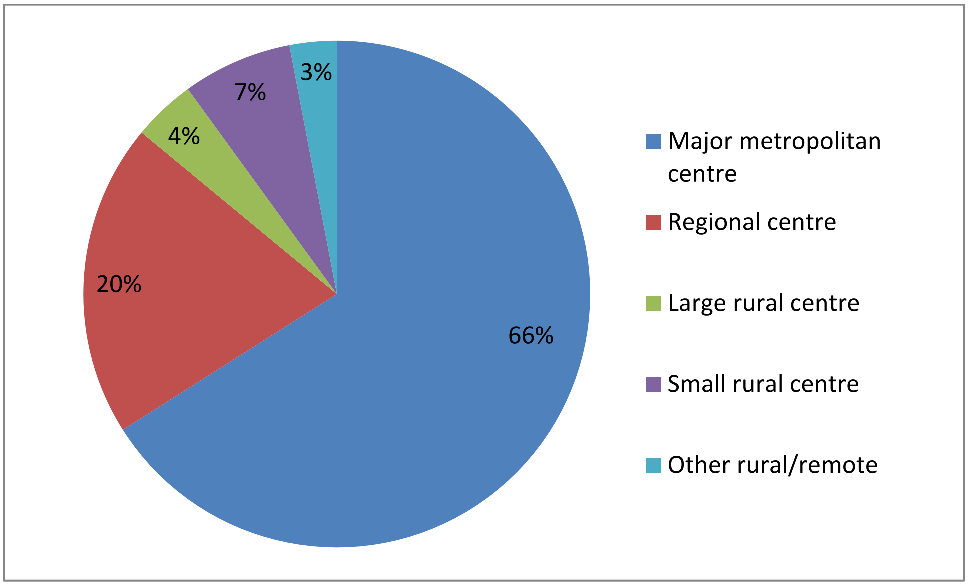
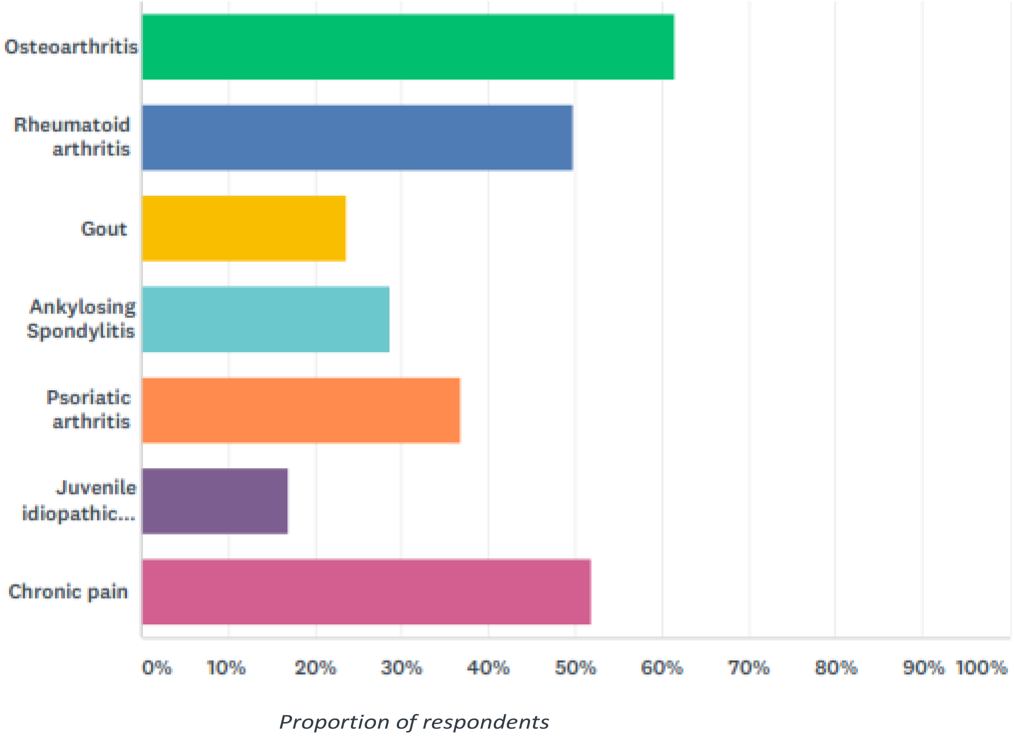


Figure 6: Public consultation respondents – conditions of interest



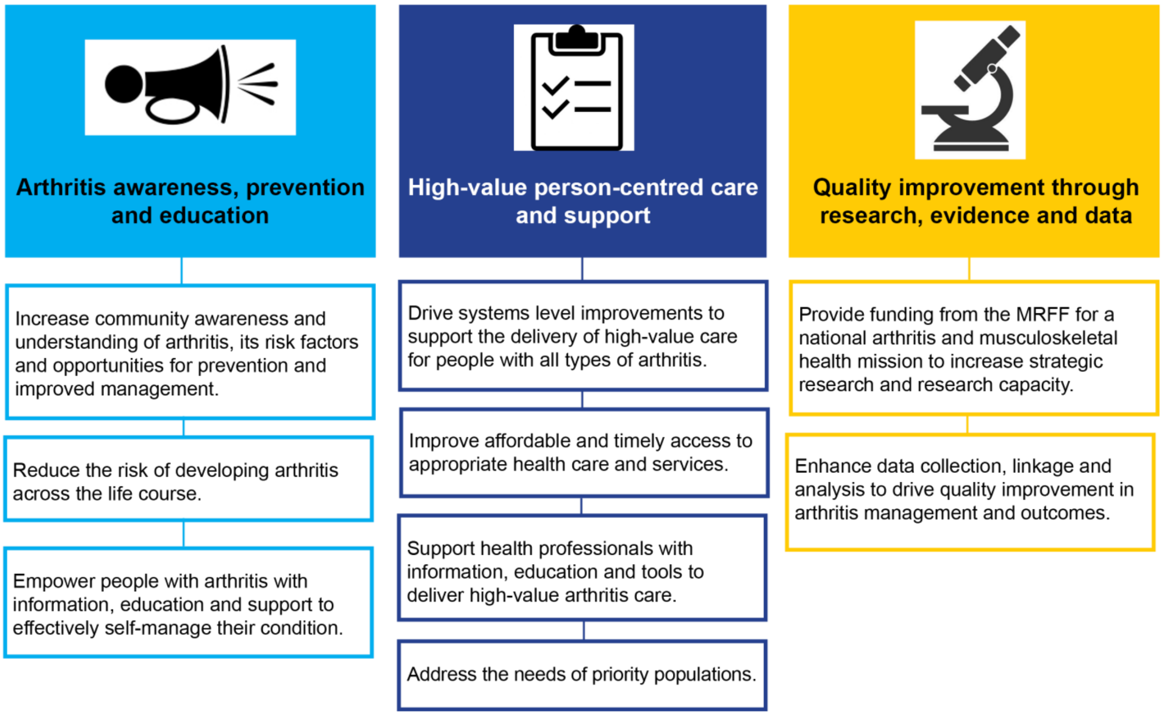
5.2 Outcomes

5.2.1 Agreement with vision, priorities and objectives

The *Draft Action Plan* set out a vision, three priority areas and nine objectives. The vision set out in the *Plan* was "Freedom from the burden of arthritis". The priorities and objectives for the *Plan* are depicted in *Figure 7*.

Respondents were very supportive of the vision and the priority areas outlined in the *Draft Action Plan*, with 88% of respondents agreeing that these were appropriate. In addition, 85% of respondents agreed that the nine objectives proposed in the *Draft Action Plan* and the action areas within these objectives were appropriate.

Figure 7: National Strategic Action Plan for Arthritis: Key priorities and objectives



Arthritis awareness, prevention and education

Increase community awareness and understanding of arthritis, its risk factors and opportunities for prevention and improved management.

Reduce the risk of developing arthritis across the life course.

Empower people with arthritis with information, education and support to effectively self-manage their condition.

High-value person-centred care and support

Drive systems level improvements to support the delivery of high-value care for people with all types of arthritis.

Improve affordable and timely access to appropriate health care and services.

Support health professionals with information, education and tools to deliver high-value arthritis care.

Address the needs of priority populations.

Quality improvement through research, evidence and data

Provide funding from the MRFF for a national arthritis and musculoskeletal health mission to increase strategic research and research capacity.

Enhance data collection, linkage and analysis to drive quality improvement in arthritis management and outcomes.

5.2.2 Priority ranking

People were asked to rank the objectives and actions outlined in the 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.

Objectives

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 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.

Actions

The Draft Action Plan set out 32 actions across the three priority areas. The following were the ten most highly-ranked actions, based on a simple average of rankings across all respondents.

1) Improve access to affordable specialist adult and paediatric rheumatology services.
2) Fund high-quality research projects and infrastructure that will lead to improved prevention, diagnosis and treatment, and support the search for cures.
3) Integrate arthritis into all health care policies, programs and reform initiatives across all levels of government in Australia.
4) Integrate the provision of patient information, education and support into health service delivery for people with arthritis.
5) Drive early diagnosis and intervention for children and adults with inflammatory arthritis.
6) Improve access to appropriate care for people in rural/remote and other under-serviced areas by expanding specialist and interdisciplinary outreach clinics, with additional support through telehealth services.
7) Improve affordable access to interdisciplinary team care delivered by appropriately skilled nurses and allied health professionals.
8) Expand existing and develop and trial new information, education and support programs to assist people with arthritis to proactively manage their condition.
9) Develop, deliver and promote a range of arthritis education and awareness campaigns tailored to different target audiences, to address identified community knowledge gaps.
10) Foster collaborative research.

Sub-group analyses of the ten 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 ten most highly-ranked actions overall. These 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.

5.2.3 Implementation

Respondents were strongly supportive of the proposed approaches to implementation outlined in the *Draft Action Plan*. In particular, many reiterated the importance of sustained and ongoing effort, collaboration and partnerships across a large number of stakeholders to deliver the *National Strategic Action Plan for Arthritis*.

6 Conclusion

A comprehensive range of consultations was undertaken to inform the development of the *National Strategic Action Plan for Arthritis.* Priority-ranking of the actions contained in the *Draft Action Plan* will help to inform priorities for implementation, taking into account differences in the perspectives of consumers and health professionals.

Appendix A - *Arthritis Roundtable Participants*

Name	Organisation	State	Area of expertise
Ms Emma Bavage	Rheumatology Health Professionals Australia	TAS	Rheumatology nursing
Professor Rachelle Buchbinder	Australian Rheumatology Association, Australia and New Zealand Musculoskeletal Clinical Trials Group	VIC	Rheumatology, Research
Ms Ainslie Cahill	Arthritis Australia	NSW	Consumer issues
Ms Libby Dunstan	Deputy CEO, Brisbane North Primary Health Network	QLD	Primary Health Networks
Mrs Karen Filocamo	Health Consumers New South Wales	NSW	Arthritis consumer
Mr Ric Forlano	Arthritis and Osteoporosis Western Australia	WA	State arthritis organisation
Professor Ian Harris	Australian Orthopaedic Association	NSW	Orthopaedic surgery
Professor David Hunter	University of Sydney, Royal North Shore Hospital	NSW	Rheumatology, research
Ms Joanne Mitchell	National Health and Medical Research Council	ACT	Research funding
Dr Kean-Seng Lim	Australian Medical Association Council of General Practice	NSW	General Practice
Mr Errol Lim	Australian Physiotherapy Association	NSW	Physiotherapy
Dr Mona Marabani	Private rheumatology practice	NSW	Private rheumatology practice
Professor Lyn March	Royal North Shore Hospital	NSW	Rheumatology, research
Ms Franca Marine	Arthritis Australia	NSW	Policy
Mrs Sarah McHarg	National Arthritis Consumer Reference Group	ACT	Carer
Mr Andrew Mills	Arthritis Australia	NSW	Observer
A/Prof Susanna Proudman	Medical Director, Arthritis Australia	SA	Rheumatology, hospital networks
Ms Kristine Riethmiller	Chair, Arthritis Australia	ACT	Consumer
Dr Davinder Singh-Grewal	Australian Paediatric Rheumatology Group	NSW	Paediatric rheumatology
Ms Colette Smith	Arthritis South Australia	SA	Consumer
Ms Robyn Speerin	New South Wales Agency for Clinical Innovation, Musculoskeletal network	NSW	Delivery of musculoskeletal Models of Care

Appendix B - *Steering Committee Members*

Name	State	Representing
A/Prof Ilana Ackerman	VIC	Australian Physiotherapy Association
Dr Claire Barrett	QLD	Australian Rheumatology Association
Professor Andrew Briggs	VIC	Curtin University
Dr Roslyn Carbon	WA	Australasian College of Sports and Exercise Physicians
Dr David Dewar	NSW	Australian Orthopaedic Association
Ms Libby Dunstan	QLD	Primary Health Networks
Professor Catherine Hill	SA	Australian Rheumatology Association
A/Prof Malcolm Hogg	VIC	PainAustralia
Ms Jane Hope	TAS	Consumer (RA)
Prof David Hunter	NSW	National Osteoarthritis Strategy
Mr Rhys Jones	TAS	Pharmacy Guild of Australia
Dr Kean-Seng Lim	NSW	Australian Medical Association
Ms Franca Marine	NSW	Arthritis Australia
A/Prof Mark Morgan	QLD	Royal Australian College of General Practitioners
A/Prof Susanna Proudman (Chair)	SA	Arthritis Australia
Ms Alice Rice	NSW	Private Healthcare Australia (nib)
Ms Colette Smith	SA	Consumer (IA)
Ms Emma Thompson	QLD	State based arthritis consumer organisations
Mr Kevin Thompson	ACT	Australian Government Department of Health
Ms Julia Thompson	NSW	State Health Departments
Ms Deborah Tunbridge	WA	Rheumatology Health Professionals Association
Ms Leanne Wells	ACT	Consumers Health Forum
Dr Samuel Whittle	SA	Australia and New Zealand Musculoskeletal Clinical Trials Group

Appendix C *Participants in initial targeted consultations*

Name	Organisation	State	Expertise
Dr Kate Armstrong	Aboriginal Health and Medical Research Council of NSW	NSW	Aboriginal health
A/Prof Mark Arnold	Australian Rheumatology Association, Regional Rheumatology Committee	NSW	Rural rheumatology
Dr Claire Barrett	Australian Rheumatology Association	QLD	Rheumatology
Dr Helen Benham	Princess Alexandra Hospital	QLD	Rheumatology, research
Prof Kim Bennell	University of Melbourne	VIC	Physiotherapy, research
Ms Julie Black	Arthritis South Australia	SA	Consumer organisation
Dr Stephen Brady	Alice Springs Hospital	NT	Rural rheumatology
Prof Andrew Briggs	Curtin University	WA	Physiotherapy, models of care, health service research
Prof Peter Brooks	ARA Research Committee	VIC	Rheumatology, research
Ms Lesley Brydon	Leadership Group, National Osteoarthritis Strategy	NSW	Consumer
Ms Deborah Butler	NT Department of Health	NT	State public health system
Mr Thomas Buttel	Advanced Care Working Group, National Osteoarthritis Strategy	NSW	Consumer
Dr Emma Campbell	Federation of Ethnic Community Councils of Australia	ACT	Culturally and linguistically diverse groups
Prof Peter Choong	St Vincent's Hospital	VIC	Orthopaedic surgery
Sr Mary-Lynne Cochrane	NSW ACI Pain Network		Consumer
Ms Naomi Creek	Creaky Joints Australia	VIC	Consumer
Dr Jim Croker	Private practice	NSW	Rural rheumatology
Ms Rebecca Davey	Arthritis ACT	ACT	Consumer organisation
Mr David Menzies	South Eastern Melbourne Primary Health Network	VIC	Primary Health Network
Ms Danielle Dunleavy	National Arthritis Consumer Reference Group	SA	Consumer
Mr Phil Edmondson	Primary Health Tasmania	TAS	Primary Health Network
Ms Wendy Favorito	National Arthritis Consumer Reference Group	NSW	Consumer
Ms Karen Filocamo	Early Care Working Group, National Osteoarthritis Strategy	NSW	Consumer
Mr Paul Forrestal	National Arthritis Consumer Reference Group	WA	Consumer
Ms Hilary Fowler	Arthritis Northern Territory	NT	Consumer organisation
A/Prof Kathryn Gibson	Liverpool Hospital	NSW	Rheumatology
Ms Michelle Graham	National Arthritis Consumer Reference Group	QLD	Consumer
Ms Michelle Grybaitis	Australian Medical Association		Policy

Name	Organisation	State	Expertise
Mr David Harmer	Queensland Health	QLD	State public health system
Ms Siobhan Harpur	Tasmanian Department of Health and Human Services	TAS	State public health system
Ms Fiona Hodson	Australian Pain Society	NSW	Pain services delivery
A/Prof Malcolm Hogg	Pain Australia	VIC	Pain management
Ms Julie Hulcombe	Queensland Department of Health	QLD	Allied health, state public health system
Dr Joyce Jiang	Multicultural Centre for Women's Health	VIC	Culturally and linguistically diverse groups
Mr Chris Kane	Western Australian Primary Health Alliance	WA	Primary Health Networks
Ms Margaret Knight	NSW ACI Pain Network	NSW	Consumer
Kate Lemass	N/A	NSW	Consumer
Dr Kean-Seng Lim	Australian Medical Association	NSW	General Practice
Prof David Lloyd	School of Allied Health Sciences, Griffith University	NSW	Sports injury prevention, research
Prof Lyn March	Royal North Shore Hospital	NSW	Rheumatology, research
Ms Sarah McHarg	National Arthritis Consumer Reference Group	ACT	Carer
Ms Annie McPherson	Ankylosing Spondylitis Victoria	VIC	Consumer
A/Prof Mark Morgan	Royal Australian College of General Practitioners	QLD	General Practice
Ms Yarie Nikolic	Prevention Working Group, National Osteoarthritis Strategy	NSW	Consumer
Ms Genevieve Nolan	Musculoskeletal Australia	VIC	Consumer organisation
Ms Alison Park	National Arthritis Consumer Reference Group	TAS	Consumer
Ms Jennifer Persaud	Arthritis and Osteoporosis WA	WA	Consumer organisation
Ms Jennifer Persaud	Musculoskeletal Health Network, Western Australian Department of Health	WA	State public health system
Ms Emma Pettet	Princess Alexandra Hospital	QLD	Physiotherapy
Mr Damien Searle	Queensland Department of Health	QLD	State public health system
Ms Jackie Slyp	Arthritis Tasmania	TAS	Consumer organisation
Mr Murray Smith	National Arthritis Consumer Reference Group	NSW	Consumer
Dr Deborah Speden	Royal Hobart Hospital	TAS	Rheumatology
Ms Robyn Speerin	NSW Agency for Clinical Innovation Musculoskeletal Network	NSW	State public health system
Ms Linda Spurrier	National Arthritis Consumer Reference Group	ACT	Consumer
A/Prof Ruth Stewart	Australian College of Rural and Remote Medicine	QLD	Rural health, medical education
Mr Max Stoneman	National Arthritis Consumer Reference Group	QLD	Consumer

Name	Organisation	State	Expertise
Prof Ranjeny Thomas	Diamantina Institute	QLD	Rheumatology, research
Ms Emma Thompson	Arthritis Queensland	QLD	Consumer organisation
Prof Deborah Turner	Western Sydney University	NSW	Podiatry
Mr Murray Turner	Psoriasis Australia	VIC	Consumer
Ms Sandra Vincent	Arthritis New South Wales	NSW	Consumer organisation
Dr Liz Webber	Royal Hobart Hospital	TAS	General practice
Ms Julie Williams	Tasmanian Department of Health and Human Services	TAS	Population health
Dr Andrew Wilson	Safer Care Victoria	VIC	Chief Medical Officer
Ms Alexis Wray	SafeWork NSW	NSW	Occupational Health & Safety
Board members	Australian Rheumatology Association	AUS	Rheumatology
Members	Rheumatology Health Professionals Association	AUS	Rheumatology nursing and allied health professionals
Members	Australian Paediatric Rheumatology Group	AUS	Paediatric rheumatology

Appendix D *Public Consultation – Survey questions*

ARTHRITIS AUSTRALIA

Consultation on the DRAFT National Strategic Action Plan for Arthritis

Closes: 7 December 2018

Introduction

Arthritis Australia is seeking stakeholder and community feedback on the draft National Strategic Action Plan for Arthritis.

The purpose of the Action Plan is to provide guidance on key priorities and actions to improve arthritis prevention and care in Australia. Arthritis Australia has led the development of the Action Plan on behalf of the Australian Government Department of Health.

Read the Consultation Draft – National Strategic Action Plan for Arthritis

The draft Action Plan has been developed with the input of a multidisciplinary Steering Committee comprising representatives of major stakeholder groups with an interest in arthritis prevention, management and care, including consumers, health professionals, researchers, policy makers and service providers. Major contributions were also provided by the project team developing the National Osteoarthritis Strategy (2018), which has informed many of the recommendations of the Plan, and participants in the Arthritis Roundtable Workshop held in December 2017. In addition, we thank the National Arthritis Consumer Reference Group and respondents to our recent consumer survey for sharing their experience of living with arthritis and their ideas for improving arthritis care and support.

Survey

Please provide your views on the draft National Strategic Action Plan for Arthritis by completing this survey. The survey should take about 15-20 minutes to complete.

Please note that you will need to complete the survey in one sitting as your responses cannot be saved until submitted.

The survey will close on Friday 7 December 2018.

If you have any queries, please email: policy@arthritisaustralia.com.au

Please click the button below to begin the survey.

Section 1 – Demographics

1. Are you providing your response as: (pick all that apply)

- Person with arthritis
- Policy maker
- Family member or carer for someone with arthritis
- Researcher/academic
- Health professional
- Other (please specify)

2. Are you providing your response on behalf of an organisation?

- No
- Yes (if so, please provide your name and position, as well as the name of the organisation)

3. If you are a health professional, please specify which health profession you belong to

- Allied health professional
- General Practitioner
- Nurse
- Rheumatologist
- Other physician/specialist
- Specialist nurse Surgeon
- Pharmacist
- I am not a health professional.
- Other (please specify)

4. In which of the following conditions do you have an interest? (tick all that apply)

- Osteoarthritis
- Rheumatoid arthritis
- Ankylosing Spondylitis
- Psoriatic arthritis
- Juvenile idiopathic arthritis
- Gout
- Chronic pain
- Other (please specify)

5. Do you identify as

- an Aboriginal or Torres Strait Islander person
- a person from a culturally and linguistically diverse background

6. Where are you based?

- Australian Capital Territory
- New South Wales

- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia
- National (if responding on behalf of an organisation)
- Other (please specify)

7. In what area do you live?

- Major metropolitan centre
- Regional centre
- Large rural centre
- Small rural centre
- Other rural
- Remote

Section 2 - Feedback on the DRAFT National Strategic Action Plan for Arthritis

Questions 8-10 refer to the introductory information included in the Action Plan in the sections titled *'About this Action Plan', 'What is arthritis', 'The challenge of arthritis'* and *'Overview'* (pages 4-11)

8. Does the introductory material for the Action Plan provide adequate context and background for why action is required?

- Yes
- No - If not, please provide comments on how this section could be improved (max 300 words).

9. Do you agree with the vision and the three priority areas for the Action Plan?

- Yes
- No - If not, please provide comments on what you think should be changed and why (max 300 words).

10. Do you agree, in general terms, that the nine objectives and action areas proposed are appropriate?

- Yes
- No - If not, please provide comments on what you think should be changed and why (max 300 words)

Priority 1 - Arthritis awareness, prevention and education

Questions 11-14 relate to the objectives and actions proposed for *Priority 1 - Arthritis awareness, prevention and education* (pages 12-15)

11. Does this section adequately address the key objectives and actions required for this priority?

- Yes
- No - If not, please explain what should be changed and why (max 300 words).

12. Which of the proposed objectives do you consider to be the most important to address for this priority? (scale of 1-5 with 1 most important and 5 least important)

12.1 Increase community awareness and understanding of arthritis, its risk factors and opportunities for prevention and improved management.

12.2 Reduce the risk of developing arthritis across the life course

12.3 Empower people with arthritis with information, education and support to effectively self-manage their condition.

13. Please rate the proposed actions for this priority in terms of importance for implementation over the next 2-3 years (1 most important, 5 least important)

1.1.1 Develop, deliver and promote a range of arthritis education and awareness campaigns tailored to different target audiences, to address identified community knowledge gaps.

1.1.2 Integrate arthritis into all health care policies, programs and reform initiatives across all levels of government in Australia.

1.2.1 Work with government and other stakeholders to support the development and implementation of the national obesity strategy.

1.2.2 Raise awareness of the link between obesity, physical inactivity, smoking and arthritis.

1.2.3 Develop and implement a national sports injury prevention program to reduce the incidence of sports injuries associated with increased arthritis risk.

1.3.1 Integrate the provision of patient information, education and support into health service delivery for people with arthritis.

1.3.2 Expand existing and develop and trial new information, education and support programs to assist people with arthritis to proactively manage their condition.

1.3.3 Develop and promote new consumer information resources to address identified resource gaps and unmet needs.

1.3.4 Develop and disseminate consumer-focused guides or standards of care for people with arthritis so they know what care they should receive.

14. Do you have any comments on the proposed implementation approaches outlined for this priority? (max 300 words)

- Yes - If yes, please explain your choice.
- No

Priority 2 - High-value, person-centred clinical management, care and support

Questions 15-18 relate to the objectives and actions proposed for *Priority 2 - High-value, person-centred clinical management, care and support* (pages 16-24)

15. Does this section adequately address the key objectives and actions required for this priority?

- Yes
- No - if not, please explain what should be changed and why (max 300 words).

16. Which of the proposed objectives do you consider to be the most important to address for this priority? (scale of 1-5 with 1 most important and 5 least important)

2.1 Drive systems level improvements to support the delivery of high value care for people with all types of arthritis.

2.2 Improve affordable and timely access to appropriate health care and services.

2.3 Support health professionals with information, education and tools to deliver high-value arthritis care.

2.4 Address the needs of priority populations.

17. Please rate the proposed actions for this priority in terms of importance for implementation over the next 2-3 years (scale of 1-5 with 1 most important and 5 least important)

2.1.1 Establish and fund a National Musculoskeletal Network to engage with and align efforts across multiple stakeholders, sectors and levels of the health system to drive improvements and monitor performance in arthritis prevention and management.

2.1.2 Support the development, implementation and funding of evidence-based musculoskeletal models of care across Australia to guide the delivery of appropriate health services for people with arthritis.

2.1.3 Trial and evaluate innovative models of care to assess their suitability for delivering better care for people with arthritis and to improve care coordination.

2.1.4 Provide dedicated funding to Primary Health Networks (PHNs) to develop, deliver and commission programs to address the needs of people with arthritis in their area.

2.2.1 Drive early diagnosis and intervention for children and adults with inflammatory arthritis.

2.2.2 Improve access to affordable specialist adult and paediatric rheumatology services.

2.2.3 Improve affordable access to interdisciplinary team care delivered by appropriately skilled nurses and allied health professionals.

2.2.4 Increase the uptake of effective lifestyle and self-management interventions for people with arthritis.

2.2.5 Improve equitable and timely access to appropriate surgical care for people with arthritis.

2.3.1 Establish and promote guidelines and systems to assist health professionals to provide high-value clinical care for people with different types of arthritis.

2.3.2 Develop and deliver a national information, training and education framework to upskill health professionals and other potential workforce providers to deliver appropriate management and care for people with arthritis.

2.3.3 Develop support tools and systems to assist health professionals to deliver appropriate care.

2.4.1 Improve access to appropriate care for people in rural/remote and other under-serviced areas by expanding specialist and interdisciplinary outreach clinics, with additional support through telehealth services.

2.4.2 Develop information and education resources and health services that are culturally appropriate and address the needs of Aboriginal and Torres Strait Islander peoples and culturally and linguistically diverse groups.

2.4.3 Ensure appropriate recognition of the impact of arthritis-related disability on people's lives and incomes in assessment processes for disability support services and welfare payments.

2.4.4 Develop and deliver services and programs to improve arthritis and musculoskeletal pain management in older people both in the community and in residential aged care.

18. Do you have any comments on the proposed implementation approaches outlined for this priority?

- Yes - If yes, please explain your choice.
- No

Priority 3 - Quality improvement through research, evidence and data

Questions 19-22 relate to the actions areas and actions proposed for *Priority 3: Quality improvement through research, evidence and data* (pages 25-27)

19. Does this section adequately address the key objectives and actions required for this priority?

- Yes
- No - If not, please explain what should be changed and why (max 300 words).

20. Which of the proposed objectives do you consider to be the most important to address for this priority?

3.1 Provide funding from the Medical Research Future Fund (MRFF) for a national arthritis and musculoskeletal health mission to increase strategic research and research capacity in the field

3.2 Enhance data collection, linkage and analysis to drive quality improvement in arthritis prevention, management and outcomes.

3.3. Please rate the proposed actions for this priority in terms of importance for implementation over the next 2-3 years (scale of 1-5 with 1 most important and 5 least important)

21. Please rate the proposed actions for this priority in terms of importance for implementation over the next 2-3 years (scale of 1-5 with 1 most important and 5 least important)

3.1.1 Establish and fund a virtual National Arthritis and Musculoskeletal Research Institute to drive the strategic expansion of research into these conditions in Australia.

3.1.2 Build the arthritis and musculoskeletal research workforce through dedicated funding for research fellowship programs.

3.1.3 Foster collaborative research.

3.1.4 Fund high-quality research projects and infrastructure that will lead to improved prevention, diagnosis and treatment, and support the search for cures.

3.2.1 Fund the development and implementation of a national data strategy to provide a clearer picture of the prevalence, prevention, management, treatment and outcomes for arthritis and musculoskeletal conditions and to support benchmarking and quality improvement.

3.2.2 Expand and enhance existing arthritis registries/databases

3.2.3 Embed data collection into hospital and clinical management systems to capture and analyse treatment and outcomes data to inform clinical decisions and drive quality improvement.

22. Do you have any comments on the proposed implementation approaches outlined for this priority?

- Yes - If yes, please explain your choice.
- No

Section 3 - Achieving Progress

23. Do you have any comments in relation to the proposed approach to implementing and monitoring the Plan? (max 300 words) (pages 28-29)

24. Are there any other comments relating to the Action Plan that you would like to make? (max 500 words)

Thank you for completing this survey. The final Action Plan will be made available on the Arthritis Australia website at www.arthritisaustralia.com.au by early 2019.