

Impactful Arthritis Research

RESEARCH AUSTRALIA
CONNECTING · ENGAGING · INFLUENCING

Arthritis AUSTRALIA

About Research Australia

Research Australia is the national alliance representing the entire health and medical research pipeline, from the laboratory to patient and the marketplace.

OUR VISION: Research Australia envisions a world where Australia unlocks the full potential of its world-leading health and medical research sector to deliver the best possible healthcare and global leadership in health innovation.

OUR MISSION: To use our unique convening power to position health and medical research as a significant driver of a healthy population and contributor to a healthy economy.

OUR ROLE:

Engage
Australia in a conversation about the health benefits and economic value of its investment in health and medical research.

Connect
researchers, funders and consumers to increase investment in health and medical research from all sources.

Influence
government policies that support effective health and medical research and its routine translation into evidence-based practices and better health outcomes.

This report has been commissioned by Arthritis Australia.

Research Australia would like to acknowledge the contributions of:
Professor Wendy Lipworth, Macquarie University, Sydney, Australia
Dr Breanne Kunstler & Dr Denise Goodwin, BehaviourWorks Australia, Monash Sustainable Development Institute, Monash University, Melbourne, Australia

Nadia Levin
CEO & Managing Director
02 9295 8547 nadia.levin@researchaustralia.org

www.researchaustralia.org
384 Victoria Street Darlinghurst NSW 2010

This document and the ideas and concepts set out in this document are subject to copyright. No part of this document, ideas or concepts are to be reproduced or used either in identical or modified form, without the express written consent of Research Australia Limited ABN 28 095 324 379.

About Arthritis Australia

Providing information and support to people living with arthritis

Arthritis Australia is Australia's leading national arthritis charity. We work in collaboration with affiliated arthritis organisations in the ACT, New South Wales, Northern Territory, Queensland, South Australia, Tasmania and Western Australia to deliver information and support to people living with more than 100 types of arthritis.

Our vision is to achieve freedom from arthritis for the more than four million Australians of all ages who currently live with arthritis and for the many more who will develop these conditions in the future.

To achieve our vision, our key strategies are to provide information and support to people affected by arthritis, to fund research into better care and potential cures, and to advocate for policy and programs to ensure people with arthritis get the treatment, care and support they need.

We also work in partnership with peak health organisations, the federal government and national corporations to support collective goals and to seek funding to sustain our organisational purpose and activity.



Consumer Support

We provide comprehensive information resources to help people live well with arthritis and, through Affiliated state and territory arthritis organisations, deliver a comprehensive range of information, education and support services.



Research

We are the leading non-government funders of arthritis research in Australia and work in partnership with the university and medical sector to support and advocate for increased funding for research into arthritis and musculoskeletal conditions.



Advocacy

We advocate to the government and industry for policies, programs and funding for initiatives to ensure everyone facing the challenge of arthritis gets the care and support they need to live their best possible life.



Sustainability

To help fund and support our activities to achieve our organisational vision, we develop partnerships with national organisations with aligned values.



National Partnerships

We work collaboratively with Affiliated arthritis organisations and other peak health organisations to develop and deliver national programs and to support our common goals of improving the health and wellbeing of people living with arthritis.

Arthritis AUSTRALIA



In my 48 years of having arthritis, no one has ever asked me about my experience."

ROUNDTABLE PARTICIPANT

Contents

Introduction 10
Building on strong foundations 11

How Research Australia has arrived at these recommendations 12

Summary of recommendations 14
Advocacy targets 14
Research investment targets 15
Improved research administration 16

Drawing on international experience 18
Versus Arthritis (UK) 18
Arthritis Foundation (USA) 19
Arthritis New Zealand 19

The opportunity: Arthritis Australia as the anchor point for Australia's arthritis research 20

Advocacy targets 22
Recommendation 1: Economic Analysis 23
Recommendation 2: Consumer Engagement 24
Recommendation 3: Juvenile arthritis 26
Recommendation 4: National survey 27

Research Investment targets 29
Research area 1: Better Care 30
Research area 2: Basic Research 32
Research area 3: Priority Populations 34
Research area 4: Cross cutting research 35

Improved Research Administration 36
Coordinating siloed and fragmented arthritis research 38
Measuring the impact of Arthritis Australia's research investment 39

Next steps 40

Appendix A 41

Appendix B 42

Glossary of Key Terms

Term	Acronym	Definition
Australian Research Council	ARC	Commonwealth entity and advises the Australian Government on research matters, administers the National Competitive Grants Program (NCGP), a significant component of Australia's investment in research and development, and has responsibility for Excellence in Research for Australia (ERA).
Allied health		Broad range of health professionals who are not doctors, dentists, nurses or midwives. Regulated allied health professions include; Chinese medicine practitioners, chiropractors, medical radiation practitioners, occupational therapists, optometrists, osteopaths, pharmacists, physiotherapists, podiatrists and psychologists.
Arthritis		Inflammation of the joints that can cause pain and stiffness. Arthritis is a broad term that includes many specific conditions, like rheumatoid arthritis, osteoarthritis and juvenile idiopathic arthritis.
Arthritis Australia's National Research Program		Along with education and assistance, Arthritis Australia spearheads the effort to further knowledge of arthritis and to search for cures. Much of the work is directed toward raising funds to provide grants, fellowships and scholarships for research into arthritis and related conditions.
Consumer engagement in research		Research institutions, researchers, consumers, and community members working collaboratively to support, facilitate and value the contribution that consumers and community members make to research, and its development, conduct and communication. [1]
Cross cutting research		In the context of this report, cross cutting research refers to research activity whose outputs are potentially applicable across multiple types of arthritis or musculoskeletal conditions.
Juvenile Idiopathic Arthritis	JIA	The name given to a number of types of arthritis that occur in children.
Medical Research Future Fund	MRFF	Ongoing research fund set up by the Australian Government in 2015. The MRFF aims to transform health and medical research and innovation to improve lives, build the economy and contribute to health system sustainability. In July 2020 it grew to $20 billion. The net interest from the fund pays for important health and medical research projects.

1 Sourced from NHMRC Statement of Consumer and Community Involvement in Health and Medical Research. Available at: https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-researc

Term	Acronym	Definition
Musculoskeletal disease		Conditions or diseases that impact the musculoskeletal system, including the bones, joints and muscles. These can be narrowed down into specific conditions, such as arthritis.
National Health and Medical Research Council	NHMRC	An independent statutory agency within the portfolio of the Australian Government Minister for Health and Ageing. The NHMRC creates pathways to a healthier future through research funding, health guidelines and ethical standards.
National Strategic Action Plan for Arthritis	National Action Plan	Led by Arthritis Australia in 2019 with funding from the Commonwealth Department of Health, the National Action Plan outlines key priorities for preventing arthritis, investing in research and improving treatment support for people living with arthritis.
Osteoarthritis	OA	Condition that affects the whole joint including bone, cartilage, ligaments and muscles. Although often described as 'wear and tear', OA is now thought to be the result of a joint working extra hard to repair itself.
Philanthropic sector		In this report, refers to the 33-arthritis research-related charities in Australia as identified by Research Australia. Their activities can include both funding and/or conducting arthritis research.
Private sector		In this report, refers to the 24 commercial organisations (pharmaceutical and medical technology companies) supporting arthritis research. This includes both funding and/or conducting arthritis research.
Pure basic research		Experimental and theoretical work undertaken to acquire new knowledge without looking for long term benefits other than the advancement of knowledge.[2]
Research		The investigation into a topic that is unknown or requires further exploration. For example, many investigations have been completed by researchers (often PhD qualified people at universities) into the treatments for arthritis, but some might believe that more research is needed into specific treatments.
Rheumatoid arthritis	RA	An autoimmune disease that causes pain and swelling of the joints.
Strategic basic research		Experimental and theoretical work undertaken to acquire new knowledge directed into specified broad areas in the expectation of practical discoveries. It provides the broad base of knowledge necessary for the solution of recognised practical problems.[3]

2 Sourced from ABS 1297.0 – Australian and New Zealand Standard Research Classification (ANZSRC), 2008. Available at: https://www.abs.gov.au/ausstats/abs@.nsf/Products/1297.0~2008~Main+Features~Chapter+2,Type+of+Activity?OpenDocument#:~:text=Strategic%20basic%20research%20is%20experimental,solution%20of%20recognised%20practical%20problems.

3 ibid

Executive Summary

The following report presents recommendations to guide how Arthritis Australia directs future investment that is of value to consumers, demonstrates sector leadership and positions Arthritis Australia to leverage government investment through stronger advocacy targets and options for co-investment with government and other philanthropic organisations.

RECOMMENDATIONS

ADVOCACY TARGETS

- **Economic analysis of the financial**, impact of arthritis people's lives and Australia's health system and economy.
- **Pilot models of consumer research engagement** across one form of arthritis.
- **Capitalise on the increased policy attention on juvenile arthritis** through seeking opportunities for partnership with other arthritis charities focused on juvenile arthritis.
- **National survey** of people with arthritis to capture their lived experience, the needs of people who are living with the disease and what their research priorities are.

RESEARCH INVESTMENT TARGETS

- **Better Care:** coordinated and bundled care with a focus on allied health.
- **Basic Research:** causes of arthritis, identification of symptoms, prevention.
- **Priority Populations:** arthritis research for populations identified as high priority, including Aboriginal and Torres Strait Islander Peoples, people living in rural and remote areas, and people with disabilities in managing arthritis.
- **Cross Cutting Research:** coordinating funding advocacy efforts with musculoskeletal diseases.

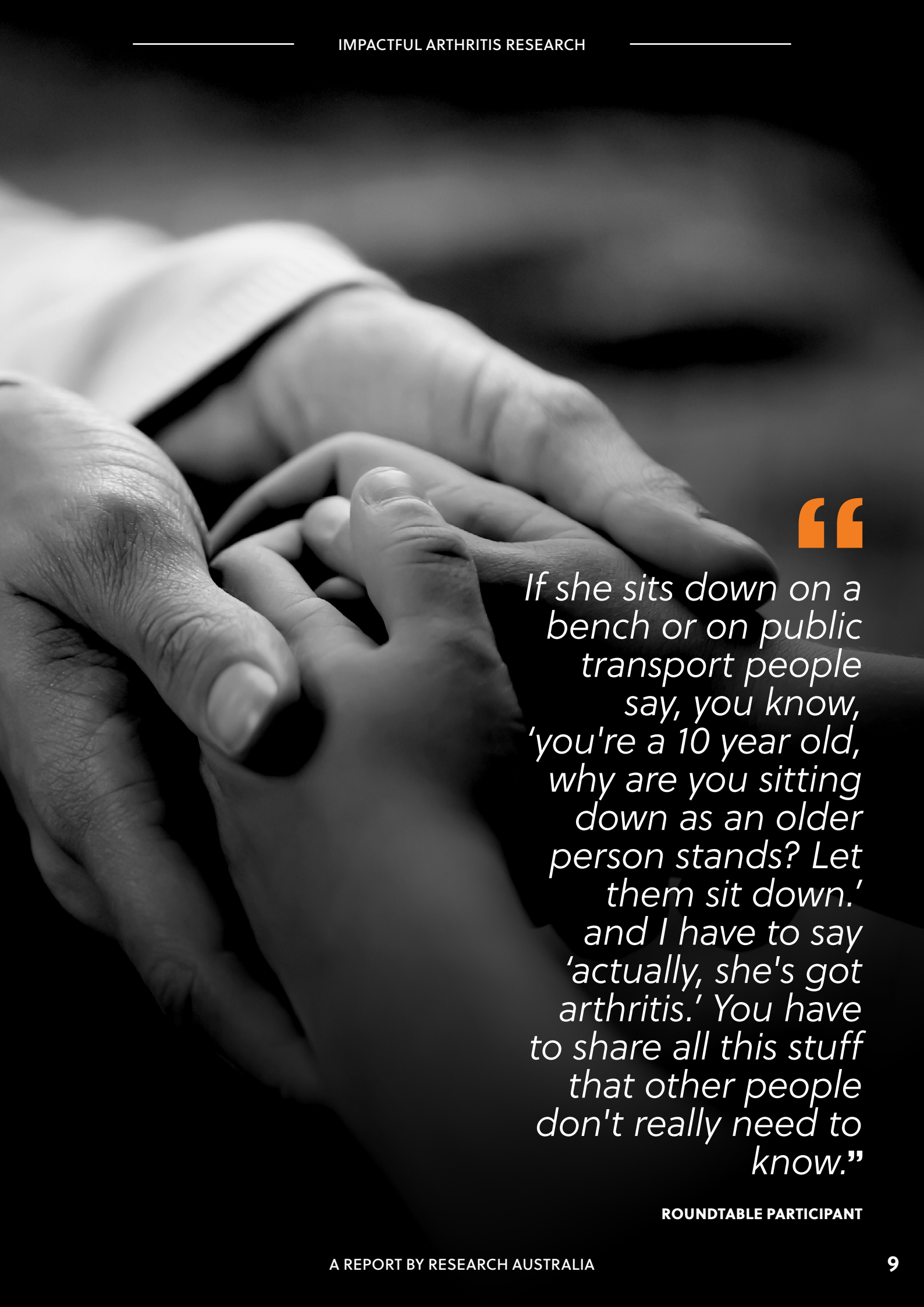
ENABLERS OF SUCCESS: IMPROVED RESEARCH ADMINISTRATION

COORDINATING SILOED AND FRAGMENTED ARTHRITIS RESEARCH

- Balance the research portfolio between investigator led and priority-driven research
- Map existing arthritis research infrastructure, registries and biobanks

MEASURING THE IMPACT OF ARTHRITIS AUSTRALIA'S RESEARCH INVESTMENT

- Revisit the grants application process so impact is considered from the outset
- Develop an Evaluation Framework
- Develop a reporting tool for the research funding program



If she sits down on a bench or on public transport people say, you know, 'you're a 10 year old, why are you sitting down as an older person stands? Let them sit down.' and I have to say 'actually, she's got arthritis.' You have to share all this stuff that other people don't really need to know."

ROUNDTABLE PARTICIPANT

Introduction

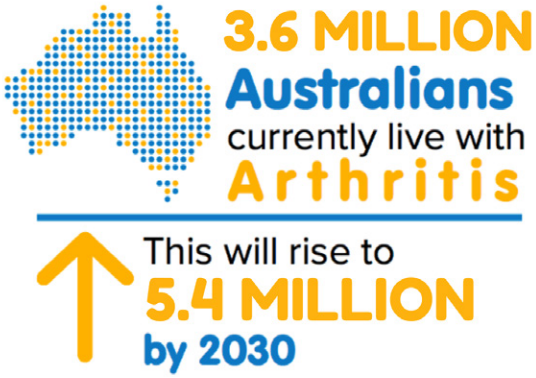
For more than 70 years, arthritis researchers have sought the support and leadership of Arthritis Australia in turning their work into treatments and solutions for the nearly 4 million Australians living with arthritis. Australia would not have access to the expertise in arthritis we have today, without Arthritis Australia's role as the key champion of arthritis research.

Australia has many of the world's top researchers in the field of arthritis, yet arthritis research is chronically underfunded, when the burden of disease is considered. Arthritis is one of most common, costly and disabling chronic conditions in Australia, but government funding for arthritis research is lower than, and falling behind, funding for just about any other major chronic condition.

A recent study found that musculoskeletal research received 1% of the Federal Government's Medical Research Future Fund (MRFF) while cancer receives 16%.[4] Burden of disease is just one of the factors required to be considered in determining MRFF research priorities. A range of funding options, including philanthropy, industry and public funding (like the MRFF), must be considered when looking to further funding for arthritis research.

Now is the time to amplify the impact of arthritis research by engaging the strong and active national arthritis community that Arthritis Australia leads. Through closer consumer engagement, Arthritis Australia's research activity can be more closely aligned with the needs and wants of the 1 in 7 Australians living with arthritis. As the national convening point for Australia's arthritis efforts, Arthritis Australia can bring consumers together with the Government, charitable and the private sector organisations working across this space to facilitate research that truly reflects community need.

The challenge is how Arthritis Australia positions itself to be able to do this given competing priorities in the arthritis sector and health and medical research more broadly. Research Australia's strength lies in its independent and neutral position across the entire health and medical research pipeline from the laboratory through to the patient and the marketplace.



Arthritis Australia engaged Research Australia's expertise in health and medical research policy to harness Arthritis Australia's existing policy and advocacy work and provide a pathway forward for Arthritis Australia to leverage government investment and attract further philanthropic and commercial investment in meaningful arthritis research.

As the national peak body for Australian health and medical research, Research Australia takes the position that research must be supported at all stages of the research pipeline, from fundamental research right through to health service delivery. It is that 'bench to bedside' approach that we have brought to this project, seeking to bring the voices of Arthritis Australia's strong and active consumer networks to the design of research.

4 Medical Journal of Australia - 2021 - Gilbert - A comparison of the distribution of Medical Research Future Fund grants.pdf

Arthritis Australia's strong legacy and track record is recognised by Australian health and medical researchers, 72% of whom have received funding for their research from Arthritis Australia.[5] In such a crowded and complicated landscape of philanthropic organisations dedicated to arthritis (33 organisations across Australia), this figure is true testament to Arthritis Australia's significant role in Australian research funding landscape.

This, coupled with the finding that the majority of philanthropic organisations funding arthritis research are focused on funding just one type of arthritis, could be capitalised on to further position Arthritis Australia as the overarching umbrella group for all charities working in arthritis, and particularly those that are funding arthritis research.

This report presents a series of recommendations to consolidate Arthritis Australia's role as the leader in a crowded marketplace of arthritis research investors and advocates and ensure that Australia better harnesses the immense research talent that exists in this field.

Building on strong foundations

Arthritis Australia has an impressive track record in policy and advocacy, reflected in the development and implementation of the National Strategic Action Plan for Arthritis (the National Action Plan), and thought leadership pieces such as its report making the case for more access to rheumatology nursing in Australia.

This progress has been built upon in recent years with Arthritis Australia's development of a suite of online consumer information resources, and its advocacy role in the Australian Government's Standing Committee on Health, Aged Care and Sport Inquiry into childhood rheumatic diseases [6], and 2022 Federal Election Campaign. [7] At all stages of these conversations, Arthritis Australia has firmly cemented its position as Australia's leading arthritis charity. This report identifies opportunities to build on the extensive progress made by Arthritis Australia to maximise the National Research Program with a sharper focus on consumers and impact.

A key strength lies in Arthritis Australia's national network of affiliate organisations with strong community engagement and links into state and territory governments. This national affiliate network has helped make Arthritis Australia a known brand, trusted across both the research community and the community of Australians with lived experience of arthritis.



Nearly three quarters of Australia's arthritis researchers have received funding from Arthritis Australia

From Research Australia's over 20-year history in health and medical research, we know that for consumer driven research, a national, collaborative research agenda has the greatest chance of success. This national network holds valuable expertise that is essential to ensuring Arthritis Australia continues to be the anchor point for arthritis research in Australia.

Long-term fellowships, such as the Florance and Cope Chair of Rheumatology, at the University of Sydney, formed almost 40 years ago, has been instrumental in advancing research and education in musculoskeletal sciences. Historically, these fellowships have been focused on rheumatology with close partnership between Arthritis Australia and the Australian Rheumatology Association. There is an opportunity to build on the strong foundations already laid to align Arthritis Australia's future research program with the action areas outlined in the National Action Plan.[8]

5 Research Australia's first report to Arthritis Australia, Understanding the arthritis research landscape, available at https://arthritisaustralia.com.au/programs-research/research-australia/report-1/
6 https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases
7 https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2022/04/AA-Fed-Election-Platform-2022-4high-res.pdf
8 ibid

Arthritis Australia's position as the peak body for consumers with all medical conditions (over 100) that are classified under the umbrella term 'arthritis' is testament to its network of leading academics and experts on their Board of Directors, Scientific Advisory Panel and Grants Assessment Committee. These groups are essential in providing Arthritis Australia with a strategic direction that is guided by the expertise and experience of leaders in arthritis research, treatment and management. Research Australia knows there is the research capability – both within Arthritis Australia and outside – now is the time to bring it into sharper focus, not just as a nice to have but a must have.

How Research Australia has arrived at these recommendations

The recommendations presented in this report are built from a staged program of work aimed at achieving increased investment in consumer driven arthritis research and seeing Arthritis Australia more strongly placed as the national anchor point for arthritis research.

Research Australia undertook a detailed review of Australia's arthritis research landscape including the funding allocations historically and trends in meeting contemporary population needs and indeed, expectations. Research Australia's first report, *Understanding the arthritis research landscape*[9], presented an articulation of the areas of research needed to support the strategic priorities identified in the National Action Plan.

This included potential research priorities such as impacts of arthritis, modifiable risk factors of arthritis, enhancing the knowledge and skills of healthcare practitioners involved in arthritis care, and collaborative research involving partnerships with consumers and other stakeholders. Research Australia then conducted a gap analysis of existing arthritis research to inform where more research is needed to meet the priorities identified above. Research Australia mapped stakeholders currently funding arthritis research and opportunities for strategic partnerships to help Arthritis Australia identify opportunities to leverage government investment and attract philanthropic investment.

This work was then built upon with the results of detailed consumer input from over 100 people with lived experience of arthritis to prioritise research in a way that reflects the needs of the communities Arthritis Australia represents. The second report presented to Arthritis Australia, *What consumers want: identifying the unmet needs of Australians with arthritis* [10], documents Research Australia's direct work with consumers with lived experience of three types of arthritis – osteoarthritis, rheumatoid arthritis, and juvenile idiopathic arthritis. Research Australia took the research areas identified in the landscape analysis of, *Understanding the arthritis research landscape* to consumers to understand what they prioritise from existing research and where they think more research is needed. Closer engagement with consumers will help Arthritis Australia, as a crucial funder of arthritis research, advocate for the research which matters most to those with lived experience of arthritis.

Research Australia has provided a summary of the results of this early work at Appendix A and Appendix B. For a full copy of Research Australia's reports, *Understanding the arthritis research landscape and What consumers want: identifying the unmet needs of Australians with arthritis*, please visit Arthritis Australia's website here.

Research Australia also looked at international comparisons and suggested areas for Arthritis Australia to explore further.

9 Available at: https://arthritisaustralia.com.au/programs-research/research-australia/report-1/
10 Available at: https://arthritisaustralia.com.au/programs-research/research-australia/report-2/



It's very easy to slate older people with osteoarthritis and simply say it's wear and tear or it's one of those issues of ageing, which I don't agree with."

ROUNDTABLE PARTICIPANT

Summary of recommendations



Advocacy targets

Key short- and medium- term advocacy projects that will enable Arthritis Australia to build the case for increased public investment in arthritis research and refine the 'ask' to government and other research funders. Arthritis Australia's advocacy for a dedicated MRFF arthritis and musculoskeletal research mission, as indicated in the recent 2022 election platform, is an admirable long-term target. **However, Research Australia believes there are key short- and medium-term actions Arthritis Australia can take which would assist in further building the case for this MRFF mission.**

1 **Conduct economic analysis of the financial,** impact of arthritis people's lives and Australia's health system and economy. This should explore both the personal cost of arthritis and the broader, productivity cost of arthritis to Australia's economy. This will build the case for co-investment in research priorities identified by Arthritis Australia.

2 **Harness a community of research active consumers by developing a model for consumer research engagement and piloting it across one form of arthritis.** Research Australia recommends piloting models of consumer engagement across Rheumatoid Arthritis, utilising Arthritis Australia's existing platform of myRA and connections to the Australian Rheumatology Association. This will not only ensure Arthritis Australia's funding program is consumer driven but also enable Arthritis Australia to leverage government investment and attract philanthropic investment for research identified as a priority by consumers.

3 **Capitalise on the increased policy attention on juvenile arthritis (e.g. Australian Government Inquiry into juvenile rheumatic diseases) through seeking opportunities for partnership with other arthritis charities focused on juvenile arthritis,** e.g. Juvenile Arthritis Foundation Australia (JAFA). Arthritis Australia's focus on arthritis in general is its key point of difference. Partnering with smaller, more targeted charities within the space will assist in positioning Arthritis Australia as the overarching umbrella group for all arthritis charities.

4 **Develop a national survey of people with arthritis to capture their lived experience, the needs of people who are living with the disease and what their research priorities are.** This could be modelled on the Arthritis Foundation's Live Yes! INSIGHTS program[11] or Research Australia's annual public opinion poll[12]. This will provide Arthritis Australia with a consistent evidence base of priorities and areas of unmet need to take to government and/or other arthritis research funders.

11 https://www.arthritis.org/liveyes/insights
12 https://researchaustralia.org/reports/public-opinion-polling-2/



Research investment targets

Long-term fellowships, such as the Florance and Cope Chair of Rheumatology at the University of Sydney, formed almost 40 years ago, have been instrumental in building a foundation of strong arthritis researchers in Australia. Historically, these fellowships have been focused on rheumatology with close partnership between Arthritis Australia and the Australian Rheumatology Association. There is an opportunity to build on the strong foundations already laid to align Arthritis Australia's future research program with the action areas outlined in the National Action Plan.

Arthritis Australia should pursue research investment in areas identified as priorities by people with lived experience of arthritis, and where there is existing research capability but not dedicated funding. As a priority, Arthritis Australia could fund:

1. **Better Care: coordinated and bundled care with a focus on allied health.** Research to support the delivery of better arthritis care is a strong area of need. Current research into models of care covers a variety of topics but there is no overarching, systematic approach to this field of research and how it can best meet consumer need. This is an attractive area for government co-investment along with private health care providers, assuming Arthritis Australia can demonstrate the health system savings associated.

2. **Basic Research: causes of arthritis, identification of symptoms, prevention.** There is the opportunity to offer joint funding with Arthritis Australia's State and Territory Affiliate Organisations through scholarships or fellowships. Demonstrating that consumers are identifying this is a priority and that there will be consumer co-design would help in achieving private sector or government co-investment.

3. **Priority Populations: arthritis research for populations identified as high priority.** The National Action Plan states that there should be more arthritis research on populations that have been identified as high priority by both patient groups and clinicians caring for them. There is an identified lack of research into the experiences of Aboriginal and Torres Strait Islander Peoples, people living in rural and remote areas, and people with disabilities in managing arthritis. Research Australia suggests Arthritis Australia seek co-investment from more specific arthritis charities for research into and for these priority populations.

4. **Cross cutting research: coordinating funding advocacy efforts with musculoskeletal diseases.** The potential research priorities identified through analysis of the National Action Plan are all potentially cross-cutting and could be potentially applicable across multiple types of arthritis or musculoskeletal conditions and/or applicable to neglected arthritis diseases. Arthritis Australia can coordinate funding between organisations focused on arthritis specifically and musculoskeletal disease more generally. By clarifying and embracing these future partnerships and ventures, Arthritis Australia can enhance its national impact and open broader funding and advocacy opportunities. This also demonstrates prudent use of funding and is a great national example of championing collaborative research, reducing duplication across the health and medical research pipeline.



Improved research administration

Research Australia recommends Arthritis Australia look at the application and judging process for funds it issues through the National Research Program. **This will help ensure Arthritis Australia's research funding has the most impact for the communities Arthritis Australia represents and is a sustainable source of funding for progressing innovative, leading edge arthritis research in Australia.** Arthritis Australia could or should consider:

1 **Balance the research portfolio between investigator led and priority-driven research.** This would allow Arthritis Australia to maintain its key, foundational role in supporting the existing pool of Australian arthritis research talent, while driving new research activity in areas such as allied health and the coordination of arthritis care that consumers have identified as a priority.

2 **Map existing arthritis research infrastructure, registries and biobanks.** Arthritis research is predominantly investigator-led, aimed at improving research quality and capacity such as the development of the Australian Arthritis and Autoimmune Biobank Collaborative (A3BC) and the development and expansion of arthritis registries including the OPAL Rheumatology database.[13] However these efforts to date have tended to be siloed and fragmented. There is scope to enhance collaboration through a mapping exercise of existing arthritis registries and biobanks, pulling together the fragments into a national approach to arthritis research infrastructure.

3 **Revisit the grants application process so impact is considered from the outset.** This could be modelled on research impact statements that identify how their research findings would potentially be translated to improve the health of Australians living with arthritis.

4 **Develop an Evaluation Framework** for Arthritis Australia's National Research Program, combining traditional measures of economic impact with translational health system impacts and consumer or patient sentiment to evaluate research impact. This would be particularly impactful in an evidence-led approach to future funding requests or co-investment opportunities.

5 **Develop a reporting tool for the research funding program.** Research Australia recommends Arthritis Australia explore novel software such as Grow Impact[14] which enables funding bodies and researchers to communicate the impact of their investment to society, other funding stakeholders, and demonstrate return on investment.

13 National Strategic Action Plan for Arthritis, p.32, https://arthritisaustralia.com.au/wordpress/wpcontent/uploads/2019/03/2019-National-Strategic-Action-Plan-for-Arthritis.pdf

14 For more information see: https://www.growimpact.com.au/



I had a brilliant GP that didn't knock around in the initial stages and referred me to a really good rheumatologist. Both of them do communicate and the rheumatologist I have had for 23 years does actually listen."

ROUNDTABLE PARTICIPANT

Drawing on international experience

This chapter outlines three major arthritis charities globally and the work they do relating to research funding and programs. There are several areas that Research Australia suggests Arthritis Australia explore further.

Versus Arthritis (UK)

Versus Arthritis is the United Kingdom's largest charity supporting the 10 million people living with arthritis in the country. They are building on the legacies and expertise of both Arthritis Research UK and Arthritis Care to change the view that arthritis is an inevitable part of ageing.[15] Their Research Strategy 2022-2026 sets a pathway for *"research to make arthritis preventable, manageable and treatable"*.[16] The Strategy sets out four priority areas for arthritis research over the next four years: early detection and prevention, targeted treatments, living well, and people and partnerships. To build this Strategy, Versus Arthritis developed a report on the value of MSK research, and the gaps that need to be addressed in the UK[17] – similarly to the work Arthritis Australia has commissioned Research Australia to conduct.



Suggested areas for further exploration:

- Versus Arthritis publicises research studies on their website that are funded by Versus Arthritis and currently recruiting participants, including information on how arthritis consumers can participate or find out more. They also share research studies supported by other funders which are recruiting.[18]
- Versus Arthritis has Research Partners, who are people with experience of living with arthritis who work as equal partners in all research activities, ensuring the research Versus Arthritis funds and supports is of the highest quality.[19]
- Aside from the areas of research investment outlined in the Research Strategy, Versus Arthritis also depicts its rich legacy of investing in life changing interventions through collateral advertised on their website, thus making the case to potential donors for the future of their research program.[20]

15 https://www.versusarthritis.org/about-us/
16 https://www.versusarthritis.org/research/introducing-our-research-strategy/
17 https://www.versusarthritis.org/media/23657/msk-research-case-for-support-nov20.pdf
18 https://www.versusarthritis.org/research/get-involved-in-our-research/find-a-research-study/
19 https://www.versusarthritis.org/get-involved/our-current-volunteering-opportunities/research-partner/
20 https://www.versusarthritis.org/media/17906/research-timeline-poster-sept19.pdf

Arthritis Foundation (USA)

As the largest US charity dedicated to arthritis, the Arthritis Foundation champions the fight to conquer arthritis with life-changing science, resources, advocacy and community connections. Since 2018 the Arthritis Foundation has supported over 20 research projects, with $USD 12 million provided for osteoarthritis research at 15 institutions and $USD 12 million for juvenile arthritis research. The Arthritis Foundation is not just a funder of research, but an active partner through four scientific initiatives, lending its expertise and channelling volunteers and critical patient insights of their Live Yes! Arthritis Network. This ensures a portfolio of programs directly support the arthritis community and represent the voice of the patient.[21]

Suggested areas for further exploration:

- The Live Yes! Arthritis Network[22] is an important gateway for people with lived experience of arthritis to find support and to connect them with valuable research projects currently underway.
- Their Live Yes! Program also provides Live Yes! INSIGHTS[23] program comprised of two surveys – one aimed at people living with arthritis 18 years and older, and another aimed at parents of children aged 5-17 that live with juvenile arthritis. The survey is designed to capture lived experience about a symptom or some other important aspect of how arthritis affects individuals' daily function and mobility. This program helps to show a composite picture of life with arthritis, the needs of people who are living with the disease and what their priorities are.
- The Arthritis Foundation's website also showcases key research leaders and experts they are funding. This helps to shine a light on the research capacity they have invested in and the value their program provides to the management and treatment of arthritis.
- PARTNERS is a patient-powered research network which seeks to involve people with rheumatic diseases and their families in the process of research. Consumers are involved in the network through activities such as online surveys, serving on committees, contributing to a project, providing ideas for research topics, or participating in a research study.

Arthritis New Zealand

Arthritis New Zealand's (Arthritis NZ) 2017-2021 Strategic Plan[24] sets out four key priority areas, one of which is to ensure *"New Zealand research will contribute to finding a cure for arthritis"*. Arthritis New Zealand reviewed its Research Grants priorities in 2013 and its research objectives in 2018. The reviews proposed a primary focus on the objective to: "contribute to the growing body of research that documents and describes the impact of arthritis on the individual, the community and the wider New Zealand society". Arthritis NZ also proposed updating its research priorities and developing a research strategy and plan in conjunction with key stakeholders.

Arthritis NZ's Research Strategy takes a sophisticated approach to encapsulating the important role of a national, central coordinating agency can play in directing research that speaks to current need within the community but also sets a pathway for innovative research that can meet future needs.

21 https://www.arthritis.org/science/initiatives/scientific-research
22 https://www.arthritis.org/liveyes
23 https://www.arthritis.org/liveyes/insights
24 https://www.arthritis.org.nz/wp-content/uploads/2016/10/Draft-Strategic-Plan.pdf

The opportunity: Arthritis Australia as the anchor point for Australia's arthritis research

As identified in the National Action Plan, there is scope to enhance collaboration amongst the major arthritis research funders (such as charities and commercial players) and adopt a more strategic approach to research that is meaningful to people with living with arthritis.

Arthritis research is predominantly investigator-led, aimed at improving research quality and capacity such as the development of the Australian Arthritis and Autoimmune Biobank Collaborative (A3BC) and the development and expansion of arthritis registries including the OPAL Rheumatology database.[25] However as mentioned, these efforts to date have tended to be siloed and fragmented. Given both the prevalence and burden of arthritis as a group of diseases, there is an opportunity to strengthen the role of those with lived experience of arthritis in guiding Arthritis Australia's National Research Program.

Balancing the research portfolio between investigator led and priority-driven research would allow Arthritis Australia to maintain its key, foundational role in supporting the existing pool of Australian arthritis research talent, while driving new research activity in areas such as allied health and the coordination of arthritis care that consumers have identified as a priority.

There is also an opportunity to harness the power of a research active arthritis community into Arthritis Australia's research funding program. Consumer engagement is the future of research and Arthritis Australia has an incredibly active community ready and able to assist. Consumer engagement can take many forms including participation in research and clinical trials, assisting in the design of specific research projects, or providing input and feedback for the identification of Arthritis Australia's research priorities. Remaining engaged with consumers as an ongoing project would further capitalise on this community which has demonstrated its willingness and appreciation at being included in research related endeavours.

In conducting this review of Arthritis Australia's research portfolio, Research Australia has engaged over 100 consumers with JIA, OA and RA. Overwhelmingly, there is strong interest from Arthritis Australia's consumer communities in being more closely engaged in research, with 91% of survey respondents said they would be willing to assist in designing research into arthritis and this message was echoed across the three Roundtables conducted with those living with arthritis.[26]

> *"Australia has immense arthritis research talent. Arthritis Australia has a key role in promoting meaningful and sustainable research investment to meet the health needs of the 1 in 7 Australians living with arthritis."*
>
> **PROFESSOR SUSANNA PROUDMAN, CHAIR, SCIENTIFIC ADVISORY PANEL, ARTHRITIS AUSTRALIA**

25 National Strategic Action Plan for Arthritis, p.32, https://arthritisaustralia.com.au/wordpress/wpcontent/uploads/2019/03/2019-National-Strategic-Action-Plan-for-Arthritis.pdf

26 Research Australia's second report to Arthritis Australia, What consumers want: identifying the unmet needs of Australians living with arthritis, available at: https://arthritisaustralia.com.au/programs-research/research-australia/report-2/

Reflecting the values that underpin consumers' priorities in the National Research Program would position Arthritis Australia as a model not only for the arthritis research community but consumer focused health and medical research more broadly. Ultimately, this will cement Arthritis Australia's role as the leading organisation in coordinating arthritis research in Australia.

The next chapter of this report focuses on investment and the future of arthritis related research and the opportunities to make measured but significant advancement in this discipline for researchers and the beneficiaries of such research.

The following three chapters present recommendations to guide how Arthritis Australia directs future investment that is of value to consumers, demonstrates sector leadership and positions Arthritis Australia to leverage government investment through stronger advocacy targets and options for co-investment with government and other philanthropic organisations.



Advocacy targets:

Key short- and medium- term advocacy projects that will enable Arthritis Australia to build the case for increased investment in arthritis research and refine the 'ask' to government and other research funders.



Research investment targets:

Suggested areas for Arthritis Australia's research investment which have been identified as priorities by people with lived experience of arthritis, and where there is existing research capability but not dedicated funding.



Improved research administration:

Recommendations about bringing Arthritis Australia's National Research Program into greater focus through governance measures that will ensure it has the most impact for the communities Arthritis Australia represents and is a sustainable source of funding for arthritis research in Australia.

Advocacy targets

Arthritis Australia has an impressive track record in policy and advocacy, reflected in the development and implementation of the National Action Plan, and thought leadership pieces such as its report making the case for more access to rheumatology nursing in Australia.

This progress has been built upon in recent years with Arthritis Australia's development of a suite of online consumer information resources, and its advocacy role in the Australian Government's Standing Committee on Health, Aged Care and Sport Inquiry into childhood rheumatic diseases [27], and 2022 Federal Election Campaign.[28] At all stages of these conversations, Arthritis Australia has firmly cemented its position as Australia's leading arthritis charity. There is potential to build on the extensive progress made by Arthritis Australia, with stronger advocacy targets that will help Arthritis Australia leverage government investment, as recommended below.

At all stages of these conversations, Arthritis Australia has firmly cemented its position as Australia's leading arthritis charity.

Focusing Arthritis Australia's advocacy for a MRFF Mission

The MRFF is significantly reshaping the landscape of Australian medical research and innovation and has become an often-sought stream of funding for diseases and disorders impacting Australians. Between January 2019 and August 2021, the MRFF provided a total of ~$1.4 billion for health and medical research. Of this, ~$4 million was targeted specifically to arthritis.[29] For example, a recent study found that musculoskeletal research received 1% of the Federal Government's MRFF funding while cancer receives 16%.[30]

Arthritis Australia's advocacy for a dedicated MRFF arthritis and musculoskeletal research mission, as indicated in the recent 2022 election platform, is an admirable long-term target. A dedicated MRFF mission for arthritis is needed. However, Research Australia believes there are key short- and medium-term actions Arthritis Australia can take which would assist in further building the case for this MRFF mission. The recommendations below are about building the case for arthritis research.

Research Australia recommends the following four advocacy targets that will help Arthritis Australia access and, in some cases, leverage government investment. This is further expanded upon in the partnership and investment opportunities as referenced in Research Australia's first report, *Understanding the arthritis research landscape*.[31]

27 https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases
28 https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2022/04/AA-Fed-Election-Platform-2022-4high-res.pdf
29 Research Australia (2021) Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/
30 Medical Journal of Australia - 2021 - Gilbert - A comparison of the distribution of Medical Research Future Fund grants.pdf
31 Available at: https://arthritisaustralia.com.au/programs-research/research-australia/report-1/

RECOMMENDATION 01

ECONOMIC ANALYSIS

Research Australia proposes Arthritis Australia undertake economic analysis of the financial impact of arthritis on those living with the condition and broader productivity impacts on Australia's health system and economy.

This evaluation should pick up the cost of managing and treating the disease to those living with arthritis, reflecting the complex and multidisciplinary care needed. This should also capture the difference in cost between public and private health care systems.

The impact, particularly the economic impact, of arthritis is identified as a potential priority research area from Research Australia's synthesis of the National Action Plan against current arthritis research in Australia.

Research Australia's study of arthritis research shows that more than 25 articles have been published in the last three years exploring the burden of arthritis.[32] These cover a range of arthritis types and address a wide range of issues, including quality of life in general and specific topics (e.g. psychological wellbeing, work-related issues, fatigue, sleep, capacity for physical activity, relationships).

However, their focus is mainly on individuals with arthritis and there is very little on the burden arthritis places on carers, communities, health systems or welfare systems and the economy. More comprehensive research into these aspects could be important in its own right and serve Arthritis Australia's advocacy purposes.

Arthritis Australia's last study on the current and future impacts of arthritis (both on health and wealth) was conducted in 2016. Although this has provided a valuable evidence-base for advocacy now is the time, six years on, for this to be updated to reflect the economic impact of arthritis on carers, communities and health systems and the economy. Importantly, updated economic analysis can use valuable, existing datasets to analyse the current impacts of arthritis on Australians and our health system.

> *"Mental health support is very much needed but not available. Individual counselling at $200 for 50 minutes with a regular counsellor is too expensive on the pension and not targeted at this specific condition."*
>
> **SURVEY RESPONDENT**

An economic evaluation will assist in providing a key pathway for co-investment in the research priorities identified by Arthritis Australia which will be discussed in the next chapter of this report.

32 Research Australia (2021) Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/

RECOMMENDATION 02

CONSUMER ENGAGEMENT

Research Australia recommends Arthritis Australia harnesses a community of research active consumers by developing a model for consumer research engagement and piloting it across one form of arthritis.

Arthritis Australia has an incredibly active consumer community ready and able to assist Australia's arthritis research. Using a combination of Roundtables and short survey, Research Australia engaged over 100 people with lived experience of RA, OA and JIA. 91% of survey respondents said they would be willing to assist in research and the design of it. Only one respondent said they were unsure, and no consumers said they wouldn't want to be involved in research.[33]



91% OF SURVEY RESPONDENTS said they would be willing to assist in research and the design of it.

People living with arthritis want to be engaged in the research process and it is clear that partnering with the community makes research stronger. Public involvement right at the beginning of a project helps researchers to identify new research topics and to modify their research questions.[34] Consumer co-design can also influence what research outcomes are measured as well as how they are measured, helping make the research findings more relevant and valuable to the people who want to use them.[35]

By building a refreshed research strategy around consumer need and connecting the consumer community to researchers, Arthritis Australia can be a beacon of inspiration for the broader research community, an exemplar of meaningful consumer research co-design.

Many other philanthropic organisations' grants programs stipulate that any research funded should be consumer focused. For example, Musculoskeletal Australia state they will support research that involves consumers as research partners. This includes:

> *"Collaborating as a consumer partner on projects as either an associate investigator or as a member of an advisory committee; facilitating consumer engagement for researchers that are looking for consumer advisors to assist in the planning and development of a research project; and promoting research studies to the wider community through our networks, social media channels, e-newsletter and website, particularly those looking to recruit participants".*[36]

33 Research Australia (2022), What consumers want: identifying the unmet needs of Australians living with arthritis, https://arthritisaustralia.com.au/programs-research/research-australia/report-2/
34 Whear et al (2012) Establishing local priorities for a health research agenda, Health Expectations, 18, pp. 8-21. Available at: https://pubmed.ncbi.nlm.nih.gov/23216859/
35 Health Research Authority (UK) /INVOLVE 2016 Public involvement in research: impact on ethical research
36 https://www.msk.org.au/for-researchers/

The National Action Plan's Priority 3.1.4 states that research funding should "foster collaborative research" and that this should entail "interdisciplinary research partnerships between universities, research organisations, health services, industry and consumer groups". While this statement does mention consumer groups, they are only one of several stakeholders listed and there is no articulation of specifically how individual consumers should be involved in research.

This is a significant lacuna both because Arthritis Australia is a consumer-focused organisation and many of its strategic priorities can only be achieved with systematic consumer input. This includes priorities into which the need for consumer input is obvious (e.g., research into patient and carer experiences and self-management strategies) and those in which it is less obvious (e.g., the need for researchers to routinely collect and analyse patient-reported outcome measures when they develop and use databases and registries).

> *"There is an opportunity for Arthritis Australia to cement the involvement and participation of Australians with lived experience of arthritis in our research projects, from project design to research translation."*
>
> **PROFESSOR DAVID HUNTER, FLORANCE AND COPE CHAIR OF RHEUMATOLOGY, UNIVERSITY OF SYDNEY**

There is the opportunity for Arthritis Australia to be the 'connector' for arthritis researchers and people living with arthritis, enabling researchers to find consumers willing to participate in their work, and outlining research opportunities for people with arthritis to assist in designing and/or participating in. Research Australia recommends Arthritis Australia pilot consumer engagement models across one form of arthritis. This would assist in understanding how they can build consumer co-design into the future of their National Research Program.

The pilot of consumer engagement models would build on work conducted to date to better understand what research to fund, and to more clearly articulate how consumers should be involved in decisions about the design, conduct and dissemination of the research projects it funds. This will assist in the ongoing articulation and refinement of research priorities and ensure that research funded by Arthritis Australia meets the needs of consumers. Any approach should include training for researchers on how to meaningfully engage and collaborate with consumers. Likewise, any approach should include training for consumers on how to participate in the research process and meaningfully share their lived experience of and expertise in arthritis, in all its forms.

RECOMMENDATION 03

JUVENILE ARTHRITIS

Research Australia recommends Arthritis Australia capitalise on the increased government attention on juvenile arthritis by seeking opportunities for partnership with other arthritis charities focused on juvenile arthritis.

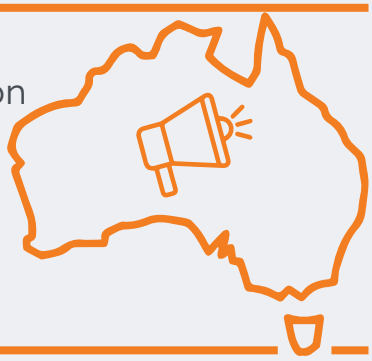
Of the (at least) 33 Australian charities focused on arthritis, Arthritis Australia is the only organisation that explicitly advocates for all types of arthritis.[37] Research Australia's analysis has identified just how complex Australia's arthritis philanthropic sector is. Most charities working in arthritis are, however, dedicated to funding or conducting research into one of the twenty-seven common types of arthritis identified by Arthritis Australia.[38] The focus on Arthritis Australia on arthritis in *general* is its key point of difference.

Recently conversations have increased about the prevalence of arthritis in children, predominantly due to the Australian Government's Standing Committee on Health, Aged Care and Sport Inquiry into childhood rheumatic diseases.[39] Arthritis Australia were deeply involved in this Inquiry, providing submissions and appearing at the Inquiry in March 2022. These conversations have been accompanied by funding announcements of $21.6 million to improve diagnosis, treatment and care for juvenile arthritis and other musculoskeletal disorders.[40]

There is the opportunity to capitalise on the increased government attention on juvenile arthritis by seeking partnership on advocacy projects with arthritis charities focused on juvenile arthritis. For example, Juvenile Arthritis Foundation Australia (JAFA), Children's Arthritis Research Institute, Kids Arthritis Incorporated, and Zoe's Angels. This would assist in positioning Arthritis Australia as the overarching umbrella group for a very complex philanthropic sector.

> *"...it doesn't stop being juvenile arthritis when you turn 18."*
>
> **ROUNDTABLE PARTICIPANT**

Arthritis Australia is the only organisation that **EXPLICITLY ADVOCATES FOR ALL TYPES OF ARTHRITIS** in Australia.



37 Research Australia (2021), Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/
38 Sourced from: https://arthritisaustralia.com.au/what-is-arthritis/types-of-arthritis/
39 https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/rheumaticdiseases
40 greghunt.com.au/21-6-million-for-juvenile-arthritis-and-other-musculoskeletal-disorders/

RECOMMENDATION 04

NATIONAL SURVEY

Research Australia recommends Arthritis Australia develop a national survey of people with arthritis to capture their lived experience, the needs of people who are living with the disease, and what their research priorities are.

Research Australia's survey of Australians with OA, RA and JIA was very well received by the community.[41] There is the opportunity to harness this incredibly active consumer community through a national survey covering *all* types of arthritis to capture their needs, and particularly unmet needs, and what their research priorities are.

This could be modelled on the Arthritis Foundation's Live Yes! INSIGHTS program[42] which comprised of two surveys – one aimed at people living with arthritis 18 years and older, and another aimed at parents of children aged 5-17 that live with juvenile arthritis. The survey is designed to capture lived experience about a symptom or some other important aspect of how arthritis affects individuals' daily function and mobility. The survey helps to show a composite picture of life with arthritis, the needs of people who are living with the disease and what their priorities are.

Research Australia also conducts an annual survey in partnership with Roy Morgan exploring the public's opinion on health and medical research[43] and would be willing to assist Arthritis Australia in designing this national survey.

A survey of Australians with arthritis, which is either conducted annually or every 3 years, will provide Arthritis Australia with a consistent evidence base of priorities and areas of unmet need to take to government and/or other arthritis research funders.

A consumer sentiment survey can further explore consumer research priorities. From Research Australia's conversations with consumers it is clear that there is further opportunity to explore consumers' preferences for research in areas such as, reproductive health, mobility and driving, pain, and brain fog.

There is the opportunity for a national survey of this kind to also be useful in meet Arthritis Australia's other strategic priorities outside of research, including consumer support and consumer advocacy. While this survey is a valuable advocacy tool in its own right, it can also inform the development of Arthritis Australia's consumer engagement model.

> *"It's not obvious that there's anything wrong with you at all and it's been particularly tricky to negotiate at school... You know, why is she using a laptop rather than handwriting? Because her hands are very sore after a short period of time, but you know, she doesn't want to be explaining that all the time."*
>
> **ROUNDTABLE PARTICIPANT**

41 Research Australia (2022), What consumers want: identifying the unmet needs of Australians living with arthritis, https://arthritisaustralia.com.au/programs-research/research-australia/report-2/
42 https://www.arthritis.org/liveyes/insights
43 https://researchaustralia.org/reports/public-opinion-polling-2/



I don't do paid work, because I just couldn't do it with all my health issues and look after children."

ROUNDTABLE PARTICIPANT

Research Investment targets

Arthritis Australia's current National Research Program is a valuable source of funding for arthritis research in Australia. **72% of researchers Research Australia surveyed stated they had, at one point, received funding for their research by Arthritis Australia.**[44] It is clear from both arthritis consumers and researchers themselves that there is a large body of work not yet developed but much needed to improve the quality of life and treatment options for Australians living with arthritis.

Research Australia looked closely at the National Action Plan to identify strategic priorities not yet being actioned through research activity and/or funding. Detailed analysis and identification of potential priority areas for research funding from the National Action Plan are captured in Research Australia's first report.[45]

The following research investment targets have been determined based on the research priority areas identified through Research Australia's analysis of the National Action Plan. In consultation with consumers, Research Australia has also identified the research areas people with lived experience of arthritis believe are a priority.[46]

There are partnership and investment opportunities to further progress in each neglected research area that that Research Australia has also identified. As the only arthritis advocacy group to represent all forms of arthritis, Arthritis Australia has a key role to play in bringing the other groups in the sector together to coordinate funding for some significant grants in priority areas.



44 Research Australia (2021), Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/
45 Ibid
46 Research Australia (2022) What consumers want: identifying areas of unmet need by Australians living with arthritis, https://arthritisaustralia.com.au/programs-research/research-australia/report-2/

RESEARCH AREA 01

BETTER CARE

Research area: coordinated and bundled care with a focus on allied health

Research to support the delivery of better arthritis care is a strong area of need – as identified by an analysis of current research activity and identified by consumers. Arthritis Australia can lead in 'filling this gap' with a closer look at mapping the care journey for one form of arthritis (e.g., Rheumatoid Arthritis), with the opportunity to continue their strong relationship with the Australian Rheumatology Association (ARA). There is the opportunity to direct research funding into designing models for coordinated and bundled care with a focus on allied health.

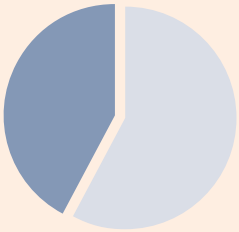
This is an attractive area for government co-investment along with private health care providers, assuming you can demonstrate the health system savings associated. Research Australia suggests modelling this work on successful projects in the oncology space.[47]

Research Australia findings:

Current research into models of care covers a variety of topics but there is no overarching, systematic approach to this field of research and how it can best meet consumer need. Arthritis researchers surveyed by Research Australia highlighted the need for more research on integrated models of care and interdisciplinary collaboration. There is also very little research activity on the best ways to fund arthritis care and support. For instance, analysis of NDIS packages or bundled care payment plans for private patients.[48]

This is also a major area of unmet need as identified by arthritis consumers. Roundtable participants noted that their care teams commonly communicate ineffectively with each other and there was a common wish to have a disease coordinator as a 'one stop shop' for care management. Over half (58%) of survey respondents believe that research into better managing their care is needed. Consumers consulted also highlighted that it is expensive to pay for treatment (including medications and many appointments with different clinicians), attend in-person appointments (e.g. travel costs) and make lifestyle modifications (e.g. to the person's environment, work, and school commitments).[49]

OVER HALF (58%) of survey respondents believe that research into better managing their care is needed.



"The occupational therapists have been great. Every difficulty I have from opening jars to getting up and down steps to making my bed or not making my bed...that's been a huge support."

ROUNDTABLE PARTICIPANT

47 Led by Professor Christobel Saunders AO who presented this work at Research Australia's Health Economics Roundtable in October 2021. More information available at: https://www.ciccancer.com/about

48 Research Australia (2021), Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/

49 Research Australia (2022), What consumers want: identifying areas of unmet need by Australians living with arthritis, https://arthritisaustralia.com.au/programs-research/research-australia/report-2/

Care coordination can be reframed so it is consumer centric acknowledging that arthritis is not a single disease point, there are over 100 forms of arthritis which all provide different care experiences. Research in this space could also consider what would be appealing to funders and health service implementers, such as preventing avoidable hospitalisations. Research into the arthritis care journey must consider the differences experienced by Australians living with arthritis.

Australians with lived experience of arthritis also stressed that allied health is a valued source of arthritis management and treatment. Specifically, for people with OA and RA, the use of diet and exercise strategies have helped them manage their condition but information about what strategies to try and evidence of their efficacy is infrequently provided by health professionals. This theme often coincided with the suggestion for better access to allied health services. Traditional pharmaceutical treatments continue to be the main source of treatment for survey respondents (66%). However, exercise management (58%), nutrition and diet modification (41%) and physiotherapy (37%) were also highlighted as useful treatment methods.[50]

> *"Consulting multiple allied health professionals, you know specialists, and they tell her that she needs to do something else [for her care] and her response is 'but I've got no energy to do that, you know, you're asking me to do yet another thing, and now that's going to involve making another appointment. I haven't even got the energy to go to school.' That's a really big problem."*
>
> **ROUNDTABLE PARTICIPANT**

Partnership opportunities to strengthen advocacy:

- Australian Rheumatology Association
- State and Territory Governments
- National peak bodies representing allied health, e.g. Allied Health Professions Australia

Opportunities for co-investment:

- MRFF
- Health insurers
- Private health providers

50 ibid

RESEARCH AREA 02

BASIC RESEARCH

Research areas: causes of arthritis, identification of symptoms, prevention

Research Australia suggests including basic research in future funding. There is the opportunity to seek joint funding with Arthritis Australia's State and Territory Affiliate Organisations through scholarships or fellowships. Future investment could be modelled on successful initiatives within Arthritis Australia's network such as the Arthritis Queensland Chair of Rheumatology which has been funding leading Australian rheumatologists for 20 years.

Demonstrating that consumers are identifying this is a priority and that there will be consumer co-design for research conducted would help in achieving private sector or government co-investment. It is also an important step in demonstrating Arthritis Australia as the convening point for Australia's leading and innovative arthritis research.

Research Australia findings:

People with arthritis want to know the aetiology and pathology of arthritis – what is the nature and cause of arthritis, and why did they get diagnosed with this disease. Pure basic research and strategic basic research have a key role to play in meeting these areas of unmet need.

Basic research can be classified as experimental and theoretical work undertaken to acquire new knowledge without looking for long term benefits other than the advancement of knowledge. This can also include strategic basic research which is undertaken to acquire new knowledge directed into specified broad areas in the expectation of practical discoveries.

Basic research into arthritis is not only supported by the researchers themselves but also Australians with lived experience of arthritis.[51] This is an important point for Arthritis Australia's advocacy. It is important that any future basic research funded by Arthritis Australia is underpinning by strong consumer and clinician co-design.

People with arthritis want to know the aetiology and pathology of arthritis – what is the nature and cause of arthritis, and why did they get diagnosed with this disease. Pure basic research and strategic basic research have a key role to play in meeting these areas of unmet need.

51 Research Australia (2022), What consumers want: identifying the unmet needs of Australians living with arthritis, https://arthritisaustralia.com.au/programs-research/research-australia/report-2/

Arthritis is often described as a condition affecting the joints. This is oversimplified and misses many of the signs and symptoms that are associated with arthritis that negatively impact quality of life. Consumers reported that increased awareness of the various common and less common signs and symptoms associated with arthritis is needed to support people with arthritis to participate in society without prejudice.

Research into primary prevention was also identified in the gap analysis of current arthritis research activity and raised by people with arthritis as an area of unmet need. Currently there is little research activity specifically focused on primary prevention of arthritis, which is a potential priority area identified from the National Action Plan.[52] However, it must be noted that there is likely overlap with work addressing risk factors for other conditions (musculoskeletal and other). Consumers have also highlighted that they would like to be able to take preventative measures and that if research were able to assist them they would be willing to participate.

> *"Mental health support is very much needed but not available. Individual counselling at $200 for 50 minutes with a regular counsellor is too expensive on the pension and not targeted at this specific condition."*
>
> **SURVEY RESPONDENT**

Partnership opportunities to strengthen advocacy:

- Arthritis Australia's State and Territory Affiliate Organisations

Opportunities for co-investment:

- Australian Research Council (ARC)
- National Health and Medical Research Council (NHMRC)

52 Research Australia (2021), Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/

RESEARCH AREA 03

PRIORITY POPULATIONS

Research Areas: arthritis research for populations identified as high priority

Of the (at least) 33 Australian charities focused on arthritis, Arthritis Australia is the only organisation that explicitly advocates for all types of arthritis. Research Australia's analysis shows just how complex Australia's arthritis philanthropic sector is. Most charities working in arthritis are, however, dedicated to funding or conducting research into one of the twenty-seven common types of arthritis identified by Arthritis Australia.[53] The focus on Arthritis Australia on arthritis in general is its key point of difference.

Arthritis Australia could position itself as the overarching umbrella group and key convening point for research conducted by all arthritis charities. Research Australia suggests Arthritis Australia seek co-investment from more specific arthritis charities for research into and for these priority populations.

Research Australia also suggests expanding scope to seeking co-investment from other health charities dedicated to certain populations. For example, Lowitja Institute or National Aboriginal Community Controlled Health Organisation (NACCHO) for Aboriginal and Torres Strait Islander Peoples.

Research Australia findings:

The National Action Plan states that there should be more arthritis research on populations that have been identified as high priority by both patient groups and clinicians caring for them:

a. Aboriginal and Torres Strait Islander Peoples
b. People living in rural and remote areas
c. People with disabilities

Overall, there is little current research activity on and for these population groups. There is some work on the work-related experiences of younger people with arthritis, arthritis in older populations, telehealth and community-based interventions in rural populations, and other neglected groups e.g., haemochromatosis-associated arthritis.[54]

Research Australia's analysis found no research funding in the past 3 years on Aboriginal and Torres Strait Islander Peoples but some future articles under review. Research Australia notes Arthritis Australia has initiated funding for research into Aboriginal and Torres Strait Islander people living with arthritis with Janssen, and one of the Action Plan grants includes the development of arthritis resources for Aboriginal and Torres Strait Islanders, led by Arthritis and Osteoporosis WA in partnership with the National Aboriginal Community Controlled Health Organisation (NACCHO).

Partnership opportunities to strengthen advocacy:

- Private sector: 24 organisations supporting arthritis research

Opportunities for co-investment:

- Philanthropic sector: including but not limited to 33 arthritis research-related charities
- NHMRC
- MRFF

53 Sourced from: https://arthritisaustralia.com.au/what-is-arthritis/types-of-arthritis/
54 Research Australia (2021), Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/

RESEARCH AREA 04

CROSS CUTTING RESEARCH

Research areas: Coordinating funding advocacy efforts with musculoskeletal diseases

In the context of this Report, cross cutting research refers to research activity whose outputs are potentially applicable across multiple types of arthritis or musculoskeletal conditions. There is an opportunity in both Arthritis Australia's agenda and in the broader research community to coordinate funding and advocacy between arthritis specifically and musculoskeletal disease more generally. By clarifying and embracing these future partnerships and ventures, Arthritis Australia can enhance its impact and open broader funding and advocacy opportunities. It is, for example, possible that projects that cut across multiple domains would have broader impact and be more attractive to funding agencies.

Arthritis Australia has a key convening role to play in bringing the right researchers, charities, and commercial partners together with government to attract larger-scale funding. By expanding its scope to bring charities engaged in musculoskeletal research 'into the tent', Arthritis Australia can further position itself as the anchor point for Australia's arthritis and musculoskeletal research.

Research Australia findings:

The potential research priorities identified through analysis of the National Action Plan are all potentially cross-cutting and/or applicable to neglected arthritis diseases. Most funding and all published research is disease specific. However, there are some recently funded large initiatives. For example, Centres of Research Excellence and Investigator Grants are focused on arthritis in general or musculoskeletal disease in general (including arthritis).[55]

In order to facilitate more cross-cutting research, Arthritis Australia could look to co-fund research with other philanthropic organisations that conduct cross-cutting research. For example, one of Arthritis New Zealand's three research priorities is the multidisciplinary management of arthritis. This priority covers innovative approaches in the management of all types of arthritis and can include self-management programmes, physiotherapy, podiatry, pharmacological interventions, complementary medicine, and other areas.

There is currently a lack of clarity as to whether Arthritis Australia should co-fund projects and coordinate funding advocacy efforts with groups that focus on musculoskeletal diseases more generally. A similar point applies to whether Arthritis Australia wishes to align its advocacy efforts with groups advocating for research into:

- conditions and problems that affect patients with both arthritis and other conditions (e.g., pain in general, disability, mobility difficulties, psychosocial and economic distress);
- risk factors that cause both arthritis and other diseases (e.g., poor diet and sedentary lifestyle); and
- comorbidities that affect patients with both arthritis and other condition (e.g., heart disease and diabetes).

Partnership opportunities to strengthen advocacy:

- Pain Australia
- Musculoskeletal Australia

Opportunities for co-investment:

- Public sector: key federal and state health and medical research funding streams (e.g. MRFF, NHMRC)
- Private sector: 24 organisations supporting arthritis research

55 Research Australia (2021), Understanding the arthritis research landscape, https://arthritisaustralia.com.au/programs-research/research-australia/report-1/

Improved Research Administration

Arthritis Australia's National Research Program has been an often-sought source of funding and support for Australia's leading arthritis and musculoskeletal researchers. The Program receives a considerable number of applications each year, which are peer-reviewed, including consumer input, by a panel of experts including Arthritis Australia's Medical Director, and the Chair of Arthritis Australia's Research Grants Assessment Committee who has seniority and expertise in the field.

The programme provides funding through:

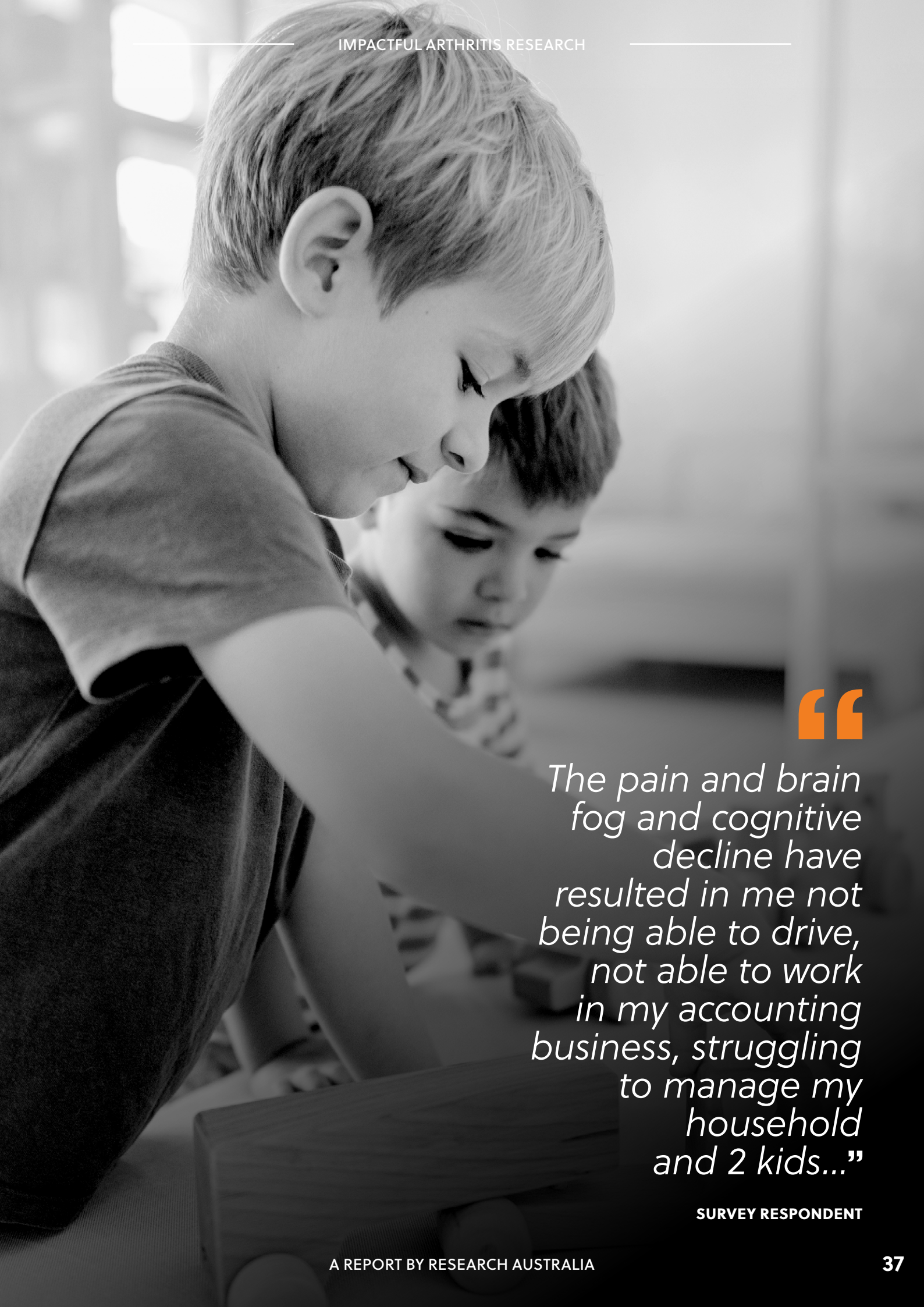
- fellowships;
- scholarships;
- project grants and grants in aid; and has a
- a focus on translational research.

Australia would not have access to the expertise in arthritis we have today, without Arthritis Australia's role as the key champion of arthritis research.

In addition to advocacy and research funding targets, Research Australia suggests Arthritis Australia look at the governance currently underpinning their National Research Program. The recommendation below is about bringing Arthritis Australia's research funding program into greater focus to make sure it has the most impact for the communities Arthritis Australia represents and is a sustainable source of funding for progressing innovative, leading edge arthritis research in Australia.

"I sing in a choir and sometimes we are required to click to the beat, and I cannot click my fingers, because that gives shooting pains my hand, so I clap instead, which is not quite the same."

ROUNDTABLE PARTICIPANT



"The pain and brain fog and cognitive decline have resulted in me not being able to drive, not able to work in my accounting business, struggling to manage my household and 2 kids..."

SURVEY RESPONDENT

Coordinating siloed and fragmented arthritis research

Arthritis research is predominantly investigator-led, aimed at improving research quality and capacity such as the development of the Australian Arthritis and Autoimmune Biobank Collaborative (A3BC) and the development and expansion of arthritis registries including the OPAL Rheumatology database.[56] However these efforts to date have tended to be siloed and fragmented.

To progress in coordinating this siloed investigator-led research, Research Australia proposes:

1. **Balance the National Research Program between investigator led and priority driven research.** The research investment targets recommended earlier are areas of research identified as both research gaps and priorities identified by consumers. Arthritis Australia should consider making a conscious effort to balance its research portfolio between investigator led and consumer driven research. This will allow Arthritis Australia to maintain its key, foundational role in supporting the existing pool of Australian arthritis research talent, while driving new research activity in areas such as allied health and the coordination of arthritis care that consumers have identified as a priority.

2. **Map existing arthritis research infrastructure, registries, and biobanks.** One part of the National Action Plan (Objective 3.2) articulates in detail how to "enhance data collection, linkage and analysis to drive quality improvement in arthritis prevention, management and outcomes". This is well-developed and clearly articulated and should be retained as a potential research priority. Research Australia applauds the recent development of Australian Arthritis and Autoimmune Biobank Collaborative (A3BC) and the development and expansion of arthritis registries including the OPAL Rheumatology database. There is scope to enhance collaboration through a mapping exercise of existing arthritis registries and biobanks, pulling together the fragments into a national approach to arthritis research infrastructure. This work could build on the early mapping done by Arthritis Australia in 2019, prior to the development of the National Action Plan, to focus on exposing gaps in arthritis research infrastructure.[57] It is critical that, where appropriate, any publicly funded research infrastructure, registry or biobank ensures that the data collected is publicly available, this should be a key consideration of the mapping exercise.

56 National Strategic Action Plan for Arthritis, p.32, https://arthritisaustralia.com.au/wordpress/wpcontent/uploads/2019/03/2019-National-Strategic-Action-Plan-for-Arthritis.pdf
57 https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2019/08/190618-Stocktake-of-arthritis-activities_final.pdf

Measuring the impact of Arthritis Australia's research investment

Better capturing the outcomes and impact of the research Arthritis Australia funds and developing markers of success for research will ensure Arthritis Australia's National Research Program is strategic and sustainable.

An example of output, outcome and impact
Output: researchers publish their research, identifying a new and more effective model of care for arthritis
Outcome: the new model of care is adopted as routine clinical practice
Impact: the new model of care leads to improvements in the quality of life of people with arthritis

It is frequently stated that it takes an average of 17 years for research evidence to reach clinical practice.[58] This timeframe presents challenges in measuring the impact of health and medical research. Nonetheless there is merit in projecting future benefit, to demonstrate the expected impact of Arthritis Australia's research investment. In the short term, much of the measurement will be of activity (output) rather than outcome or impact. Over time, the value of past projects will become clearer as they progress towards adoption in clinical practice, including as new medications or models of care.

It is important for any research funding structure – no matter how big or small – to define what success is. How will Arthritis Australia measure this success and keep the researchers accountable for the projects you are funding?

Research Australia recommends the following as impact measures of Arthritis Australia's research investment:

1. **Revisit the grants application process** so impact is considered – by researchers particularly – from the outset of investment. This could be modelled on research impact statements that identify how their research findings would potentially be translated to improve the health of Australians living with arthritis.
2. **Develop an Evaluation Framework for Arthritis Australia's National Research Program.** This could be modelled on work Research Australia conducted for the Australian Department of Health for the MRFF, one of the two main federal funding streams for health and medical research. This Framework combined traditional measures of economic impact, including improved workforce participation, commercialisation, and the like, with translational health system impacts and consumer or patient sentiment to evaluate research impact.
3. **Develop a reporting tool for the research funding program.** Research Australia recommends Arthritis Australia explore novel software such as Grow Impact[59] to assist in tracking the progress of research towards real impacts over time. This software enables funding bodies and researchers to communicate the impact of their investment to society, other funding stakeholders, and demonstrate return on investment.

Further exploring novel software and models for a refreshed National Research Program will ensure Arthritis Australia's future research investment is directed to achieving impact. These models are not intended to create more red tape, but rather track the progress of Arthritis Australia's investment towards impact. This can be key in making the case to potential donors for the future of the National Research Program.

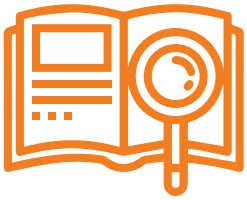
58 Westfall J, Mold J, Fagnan L Practice-based research – "Blue Highways" on the NIH roadmap. JAMA2007; 297:403-6 [PubMed]
59 For more information see: https://www.growimpact.com.au/

Next steps

This report presents a series of recommendations to consolidate Arthritis Australia's role as the leader in a crowded marketplace of arthritis research investors and advocates to ensure that Australia amplifies this research impact by engaging the strong and active support of the arthritis community.

As the national peak body for the entire health and medical research, Research Australia conducted a staged program of work to harness Arthritis Australia's existing policy and advocacy work and review its research investment and advocacy strategy. This has all been done with funding in mind, making sure Australia's excellent arthritis research capability is matched with strategic and sustainable funding. Both in terms of Arthritis Australia's National Research Program and as a pathway for Government co-investment.

As a first step, Research Australia recommends Arthritis Australia looks to action the following short- and medium-term targets:



01

Economic analysis of arthritis, exploring both the personal cost of arthritis and the impact on the Australian economy.



02

Pilot of consumer engagement models across one form of arthritis



03

Revisit the grants application process

Now is the time to amplify this research impact by engaging the strong and active national arthritis community that Arthritis Australia leads. Through closer consumer engagement, Arthritis Australia's research activity can be more closely aligned with the needs and wants of the 1 in 7 Australians living with arthritis. As the national convening point for Australia's arthritis efforts, Arthritis Australia can bring consumers together with the Government, charitable and the private sector organisations working across this space to facilitate research that truly reflects community need.

Appendix A: Report 1 key findings

Understanding the arthritis research landscape

1. **There is limited Australian research activity in many of the strategic priorities identified in the *National Strategic Action Plan for Arthritis*.** Arthritis Australia should explicitly align its research strategy with existing research. Alternatively, it could seek to initiate research in areas identified by the National Action Plan as strategic priorities where there is currently a lack of research activity.

2. **Arthritis Australia has a key convening role to play in bringing the right researchers and charities together with government to develop new research partnerships capable of attracting larger-scale funding.** At least 72% of Australian health and medical researchers engaged in arthritis research have been funded, at least in part, by Arthritis Australia. Arthritis Australia could identify and support leading and emerging investigators working on National Action Plan priority areas, and partner with government agencies and other philanthropic organisations to attract alternative sources of research funding. Together with its state affiliates, Arthritis Australia has Australia's largest and most established national network of arthritis advocates and consumers. The approach to research funding should seek to leverage this national network, developing projects which are consumer co-designed and deliver cross-jurisdictional impact.

3. **Of the (at least) 33 Australian charities focused on arthritis, Arthritis Australia is the only organisation that explicitly advocates for all types of arthritis.** Arthritis Australia can also position itself as the group that ensures research is conducted into arthritis in general and into types of arthritis that are not currently addressed by any other philanthropic organisations.

4. **There is an opportunity in both Arthritis Australia's agenda and in the broader research community to more clearly delineate between arthritis specifically and musculoskeletal disease more generally.** By clarifying this distinction, Arthritis Australia could further elucidate its "niche" in the sector, enhance its impact and open up broader funding and advocacy opportunities.

5. **By stipulating how consumers should be involved in its research-related activities, Arthritis Australia can ensure that the research it funds meets the needs of consumers.** Modes of consumer engagement are not currently specified in Arthritis Australia's research program but could be incorporated to assist in the ongoing articulation and refinement of research priorities.

6. **There is a dynamic private sector with an interest in arthritis research.** There are opportunities for Arthritis Australia to collaborate with the private sector, including pharmaceutical and medical technology companies, through targeted research funding partnerships and to advocate for private investment in particular kinds of research.

Appendix B: Report 2 key findings

What consumers want: identifying the unmet needs of Australians with arthritis

Common themes from the literature

There is a body of existing work looking at what consumers themselves identify as the unmet healthcare needs of those living with – or caring for those living with – JIA, OA and RA. A search across 81 Australian and international academic publications and grey literature sources identified the following common themes associated with future research needs and unmet needs of people with JIA, OA and RA:

Common consumer themes identified in both Australian and international literature:

1. Efficacy and safety of new medications and management plans, including alternative therapies, especially for pregnancy planning
2. Information about management strategies, including available drugs, drug safety assistive devices, exercise, alternative therapies etc.
3. Information about effective community engagement (e.g. financial management, work, activities of daily living[60])
4. Increased service and specialist availability and accessibility
5. Knowing where to find reliable information

Common consumer themes in Australian literature only:

6. Increased clinician knowledge of the condition
7. Guidance for self-management
8. Effective and collaborative care coordination, including having all clinicians working together and providing non-conflicting information

Common consumer themes in international literature only:

9. Information on prognosis and likely progression
10. Better practitioner communication skills and rapport development
11. Opportunities for social interaction with others with the same condition and their families

Key consumer themes across the three types of arthritis investigated – RA, OA, JIA

Using a combination of Roundtables and short survey, Research Australia engaged over 100 people with lived experience of RA, OA and JIA.

1. Help is hard to find

Getting an accurate diagnosis and appropriate referral to ensure adequate arthritis management is very difficult. 42% of survey respondents saw multiple clinicians/allied health professionals before receiving a diagnosis.

2. Care is hard to coordinate

Care teams commonly communicate ineffectively with each other (e.g. by not using My Health Record) and there is a common wish to have a disease coordinator as a 'one stop shop' for care coordination.

60 These can be community based, personal (like toileting), and domestic (like vacuuming).

3. Managing arthritis is expensive
It is expensive to pay for treatment (including medications and many appointments with different clinicians), attend in-person appointments (e.g. travel costs) and make lifestyle modifications (e.g. to the person's environment, work and school commitments). Financial support is important.

4. Loss of physical and mental function is common
Function loss can prevent the person from participating in activities they enjoy and can lead to discrimination at school and other areas (e.g. public transport).

5. A grieving process is associated with diagnosis
People diagnosed with arthritis can grieve the loss of current and future function. Psychological support during the grieving process is needed by people with arthritis but is not being sufficiently provided.

6. Conflicting information is commonly given
Conflicting information can cause confusion, frustration and disappointment in the care being received. People often do their own research to find answers and clarity. The majority of survey respondents (65%) discovered new ways to manage and treat their arthritis from doing their own research. However, the quality and quantity of information can be inadequate, particularly for JIA.

7. Allied health is a valued source of arthritis management and treatment
Medications are an important part of arthritis management. However, consumers report significant benefit from the inclusion of allied health. Specifically, for people with OA and RA, the use of diet and exercise strategies have helped them manage their condition but information about what strategies to try and their evidence of effect is infrequently provided. This theme often coincided with the suggestion for better access to allied health services. Traditional pharmaceutical treatments continue to be the main source of treatment for survey respondents (66%). However, exercise management (58%), nutrition and diet modification (41%) and physiotherapy (37%) were also highlighted as useful treatment methods.

8. Arthritis is complex
Arthritis is often described as a condition affecting the joints. This is oversimplified and misses many of the signs and symptoms that are associated with arthritis that negatively impact quality of life. Increased awareness of the various common and less common signs and symptoms associated with arthritis is needed to support people with arthritis to participate in society without prejudice.

9. Everyone's arthritis experience is different.
There is no 'one size fits all' to arthritis management regardless of the arthritis subtype. People want tailored care that meets their unique needs. Consumers also commented on the need for intersectional research (e.g. CALD communities, Aboriginal and Torres Strait Islander Peoples), understanding the economic and demographic factors that may affect the quality of patient outcomes, improving community understanding of arthritis, and offering mental health support.

10. Consumers want to be involved in research
Arthritis Australia has a very engaged and active consumer cohort. This was reflected in discussions at the three Roundtables and from survey respondents. 91% of survey respondents said they would be willing to assist in designing research into arthritis. No respondents answered 'no' to this question, and 9% (one respondent) was 'unsure and/or don't know'.

Although there are several overlapping themes that have been identified across the three roundtables and survey, it must be acknowledged that people with each condition have unique experiences. This is especially true for the JIA group, where children and their carers made it very clear that it is time that JIA was recognised and managed independently of other arthritis types.

RESEARCH AUSTRALIA

CONNECTING · ENGAGING · INFLUENCING

Arthritis AUSTRALIA

RESEARCH AUSTRALIA LIMITED
ABN 28 095 324 379

384 Victoria Street
Darlinghurst NSW 2010

T 02 9295 8547
E admin@researchaustralia.org

researchaustralia.org