

Understanding the arthritis research landscape

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.

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

Index



National Strategic Action Plan for Arthritis (National Action Plan):

- This is the key document referred to in this report and can be found here.
- Research Australia has analysed this document to understand potential research priorities for Arthritis Australia.
- The development of the National Action Plan in 2019 was led by Arthritis Australia with funding from the Australian Government Department of Health.

List of tables:

1. Types of research that would be needed to deliver on the National Strategic Action Plan for Arthritis
2. Gap analysis
3. Philanthropic organisations
4. Arthritis Australia's State and Territory Affiliate Organisations
5. Private sector organisations

List of appendixes:

A. Gap analysis search strategy
B. Analysis of funding streams (provided as an attachment)

Contents

Introduction 6

Summary of key findings and opportunities 8

Identification of potential research priorities in the National Strategic Action Plan for Arthritis 10

Research priorities generated by the National Strategic Action Plan for Arthritis 10

Gap analysis: Where more research is needed to deliver on the National Strategic Action Plan for Arthritis 14

Who funds Australian arthritis research 26

Philanthropy – Charities and not-for-profits 28

Public sector – Australian Government 31

Public sector – State and territory governments 34

Private sector – Pharmaceutical and/or commercial 35

Key findings and opportunities: Arthritis Australia's research strategy and current research gaps 36

Next steps 40

Introduction

Arthritis Australia has an impressive track record in policy and advocacy, reflected in the *National Strategic Action Plan for Arthritis (the National Action Plan)*.

As identified in the National Action Plan, there is scope to adopt a more strategic and collaborative approach to arthritis research in Australia. At present, however, the National Action Plan does not specify precisely what the focus of this research should be. Arthritis Australia has identified this an opportune time to harness its existing policy and advocacy work and review its research investment and advocacy strategy, and has commissioned Research Australia to assist in this redevelopment.

Research Australia is the national alliance representing the entire health and medical research pipeline from the laboratory through to the patient and the marketplace. Research Australia has demonstrated expertise in guiding policy for health and medical research, including providing credible, politically neutral, policy advice for 20 years. Our perspective always includes promoting high quality research at all stages of the research pipeline, from fundamental research right through to health service delivery, with the ultimate goal of improving Australians' health outcomes.

This report is the first of three reports that Research Australia is preparing for Arthritis Australia. It presents:

1. An articulation of the areas of research needed to support the strategic priorities identified in the National Strategic Action Plan for Arthritis;
2. A preliminary gap analysis of existing arthritis research to inform where more research is needed to meet the priorities identified in the National Strategic Action Plan for Arthritis; and
3. A map of stakeholders currently funding arthritis research in Australia and a summary of the types of research that have been funded by these stakeholders over the past three years.

The findings contained in this first report will be built upon through direct consumer engagement. Report 2, will identify consumers' priorities and values, giving Arthritis Australia a solid evidence base from which to refocus its research funding and advocacy efforts so that they are sustainable; aligned with Arthritis Australia's consumer-focused ethos and the strategic priorities, as articulated in the National Action Plan.

Report 3 will present 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.



Summary of key findings and opportunities



1 There is limited Australian research activity in many of the strategic priorities identified in the *National Strategic Action Plan for Arthritis.*

Arthritis Australia could 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. The consumer-based research being conducted by Research Australia will help to identify which of these gaps should be given priority in funding efforts, this will be covered in Report 2.

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 that 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.

Models 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 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.

Identification of potential research priorities in the National Strategic Action Plan for Arthritis

The first question that Research Australia set out to answer was: To what extent does Arthritis Australia's current research strategy align with:

1. the strategic priorities generated by the National Strategic Action Plan for Arthritis; and
2. the kinds of research that those living with arthritis (and their carers) prioritise and value?

Research priorities generated by the *National Strategic Action Plan for Arthritis*

The *National Strategic Action Plan for Arthritis* was analysed to identify the arthritis research needed to deliver on its vision for 'freedom from the burden of arthritis'[1]. The identified potential research priorities are articulated in **Table 1** below. Importantly, these categories do not simply restate the contents of the National Action Plan but, rather, present a higher order synthesis of potentially "researchable" themes and categories that cut across the entire National Action Plan.

This included an analysis of both:

- Explicit research priorities described in the National Action Plan's Priority 3 "Research, Evidence and Data"; and
- Research priorities implicit in other sections of the National Action Plan—based on the assumption that if Arthritis Australia considers these issues and activities to be important, then it would want to fund and advocate for research that informs them.

An inductive qualitative research approach—informed by Morse's outline of the cognitive basis of qualitative research[2] and Charmaz's outline of data analysis in grounded theory[3]—was used to develop these categories. This involved initial coding the National Action Plan via line-by-line analysis, followed by synthesis of these codes into more abstract categories and sub-categories. A process of constant comparison was used, with continual refinement and enrichment of codes as new data emerged. Data analysis continued until categories were saturated (i.e., all codes appeared to fit under one or more of the existing categories).

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 section is well-developed and clearly articulated and should be retained as a potential research priority.

1 Commonwealth of Australia as represented by the Department of Health. 2019. The National Strategic Action Plan for Arthritis. Page 6
2 Morse, J.M. 1994. ""Emerging from the data": The cognitive processes of analysis in qualitative inquiry." In Critical issues in qualitative research methods, edited by J.M. Morse. Thousand Oaks, CA: Sage.
3 Charmaz, Kathy. 2006. Constructing grounded theory: a practical guide through qualitative analysis. London: SAGE



Table 1: Types of research that would be needed to deliver on the *National Strategic Action Plan for Arthritis*

Category	Subcategories
1: Establishment or use of data and tissue collections	• Research biobanks • Research/quality assurance registries or databases • Research surveys (e.g., regular national surveys) • Clinical, administrative datasets for research or with the potential for research use • Digital applications or tracking tools for research or with the potential for research use
2: Research on the impacts of arthritis (burden of disease)	• Impacts on consumers/patients (e.g., pain and disability, independence, ability to work, ability to participate in social activities, mental wellbeing) • Impacts on carers • Impacts on communities • Impacts on health systems • Impacts on welfare systems • Impacts on the economy
3: Research on populations[4] that have been identified as high priority	• Aboriginal and Torres Strait Islander Peoples • People living in rural and remote areas • People with disabilities
4: Research on modifiable risk factors[5] for arthritis	• Structural changes focused on modifiable risk factors • Policy changes focused on modifiable risk factors • Health interventions focused on modifiable risk factors • Health promotion focused on modifiable risk factors (aimed at community, policymakers and/or health professionals) • Awareness raising focused on modifiable risk factors (aimed at community, policymakers and/or health professionals)
5: Research aimed at assessing or enhancing the quality of interventions for arthritis	• The person-centredness, cultural appropriateness, comprehensiveness/holism of interventions • The degree to which patients are actively involved in design of interventions and are facilitated to self-manage • The cost effectiveness (or other measures of economic "value") • Their affordability for patients • Their accessibility (including timeliness of access, equity of access) • Their "real world" effectiveness • Consumer experiences of them or satisfaction with them (including patient-reported outcome measures) • Health professionals' experiences of them or satisfaction with them • Their effectiveness according to external benchmarks

4 Including both patient groups and clinicians caring for these groups
5 Including risk factors such as sports injury prevention and post-injury rehabilitation, physical activity, weight loss, smoking cessation

Category	Subcategories
6: Research aimed at improving the broader processes, systems and structures in which arthritis care takes place	• Workforce building (e.g., specialists for paediatrics or inflammatory arthritis; transition care from paediatrics to adult services; rheumatology nurse practitioners; upskilled exercise practitioners and sports medicine) • Models of care; patient pathways • Clinical networks; Community-based interdisciplinary clinics; Advanced practice physiotherapy clinics • Telehealth services; Outreach services • Funding models (e.g., public and private reimbursement models; disability support models; funding for patients to attend care programs)
7: Research aimed at enhancing the knowledge and skills of healthcare practitioners and others involved in arthritis care[6]	• Education programs (e.g., identification of key skill sets and competencies, micro-credentialling, university curriculum development) • Clinical support tools (e.g., Clinical guidelines, clinical standards of care, clinical information systems, care pathways, GP toolkits, template management plans, decision aids)
8: Research aimed at educating and supporting consumers (patients) about their disease and how to manage it	• Healthcare and community-based arthritis educators • Digitally enabled patient support programs • Telephone coaching programs • Children's camps and programs • Online information repositories • Peer support • Infoline support • Workplace resources • Guides and fact sheets re care, disability support and payment
9: Collaborative research involving partnerships with consumers and other stakeholders	• People with arthritis, families and carers, consumer groups; communities (including Aboriginal and Torres Strait Islander peoples and other culturally and linguistically diverse groups; rural health groups) • Governments and agencies • Healthcare professionals, networks, and organisations • Industry, including health insurance providers, pharmaceutical and devices industry, digital product developers • Organisations active in chronic disease prevention and promotion of physical activity • Educational institutions • Aged care providers
10: Research that cuts across all types of arthritis or focuses on types of arthritis that are currently neglected by other funding organisations	

6 Including health/fitness workers; school workers; aged care workers; pharmacy assistants

Gap analysis: Where more research is needed to deliver on the National Strategic Action Plan for Arthritis

A literature review was conducted to identify studies published on arthritis[7] over the past three years with Australian corresponding authors [See Appendix A for search strategy]. This review of published arthritis research will enable Arthritis Australia to most effectively invest in research which is both novel and effective in preventing, treating and managing arthritis. An understanding of the distribution of research between common types of arthritis is required to understand the arthritis research gaps and how Arthritis Australia can fill these gaps.

Key Federal funding streams were analysed to determine whether existing research in Australia aligns with the strategic priorities generated by the National Strategic Action Plan for Arthritis. In order to articulate in greater detail what kind of arthritis research is being publicly funded, our research examined MRFF and NHMRC funding of arthritis research from January 2019 to September 2021. The full results of the funding analysis are presented in Appendix B (provided to Arthritis Australia as an attachment).

The results of a detailed survey 62 health and medical researchers with specific expertise in arthritis was then used to validate this analysis. Survey participants ranged from universities, medical research institutes, local health districts, state and territory health departments, commercial organisations, and charities.

The results of this gap analysis are presented in **Table 2**. Health and medical research is undertaken in a complex ecosystem, with private sector, not-for-profit and public sector involvement in both the conduct and funding of research. Research Australia used both desktop research and the survey findings to generate a comprehensive picture the current ecosystem of funding for arthritis research.

The sectors to be investigated were agreed upon by Research Australia and Arthritis Australia. They are:

philanthropy – charities and not-for-profits;
public sector – federal, state and territory governments; and
private sector – pharmaceutical and commercial.

Health and medical research is undertaken in a complex ecosystem, with private sector, not-for-profit and public sector involvement in both the conduct and funding of research. Research Australia used both desktop research and the survey findings to generate a comprehensive picture the current ecosystem of funding for arthritis research.

7 Note: in determining what counted as "arthritis' research for the literature review and Federal Government funding analysis, the following topics were excluded unless explicitly related to arthritis: other bone and cartilage disorders; pain in general (including joint/back pain) or other pain disorders; Injury in general; inflammation in general; autoimmunity in general; systemic diseases e.g. SLE, systemic sclerosis. While the number of publications and proportion of funding dedicated to arthritis would have been larger if these conditions had been included, it cannot be assumed that all research into the excluded conditions would be relevant to arthritis (for example, much research into pain could be focused on acute injuries, and research into systemic conditions could be focused on issues that are not relevant to patients whose disease manifests primarily with arthritis—for example pulmonary or cutaneous manifestations of systemic diseases). That said, further research could be conducted to determine what proportion of "excluded" research pertains to arthritis.

Table 2: Gap analysis

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed

Research using databases, biobanks, data linkage	• There have been at least 20 molecular epidemiology and population studies using biobanks and databases
	• These cover a wide range of diseases including OA, ankylosing spondylitis, gout, JIA, RA, scleroderma and septic arthritis
	• A few articles have also been published discussing the establishment and utilisation of specific biobanks and databases
	• From a publication perspective, seems particularly strong in studies related to arthroplasty using the Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)
	• Can broadly be classified into
	  • Large cross-cutting initiatives e.g., the A3BC study, OPAL and the projects that use them
	  • Disease-specific collections (e.g., Perth Lupus Registry, Australian Scleroderma Interest Group biobank and database, Australian Rheumatology Association Database (ARAD) for inflammatory arthritis) and the projects that use them
	  • Collections that are part of international musculoskeletal disease initiatives (e.g., GLAD (Good Life with osteoarthritis) Australia database, NIH Osteoarthritis Initiative) and the projects that use them,
	  • Collections that go beyond just musculoskeletal disease (e.g., Bettering the Evaluation and Care of Health-BEACH, North West Adelaide Health study) and the projects that use them
		• Development or use of digital applications or tracking tools for research (or with the potential for research use)
		• Survey participants noted the need for better government and philanthropic funding of research that leverages data collection that takes place in private/community rheumatology practice and "real world" evidence generation more generally

EXAMPLES

The A3BC project:
"A national musculoskeletal and autoimmune disease biobanking network developing state-of-the-art data collection, data linkage, big data analytics and machine-learning capabilities for enabling and translating research discovery. It integrates a broad range of 'omic' (genomic, microbiomic etc), patient-reported (demographics, treatment, quality of life, diet etc), medical and administrative health data from people with arthritis and autoimmune disorders across Australia. Collected data and biological samples are deidentified, processed, stored and made available for ethics-approved, open-access research into understanding causes and improving treatment and prevention towards finding cures for arthritis and autoimmune conditions." https://a3bc.org.au

OPAL rheumatology (Optimising Patient outcomes in Australian rheumatology)
"An ongoing research program using an aggregated dataset from the EMRs of 220,000+ patients being managed by 112 rheumatologists around Australia. The OPAL dataset contains clinical records from approximately 30-40% of Australian patients seen by a rheumatologist, is considered representative of the Australian population and includes all conditions referred to a rheumatologist. Diseases studied to date include rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis, lupus, vasculitis, and other rare rheumatic diseases. Research projects include: - cohort studies to understand the real world burden of disease, clinical management strategies, clinical outcomes and unmet patient needs - biomarkers and predictors of response to treatment - health-related quality of life - real world utilisation and effectiveness of medicines, comparing newly available therapies with the standard of care - treatment patterns and outcomes (including sequence of treatment, combinations) - pathways and time from symptom onset to disease control - replicating randomised clinical trials in silico - medicine safety including adverse reactions, comorbidities and contraindications - Reasons for medication discontinuation (safety, efficacy, delivery, patient non-adherence etc) - validation of technology to enhance routine clinical care to facilitate data-driven chronic disease management." https://www.opalrheumatology.com.au

Table 2: Gap analysis cont.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed

Impacts/burden of arthritis	• More than 25 articles published in past 3 years
	• These cover a range of arthritis types including OA, RA, ankylosing spondylitis, fibromyalgia, gout, inflammatory arthritis, psoriatic arthritis, SLE
	• In combination, the above address a wide range of issues including quality of life in general and specific topics (psychological wellbeing, work-related issues, fatigue, sleep, capacity for physical activity, financial burden/healthcare costs, relationships, sexual function)
	• Includes some reviews and qualitative syntheses
		• Focus is on burden on patients. There is little on
		  • Burden on carers
		  • Burden on communities
		  • Burden on health systems
		  • Burden on welfare systems/the economy
		(More of this kind of research could be important in its own right, and serve advocacy purposes).
		• Even with patients, many topics covered but does not seem systematic

EXAMPLES

Occupational burden
Berkovic, D., Briggs, A.M., Ayton, D., Parker, C. and Ackerman, I., 2021. *Arthritis-related work Outcomes experienced by younger to middle-aged adults: a systematic review.* Occupational and Environmental Medicine, 78(4), pp.225-236.

Social/relational burden
Restoux, L.J., Dasariraju, S.R., Ackerman, I.N., Van Doornum, S., Romero, L. and Briggs, A.M., 2020. *Systematic review of the impact of inflammatory arthritis on intimate relationships and sexual function.* Arthritis care & research, 72(1), pp.41-62

Psychological burden
Kelly, K., 2021. *Ankylosing spondylitis and undifferentiated spondyloarthritis: The relationship between living with these diseases and psychological well-being.* Musculoskeletal Care, 19(2), pp.158-164.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed

Modifiable risk factors (primary prevention)	• Some work on injury prevention and management (to reduce likelihood of progression to arthritis)
	• note, however, that injury prevention research is broader than arthritis (i.e., includes types of injuries that cannot progress to arthritis)
		• Very little specifically focused on primary prevention of arthritis, but
		  • there is likely overlap with work addressing risk factors for other conditions (musculoskeletal and other)
		  • there is work on modifying risks to reduce disease progression or recurrence (i.e., secondary prevention)
		  • There is work on understanding the aetiology of disease, which will provide insights into preventative approaches (e.g. understanding joint biomechanics as they relate to sports injury prevention programs)
		• Several survey participants noted that prevention/management of modifiable risk factors should be a focus of future research

EXAMPLES

Funded project
Investigator Grant (2020) Steven Filbay, University of Melbourne, $645,000 over 5 years
"Addressing evidence gaps and developing a novel treatment to reduce the burden of post-traumatic knee osteoarthritis"

Published research
Finch, C.F., Gray, S.E., Akram, M., Donaldson, A., Lloyd, D.G. and Cook, J.L., 2019. Controlled ecological evaluation of an implemented exercise-training programme to prevent lower limb injuries in sport: population-level trends in hospital-treated injuries. British Journal of Sports Medicine, 53(8), pp.487-492.

Table 2: Gap analysis cont.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed
High-priority populations	Some work on: • Work-related experiences of younger people with arthritis (2 articles) • Arthritis in older populations • Telehealth and community-based interventions in rural populations • Other neglected groups e.g., haematochromatosis-associated arthritis	• Overall, very little on this priority area • Nothing funded in past 3 years on Aboriginal and Torres Strait Islander groups but some future-looking articles published or under review • Survey participants identified children and people with haematochromatosis-associated arthritis as priority populations for future research

EXAMPLES

OPUS Centre of Research Excellence (2017-2021) had ECCO workstream (Advocating for Equity, Collaboration and Culturally secure Osteoarthritis care for Aboriginal Australians):
"ECCO was inspired by a group of clinicians and service providers in WA who noticed the impact that osteoarthritis was having on health and wellbeing in the regional and remote Aboriginal communities in which they lived and worked.
Together with a team of researchers, the group conducted a systematic review to better understand the landscape of osteoarthritis in the wider Aboriginal community.
The outcomes revealed osteoarthritis to be an unmet health need with a mismatch between the burden of osteoarthritis and access to care on a national scale. Bringing together the cultural expertise of the WA group and the osteoarthritis expertise of OPUS, ECCO was created to address this mismatch though consumer-led research prioritising Aboriginal voices."
https://opus-tjr.org.au/programs/ecco-2/

OPUS-related publications (outside timeframe of this review):

Lin, I.B., Bunzli, S., Mak, D.B., Green, C., Goucke, R., Coffin, J. and O'Sullivan, P.B., 2018. Unmet Needs of Aboriginal Australians With Musculoskeletal Pain: A Mixed-Method Systematic Review. Arthritis care & research, 70(9), pp.1335-1347.

O'Brien, P; Prehn, R; Rind, N; Lin, I; Choong, PF; Bessarab, D; Coffin, J; Mason, T; Dowsey, MM; Bunzli, S. Laying the foundations of meaningful community engagement in Aboriginal health research: Establishing a community reference group and terms of reference in a novel research field. (Under Review)

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed

Quality of care	• Significant proportion of funding and published research oriented towards quality including promoting:
	  • evidence-based practice
	  • accessibility of care (including affordability)
	  • value-based care,
	  • adherence to care
	  • person/patient-centeredness of care (including development of patient-reported outcome measures and patient-reported experience measures)
		• Almost all funding going to quality of care is for arthritis in general and for OA. (There is, however, more disease variation in published articles).
		• Many topics covered but does not seem systematic
		• Nothing on cultural appropriateness (note overlap with gap in high priority populations)
		• Survey participants noted need for more research to support patient-centred care non-surgical approaches to treatment and more comparative effectiveness and cost-effectiveness research.

EXAMPLES

Evidence-based practice and value-based practice
Investigator Grant (2021) Rachelle Buchbinder, Monash University $2.9 million over 5 years
"Better evidence more rapidly implemented to optimise health for people with musculoskeletal conditions"

Access to care (see also models of care)
Investigator Grant (2020) Joshua Zadro , University of Sydney $645,000
"Can e-Health improve access to effective and affordable care for musculoskeletal conditions?"

Patient-centered care
Fairley, J.L., Seneviwickrama, M., Yeh, S., Anthony, S., Chou, L., Cicuttini, F.M., Sullivan, K., Briggs, A.M. and Wluka, A.E., 2021. Person-centred care in osteoarthritis and inflammatory arthritis: a scoping review of people's needs outside of healthcare. BMC musculoskeletal disorders, 22(1), pp.1-18.

Patient-reported outcomes
Teo, P.L., Hinman, R.S., Egerton, T., Dziedzic, K.S., Kasza, J. and Bennell, K.L., 2020. Patient-reported quality indicators to evaluate physiotherapy care for hip and/or knee osteoarthritis-development and evaluation of the QUIPA tool. BMC Musculoskeletal Disorders, 21(1), pp.1-11.

Table 2: Gap analysis cont.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed
Models of care	• Significant proportion of funding and published research oriented toward investigating new ways of delivering care including investigations of: • tertiary hospital clinics • primary care services • shared care • multidisciplinary care • telehealth services (internet and phone) • online services e.g. online decision aids, online support • self-management approaches • peer support approaches • use of specialists e.g., specialist rheumatology nurses • transition from paediatric to adult care • community-based interventions • enhancing carers' capacity	• 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. • Researcher survey participants noted need for more research on integrated models of care and interdisciplinary collaboration

EXAMPLES

The PARTNER study
"To increase the uptake of key clinical recommendations for non-surgical management of knee osteoarthritis (OA) and improve patient outcomes, we developed a new model of service delivery (PARTNER model) and an intervention to implement the model in the Australian primary care setting. We will evaluate the effectiveness and cost-effectiveness of this model compared to usual general practice care."
Hunter, D.J., Hinman, R.S., Bowden, J.L., Egerton, T., Briggs, A.M., Bunker, S.J., Kasza, J., Forbes, A.B., French, S.D., Pirotta, M. and Schofield, D.J., 2018. Effectiveness of a new model of primary care management on knee pain and function in patients with knee osteoarthritis: Protocol for THE PARTNER STUDY. BMC musculoskeletal disorders, 19(1), pp.1-16.

Telehealth
Investigator Grant (Joshua Zadro, University of Sydney)
'Can e-Health improve access to effective and affordable care for musculoskeletal conditions?'
Hinman R, Campbell P, Lawford B, Briggs A, Gale J, Bills C, Kasza J, Harris A, French S, Bunker S, Forbes A, Bennell K. Telephone-delivered exercise advice and support by physiotherapists for people with knee osteoarthritis: the Telecare randomised controlled trial. British Journal of Sports Medicine. 2020;54(13):790-797.

Peer support
Maclachlan LR, Mills K, Lawford BJ, Egerton T, Setchell J, Hall LM, Plinsinga ML, Besomi M, Teo PL, Eyles JP, Mellor R, Melo L, Robbins S, Hodges PW, Hunter DJ, Vicenzino B, Bennell KL. Design, Delivery, Maintenance, and Outcomes of Peer-to-Peer Online Support Groups for People With Chronic Musculoskeletal Disorders: Systematic Review. J Med Internet Res. 2020;22:e15822.

Self-management
Nelligan RK, Hinman RS, Kasza J, Crofts SJC, Bennell KL. Effects of a Self-directed Web-Based Strengthening Exercise and Physical Activity Program Supported by Automated Text Messages for People With Knee Osteoarthritis: A Randomized Clinical Trial. JAMA Intern Med. 2021;181(6):776-78

Integrated/Multidisciplinary care
Investigator Grant (Christopher Willians, Universsity of Newcastle)
Advancing integration of care for musculoskeletal conditions and chronic disease risks
Livings R, Naylor JM, Gibson K, et al. Implementation of a community-based, physiotherapy-led, multidisciplinary model of care for the management of knee osteoarthritis: protocol for a feasibility study. BMJ Open 2020;10:e039152. doi:10.1136/ bmjopen-2020-039152

Allied health
Counsell, A.B., Nguyen, A.D., Baysari, M.T., Kannangara, D.R., Gamboa, S. and Day, R.O., 2021.
Expanding the role of Australian community dietitians in gout management. International Journal of Rheumatic Diseases, 24(11), pp.1402-1408.

Paediatric to adult transition
Jiang, I., Major, G., Singh-Grewal, D., Teng, C., Kelly, A., Niddrie, F., Chaitow, J., O'Neill, S., Hassett, G., Damodaran, A. and Bernays, S., 2021. Patient and parent perspectives on transition from paediatric to adult healthcare in rheumatic diseases: an interview study. BMJ open, 11(1), p.e039670.



Table 2: Gap analysis cont.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed
Workforce (education and capacity building)	• Some activity on health professional education	• Very little on workforce capacity building (beyond education/skill building) • Survey participant argued for research to enhance general practitioners' knowledge

EXAMPLES

Professional education
Jones SE, Campbell PK, Kimp AJ, Bennell K, Foster NE, Russell T, Hinman RS. Evaluation of a Novel e-Learning Program for Physiotherapists to Manage Knee Osteoarthritis via Telehealth: Qualitative Study Nested in the PEAK (Physiotherapy Exercise and Physical Activity for Knee Osteoarthritis) Randomized Controlled Trial. J Med Internet Res. 2021;23(4):e2587

Barton, C.J., Kemp, J.L., Roos, E.M., Skou, S.T., Dundules, K., Pazzinatto, M.F., Francis, M., Lannin, N.A., Wallis, J.A. and Crossley, K.M., 2021. Program evaluation of GLA: D® Australia: Physiotherapist training outcomes and effectiveness of implementation for people with knee osteoarthritis. Osteoarthritis and Cartilage Open, 3(3), p.10017

Undergraduate education
Ladurner, A., Nijman, T., Gill, T.K. and Smitham, P.J., 2020. The impact of a hands-on arthrocentesis workshop in undergraduate medical education. BMC Medical Education, 20(1), pp.1-9.

Workforce
Australian Rheumatology Association is funding a Workforce Needs Analysis

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed
Funding models	• Two highly specific papers on funding of biological therapies in psoriatic arthritis and direct healthcare costs in SLE)	• Very little research on the best ways to fund arthritis care e.g., analysis of NDIS packages or bundled care payment plans for private patients. • One survey participant suggested that future research should focus on funding models to reduce waiting lists

EXAMPLES

Yeo, A.L., Koelmeyer, R., Kandane-Rathnayake, R., Golder, V., Hoi, A., Huq, M., Hammond, E., Nab, H., Nikpour, M. and Morand, E.F., 200. Lupus Low Disease Activity State and Reduced Direct Health Care Costs in Patients With Systemic Lupus Erythematosus. Arthritis Care & Research, 72(9), pp.1289-1295.

Pontifex, E.K., Dissanayake, K., Bursill, D. and Gill, T., 2019. Prevalence of minimal disease activity in Australian patients with Psoriatic Arthritis: Assessing the outcome of national funding criteria for biologic Disease-modifying antirheumatic drug prescribing. International Journal of Rheumatic Diseases, 22(2), pp.262-268.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed

Patient information, education and support	• Some activity here (overlaps with self-care models of care and patient-centred care)
	• Three funded projects include education as a component, all on osteoarthritis education; more disease variety in published articles
	• Includes research into
	  • a) assessing patient information needs
	  • b) testing interventions e.g., comprehensive web-based educational resources, online skills training programs, medicine information sheets, peer support programs
		• Research into
		  • Healthcare and community-based arthritis educators
		  • Telephone coaching programs
		  • JIA kids camps and programs
		  • Online information repositories
		  • Infoline support
		  • Workplace resources
		  • Guides and fact sheets re care, disability support and payment
		• Survey participants noted the need for more research to empower patients to engage with primary care – this will be further tested through the consumer engagement piece covered in Report 2.

EXAMPLES

Kim Bennell, NHMRC Investigator Grant 2019, $2,848,000
Improving outcomes for people with knee osteoarthritis: Overcoming patient and clinician barriers

Stanton, T.R., Karran, E.L., Butler, D.S., Hull, M.J., Schwetlik, S.N., Braithwaite, F.A., Jones, H.G., Moseley, G.L., Hill, C.L., Tomkins-Lane, C. and Maher, C., 2020. A pain science education and walking program to increase physical activity in people with symptomatic knee osteoarthritis: a feasibility study. Pain Reports, 5(5).

Inderjeeth, C.A., Boland, E., Connor, C., Johnson, C., Jacques, A. and McQuade, J., 2021. Evaluation of an ankylosing spondylitis education and self-management program: Beneficial effects on ankylosing spondylitis specific outcomes. International Journal of Rheumatic Diseases, 24(3), pp.434-444.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed
Accessibility; reduction of disability	• A few highly specific papers on pillows, auto-injection devices, footwear	• Overall, very little here which presents an opportunity for Arthritis Australia to invest in mobility research with impact across all forms of arthritis and potential engagement with the medical technology industry.

EXAMPLES

Aw, J., Griffiths, H., Zochling, J., Lanzafame, A. and Jordan, A., 2021. Usability of the Certolizumab Pegol Auto-Injection Device in Australian Patients with Chronic Rheumatic Diseases: Results from a Market Research Study. Patient Preference and Adherence, 15, p.1469.

Unsworth, C.A., Rawat, V., Sullivan, J., Tay, R., Naweed, A. and Gudimetla, P., 2019. "I'm very visible but seldom seen": consumer choice and use of mobility aids on public transport. Disability and Rehabilitation: Assistive Technology, 14(2), pp.122-132

Gordon, S.J., Grimmer, K.A. and Buttner, P., 2019. Pillow preferences of people with neck pain and known Spinal degeneration: a pilot randomized controlled trial. European journal of physical and rehabilitation medicine, 55, pp.783-791.

Table 2: Gap analysis cont.

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed

Collaborative research	• These results were derived from the survey only
	• Participants reported collaborations between researchers in academic and philanthropic organisations and:
	  • software/IT companies
	  • pharmaceutical companies
	  • patient representatives
	  • teaching hospitals
	  • aged care facilities
	  • private health insurers
		• Nothing reported in survey on collaborations with
		  • carers,
		  • communities (including Aboriginal and Torres Strait Islander peoples and other culturally and linguistically diverse groups; rural health groups)
		  • government agencies
		  • organisations active in chronic disease prevention and promotion of physical activity
		  • educational institutions

EXAMPLES

OPAL rheumatology (Optimising Patient outcomes in Australian rheumatology)
"OPAL has a long-standing partnership with an Australian technology company that provides the clinical Software from which the OPAL dataset is generated. OPAL investigators have positions within numerous universities and teaching hospitals around Australia. OPAL has partnered wth numerous local and global pharma companies on research to generate real world evidence. OPAL has appointed a patient representative to the board of directors, and involves patient representatives in strategic research planning and study design."

Potential Priority Research Areas (see Table 1)	What priority topics are addressed	Where more research is needed
Cross-cutting research	• Some recently funded large initiatives e.g. Centres of Research Excellence and Investigator Grants are focused on arthritis in general or musculoskeletal disease in general (including arthritis)	• Most funding and almost all published research is disease-specific • Not clear from project abstracts whether research on 'musculoskeletal disease' is actually cross-cutting

EXAMPLES

Various NHMRC and MRFF grants on:

'Closing the evidence-practice gap in occupational health practices to prevent musculoskeletal disorders'

'Better evidence to more rapidly implemented to optimise health for people with musculoskeletal conditions'

'Can e-Health improve access to effective and affordable care for musculoskeletal conditions?'



Who funds Australian arthritis research

The sectors to be investigated were agreed upon by Research Australia and Arthritis Australia. They are:

philanthropy – charities and not-for-profits;
public sector – federal, state and territory governments; and
private sector – pharmaceutical and commercial.

Research Australia has focused particularly on the philanthropic sector after identifying this as the most crowded area of arthritis research investors in Australia. The multiple sources of health and medical research funding are usually interrelated, either through the researcher funding or the administering institution. The following analysis of philanthropic activity will naturally inform what the research investment 'ask' to government needs to be. It will identify what research is philanthropically funded and which research government should take responsibility for. This will form the basis for a series of Recommendations in Report 3.

Research Australia's methodology and search strategy draws on our 20 years of experience serving the health and medical research community and our unique, detailed knowledge of all stages of the health and medical research pipeline and all key stakeholder groups.

This method has then been extended through a detailed analysis of state and federal registers including the Australian Charities and Not-for-profits Commission (ACNC) register, and Australian and New Zealand Clinical Trial Registry (ANZCTR).



Sources of funding: The desk research, survey, and funding analysis revealed that arthritis research is funded by all three sectors (philanthropic, public and private). The survey revealed that of those conducting research, **77.36% said they had received funding for arthritis research programs or projects in the past 3 years.**



Types of research: Based on the survey, the most common types of research being conducted in the sector are observational studies and randomised trials, followed by implementation research. This appeared to be broadly consistent with the results of the NHMRC and MRFF funding analysis. Over 180 articles with Australian corresponding authors have been published over the past 3 years, with approximately half of these reporting basic scientific and clinical research and half focusing on burden of disease, health services and health promotion topics.



Philanthropy – Charities and not-for-profits

Charities and not-for-profits both fund and undertake health and medical research. Many hospitals and health providers that participate in and support research are also charities. There are also many independent charities that raise money specifically for health and medical research or fund health and medical research as one of their purposes.

In much the same way that governments invite applications for grants subject to specific eligibility criteria, many charitable organisations do the same. Many 'mission driven' charities invite applications for funding for specific purposes related to their own objectives. These range from small grants for individual students and researchers (e.g., funding travel to conferences, scholarships and fellowships) to long term funding for a whole team or institute.

Our analysis identified 33 arthritis-related charities with the majority (58%) funding research but only a minority (9%) conducting research and a further 9% both funding and conducting research. Eight charities were also identified who neither fund nor conduct research. However, they are key stakeholders to be considered by Arthritis Australia because their specialist focus on certain types of arthritis could facilitate partnerships that give Arthritis Australia new opportunities to extend research into areas of previously unmet need. These figures and analysis exclude Arthritis Australia's State and Territory Affiliate Organisations.

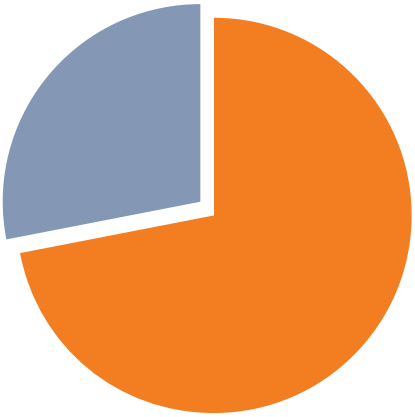
Table 3: Philanthropic Organisations

Charities that fund research	• Juvenile Arthritis Foundation Australia • Lions Rheumatism & Arthritis Medical Research Foundation • Haemochromatosis Australia • Lupus Association of NSW • Lupus Association of Tasmania • Scleroderma Australia • The Scleroderma Association of NSW • Scleroderma Victoria Inc. • The Australian Sjögren's Syndrome Association • Occupational Therapy Australia • Physiotherapy Research Foundation, Australian Physiotherapy Association • Australian Orthopaedic Association Research Foundation • Osteopathy Australia • AVANT Foundation • Clifford Craig Foundation • Norman Beischer Medical Research Foundation • Raine Medical Research Foundation • Spinnaker Health Research Foundation • Bone Health Foundation
Charities that conduct research	• Children's Arthritis Research Institute • Creaky Joints • The Pain Society
Charities that fund and conduct research	• Musculoskeletal Australia • International Musculoskeletal Research Institute Inc • Australian Orthopaedic Association
Other charities worth further consideration	• Kids Arthritis Incorporated • Ankylosing Spondylitis Victoria • Zoe's Angels • Fibromyalgia Support Network of WA • Scleroderma Queensland • Pain Australia • Chronic Pain Australia • Australian Association of Musculoskeletal Medicine

The amount of funding committed to arthritis research differs between each charity. However, most organisations have similar types of grants – including seeding or project grants and scholarships for PhD students or early career researchers. Research grants and scholarships range from the individual value of $6,500 to $50,000. Examples include:

- Australian Physiotherapy Association, Physiotherapy Research Foundation – in 2020 they awarded $60,000 to a strategy led research project into the effectiveness of telehealth by physiotherapists in Australia during the COVID-19 pandemic.[8]
- Australian Orthopaedic Association Research Foundation – in 2019 they offered a $50,000 per annum PhD scholarship for 3 years which consisted of a $45,000 stipend and $5,000 departmental maintenance.[9]

The survey revealed that, of the 62 respondents, 63% (n=24) had received funding from the philanthropic sector (excluding Arthritis Australia and its affiliate organisations). 72% had received funding from Arthritis Australia. In such a crowded and complicated landscape of philanthropic organisations dedicated to arthritis (33 organisations across Australia), this figure is a true testament to Arthritis Australia's strength in the ecosystem. This, coupled with the finding that the majority of philanthropic organisations funding arthritis research are focused on funding just one type of arthritis, should be capitalised on the further position Arthritis Australia as the overarching umbrella group for all charities working in arthritis, and particularly arthritis research.



72% ARTHRITIS RESEARCHERS HAD RECEIVED FUNDING FROM ARTHRITIS AUSTRALIA. In such a crowded and complicated landscape of philanthropic organisations dedicated to arthritis (33 organisations across Australia), this figure is a true testament to Arthritis Australia's strength in the ecosystem.

8 More information available at: https://australian.physio/sites/default/files/PRF_Project_Brief_Telehealth_Evaluation_v3.pdf
9 More information available at: https://www.aoa.org.au/research/research-foundationM/grants

In recognition of the key role of Arthritis Australia's State and Territory Affiliate Organisations, Research Australia has conducted separate analysis into these organisations and their contribution to arthritis research in Australia. Table 3 below outlines their contribution to arthritis research in Australia. In addition to their own research funding, the State and Territory Affiliate Organisations regularly contribute to Arthritis Australia's National Research Program.

Table 4: Arthritis Australia state and territory affiliate organisations

State and Territory Affiliate Organisation	Contribution to arthritis research
Arthritis Queensland	For over 20 years they have funded the Arthritis Queensland Chair in Rheumatology at the University of Queensland for $150,000 per annum (the current funding period runs until 31 December 2022). Their Grant program also included two competitive grants, fellowship ($50,000) and grant in aid ($15,000) but they withdrew from the program in 2019. Arthritis Queensland have approximately $1.2 million in funds allocated for research projects and are looking at a new research strategy which will consider a broader range of project types (for example, epidemiological research, research into the impact of their programs).
Arthritis & Osteoporosis Tasmania	Contributed funding to the Arthritis Queensland Chair in Rheumatology, Professor Ranjeny Thomas. Arthritis Tasmania also provides funding to the Menzies Institute at the University of Tasmania to support the musculoskeletal research team.
Arthritis New South Wales	They have funded a small proportion of arthritis research over the past few years. However, this will be a focus for the organisation moving forward.
Arthritis South Australia	They received a large bequest of $150,000 to fund post-doctoral arthritis research. Arthritis South Australia also fund trainee rheumatologists in partnership with the Australian Rheumatology Association.
Arthritis & Osteoporosis Western Australia	They were the major force behind the establishment of the Chair of Rheumatology & Musculoskeletal Medicine position at the University of Western Australia.

Public sector – Australian Government

Approximately $7.9 billion is spent on health and medical research in Australia each year.[10] While only a small proportion of research is undertaken directly by the Australian Government, it is responsible for providing funding for a much larger proportion.

Australian Government funding for arthritis research is predominantly allocated through two funding bodies: the National Health and Medical Research Council (NHMRC) and Medical Research Future Fund (MRFF).

The following breakdown of funding shows that a very small proportion of Australian Government funding is dedicated specifically to arthritis (bearing in mind the deliberately narrow definition of 'arthritis research' discussed above'.

MRFF:
- Total funding Jan 2019-Aug 2021: ~$1.4 billion[11]
- Funding targeted specifically to arthritis: ~$4 million

NHMRC:
- Total funding: Jan 2019-Aug 2021: ~$2.6 billion[12]
- Funding targeted specifically to arthritis: ~$25 million

Our review of NHMRC and MRFF grants revealed that twenty-six grants on arthritis have been funded by NHMRC and MRFF over the past three years. These cut across the full range of schemes including NHMRC Centres of Research Excellence, Ideas, Investigator and Partnership grants. However, only four arthritis-specific grants have been funded through the MRFF.

Some key arthritis-specific initiatives that have been funded by NHMRC over the past three years include:

- **A NHMRC Centre for Research Excellence "CRE for better outcomes in inflammatory arthritis"** (March, 2021, $2.5 million), which aims to find the right treatment for children and adults with inflammatory arthritis to give the best path to symptom relief with least risk of side effects. It will build on a national data-base and biospecimens bank (A3BC-ARAD) to collect a broad range of patient-reported, biological, environmental and health information to unlock the answers using big-data analysis. It will also build a resource and workforce to continue to look for cures to deliver the best outcomes for patients and society.
- **A NHMRC Investigator Grant "Better evidence more rapidly implemented to optimise health for people with musculoskeletal conditions"** (Buchbinder, 2020, $2.9 million), which aims to improve outcomes for people with musculoskeletal conditions through better evidence, more rapid uptake of evidence into practice, and better strategies to reduce low-value care.
- **A NHMRC Investigator Grant "Advancing integration of care for musculoskeletal conditions and chronic disease risks"** (Williams 2019), $1.5 million, which will test new ways of optimising care across health systems to integrate better management of musculoskeletal conditions and associated chronic disease risks.

10 https://researchaustralia.org/category/hmr-facts/
11 MRFF Grant recipients https://www.health.gov.au/resources/publications/medical-research-future-fund-mrff-grant-recipients
12 Results of NHMRC Grant Application Rounds https://www.nhmrc.gov.au/funding/data-research/outcomes#

- **A NHMRC Partnership Grant "Improving outcomes for hip osteoarthritis: program evaluation of HipHealth, an evidence-based telehealth exercise and weight loss program"** (Bennell 2021, $1 million), which will implement and evaluate an education, exercise and weight loss program delivered remotely by physiotherapists and dietitians. The program will be tested in the private health insurance setting with view to future scale-up in this and other settings. A NHMRC Investigator Grant "Transforming treatment options and delivery of care for osteoarthritis" (Hunter, 2020, $2.5 million), which will leverages established resources and existing funding to investigate the key challenges for OA in the next decade, including 1) Further enhancing the methods for disease modification trials and deploy novel trials, and 2) Optimising the delivery of care for those with extant disease.
- **A NHMRC-NIHR Collaborative Research Grant "Reverse or Anatomical (replacement) for Painful Shoulder Osteoarthritis: Differences between Interventions"** (Page 2021, $1.5 million) which will produce evidence about the benefits, harms and cost-effectiveness of each shoulder surgery to enable patients to receive the best type of surgery.
- **A NHMRC Investigator Grant "Optimizing the management of osteoarthritis through research and innovation"** (Cicuttini 2020, $2.9 million) that will test new treatments aimed at slowing disease progression and reducing pain in osteoarthritis (OA) by targeting specific disease pathways (metabolic factors and inflammation) and examine the causes of hip OA.
- **A NHMRC Ideas Grant "Mechanisms and management of osteoarthritis pain"** (Ivanusic 2019, $1 million), which will determine how osteoarthritis affects the function of nerves in bone and joint, if the GDNF family of ligands are involved, and if blocking their action will prevent osteoarthritis induced changes in nerve activity and pain.
- **An ARC Training Centre "ARC Training Centre for Joint Biomechanics"** (Thomas 2021, $3.9 million), which will work to train an industry-ready workforce, capable of creating and applying new technologies in orthopaedics and joint biomechanics

The survey revealed that of the 62 respondents, 53% (n=20) had received funding from the Federal Government and 16% (n=6) had received funding from State or Territory Governments.



Public sector – State and territory governments

State and territory governments are responsible for funding research undertaken within the state and territory hospital systems; the provision of support to medical research institutes (MRIs) for the indirect costs of research; and other programs to support R&D, a portion of which funds health and medical research. State and territory governments also provide capital funding for stand-alone research institutions (e.g., the South Australian Health and Medical Research Institute) and for organisations that combine research with health care delivery (e.g., the Victorian Comprehensive Cancer Centre).

Our analysis identified the following state and territory programs aimed at supporting arthritis research:

- NSW Agency for Clinical Innovation Musculoskeletal Network – The NSW Network was convened in early 2009 to advise the NSW Health system on the best way to improve services for the people of NSW with musculoskeletal conditions.
- WA Health Musculoskeletal Health Network – The WA Network aims to improve health outcomes for people with musculoskeletal conditions and chronic pain. They develop and review models of care, frameworks and guidelines to provide a cohesive and consistent plan for health care across WA.

Private sector – Pharmaceutical and/or commercial

25% of all health and medical research expenditure is in the private sector.[13] **Our analysis identified 24 private sector companies supporting arthritis research. 54% of these companies fund research and 46% conduct research.**

While it is difficult to estimate the amount of money spent by these private companies on arthritis research, the potential importance of this sector for arthritis research cannot be overestimated.

Arthritis Australia has engaged or collaborated with 54% of the organisations identified through our stakeholder mapping through a range of means including Arthritis Australia's educational grants, Medicines Australia Community Chest Partners, or sponsoring Arthritis Australia's myRA. Recently, Arthritis Australia partnered with Jannsen to fund an Aboriginal and Torres Strait Islander fellowship. This is a 12 month fellowship of $50,000 which is targeted to supporting and progressing the arthritis research conducted by an Aboriginal and Torres Strait Islander person.

The survey of research conductors and funders revealed that of the 62 respondents, 32% (n=12) had received funding from the private sector to conduct research. **Table 5** below identifies the private sector organisations that engage in arthritis research either by funding, conducting or both funding and conducting research.

13 based on Australian Bureau of Statistics (ABS) data, 2017/18. Available at: https://researchaustralia.org/category/hmr-facts/

Table 5: Private Sector Organisations

Private sector organisations that fund research	• Abbott Australasia Pty Ltd • Medacta Australia • Ossur • Regeneus Ltd • Stryker Australia • Akaal Pharma • Bristol-Myers Squibb Australia
Private sector organisations that conduct research	• Werfen Australia • Arthritis Relief Plus • UCB Australia • Janssen • Eli Lilly • Novartis • Sandoz (a Novartis division) • Gilead • Sanofi • GlaxoSmithKline • Menarini
Private sector organisations that fund and conduct research	• Corin (Australia) Pty Ltd • Zimmer Biomet Australia • Pfizer • AbbVie • Roche • Boehringer Ingelheim Pty Ltd

Key findings and opportunities: Arthritis Australia's research strategy and current research gaps

Research Australia's analysis has found the following:

1. There is limited Australian research activity in many of the strategic priorities identified in the National Strategic Action Plan for Arthritis

Overall, with the exception of research using collections of data and research into quality of care, there is limited research activity in the potential research priorities generated by the National Action Plan. No category is fully saturated—even where research has been conducted it is often idiosyncratically linked to a particular sub-topic, disease, population or geographical area and therefore not obviously generalisable. Areas that appear to be particularly neglected are:

- Research into the needs, experiences and care of specific populations, most notably:
  - Aboriginal and Torres Strait Islander peoples (and the need for culturally appropriate care);
  - Children with arthritis; and
  - Patients in rural areas (other than studies of telehealth).
- Research into the burden of arthritis on people other than patients (e.g., carers, communities, health systems, welfare systems and the economy).
- Research into primary prevention of arthritis.
- Research into ways of enhancing the arthritis workforce or improving system funding models.
- Research into ways of reducing disability, e.g., by enhancing mobility.

Opportunity:

Arthritis Australia 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. The consumer-based research being conducted by Research Australia will help to articulate which of these gaps should be given priority in funding efforts.

2. Arthritis Australia has a key convening role to play in bringing the right researchers, charities and commercial partners together with government to 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. Together with its state affiliates, Arthritis Australia has Australia's largest and most established national network of arthritis advocates and consumers.

Opportunity:

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. 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.

Our 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.[14] The focus of Arthritis Australia on arthritis in general is its key point of difference.

Opportunities:

Arthritis Australia could position itself as the overarching umbrella group and key convening point for research conducted by all arthritis charities.

Arthritis Australia could also position itself as the group that ensures that research is conducted into 1) arthritis in general and 2) types of arthritis that are not currently addressed by any other philanthropic organisations.

In order to facilitate this, 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.

Importantly, the potential research priorities identified through analysis of the National Action Plan **(Table 1)** are all potentially cross-cutting and/or applicable to neglected diseases. For example, any research into the experiences of Aboriginal and Torres Strait Islanders, carer experiences, health service design (and so on) could be framed as either a cross-cutting project, not singling out any particular kind of arthritis, or be directed to a specific neglected type of arthritis.

14 Sourced from: https://arthritisaustralia.com.au/what-is-arthritis/types-of-arthritis/

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

There is currently 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)

Opportunity

By clarifying this distinction, Arthritis Australia could further elucidate its "niche" in the sector, 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.

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

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."[15]

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 consumers, they are only one of several stakeholders listed and there is no articulation of specifically how consumers should be involved in research.

This is a significant lacuna both because Arthritis Australia is a consumer-focused organisation and because 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).

Opportunity

Arthritis Australia could work with the consumers it represents to more clearly articulate how consumers should be involved in its decisions about what research to fund; and in 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.

6. There is a dynamic private sector with an interest in arthritis research

Opportunity

There are significant opportunities to collaborate with the private sector, including pharmaceutical and medical technology companies, through targeted research funding partnerships. This will provide leverage to drive projects that are important to Arthritis Australia and strengthen Arthritis Australia's leadership in the sector. It might also be possible for Arthritis Australia to advocate for private investment in particular kinds of research.

15 Sourced from: https://www.msk.org.au/for-researchers/

Next steps

This report is one of three interlinked reports that will be prepared by Research Australia.



Report 1 (current report) – Understanding the arthritis research landscape



Report 2 – What consumers want: identifying the unmet needs of Australians living with arthritis



Report 3 – Impactful arthritis research

The results of Report 1 will be built upon with the results of detailed consumer input from those with lived experience of arthritis to prioritise research in a way that reflects the needs to the communities Arthritis Australia represents. Research Australia will look at the research areas identified through this landscape analysis and the National Strategic Action Plan for Arthritis to understand what consumers prioritise from existing research and where they think more research is needed.

This report has identified the complexity of the arthritis research landscape in Australia, and we recognise we won't have possibly captured all of it here.

Research Australia suggests repeating this landscape and gap analysis every 3 years to update both the information for Arthritis Australia and consumer audiences.[16] There is also the opportunity for review and analysis of prior efforts to ensure both the opportunity and impact are being recognised through future investments.

16 Most research projects span 3-5 years. Therefore Research Australia recommends a 3 year time span to avoid major gaps in Arthritis Australia's understand of what is going on in the health and medical research ecosystem.



Appendix A: Gap Analysis Search Strategy

Funding review

Funding bodies:

- National Health & Medical Research Council https://www.nhmrc.gov.au/funding/data-research/outcomes
- Medical Research Future fund https://www.health.gov.au/resources/publications/medical-research-future-fund-mrff-grant-recipients
- [Other funders will be captured via stakeholder map and survey]

Years: 2019-2021 (up tSeptember)

Search terms:

- arthritis, gout, ankylosing spondylitis, osteomyelitis, familial mediterranean fever, dermatomyositis, scleroderma, lupus, SLE, polymyalgia rheumatica, fibromyalgia, ross river virus, sever's disease, sjogren's syndrome, sports injury
- joint, bone, cartilage, autoimmun,* inflammat,* rheum,* musculoskeletal, orthop,* physiotherapy, pain

Not included unless *explicitly related tarthritis:*

- Other bone and cartilage disorders
- Pain in general (including joint pain) or other pain disorders
- Injury in general
- Inflammation in general
- Autoimmunity in general
- Systemic diseases e.g. SLE, systemic sclerosis

Literature review

Database: Web of Science

Date range: Jan 2019-Dec 2021 (includes articles published online in advance of issues)

Search terms:

- General terms [anywhere in article]
  - "arthritis" OR "gout" OR "ankylosing spondylitis" OR "osteomyelitis" OR "familial mediterranean fever" OR "dermatomyositis" OR "scleroderma" OR "systemic sclerosis" OR "lupus" OR "SLE" OR "polymyalgia rheumatica" OR "fibromyalgia" OR "ross river virus" OR "sever's disease" OR "sjogren*" OR "sports injury"
  - AND
  - "Australia"
- Specific terms [in abstract]
  - "data linkage" OR "biobank" OR "registry" OR "register"
  - "burden" OR "impact" OR "cost" OR "disability"
    - Excluding epidemiological articles on prevalence and physical complications
  - "aboriginal" OR "indigenous" OR "rural" OR "regional"
  - "prevention" OR "modifiable risk" OR "policy change" OR "health promotion" OR
  - "awareness" OR "weight loss" OR "exercise" OR "diet"
    - Excluding epidemiological studies of risk factors
    - Excluding secondary prevention/prevention of complications
- "person-cent*ed*" OR "patient-cent*ed" OR "shared decision-making" OR "cultural* approp*" OR "cost-effective*" OR "value" OR "affordab*" OR "real world effectiveness" OR "consumer experience" OR "consumer satisfaction" OR "benchmark*" OR "PROM" OR "conservative" OR "appropriate*"
  - Excluding standard effectiveness research
- "access*" OR "workforce" OR "p*ediatric" OR "service*" OR "specialist" OR "nurse practitioner"
- "care pathway" OR "model of care" OR "network" OR "interdisciplinary" OR "multidisciplinary" OR "telehealth" OR "outreach" OR "self-manage*" OR "self-care" OR "digital" OR "m-health" OR "mobile health" OR "guideline" OR "standard of care" OR "information system" OR "care pathway" OR "toolkit" OR "management plan" OR "decision aid"
- "reimbursement" OR "payment" OR "insurance" OR "MBS" OR "medical benefits schedule" OR "PBS" or "Pharmaceutical Benefits Scheme" OR "welfare" OR "disability support"
- "education" OR "training" OR "skill" OR "compenenc*" OR "credential*" OR "curriculum"
- "support" OR "coaching" OR "information" OR "resource" OR "guide*" OR "factsheeet"
- "accessible design" OR "universal design"

Not included unless *explicitly related to arthritis:*

- Other bone and cartilage disorders
- Pain in general (including joint pain) or other pain disorders
- Injury in general
- Inflammation in general
- Autoimmunity in general
- Systemic diseases e.g. SLE, systemic sclerosis

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