

What consumers want: Identifying the unmet needs of Australians living with arthritis

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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 has engaged behaviour change scientists from Behaviour Works Australia at the Monash Sustainable Development Institute, Monash University to conduct the research in this document and three roundtables with people living with or affected by arthritis.

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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.

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- Osteoarthritis – OA
- Rheumatoid arthritis – RA

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Introduction

Arthritis is a common joint condition, with 1 in 7 Australians experiencing some form of arthritis in 2017-18, that negatively impacts the lives of those living with the condition and the people who care for them (Australian Institute of Health and Welfare, 2020).

For example, 50% of those with arthritis reported experiencing moderate to severe pain in 2017-18 (Australian Institute of Health and Welfare, 2020). The loss of productivity and quality of life has negative implications for society more broadly, with the management of osteoarthritis alone costing the Australian economy $3.5 billion in 2015-16 (Australian Institute of Health and Welfare, 2020).

> *"The number of people with osteoarthritis is expected to increase nationally from almost 2.2 million in 2015 to almost 3.1 million Australians in 2030. The number of people with rheumatoid arthritis is projected to increase from 422,309 in 2015 to 579,915 in 2030" (Ackerman et al., 2018, p. 877)*

Despite this trajectory, funding for musculoskeletal research has declined in recent years (Musculoskeletal Australia, 2020a). It is necessary to identify research of value to those living with arthritis so that future funding from government, philanthropy and the private sector is used wisely.

This report is the second of three reports that Research Australia is preparing for Arthritis Australia.

1. In Report One, *Understanding the arthritis research landscape*[1] Research Australia conducted a landscape and gap analysis of arthritis research activity in Australia and the stakeholders currently funding this research.
2. This report documents three activities to identify unmet health care needs reported by those with lived experience of juvenile idiopathic arthritis (JIA), osteoarthritis (OA) and rheumatoid arthritis (RA)

   a. Desktop review of existing work focused on consumer need
   b. Three Roundtables
   c. Survey
3. In Report Three, Research Australia will present a series of recommendations on consolidating Arthritis Australia's role as a leader in arthritis research and to enable the organisation to invest in research with translational outcomes that are of value to the consumers and communities Arthritis Australia serves.

Specifically, the aim of this work (report 2) is to identify the unmet health care needs reported by people living with arthritis. This will help expose current research gaps in the area of arthritis. Closer engagement with consumers will help Arthritis Australia, as a crucial funder of arthritis research, to advocate for the research which matters most to those with lived experience of arthritis.

1 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/



Summary of key findings

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. This existing body of work is the starting point for understanding the kinds of arthritis research consumers value, and how that research might address currently unmet need.

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[2])
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

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

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.

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 as a distinct priority in its own right.

Project background

Consumer input provides the evidence needed to make better program and investment decisions both by Arthritis Australia and by government.

This will ensure research funding is directed towards outcomes which tangibly improve quality of life for the nearly four million Australians[3], of all ages, living with arthritis.

Drawing on the impressive policy work already undertaken by Arthritis Australia, Research Australia has worked directly with consumers and those with lived experience of arthritis to prioritise research in a way which reflects the needs of the communities Arthritis Australia represents. Combining more detailed consumer input with the policy work already done will lead to a clearer strategy for Arthritis Australia's research investment and help refine the research 'ask' to government.

Research Australia and behavioural change scientists from Behaviour Works Australia conducted a desktop review (Appendix 1) and three 1.5hr virtual roundtables in February 2022. Participants were eligible to participate if they were aged over 18 years and have lived experience of RA, OA or JIA as someone who has one of the conditions themselves or has cared for someone with one of the conditions.

Arthritis Australia has an incredibly active consumer community ready and able to assist. Over 200 people registered their interest in participating in the Roundtables. Due to this incredible response, Research Australia also conducted a short survey to capture the experience and feedback of consumers who expressed interest in the Roundtables but were unable to participate.

This project demonstrates that Arthritis Australia can be a beacon of inspiration for the broader research community and other arthritis philanthropic organisations, an exemplar of meaningful consumer research co-design.

3 National Strategic Action Plan for Arthritis, Commonwealth of Australia as represented by the Department of Health, 2019.

What does the literature say about consumer needs?

Literature examining all three conditions of interest reported unmet needs in relation to information provision and service availability. There were more references to unmet needs in the areas of JIA than OA and RA.

These tables outline themes identified across all included sources. The Australian literature comprises grey and peer-reviewed literature, whereas the international literature primarily comprises peer-reviewed literature.

Table 1: What research is needed to meet unmet needs of people living with arthritis?

THEME	AUSTRALIAN LITERATURE			INTERNATIONAL LITERATURE		
	JIA	OA	RA	JIA	OA	RA
Efficacy and safety of new medications and management plans (incl. alternative therapies), especially for pregnancy planning	●	●	●	●	●	●
Disease impacts to the person and economy, including indigenous communities	●	●			●	●
Prevention methods		●			●	●
Disease cause	●				●	●
Research must involve co-design (e.g. with patients, carers, researchers, family organisations and regulators)				●	●	●
Reliable assessment methods					●	●
Efficacious methods to fine tune and tailor therapies				●	●	●
Ways to improve health systems and services					●	●
Research methods and capacity building					●	●
Disease severity	●					
Prognosis and expected disease trajectory					●	
Risk factors for the disease		●				
Define subgroups of disease to improve treatments						
How to improve quality of life	●					
How to change patient behaviour, including adherence to treatments		●				
Convince people and clinicians that exercise does not harm joint cartilage		●				
Reduce unnecessary surgery (e.g. knee replacement in OA)		●				
Identify disease prevalence	●					
Enhance shared decision-making						●

Table 2: What care and information do people living with arthritis want based on existing unmet needs?

THEME	AUSTRALIAN LITERATURE			INTERNATIONAL LITERATURE		
	JIA	OA	RA	JIA	OA	RA
Information about management strategies (incl. available drugs, drug safety assistive devices, exercise, alternative therapies etc.)	●	●	●	●	●	●
Information about effective community engagement (e.g. financial management, work, ADLs)	●	●	●	●	●	●
Increased service and specialist availability and accessibility	●	●	●	●	●	●
Know where to find reliable information	●	●	●	●	●	●
Information on prognosis and likely progression		●	●	●	●	●
Increase clinician knowledge of the condition	●	●	●		●	●
Better practitioner communication skills and rapport development		●	●	●	●	●
Opportunities for social interaction with others with the same condition and their families	●		●	●	●	●
Guidance for self-management	●	●	●	●	●	
Provide up-to-date information in different formats and languages (e.g. phone, print, reliable internet sources, support groups)	●		●		●	●
Less financial burden related to disease management and assistance to overcome this		●	●	●	●	
Help to find the right care quickly (e.g. prompt and accurate referral and less wait times for appointments)	●	●			●	●
Effective and collaborative care coordination, including having all clinicians working together and providing non-conflicting information	●	●	●			●
Community modifications to support social engagement (e.g. environmental modifications at school, information for workplaces)	●		●	●	●	

THEME	AUSTRALIAN LITERATURE			INTERNATIONAL LITERATURE		
	JIA	OA	RA	JIA	OA	RA
Longer and less rushed consultation times		●	●		●	
Psychosocial support	●		●	●		
Information about how to prevent the disease occurring (incl. in family members) and getting worse		●			●	
Avoid stigma from community, school, workmates etc.	●			●		
Information on cause of disease		●		●		
Improved care transitions (e.g. from paediatric to adult rheumatology)	●			●		
Information on how to balance managing their condition and family planning (specific to women with inflammatory arthritis)			●			●
Tailored care	●					●
Be actively engaged in clinical decision making		●				
Information on diagnosis					●	
Improved medication availability (e.g. increased demand during the pandemic affected supply)			●			
Improved community knowledge about the condition through easily accessible materials (e.g. media)		●				
Use of technology to deliver care	●					

Roundtables

Research Australia and behavioural change scientists from Behaviour Works Australia conducted three 1.5hr virtual roundtables in February 2022. Participants were eligible to participate if they were aged over 18 years and have lived experience of RA, OA or JIA as someone who has one of the conditions themselves or has cared for someone with one of the conditions.

Key themes from the Rheumatoid Arthritis Roundtable

INDIVIDUAL LEVEL

- Participants were pleased that they were being consulted
- Clinicians can appear dismissive at times. Soft skills are important to ensure the person feels supported and listened to.
- Managing RA can be expensive for the person
- People can receive conflicting information from different clinicians, which can be confusing.
- People diagnosed with RA go through a grieving process where they grieve the loss of the lifestyle they had before their RA diagnosis and the loss of future opportunities afforded to people who do not have RA. Support is needed during this process.

SYSTEM LEVEL

- More information and prescription of therapies other than pharmaceuticals (e.g. exercise and diet changes) is wanted
- RA appears to be classified too simply as a condition of the joints, with the many other signs and symptoms of the disease being less well known and considered in management plans.
- The length of time it takes to receive an accurate diagnosis is often long and drawn out
- Accessing the right clinicians and management can be difficult due to not knowing who to see and not being able to see them (e.g. due to geographical barriers)
- Having a tailored and individualised approach to care is important because not everyone presents the same way with the same issues of concern.
- Clinicians working with people with RA should have specialist knowledge of arthritis and know who to refer people to in order to receive the best care

Please see Appendix 2 for additional detail and quotes.

Key themes from the Osteoarthritis Roundtable

INDIVIDUAL LEVEL

- It can be difficult to find accurate and reliable information on OA management (including different drugs that are available and other management methods)
- Managing OA can be expensive for the person
- OA diagnosis comes with a grieving process where the person grieves their loss of function. Managing this grief requires support.

SYSTEM LEVEL

- The length of time it takes to receive an accurate diagnosis is often long and drawn out
- More research is needed that examines the causes and prognosis of OA, and includes consumer consultation
- People are sick of being told OA is just "wear and tear" and a "disease of aging", and being given generic advice (e.g. weight loss) without the support to implement it
- Increased community and clinician awareness is needed in the lesser known signs and symptoms of OA, such as strength loss.
- Having a tailored and individualized approach to care is important for best patient outcomes
- Clinical care and research can appear siloed, preventing best patient care and research that occurs when teams work effectively together.
- Clinicians need to communicate better to prevent people from receiving conflicting advice and to ensure care is better coordinated.

Please see Appendix 3 for additional detail and quotes.

Key themes from the Juvenile Idiopathic Arthritis Roundtable

INDIVIDUAL LEVEL

- Families can be challenged emotionally, intellectually and financially when a dependant has JIA
- Fatigue and brain fog reduces capacity to participate in school and manage complex care plans
- Managing JIA is expensive
- Modifications made to help children integrate into society (e.g. ability to use a lift at school when others need to use the stairs) can make them feel different, which is undesirable.
- Children sometimes don't like support groups because it can make them feel like they are different, or the groups will not have people they can relate to (i.e. comprised of older people)
- Can experience grief associated with loss of function and inability to participate in enjoyable activities. Need psychological support for both the child and caregivers.
- Managing medications and management plans can be stressful and overwhelming for children
- JIA is unique in that it is a type of arthritis that the person often lives with over their entire life course. Children and teens can fear the idea of losing their function, missing out on activities and needing to take medication for the rest of their lives.

SYSTEM LEVEL

- More information specific to JIA, rather than general advice on adult arthritis types, is needed
- Accessing the right clinicians to gain a quick diagnosis and correct management is hard
- People (clinicians, schools and community members) do not know about JIA and the impacts it has on someone's life
- People with JIA are often managed similarly to older adults with other arthritis types, which ignores their unique life stage (e.g. young adults with JIA want to go clubbing with friends but must be cognizant of being on medication that can be impacted by alcohol)
- Support groups should be provided to those who want and need them (e.g. parents) but require clever design to increase uptake by children.

Please see Appendix 4 for additional detail and quotes.



Findings from consumer survey

Following an incredible response from Arthritis Australia's consumer community to the invitation to participate in the Roundtables, Research Australia decided to conduct a survey to capture the experience and feedback of those who could not attend. The survey opened on 10 March 2022 and closed on 1 April 2022. Please see Appendix 5 for a list of the survey questions.

The survey was distributed by invitation only to consumers with osteoarthritis, rheumatoid arthritis and juvenile idiopathic arthritis who expressed interest in the Roundtables but were unable to attend. We received a total of 71 responses. Please see Appendix 6 for additional themes and quotes from the survey.

Types of arthritis

Of the survey respondents, 53% have osteoarthritis, 42%% have rheumatoid arthritis, 7% have juvenile idiopathic arthritis or are parents of children with juvenile idiopathic arthritis, 4% support someone with arthritis, and 11% noted they had a different type of arthritis.[4]

Due to the low participation rate of carers and those with juvenile idiopathic arthritis, the data is skewed to reflect the experiences of the majority (those with osteoarthritis and rheumatoid arthritis). The survey sample is not sufficiently large to reliably report separate responses for the different sub-groups.

The impacts of having arthritis on everyday life

The majority of respondents reported that arthritis has a medium or high impact on their ability to live their lives, with **44% stating it has a high impact and 41% saying it has a medium impact.** 10% reported arthritis has a low impact, and 6% reported 'other'. Importantly, there were no respondents who reported that arthritis has 'no impact' on their ability to live their life. The 'other' responses consisted of having a joint replacement, such as hip or knee replacement.

The majority of respondents commented that having arthritis affects their ability to conduct and participate in everyday activities and duties. Arthritis impacts their ability to open jars, brush their hair, and do household chores such as vacuuming, mopping, cleaning, lifting heavy things, getting in and out of the car, getting off the toilet and sitting on the floor. In addition, a carer for an individual living with juvenile idiopathic arthritis commented that arthritis has had a significant impact on their daughter's participation in physical activity, her ability to concentrate and her social life. This has led to their family life and activities being affected.

Respondents also reported that arthritis impacts their social life for reasons such as COVID-19 self-isolation and increased risk of contracting COVID-19 whilst on an immune suppressant drug for rheumatoid arthritis and restricting social drinking and engagement.

Respondents also commented upon the impact on mental health, one stating they feel lonely whilst another commenting they are *"losing the will to live...EVERY other day is a varying degrees of HELL"*, due to having to attend to their own health needs daily alongside having to be a husband, father and owner of a company. Many of the respondents commented on their chronic pain, which has affected their ability to walk and disrupted their sleep ability.

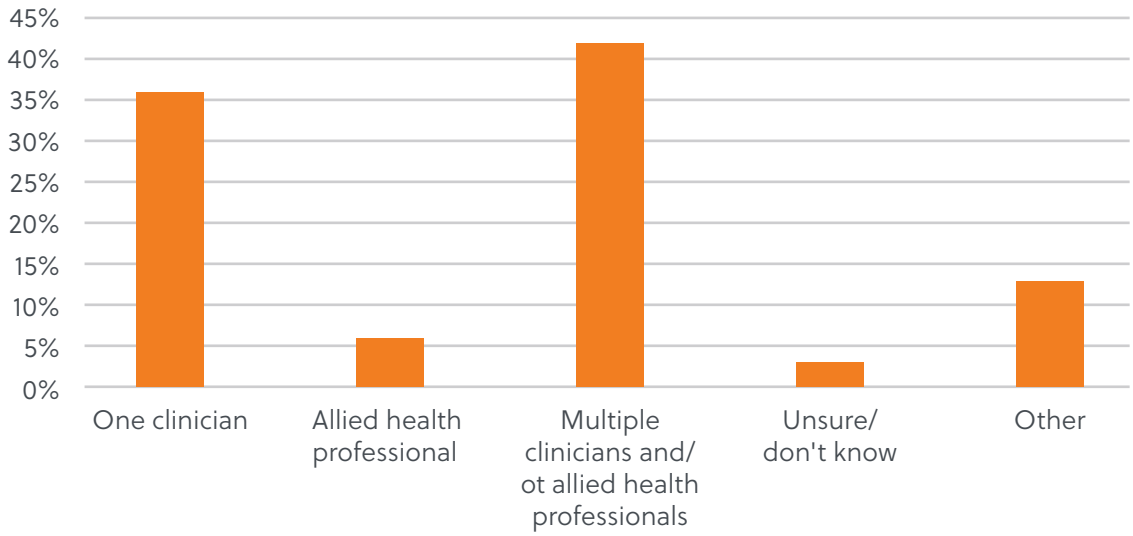
4 Other types of arthritis noted by respondents include: Juvenile dermatomyositis, Palindromic rheumatism morphing into RA, Ankylosing spondylitis, Auto-immune polyarthritis, Psoriatic arthritis, "In my feet and my two hands join and fingers".

Experience of diagnosis and treatments

42% of respondents have been to multiple clinicians and/or allied health professionals to get an accurate arthritis diagnosis, whilst 36% have seen one clinician diagnose them with arthritis.

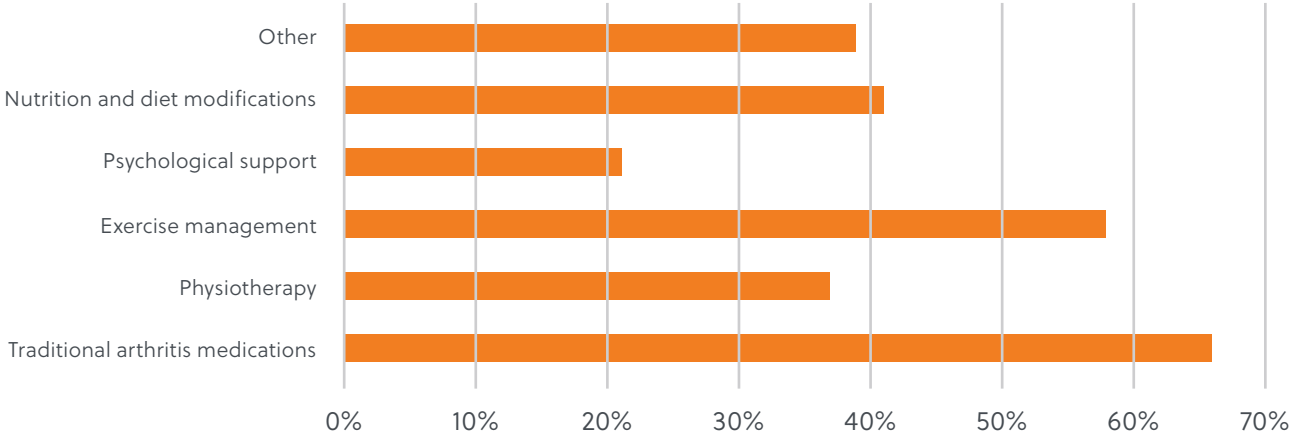
Other respondents (6%) stated they were diagnosed by an allied health professional, 3% were unsure and/or did not know, and 13% commented 'other'.[5]

Graph 1: Experience in getting an accurate arthritis diagnosis



Respondents' treatments are varied, with arthritis medication (66%) being the most used. Second was exercise management (58%), followed by nutrition and diet modification (41%), and physiotherapy (37%). Others were reported by 39% and included massage, acupuncture, and CBD oil; some commented that they have found nothing has helped with their pain.

Graph 2: Kinds of treatments found effective for arthritis



5 Other ways of diagnosis included being diagnosed in the RCH after being in hospital for six weeks with what they thought was pneumonia, no diagnosis yet, knowing others who have arthritis, and misdiagnosis.

In addition to treatment, respondents commented on how they have discovered new ways to manage and treat their arthritis. For example, 45% have found treatments from their GP or specialist, 35% from an allied health professional, 65% from doing their own research, 17% from other people living with arthritis, 20% from support organisations and 24% from other sources. Respondent comments included that support groups and Facebook groups have been helpful in finding new ways, and webinars and online recordings from centres around the world are helpful in understanding the general recommendations whilst others have not found any new ways.

Mental health and psychological support

37% think that more mental health support needs to be offered to help people living with arthritis. One respondent stated that mental health support was not initially recommended and commented that "it was not until I received support for a more acute mental health episode that I came to understand how much pain was affecting my mental state. I think mental health care should be recommended for all chronic pain suffers". Another commented that they would like psychological support when feeling stressed and anxious because of their condition. Other comments included the long waiting times, the price and difficulties accessing support in rural areas.

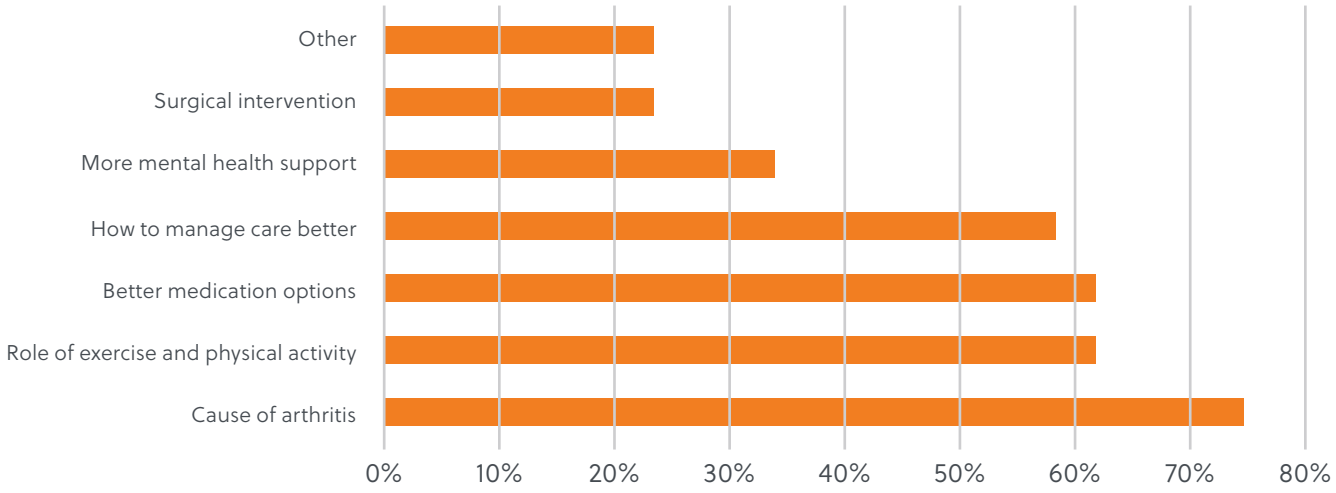
Research needed to help people living with arthritis

The results from the survey identified that there is a group of active participants who are ready to assist with research. **Participants were asked if they would be willing to assist in research and the design of it, to which 91% said yes, 0% said no, and 9% (one respondent) was 'unsure and/or do not know'.** All but one survey respondent stated that they know what a clinical trial is and 69% said they would be willing to participate in a trial in relation to their arthritis. The majority of other respondents said whether they would be willing to participate would depend on certain aspects of the trial. The reasons for not wanting or being unsure of participating in a trial include the following:

- Sensitive to medication
- Depend on the requirements of the trial
- Depends if they would have to stop taking their current medications
- Not willing to change current arthritis medication
- Time and travel commitments
- Will need to know information on the impacts of the trials
- Knowing someone who has an adverse reaction after a trial.

Further research relating to arthritis was deemed highly important in the survey results. 75% of respondents think that research into the cause of arthritis is needed. Nearly two thirds of the respondents (62%) stated that better medication options are needed and 62% also stated that research into the role of exercise and physical activity is needed. Over half of respondents (58%) think that research into better managing their care is needed, and 23% think that research into surgical intervention is needed. 23% specified 'other' options.

Graph 3: Research needed to help live with arthritis



Additional comments included research on the following:

- Brain fog
- Fatigue/ chronic fatigue
- CBD oil
- Impact on biome
- gut health and how it can be improved for clinically measurable outcomes, especially around inflammation
- The role of pain medications with inflammatory arthritis
- Into more comfortable desk chairs for people who have desk jobs
- Into what causes the inflammation that overstimulates the immune system.

Research Australia also wanted to understand the type of research needed depending on the impact of arthritis noted by the participants of the survey. 44% reported their arthritis had a high impact. Notably participants who noted high impact stated the two priority areas for research should be surgical intervention and more mental health support. Among those who reported medium impact, research into better medication and research into surgical intervention were the most important.

Comments during the Roundtables and from the survey indicate that intersectional research is also needed, with one respondent saying there is a need to "listen to people who are marginalised, e.g., CALD communities, Aboriginal people and those who do not have access to good health care due to distance or low health literacy or poverty and do not have access to Telehealth options." Another respondent noted that it would be helpful to understand the economic and demographic factors that may affect the quality of patient outcomes, in particular the differences between public and private care. The respondent stated that "I'm lucky that I can afford private rheumatology care. I think the quality of my specialist services have been excellent, and I am now on medication (biological) that has really been life changing. I have heard that other (particularly in the public system) have not had the access to the same quality of care".

Another respondent commented that "matching of drugs to the DNA of individuals to a greater extent than currently undertaken so there would be less trial and error in identifying the treatment options most likely to be effective for the individuals."

Other improvements include decreasing the costs of aids, developing community based programs, improving community understanding of arthritis, and offering mental health support.

When asked about what three things they would change that would make their life living with arthritis more accessible, the respondents noted the following:

Answers noted by four or more respondents	Answers noted by less than four respondents
Support with duties around their home	Shorter waiting list for surgeries
Easy and correct diagnosis	Get concession and health care card
Reduce fatigue and brain fog	Lower steps to get on buses
Medicare rebates for medication and government monetary support	Access to support with weight loss
Mental health support	Mobility scooter
No pain/ relieve pain/ living pain free	Online support groups
Medications that do not have side effects/ better medication	Webinars and forums where people can quickly gather information
Finding a cure	Better understanding of the role of exercise
Better community and workplace awareness	Packaging that requires less dexterity



Next steps

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



Report 1 – Understanding the arthritis research landscape



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



Report 3 – Impactful Arthritis Research

The information captured through the benchmarking project, stakeholder mapping, and consumer prioritisation will inform a series of recommendations by Research Australia to guide how Arthritis Australia:

- directs future investment in research in a way that meaningfully benefits the communities you represent;
- gives greater visibility to arthritis as a group of diseases by using research results to generate public discourse;
- demonstrates sector leadership by way of best practice in consumer engagement in research codesign and prioritisation;
- builds on the research recommendations in the National Strategic Action Plan with a detailed 'ask' to Government and other funders for research investment in particular areas of arthritis and musculoskeletal health based on evidence; and
- positions itself as the leading organisation in coordinating arthritis research in Australia with greater visibility of its research leadership role not just amongst Arthritis Australia's own federated model but more broadly amongst the health and medical research community.

Arthritis Australia has an incredibly active consumer community ready and able to assist. Arthritis Australia can be a beacon of inspiration for the broader research community and other arthritis philanthropic organisations, an exemplar of meaningful consumer research co-design.

Appendicies

Appendix 1: Desktop review of literature on unmet healthcare needs and research priorities of those with lived experience of arthritis.

Introduction

Arthritis is a common joint condition, with 1 in 7 Australians experiencing some form of arthritis in 2017-18 that negatively impacts the lives of those living with the condition and the people who care for them (Australian Institute of Health and Welfare, 2020). For example, 50% of those with arthritis reported experiencing moderate to severe pain in 2017-18 (Australian Institute of Health and Welfare, 2020). The loss of productivity and quality of life has negative implications for society more broadly, with the management of osteoarthritis (OA) alone costing the Australian economy $3.5 billion in 2015-16 (Australian Institute of Health and Welfare, 2020).

> *"The number of people with OA is expected to increase nationally from almost 2.2 million in 2015 to almost 3.1 million Australians in 2030. The number of people with RA is projected to increase from 422,309 in 2015 to 579,915 in 2030" (Ackerman et al., 2018, p. 877)*

Despite this poor prognosis, funding for musculoskeletal clinical care and research has declined in recent years (Musculoskeletal Australia, 2020a). It is necessary to identify research of value to those living with arthritis so that future funding from government, philanthropy and the private sector is used wisely. The focus of this desktop review is on identifying what research people with lived experience of arthritis want or need to live their best life with arthritis.

To do this, Research Australia has engaged behaviour change scientists from Monash University's BehaviourWorks Australia to conduct a desktop review to answer the question:

> *"What are the unmet healthcare needs and research priorities of people with lived experience of arthritis (specifically RA, OA and JA) in Australia?"*

Specifically, the aim of this work is to identify the unmet health care needs reported by people living with arthritis. This will help expose current research gaps in the area of arthritis. This review, alongside findings of future roundtables with relevant stakeholders, will assist Arthritis Australia, as a crucial arthritis research funder to target its research investment and advocacy at new ways to improve clinical care of people with arthritis and better meet consumers' needs.

This report is the second of three reports that Research Australia is preparing for Arthritis Australia. Research Australia has conducted a landscape and gap analysis of arthritis research activity in Australia and the stakeholders currently funding this research. Research Australia will capture the findings contained in this report and the research landscape analysis to present

a series of recommendations to consolidate Arthritis Australia's role as a leader in arthritis research and enable the organisation to invest in research with translational outcomes that are of value to the consumers and communities Arthritis Australia serves.

Summary of common themes

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 – juvenile idiopathic arthritis (JIA), osteoarthritis (OA) and rheumatoid arthritis (RA). This existing body of work is the starting point for understanding the kinds of arthritis research consumers value, and how that research might address currently unmet need.

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. The common themes identified below are relevant to both unmet needs as well as research gaps.

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[6])
4. Increased service and specialist availability and accessibility
5. Knowing where to find reliable information

Common consumer themes in Australian literature only:

6. Increase 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

The following pages provide a more detailed look at what was discovered through the searches of existing literature. This will be further tested through three roundtables held with people with lived experience of arthritis, which will be conducted in 2022. Once completed, a revised report will be prepared that describes the findings from both this literature review and consumer roundtables.

6 These can be community based (like paying bills), personal (like toileting), and domestic (like vacuuming).

Future research and unmet care needs in Australia

The primary themes emerging from the analysis of 25 sources of literature specific to the Australian context is outlined below [See Appendix A for methodology].

This section provides more detail behind the themes that were common across all three conditions in Tables 1 and 2 (i.e. the theme was identified in sources specific to JIA, OA and RA).

What research is needed to meet the unmet needs of Australians living with arthritis?

Literature examining all three conditions of interest reported research gaps specific to treatment and management of the condition (Table 1). There were more suggestions for future research in the areas of JIA and OA than RA.

Juvenile Idiopathic Arthritis

The suggested areas for future research in JIA primarily focused on diagnosis and drug therapies, which have been identified as the research areas receiving the most attention by clinical trials in 2021 (Lehmann & Ries, 2021). Grant funding for research into early diagnosis and improved therapeutics for chronic musculoskeletal conditions in children and adolescents is available for application as part of the National Health and Medical Research Council, Medical Research Future Fund (NHMRC MRFF) grant rounds closing February 22, 2022 (Department of Finance, 2021). This might suggest that research is beginning to address perceived gaps; however, the detail of these projects requires examination to accurately determine this.

More research into the disease itself (e.g. cause, prevalence, physical impacts and severity), as well as how to improve quality of life while living with the disease (e.g. identifying economic and social impacts), was commonly suggested (Children's Arthritis Research Institute, 2018; MOVE muscle bone & joint health & PwC, 2017; The Juvenile Arthritis Foundation Australia (JAFA), 2020a).

Additional research into discovering new biologics that are tailored to the patient (e.g. considers administration preferences) was suggested, as well as discovering the efficacy and acceptability of non-pharmaceutical treatments (Arthritis Australia, 2014; Children's Arthritis Research Institute, 2018). International organisations have also called for more research into biologics that are specifically tailored to the patient's condition (e.g. particular types of JIA) (Arthritis Foundation & CARRA, 2019).

Future research should be conducted together with patients and their families to ensure novel treatment and management plans are important to the patient and address their needs (Children's Arthritis Research Institute, 2018; Slater et al., 2016).

Osteoarthritis

The suggested areas for future research in OA primarily focused on the clinical pathway and ensuring patients receive evidence-based care, avoid unnecessary surgery and are supported to adhere to ongoing management.

How to prevent and treat OA, with specific focus on how to support treatment adherence and behaviour change, emerged as important areas for future research (Hunter et al., 2019). Part of this involves identifying risk factors to both prevent OA and to treat it early (Children's Arthritis Research Institute, 2018).

A specific focus on improving the clinical pathway for people with OA undergoing arthroplasty, which includes comprehensive screening and post-discharge care, was suggested (Wang et al., 2020). It was also suggested that more research is needed to find ways to minimise unnecessary surgical referrals and enhance the acceptance of evidence-based conservative treatments (e.g. exercise), which could potentially be addressed in the development of evidence-based clinical pathways (Australian Physiotherapy Association, 2021; Wang et al., 2020).

Understanding the overall impact of OA, particularly in Indigenous communities, was reported as a recently emerging area of interest (O'Brien et al., 2020).

Rheumatoid Arthritis

The suggested areas for future research in RA primarily focused on the efficacy of treatments and management programs.

More research into efficacious and effective treatments, including biologics and non-pharmaceutical therapies, has been suggested (Littlejohn et al., 2013). One reason for this suggestion is the need to more effectively identify the most appropriate treatment for the patient the first time, preventing patients from needing to try several treatments before finding the one that works (Lions Rheumatism and Arthritis Medical Research Foundation Australia, 2021).

Specifically, there is also a call for more research into the effectiveness and safety of patients switching between different pharmaceuticals, which is common practice in Australia during drug shortages (e.g. like those seen during the COVID-19 pandemic or simply when a pharmacist does not have sufficient stock) (Jones et al., 2017).

What do Australian consumers want based on their unmet needs?

Literature examining all three conditions of interest reported unmet needs in relation to information provision and service availability (Table 2). There were more references to unmet needs in the areas of JIA than OA and RA.

AUSTRALIAN CONSUMERS WANT BETTER INFORMATION

The literature exploring unmet needs across all three arthritis types consistently reported unmet needs related to reliable information on management strategies, community engagement and activities of daily living (ADLs).

Juvenile Idiopathic Arthritis

Access to accurate and reliable information about JIA, management programs, support programs when its needed was reported as an unmet need (Tong et al., 2013). Subsequently, addressing this need relies on the provision of reliable educational materials for patients and families that can be administered by care providers (Coda et al., 2017; Tong et al., 2013).

Information specific to community engagement and ADLs, such as where to access mobility equipment, financial assistance and careers advice, was reported as difficult to find and necessary for maintaining quality of life (Arthritis Australia, 2014; Tong et al., 2013). Information about management programs, including complications associated with medication use and the various treatments that can be used to manage pain, was reported as needed by those with experience with JIA (Tong et al., 2013). Information specific to self-management, like healthy eating behaviours to manage symptoms and function well, was also desired (Tong et al., 2013).

Importantly, all information materials need to be age-appropriate and culturally sensitive (Arthritis Australia, 2014).

Osteoarthritis

A report from Musculoskeletal Australia (previously 'MOVE Muscle, Bone & Joint Health') outlined several perceived gaps in information provision reported by people with OA. Patients reported wanting more accessible, consistent and reliable information on the following to help them become engaged in decision-making (Wluka et al., 2016):

- Causes, prevention and prognosis of OA;
- Management strategies for OA (including medications, conservative management [e.g. diet, exercise], assistive devices and self-management strategies);
- Available financial and community services to support community engagement and quality of life; and
- Surgical options.

Rheumatoid Arthritis

Unmet needs related to information provision was largely identified in the perinatal population (Ackerman et al., 2015). Pregnant women, mothers and those planning a pregnancy want more reliable and consistent information about:

- Medication safety and the effects on the unborn and breastfed child;
- Different treatment options;
- Support services available; and
- Information for families and workplaces to create safe and welcoming environments.

Difficulty finding the right information can act as a barrier to people with RA accessing information about their disease (Wluka et al., 2016). People with RA have also reported wanting more consistent and reliable information to be provided at diagnosis to support them to cope with the news and learn to manage their condition, but also more information about the course of the disease and what to expect (Arthritis Australia, 2019; Wluka et al., 2016). Adolescents with inflammatory arthritis have also reported wanting more information on their condition, including self-management strategies (Arthritis Australia, 2019).

AUSTRALIAN CONSUMERS WANT BETTER ACCESS TO THE QUALITY SERVICES THEY NEED

The literature exploring unmet needs across all three arthritis types consistently reported unmet needs related to service provision, where services were either inaccessible or simply not meeting their needs and expectations.

Juvenile Idiopathic Arthritis

Appropriate service access, presenting as experiencing long delays in receiving an accurate diagnosis and long waiting times to see a paediatric rheumatologist who is often located far away, was often reported as lacking (Arthritis Australia, 2014; Kids Arthritis, n.d.; Tong et al., 2013). More paediatric rheumatologists and timely access to trained health care providers who can advise on JIA, medications and pain management has been identified as needed in areas such as regional Queensland and New South Wales (Coda et al., 2017; Tong et al., 2013; Zoe's Angels, 2021a). Organisations such as Zoe's Angels raised $101,450 from their 2017 Gala event to train a paediatric rheumatology doctor specialist for regional Queensland in an attempt to partially meet this need (Zoe's Angels, 2017).

Having a large number of health professionals distributed across large geographical distances who do not work together to effectively coordinate patient care can make it difficult for patients and families to effectively manage their condition (Arthritis Australia, 2014; Coda et al., 2017; Tong et al., 2013). The provision of information directly from care providers, such

as management advice, when needed was reported as insufficient by those needing advice immediately. It was reported that presentations to the emergency department could be prevented if urgent advice could be provided via email or phone (Tong et al., 2013).

Services that did not meet patient needs also did so in the lack of quality, rather than simply lack of physical accessibility. For example, services that did not provide sufficient support (e.g. instruction on how to self-administer injectable medications) were deemed as not fulfilling an important need (Tong et al., 2013). Furthermore, services that are considered to add quality to usual care for the patient and family, such as mental health support and social events, are considered important but insufficient (Tong et al., 2013). It is important to note that these findings are based on dated literature and many not-for-profits create social opportunities for families and children with JIA, such as camps and gala events (e.g. Zoe's Angels, Kid's Arthritis).

Osteoarthritis

Access to the right care when needed by Aboriginal Australians has been reported as an unmet need (Lin et al., 2018). However, poor health care access (e.g. long wait times and inability to access health professionals) is not unique to Aboriginal Australians and requires addressing in other Australians with OA too (Wluka et al., 2016). Furthermore, the lack of time allocated to medical appointments has been reported to make people feel rushed and need to rely on other services to answer questions (e.g. pharmacists for medication advice) (Manias et al., 2007). Inaccessibility was also demonstrated by the cost of care (e.g. appointments) and management (e.g. medications) (Berkovic et al., 2021; Wluka et al., 2016).

Rheumatoid Arthritis

Medications have been reported as being unavailable when needed, which was exacerbated during the COVID-19 pandemic where common medications to treat RA were also being used by people attempting to manage and prevent COVID-19 (Haendel, n.d.; Jones et al., 2017).

- People with RA have reported wanting better access to health care services, including (Wluka et al., 2016):
- Having consultations that are long enough to ensure they are accessing the care and information they need;
- Services that minimize language barriers to ensure precious time with health professionals is used effectively;
- Having services close to home; and
- Have cost and insurance issues reducing access to care minimised;

Women with autoimmune rheumatic conditions in the perinatal period want access to services that can support them throughout that period and into parenthood (Arthritis Australia, 2019).

APPENDIX A: Methodology

This document outlines the findings of a desktop review that examined 81 sources of information comprising both grey (e.g. websites, organization reports) and peer-reviewed literature related to arthritis from Australia and internationally. Arthritis is a broad term covering many conditions. Rheumatoid Arthritis (RA), OA and Juvenile Idiopathic Arthritis (JIA) will be the pathology foci for this review.

Sources were identified using a mix of general website searching using the Google search engine, literature searching using Google Scholar, and open-access database searching using PubMed and the Cochrane Library. Forwards and backwards citation checks[7] were also completed on the most relevant peer-reviewed literature items identified. A list of websites for Arthritis charities and representative bodies provided by Research Australia was also used to identify relevant information to answer the following research question:

> *"What are the unmet healthcare needs and research priorities of people with lived experience of arthritis (specifically RA, OA and JA) in Australia?"*

A range of search terms were used to identify relevant information, including (but not limited to): *rheumatoid arthritis, osteoarthritis, juvenile idiopathic arthritis, arthritis, consumer, need, unmet need, patient.*

Although the original search was limited to identifying only Australian literature, international literature that appeared extremely relevant (i.e. it reported findings specific to unmet needs of people with arthritis) was also scanned for insights. International literature examining unmet needs in people with arthritis might identify similar themes to the Australian literature, so its inclusion could assist to further validate the local findings. Finally, the initial publication date of literature eligible for inclusion was set to 2016 onwards. However, extremely relevant older literature was also included.

All sources were examined for common themes associated with future research needs and unmet needs of people with JIA, OA and RA. The themes were then collated to create Tables 1 and 2, which present all identified themes and their frequency. The most common themes identified in the Australian literature were discussed in depth within the body of this document, whereas international literature was primarily used to report additional findings found in Appendices 1-3.

The themes reported herein were identified by completing a desktop review of grey literature and easily accessible peer-reviewed literature, which means that all available data might not have been found. This suggests that any absence of *particular themes does not mean that they do not exist, but instead that they have not been found during the desktop review. Furthermore, the absence of a theme does not suggest that this represents a met care need in this population, or that research is not needed in the area, but rather that it has not been identified during the review process.* A comprehensive systematic review, which can take months to years to complete, would provide a more comprehensive analysis of existing literature.

The findings of this review will be examined together with the findings from three roundtables held with people with lived experience of arthritis, which will be conducted in 2022. Once completed, a revised report will be prepared that describes the findings from both this literature review and consumer roundtables.

7 Backwards checking involves checking reference lists of published studies. Forwards checking involves checking for papers that have cited published studies of interest.

APPENDIX B: What does the international peer-reviewed literature say?

JUVENILE IDIOPATHIC ARTHRITIS

Research gaps

- What are the benefits vs risks of early aggressive treatment in systemic and polyarticular JIA? (Ruperto & Martini, 2018).
- How can disease flares be prevented once clinical remission is reached? (Ruperto & Martini, 2018).
- A better classification of JIA into homogeneous disease entities will help the development of new drugs tailored to specific JIA categories (Ruperto & Martini, 2018).
    - New drugs that selectively target molecules or pathways involved in inflammation seen in each JIA category (Ruperto & Martini, 2018).
- Need to discover laboratory and imaging biomarkers that can help in fine tuning therapies for individual patients (Ruperto & Martini, 2018).
- Links between academia, regulatory authorities and family organisations will help the planning and prioritisation of future clinical trials (Ruperto & Martini, 2018).
- Trials testing superiority of a steered treatment approach based on treat-to-target (remission) over a non-steered approach (Ravelli et al., 2018).
- Acceptance and applicability of treat-to-target strategies in clinical practice (Ravelli et al., 2018).
- Acceptance and applicability of treat-to-target strategies in low income countries (Ravelli et al., 2018).
- Determine if treat-to-target strategies should have different characteristics in adolescents (Ravelli et al., 2018).
- Impact of parent/patient evaluation, especially in the presence of pain sensitivity, in assessing targets (Ravelli et al., 2018).
- Compare remission defined clinically to remission based on imaging or biomarkers related to structural and functional outcomes (Ravelli et al., 2018).
- Identify the best modality of tapering and/or withdrawing treatments in patients reaching inactive disease or remission (Ravelli et al., 2018).

What consumers want (from unmet needs literature)

- Improved access to services that are attractive to patients and meet their needs (Min et al., 2021; Ullrich et al., 2002). For example, greater availability and easier access to comprehensive psycho-educational interventions (Barlow et al., 1999).
- Financial support (e.g. government funded care) (Min et al., 2021).
- Want to live without prejudice from school, social settings and the workplace (Min et al., 2021).
- Have good relationships with clinicians where children are directly communicated with and the parents act in a supplementary role (Min et al., 2021).
- Improved knowledge and skills in self-managing JIA and daily tasks using appropriate and evidence-based web-based approaches and face-to-face programs (Min et al., 2021).
- Want career counselling (including special employment channels to support employment) (Min et al., 2021).
- Experience physical difficulties at school (e.g. gym classes, writing and sitting for long durations, inability to play with friends)(Chomistek et al., 2019).
    - Want school facilities that are JIA-friendly where facilities are provided and suitably modified, teachers are trained and extra academic assistance is provided (Min et al., 2021). One study has reported only 23% of students using modified gyms, accommodation letters and computer access for writing (Chomistek et al., 2019).
- Improved knowledge on prognosis, course and treatment of JIA (Ullrich et al., 2002).
- Group education (Barlow et al., 1999).
- Informal support groups (Barlow et al., 1999).
- Activity weekends and summer camps (Barlow et al., 1999).
- Young people feel dismissed, abandoned, ill-prepared and out of control when transitioning from paediatric to adult rheumatology services (Kelly et al., 2020). Patients should be supported by helping them prepare for changes, making them feel like they belong and negotiating the role of the parent (Kelly et al., 2020).

Other notes

- Children and families with JIA acknowledge the importance of clinical trials but experience concern when asked to participate for the risk of receiving suboptimal care. However, concern can be alleviated if the trial is targeting a particular subtype of JIA (Min et al., 2021).

OSTEOARTHRITIS

Research gaps

- Less priority given to burden, cause, assessment, prevention, prognosis, economic evaluation, health services and systems, research capacity building, research methods and the consumer perspective compared to treatments (Bourne et al., 2018).
- New drug treatments needed with less side effects (Laufer, 2004).
- Identify a disease modifying therapy for hand OA during menopause and test it using specifically designed controlled trails against standard management (Watt, 2016).

What consumers want (from unmet needs literature)

- Information/education on:
    - Diagnosis (Chou et al., 2018; Giacomelli et al., 2014);
    - Medications (Chou et al., 2018; Giacomelli et al., 2014);
    - Exercises (Giacomelli et al., 2014);
    - How to perform daily activities as majority of sufferers can no longer perform the activities they want to perform (Giacomelli et al., 2014; Kamsan et al., 2020);
    - More information provided during treatment (Giacomelli et al., 2014);
    - Local community and sports groups (Papandony et al., 2017);
    - Self-management (Chou et al., 2018; Kamsan et al., 2020);
    - How to practice a healthy lifestyle with OA (Kamsan et al., 2020);
    - The OA disease process and prognosis (Chou et al., 2018; Kamsan et al., 2020);
    - Symptom control (Kamsan et al., 2020);
    - Prevention of disease progression (Chou et al., 2018; Kamsan et al., 2020); and
    - Information should be provided using various modes (e.g. print media, television, support groups, family, friends and reliable internet sources)(Chou et al., 2018).

- Clinicians to:
    - Give clear explanations and communicate better (Chou et al., 2018; Papandony et al., 2017);
    - Have sufficient knowledge and interest in OA (Papandony et al., 2017), or specialise in it (Chou et al., 2018);
    - Stop trivialising OA (Papandony et al., 2017);
    - Recognise them (Papandony et al., 2017);
    - Stop suggesting that treatments are only palliative because it makes the patient question treatment effectiveness (Papandony et al., 2017);
    - Provide non-pharmaceutical options like conservative management and alternative medicine options (Chou et al., 2018; Papandony et al., 2017);
    - Be accessible (Chou et al., 2018; Papandony et al., 2017);
    - Give time to the consultation and acknowledge the patient's pain, allowing them to explain and express their situation (Papandony et al., 2017); and
    - Prescribe therapies with more of a permanent benefit and therapies that can be delivered in one pill rather than many (Papandony et al., 2017).
- Cheaper medications with less out-of-pocket cost and side effects (Papandony et al., 2017).
- Better access to rehabilitation and exercise groups (Papandony et al., 2017).
- Better access to clinicians and continuity of care (Papandony et al., 2017).
- Improved awareness of living aids and home adaptations available through social services and clothing they like wearing that fits feet with OA (Papandony et al., 2017).
- Coping strategies to ensure continued engagement in social and cultural activities (e.g. kneeling during prayer) (Kamsan et al., 2020).
- Support to perform everyday tasks, such as: ADLs, exercise, social participation, environment, occupation and transport (Fairley et al., 2021).

RHEUMATOID ARTHRITIS

Research gaps

- Less research has been prioritised in RA compared to OA. Research into prognosis is prioritised more than research for treatments, burden, cause, assessment, prevention, economic evaluation, health services and systems, research capacity building, research methods and the consumer perspective (Bourne et al., 2018).
- New drug therapies needed for those who fail conventional disease-modifying antirheumatic drugs (DMARDs) such as methotrexate (MTX) (Mankia et al., 2020; Olsen et al., 2018).
- The cause of RA remains unknown and no cure has been found (Jones et al., 2017).
- Need comprehensive definition of remission in order to find a cure (Mankia et al., 2020).
- Identify ability of ultrasound, MRI and serological biomarkers to accurately predict remission and relapse risk (Mankia et al., 2020).
- Identify the best tapering strategy from DMARDs (Mankia et al., 2020).
- Women with autoimmune rheumatic diseases during pre-conception, pregnancy and early parenting lacks research in (Phillips, Williams, et al., 2018):
    - Ways to improve shared decision making in healthcare;
    - Ways to have high quality conversations during the pre-conception phase;
    - Produce evidence-based information on medication use during pregnancy and breastfeeding;
    - Identify ways to make care more personalized;
    - Alternative therapies; and
    - Efficacy of alternative therapies and peer supports that women often use but lack in evidence for efficacy, safety and mechanisms of effect.

What consumers want (from unmet needs literature)

- Information/education on:
    - DMARDs risks (El Masri et al., 2020);
    - On the contents of relevant regional health care services (Meesters et al., 2011);
    - How to access relevant regional health care services (Meesters et al., 2011);
    - Ongoing information over the disease course (Connelly et al., 2019);
    - Information in different languages (Connelly et al., 2019);
    - Better access to reliable sources (Connelly et al., 2019; Lynch et al., 2020);
    - Specific to women during pregnancy planning, fertility, pregnancy, giving birth, breastfeeding and early parenting (Chew et al., 2019; Johansen et al., 2021; Lynch et al., 2020; Phillips, Pell, et al., 2018);

    - How pregnancy can affect symptom behaviour (Chew et al., 2019);
    - How to restart medications after giving birth (Chew et al., 2019);
    - Medication safety during pregnancy (for the woman and foetus) (Chew et al., 2019; Wolgemuth et al., 2021) and breastfeeding (Williams et al., 2019) and any infertility risks associated with DMARDs (Wolgemuth et al., 2021);
    - Mobility (Phillips, Pell, et al., 2018);
    - Pain (Phillips, Pell, et al., 2018); and
    - Up-to-date information (Chakravarty et al., 2014).
- Knowledgeable clinicians (Connelly et al., 2019).
- Support to breastfeed in conjunction with managing symptoms with medication (Williams et al., 2019).
- Consistent advice from clinicians involved in their care (Chakravarty et al., 2014; Lynch et al., 2020).
- Women want clinicians to communicate with each other, rather than using them as intermediaries (Wolgemuth et al., 2021).
- Women want rheumatologists to initiate conversations about sexual and reproductive health care that's relevant to their life circumstance and personal values, and return to the topic regularly (Wolgemuth et al., 2021).
- Women and young people generally report more needs (Connelly et al., 2019).
- More timely access to healthcare (Connelly et al., 2019).
- Ways to connect with other women about pregnancy and family planning (Lynch et al., 2020).
- Better support from and communication with their doctor (specific to women planning pregnancy) (Chew et al., 2019; Lynch et al., 2020).
- Better pharmaceutical treatments for disease management (Radawski et al., 2019).
- Support to perform everyday tasks (Boumpas et al., 2019), such as: ADLs, exercise, social participation, environment, occupation and transport (Fairley et al., 2021).

Other notes

- Interprofessional and patient-professional communication specific to fertility, pregnancy and lactation for women with RA need to be improved (Briggs et al., 2016).

APPENDIX C: What does the Australian peer-reviewed literature say?

JUVENILE IDIOPATHIC ARTHRITIS

What consumers want (from unmet needs literature)

- Well-coordinated network of services that are accessible (Tong et al., 2013).
- Timely and accurate information about JIA, treatments and support services via forums, printed resources, web sites and dissemination of information by rheumatology and primary care clinics (Tong et al., 2013).
- Improved educational materials for patients and families (Coda et al., 2017).
- Adequate pharmacy support where parents are not stigmatised when asking for syringes and sharps containers for the purposes of administering medication to children (Tong et al., 2013).
- School-based advocacy that involves (Tong et al., 2013):
    - Better teacher and school understanding;
    - Less bullying from children and feeling isolated;
    - Need for academic assistance;
    - Need environmental modifications, like wheelchair ramps; and
    - Offer alternative activities.
- Improve knowledge and understanding of JIA among health care providers so children with JIA can be treated effectively (e.g. GPs and paediatricians)(Coda et al., 2017; Tong et al., 2013).
- Reduce delays in diagnosis (Tong et al., 2013) and reduce number of clinicians needing to be seen before a diagnosis is found, reducing the difficulty in obtaining a diagnosis (Coda et al., 2017).
- More paediatric rheumatologists and timely access to trained health care providers who can advise on JIA, medications and pain management (Coda et al., 2017; Tong et al., 2013).
- Provide continuity of care and coordinated care (all involved health professionals working together) to prevent contradictory advice (Coda et al., 2017; Tong et al., 2013).
- Transition to adult rheumatologists should involve ongoing contact with the paediatric rheumatologist to ensure a comfortable transition where a comprehensive medical history transfer occurs smoothly between practitioners (Tong et al., 2013).
- Obtain specialist advice via phone or email to prevent presentations to emergency (Tong et al., 2013).
- Information on financial assistance should be given and easy to find (Tong et al., 2013).
- Need for mental health services for whole family due to the overwhelm felt by everyone involved in care and experiencing JIA (Tong et al., 2013).
- Careers advice for teens looking for suitable roles (Tong et al., 2013).

- Peer support for sufferers and carers to share experiences (e.g. social events like camps) (Tong et al., 2013).
- Information about (Tong et al., 2013):
    - Complications and adverse effects of medications;
    - Diets to minimise symptoms;
    - Pharmacological, lifestyle and practical methods to reduce pain; and
    - Where to access mobility equipment.
- Training in administering injectable medications (Tong et al., 2013).

OSTEOARTHRITIS

Research gaps

- Impact of OA on indigenous communities has only recently started being addressed (O'Brien et al., 2020).
- Prevention of OA (Hunter et al., 2019).
- Treatment adherence and behaviour change (Hunter et al., 2019).
- Effective disease modification strategies (Hunter et al., 2019).
- What consumers want (from unmet needs literature)
- Less communication difficulties with health care providers reported by Aboriginal Australians (e.g. less jargon, not congruent with Aboriginal people's experiences) (Lin et al., 2018).
- Health care access for Aboriginal Australians (Lin et al., 2018).
- Identify the lived and health care experiences of Aboriginal Australians with OA to assist understanding disparities in access to care in inform health care delivery (Lin et al., 2018).
- Provide non-pharmaceutical options like conservative management and alternative medicine options (Manias et al., 2007).
- More time with the clinician to discuss medications, although patients were happy seeking this information from pharmacists who made themselves available and listened (Manias et al., 2007).
- Arthritis management can be a financial burden (Berkovic et al., 2021).

RHEUMATOID ARTHRITIS

Research gaps

- Safety of switching between different RA medications (e.g. infliximab and etanercept), which is freely allowed in Australia and can be done when pharmacy stock of one is low (Jones et al., 2017).
- More effective treatments (Littlejohn et al., 2013).

What consumers want (from unmet needs literature)

- Less communication difficulties with health care providers reported by Aboriginal Australians (e.g. less jargon, not congruent with Aboriginal people's experiences) (Lin et al., 2018).
    - Pregnant women, mothers and those planning a pregnancy want (Ackerman et al., 2015):
    - Information about medication safety/drug toxicity and effects on unborn or breastfed baby, arthritis disease process and treatments for women across the pregnancy and post-natal continuum;
    - Different treatment options;
    - Access to physical/emotional support services, including counselling services and support groups of mothers with RA;
    - RA-related information for families and workplaces;
    - Practical strategies for coping with daily challenges related to parenting, including information on physical support services to assist with household tasks post-natally and strategies and assistive devices to help with daily tasks of caring for baby;
    - Information specific to young women with RA, as opposed to just older adults;
    - Consistent messaging and advice from health care professionals; and
    - Regular review of online and paper-based information materials to ensure currency. Arthritis organisations are viewed as the best place for up to date and accessible patient information and clinician training.
- Arthritis management can be a financial burden (Berkovic et al., 2021).

Some current research projects

- New medication being developed (mavrilimumab) (Jones et al., 2017).
- Discovering ways to prevent RA using a vaccine-like approach (Jones et al., 2017).

APPENDIX D: What does the grey literature say?

JUVENILE IDIOPATHIC ARTHRITIS

Research gaps

- Prevalence of JIA (The Juvenile Arthritis Foundation Australia (JAFA), 2020a).
- Severity of JIA (The Juvenile Arthritis Foundation Australia (JAFA), 2020a).
- Impacts of JIA (damage to joints and vision, psychological impacts, lost educational, employment and social opportunities) (MOVE muscle bone & joint health & PwC, 2017; The Juvenile Arthritis Foundation Australia (JAFA), 2020a).
- Negative economic impacts (The Juvenile Arthritis Foundation Australia (JAFA), 2020a).
- Discover new biologics to switch off and manage JIA (Children's Arthritis Research Institute, 2018), are specific to particular types (e.g. JIA of the TMJ) and are more acceptable to consumers (i.e. not an injectable that exacerbates pain)(US data)(Arthritis Foundation & CARRA, 2019).
    - New pharmaceutical and non-pharmaceutical treatments needed (Arthritis Australia, 2014).
- Understand why JIA begins (Children's Arthritis Research Institute, 2018).
- Co-design with consumers.
    - (related to persistent pain, not JIA specifically) Young people want to be part of any solution to improved pain care (Slater et al., 2016).
- New research needs to focus on QOL as well as therapeutics.
    - Family-centered care is just as important as finding new drug therapies for children and families (Children's Arthritis Research Institute, 2018).
    - Drug therapies and diagnostics are the current areas receiving the most research attention in clinical trials in 2021 (Lehmann & Ries, 2021).

What consumers want (from unmet needs literature)

- Avoid stigma.
    - Kids feel like they can't share with friends what they are experiencing for fear of bullying, isolation or being excluded for being different. Creates mental and physical impacts on kids and family (Kid's Arthritis, n.d.; Zoe's Angels, 2021b).
- Finding the right care needs to be easier.
    - Takes a long time and many appointments and tests to get the correct diagnosis (Kids Arthritis, n.d.).
    - Many doctors perceived by kids as not knowing what to do to help their pain (Zoe's Angels, 2021b).
    - Specialist services, including allied health, is greatly needed in regional and far north QLD (Zoe's Angels, 2021a).
    - Zoe's Angels raised money to train a paediatric rheumatology doctor specialist for QLD regional areas (Zoe's Angels, 2017). Lack of paediatric rheumatologists in NSW is also a reported issue (Tong et al., 2013).
    - Delays in diagnosing JIA are common, where many children can wait 6 months

from symptom onset to diagnosis due to inadequate public and health practitioner awareness of JIA and limited access to specialists (some states and territories don't have any paediatric rheumatologists, despite their involvement being recommended by clinical guidelines) (Arthritis Australia, 2014).

    - Limited services, inequity of access, delays in diagnosis and treatment, fragmentation of care, lack of psychosocial support and heavy financial burden are reported by families experiencing JIA (Arthritis Australia, 2014).

- Personalised/tailored care
    - (related to persistent pain, not JIA specifically) Young people with persistent pain want and need developmentally-sensitive health services that resonate with them and use digital technologies to engage and connect them with evidence-based care (Slater et al., 2016).
    - Need age-appropriate, culturally suitable information, education and support for self-management (Arthritis Australia, 2014).
    - Care coordination and psychosocial support needed (Arthritis Australia, 2014).
- Schooling needs to be more comfortable.
    - Illness and hospital visits prevent engagement at school (Arthritis Australia, 2014).

Other notes

- New funding.
    - Government allocates $30mil for research to provide better outcomes for Australian children and young people with JIA and childhood rheumatic diseases (The Juvenile Arthritis Foundation Australia (JAFA), 2020b).
- Social support and interaction are important to kids.
    - Kids enjoy having events where they interact with other kids and families with JIA as they understand what they are going through (Kids Arthritis, n.d.; Zoe's Angels, 2021a).
- Suggestions to optimise outcomes for people with JIA (MOVE muscle bone & joint health & PwC, 2017).
    - Improve transition to adult services (commencing in adolescence) by increasing availability to prevent children stopping their medication and dropping out of the system (Arthritis Australia, 2014).

Some current research projects

- US project titled 'Live Yes!' gains patient insights on lived experience with JIA to inform research projects and community program design (Arthritis Foundation & CARRA, 2019).

OSTEOARTHRITIS

Research gaps

- Risk factors for OA.
    - OA has beginnings in childhood. Need to better understand early risk factors in children (e.g. joint hypermobility and early cartilage damage) to ensure stronger joints into the future (Children's Arthritis Research Institute, 2018).
- Many people and physiotherapists believe that exercise can harm joint cartilage (Australian Physiotherapy Association, 2021).
- Many people with knee and hip OA have arthroplasty but are disappointed with the outcome (Australian Physiotherapy Association, 2021).
- Develop and promote appropriate surgical decision aids that can be embedded into general practice (GP) (Wang et al., 2020).
- Reduce unnecessary surgical referrals by GPs by promoting evidence-based care including accessible, community-based allied health (Wang et al., 2020).
- Implement a standardised clinical pathway for surgical management of OA by using pre-surgery assessments, monitor for deterioration or improvement while waiting for surgery and emphasis prompt hospital discharge post-surgery where safe to do so (Wang et al., 2020).

What consumers want (from unmet needs literature)

- Perceived gaps in information and service provision (Wluka et al., 2016):
    - Consumers want improved information about the origins of the disease and education about their OA.
    - Long wait times for appointments and lack of access with health provide contribute to information needs being unmet.
    - More information about management strategies like medications, assistive devices, diet and weight management, exercise therapy and occupational therapy, symptom control, coping with daily life, local services, support groups and financial support and self-management strategies.
    - Want information on how to self-manage OA pain if it presents in other joints.
    - Lack information about surgical options (e.g. details about joint replacement, including risks and benefits).
    - Want information on how to prevent OA in their children and grandchildren.
    - Having more information allowed consumers to be more active in healthcare decision making and disease management.
    - Information provision impeded by receiving mixed messages – consumers want consistent, non-conflicting, clear and adequate information.
    - More information on the prognosis and likely progression of their OA early on to assist in accepting the diagnosis and ongoing management process.
    - Want to know where to find reliable information as few informational tools available to understand the disease. Want the information in writing to assist recollection.

- Dissatisfaction with practitioner related to their lack of knowledge of OA, trivialisation of OA, emphasising analgesic therapies only, rejecting complementary and alternative medicine options, poor communication skills.
- Consumers feel uncomfortable speaking about medications during medical consultations due to lack of time and embarrassment about asking for information (used pharmacists instead as they listen to their concerns).
- People with OA find that the minimal media coverage of OA is unacceptable.
- People with OA feel that official recognition of OA as a disability it needed to give it legitimacy in the eyes of the community and help them gain financial assistance.
- Costs of medications and care are concerning to consumers.

Other notes

- Suggestions to optimise outcomes for people with OA (MOVE muscle bone & joint health & PwC, 2017):
  - Increase clinician awareness of strengthening as first line therapy;
  - Reduce subsidisation of non evidence-based procedures like arthroscopy and long-term opioid use; and
  - Standardise interdisciplinary triage by using more allied health clinicians to triage referrals for join replacements.

Some current research projects

- Researcher: R Hinman. Aim: Compare two different forms of telephone-delivered support and advice for people with painful knee OA to find out which one works best for managing arthritis symptoms, and why (Musculoskeletal Australia, 2020b).
- Researcher: J Bahl. Aim: Understand the association between hip joint stress and bone marrow lesions in people with hip OA (Bone Health Foundation, n.d.).
- PARTNER Project: Aim is to evaluate whether a flexible model of primary care targeted at both general practitioners and patients and designed to facilitate the uptake of key OA clinical guideline recommendations leads to better outcomes for overweight and obese patients with knee OA and reduces health care costs, identify the key elements required to successfully engage consumers in self-management and investigate barriers and facilitators to exercise in people with these conditions and to explore new models of care for delivering exercise advice and behaviour change support (CHESM, 2015).

RHEUMATOID ARTHRITIS

Research gaps

- Treatments for RA.
    - Lack of clarity around identifying the best treatment for the patient the first time around, leading patients to needing to try several different treatments before finding the best one (Lions Rheumatism and Arthritis Medical Research Foundation Australia, 2021).

What consumers want (from unmet needs literature)

- Medications need to be more available.
    - Medications used for both arthritis and COVID-19 management can be in short supply, having adverse effects for patients and research (Haendel, n.d.).
- Want greater education, support and guidance to be provided at diagnosis and in the early stages of learning to manage and cope with inflammatory arthritis (Arthritis Australia, 2019).
- Women with autoimmune rheumatic conditions want support to help during pregnancy planning, pregnancy and early parenting (Arthritis Australia, 2019).
- Adolescents with inflammatory arthritis want more information and self-management support (Arthritis Australia, 2019).
- Barriers to accessing information about their disease (Wluka et al., 2016):
    - Lack of knowledge by clinicians in certain areas of interest (e.g. exercise prescription);
    - Poor access to or hesitancy to use reliable information sources;
    - Lack of ongoing information across the course of the disease;
    - Difficulties with communication due to language barriers for people from CALD backgrounds; and
    - Information provision impeded by receiving mixed messages – consumers want consistent, non-conflicting, clear and adequate information.
- Wants regarding service provision (Wluka et al., 2016):
    - Consultation time with practitioners are not long enough and feel rushed or inadequate;
    - Want services close to home as distance prevents help seeking;
    - Care access impeded by cost and insurance barriers - Costs of medications and care are concerning to consumers;
    - Bad consultation experiences stop people from seeking care; and
    - Prevent misdiagnosis.

Other notes

- Suggestions to optimise outcomes for people with RA (MOVE muscle bone & joint health & PwC, 2017):
    - Enhance access to subsidised biologics by removing restrictions on the maximum number of subsidised biologics through the pharmaceutical benefits scheme (PBS); and
    - Faster referral to specialists by increasing awareness of RA in primary practitioners.

FINDINGS RELATED TO JIA, RA AND OA (AND BROADER MUSCULOSKELETAL CONDITIONS AND CHRONIC/PERSISTENT PAIN CONDITIONS)

Research gaps

- Better understanding of using different forms of media (e.g. delivering general information via video and leaving consultation time for individualised information) to fill information gaps for people with musculoskeletal conditions (Wluka et al., 2016).
- Understanding consumers' needs and preferences for information content and delivery, as well as understanding the current available options, is needed to improve health outcomes for musculoskeletal conditions (Wluka et al., 2016).

What consumers want (from unmet needs literature)

- 98% of people living with chronic pain feel government are not doing enough to support people living with chronic pain (Chronic Pain Australia, 2018a).
- People living with chronic pain need more financial support and access to treatments like medicinal cannabis (Chronic Pain Australia, 2018a).
- People living with chronic pain want greater awareness of their experiences and how pain impacts their lives (Chronic Pain Australia, 2018a).
- People living with chronic pain want improved understanding that chronic pain can affect all age groups, with young people in pain feeling particularly isolated (Chronic Pain Australia, 2018a).
- People living with chronic pain rely heavily on pharmacists but can feel judged and disrespected when seeking medications. They want pharmacists to respect their privacy when reviewing medication and want to be listened to with empathy and understanding, rather than suspicion (i.e. opioid dispensing) (Chronic Pain Australia, 2018c).
- People living with chronic pain rely heavily on GPs but want better support and more effective treatment options. 90% felt their GP understood and treated their pain, but 86% faced stigma and negative attitudes in response to their pain. Most (75%) wanted GPs to be able to prescribe medicinal cannabis for pain (Chronic Pain Australia, 2018b).
- Report by Musculoskeletal Australia had 70% of respondents with RA, JIA or OA (Musculoskeletal Australia, 2021):
    - 26% of all respondents said they were currently managing well and required nothing more at this time, leaving 74% requiring something more, such as:
        - Improvements to the health care system: shorter wait times to see specialist, better referral processes to other services (e.g. physiotherapy), more help or support from health professionals, shorter wait times for surgery;
        - Better access to services: want to know what services are available, access to local services, want timely support when they need it, want better social services;
        - Better access to information: want a better understanding of their condition and how to manage it, want easy to access and understandable information; and
        - Financial support: want affordable treatment options (e.g. physiotherapy, medications), government support for ongoing cost of treatment (physical and mental health management costs).

- People need/want:
    - Affordable services and financial assistance to get the care they need;
    - Support to practice self-care/management;
    - Consumer data should be used to advocate for better care;
    - The community to better understand what musculoskeletal conditions are and how they affect people; and
    - Integrated services.

Other notes

- Specialist pain services have expanded to more people of disadvantage, but wait times are still very long for many people (Hogg et al., 2020).
- Report by Musculoskeletal Australia had 70% of respondents with RA, JIA or OA (Musculoskeletal Australia, 2021). They outlined several areas where urgent action is required to support musculoskeletal health:
    - Raise awareness of prevalence and impact of these conditions so the medical and general community can be more supportive;
    - Raise awareness of the vicious cycles experienced by people suffering musculoskeletal conditions (lack of support and the unaffordability or unavailability of care leading to worsening symptoms, reducing people's ability to be active and work, further worsening mental and psychological health);
    - Governments need to provide sufficient funding proportionate to the prevalence and impact of the conditions; and
    - People with the condition need to be at the centre of healthcare decision making and be empowered to choose the services most suited to their needs.
- Musculoskeletal Australia have modelled the savings that can be made to the health budget by making changes to how musculoskeletal conditions are managed (MOVE muscle bone & joint health & PwC, 2017).
- Arthritis Australia sought funding to produce educational and informational resources to address unmet needs (e.g. culturally appropriate resources for indigenous Australians, exercise resources for people with arthritis afraid to exercise, arthritis pain management resource to help people rely less on medication to manage pain)(Arthritis Australia, 2020).

Some current research projects

- Researcher: D Berkovic. Aim: Explore the experiences of young people aged 18-50 who are living with and managing arthritis (Musculoskeletal Australia, 2020b).
- Researcher: M Munsie. Aim: Gain a greater understanding of the experiences, views and practices of consumers who have sought information or contemplated undergoing stem cell treatments for musculoskeletal conditions. The study will also explore the views of consumer advocacy groups regarding the type of guidance they give to consumers who are contemplating stem cell therapy (Musculoskeletal Australia, 2020c).

Appendix 2: Themes from RA Roundtable

- Consumers feel like they haven't been listened to until now - surprised that they are being asked about their experiences

"in all my 48 years of having it [RA], I've never been asked by anybody that's doing research or anything [to share my experiences]...it's probably just because I wasn't at the right place at the right time."

- RA is classified too simply - it's not just a disease of the joints but has many systemic factors that have an impact on QOL (e.g. mental health, stress)
    - Fatigue
    - Low energy
    - Flares for some but for others the pain is constant
    - Strength loss
    - Mental health concerns
    - Brain fog
    - Function loss

"in high stress and increased pressure on an individual's mental health our RA symptoms are more severe"

" I would like to see the name changed from RA to Rheumatoid Disease as is the case overseas. Get rid of the word arthritis as it is a systemic disease not just related to joints"

"I know they talk about flares in arthritis. I don't understand it. I live in constant pain all the time and it's, it's debilitating."

"I couldn't walk, I couldn't do all the things that I used to do"

"can't write my own Christmas cards"

"first thing they ask is 'what's important to be able to do in your life now?' I think that's a great question to be asked"

"It's the joints but it's also my eyesight, now i've got lung issues. You know? It just goes on and on"

- Consumer's don't feel "believed" by their health care professionals (HCP) - regarding the severity of their symptoms and the symptoms experienced "one size doesn't fit all". Individualised care is needed

"So in 2018 I am diagnosed with RA, luckily at the time I was with a GP that gave a damn, and he surmised that as I had contracted Flu B whilst at work from a colleague who was ill at the time that this with my genetic history set the perfect storm for me to develop RA, so where to from there, so whilst waiting for a referral and access to a Rheumatologist, I was given Plaquenil. This was the game changer because I felt that I could move more freely than what I had been experiencing."

"the Rheumatologist could not understand how I had reacted to this medication unfavourably when everyone else was doing fine."

"he looks at me in disbelief that nothing works"

"It was clearly stated today that there is a focus on joint pain, however RA is more than that, one participant in poor health admitted to no experiences of flares, which a number of RA sufferers would suggest that they go through. We cannot improve the care of individuals if we do not provide individual care."

- New drugs targeted towards the individual using DNA sequencing helped one participant - a new-age example of 'tailored care'

"I had some DNA testing done to do matching with drugs, which was helpful to a point, but a lot of those newer medications that matching hasn't been done...if that matching was there [in the past] I could have saved myself a whole lot of angst and at least only tried those things that might have been more appropriate for me...more of that, actually matching individuals with particular drugs, without the trial and error approach, would be just absolutely brilliant, I think."

- Don't have enough time with their HCP, particularly senior ones

- HCPs can be dismissive or appear like they don't care
    - One participant received all information over the phone despite the professional knowing she was hearing impaired:

"I get five minute consultations on the phone. I've told him I'm hearing impaired but he just doesn't care, so I'm not impressed."

- Soft skills are important, where the HCP listens to the patient and communicates messages in a way they understand and have time to comprehend:

"I walk out of there and I think i've had no time to comprehend what's been said to me"

- Alternative therapies and useful tips to support community engagement need exploring and promoting (i.e. don't just focus on pharmaceuticals)

"Swimming and water aerobics really need more emphasis as does the exercise of Tai Chi, supportive and meditative exercise that assists in the overall wellbeing of the individual."

- Diet and lifestyle

"my wish is that Rheumatologists have to also know a little bit about diet, because they are happy to give you medication...but they should also know something about diet and how that could improve on the person as well."

- Nutritional supplements
- Occupational therapy to support driving, ambulating and opening jars etc.

- Can get conflicting information from different health professionals who can also be difficult to access

"For the past 5years, I travel to Moree, 4.5 hours drive to see a Rheumatologist who comes up from Sydney. He could not believe I was not already on biologics as my Qld Rheumatologists told me I did not qualify as my blood tests were all good."

"living in rural Victoria access to specialists is really poor and my personal experience with two rheumatologists has been so disappointing"

- Seek information from other people with the disease
- Seek information from the internet
- HCPs often not working together to achieve the best outcome for the patient but those who do have very satisfied patients.
    - Want a person who can navigate the system for them, like a case manager, to reduce the complexity of finding the right care when it's needed

"A nurse consultant, or somebody like that, you could go to and have a monthly appointment with like, I know, cancer patients, diabetes patients, people like that actually do have."

- HCPs not using MyHealth Record but patients want them to as it would improve their care experience via better communication

"I struggle with the brain fog and memory. I can't be repeating everything to every single damn doctor plus half of them won't even listen."

- Not all HCPs communicate poorly

"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."

"so anything I have done, the four of them [HCPs] are in the loop and they're all supporting me. Whichever one I go to, they know where i'm up to with my treatments"

- HCPs need more specialist knowledge and education, including knowing what HCPs to refer to
    - around arthritis as a pathology but the social issues that come with it
    - Better understanding of chronic pain

"It would be great if, pain management, if GPs knew about it, or even Rheumatologists, the whole idea of fatigue management and pain management was part of the normal care"

- Referral to allied health is important

"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"

"I couldn't walk steps and or drive a car, it would be nice if someone could tell me to stop using a manual car and drive an automatic car"

- Grieving for loss of past life

"The hardest thing about living with Arthritis is the loss of independence. Because I am unable to do any physical things but like to keep mentally active, I am involved in groups/organisations which I can become involved with virtually."

"I would liken post diagnosis as being similar to working through the stages of grief."

"this is something that healthcare providers can do better with supporting us in the process of accepting that fact that we have RA, particularly in very early stages."

"I could be discriminated because I had this disease"

"i've only just now started to think about, you know, that this is impacting me to such a degree that perhaps I can't consider working again."

"my life has just changed so much, this has been massive."

    - Participants felt like support to help with the mental health challenges associated with the grieving process and loss of function is important

- Length of time to diagnosis and finding best management plan can be long

    - Some participants waited years (e.g. 15 years) to be accurately diagnosed.

    - Some participants still not on a successful management plan despite having symptoms for years. Nothing working

"It took a long time for them[GP] to actually even suggest having the inflammation markers checked, because you know, I was fit and pretty healthy at that stage; I wasn't overweight. So it was quite a battle to get a final diagnosis and that took a couple of different types of people to get a referral"

"My GP picked up that I had RA and then went on annual leave...six months i'd finally got in with the rheumatologist"

- Managing arthritis can be expensive

"It seems very unfair that people over 65 don't get access to NDIS."

    - People want help to access the NDIS

    - Want GPs to automatically provide a chronic disease management plan so they can access bulk billed services (e.g. physio)

Trial participation

- online Chronic Pain Management course through Macquarie University

Appendix 3: Themes from OA Roundtable

- Time to accurate diagnosis often long
    - Access the right services is almost impossible in rural/regional areas
- Difficult to find accurate and reliable information on OA management (incl different drugs available and other management methods)
    - Support to help people exercise with pain - how do they know what amount of pain is OK to push through?

"i'd love more access to her [physio] or more access to information..which says, if you get pain here, this is the exercise you do to alleviate it. Most things you can fix by a few exercises."

"some information on what pain is good pain, you know what it's like and when to see a health professional"

    - Want to know about support groups. Those already in support groups find them valuable

"I live in a unit complex and getting to know other people in the complex is good so I can talk with them when I see them. It's really good because I live on my own so...you've got to have social interaction, as well as exercise, you've got to keep in mind that as well."

    - What to expect as OA progresses and how to slow its progression and avoid surgery
    - Are medications fixing the problem or just managing symptoms?

"regulating our use of medication and what are safe levels, like when you are thinking long term."

- Access information online
    - Also using telehealth to communicate with HCPs
    - Poor health literacy can be a barrier to understanding the information
        - Can also be hard to know if the information is reliable
    - Access information from *"the website of the arthritis society or or whatever it's called in Australia"*
- Research needed
    - Know several risk factors for OA, but can a screening tool be developed that includes risk factors and biomarkers?
        - Could biomarkers be targets for intervention?
    - Causes of OA - including informing the public of the causes

"When I finally got the diagnosis, there was so little I could find out about the origin, the history..."

"more research into the causes of osteoarthritis"

- Types of OA
- Prevent OA

"I would like to be able to take preventative measures"

- Things to do to minimise impact of OA on life
- Consumers should be involved

"we're looking at enhancing person centered care for people with arthritis. We're actually going to start asking people with arthritis how they would like to see their care being developed. One of the things that we've been really aware of is that care seems to be universal...people really want care that's specific to their particular needs, particularly people from diverse communities."

- Care and research is siloed
  - Researchers not working together but instead working in silos and replicating effort:

"too often, [researchers, not just clinicians] work in silos..[research] becomes competitive because there's little money around"

"clinicians aren't necessarily getting paid for talking to other clinicians, they're getting paid for seeing us"

- Sick of being told OA is "wear and tear" and a "disease of aging", or being given generic advice without support to implement it

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

  - Need better HCP knowledge

"I am loath to criticise GPs as they have such a huge range of responsibilities and health needs to cater for, as well as the number of people they see daily and weekly, but I must say the ones I spoke to didn't have much of a grasp on the condition. In the end I thought I understood it to a higher degree than they."

"the two main bits of advice seem to be stay mobile and lose weight"

  - Different people from age 20-60 have been told that OA is age related, which didn't sit well with younger adults - doesn't make sense

- Cost of managing OA
  - Access to hydrotherapy

"I can move in warm water like I can't move anywhere else."

"Your health fund cuts out after so many visits and you know $15 a visit twice a week, it adds up"

  - Cost of multiple services needed
  - Cost of losing function and ability to work

"The osteoarthritis hit me with a vengeance, I had a year off...I could literally not get out of bed"

- Need tailored approach to care where care is individualised
    - Physio worked for dozens of attendees but one never knew it could help and another didn't see any benefit

"I had a physio who helped me with my hands...I can now almost make a fist in my left hand"

"my doctors never recommended a physio so that might be an avenue I might try for the stiffness"

"we're looking at enhancing person centered care for people with arthritis. We're actually going to start asking people with arthritis how they would like to see their care being developed. One of the things that we've been really aware of is that care seems to be universal...people really want care that's specific to their particular needs, particularly people from diverse communities."

    - Not everyone feels pain - participant without pain "feels like a fraud"
    - Some people improved on panadol osteo, some didn't
    - One person saw improvements with diet modifications (e.g. avoiding cows milk, losing weight)

"she took me off cow's milk ...I don't have quite the pain that I used to have."

    - Hydrotherapy worked for several attendees
    - Exercises integrated into daily tasks can help

"I do a lot of computer work because it helps my hands"

    - Effective pain management programs needed to be prescribed by HCPs

"it's a difficult thing to deal with, chronic pain"

    - Shouldn't just be about joint replacements
- OA is more than just a painful joint condition but has other impacts that deserve recognition too
    - Participants wanted more awareness of how OA isn't just a joint condition and that it has other systemic effects too
    - Reduced fitness and strength (deconditioning)

"I was recounting that I no longer sort of get down on the floor with my grandchildren because it's too hard to get up."

    - Stiffness

"as long as you don't have the pain, and you can sleep, you'll deal with the stiffness."

- Sleep loss secondary to pain
- Loss of self esteem, especially if young with OA (e.g. using a disability permit, having hands that look and function different to others)

"It also impacts self esteem, when you, when you walk with a limp, for example. And perhaps more visibly showing signs of age than other people your own age and, in my case from when I was quite young."

- There's a grieving process associated with loss of function and independence that needs attention
    - E.g. unable to click fingers with everyone else during choir

"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. I'm afraid of shaking somebody's hand and I love a good handshake."

"I do take paracetamol every day. I'm quite active, I go to yoga or ride a bike or walking. Walking is sometimes [suggesting walking is sometimes difficult]...my walking's Okay, but. particularly in the cold weather, I find I get a lot of pain in my lower back and I can't walk."

"I think there needs to be much better education to health professionals to help people that are younger come to terms with the impact that arthritis does have on people"

"one of the things that i've had to come to terms with on a regular basis is grieving about my loss of function or my loss of quality of life and my daily activities. And it really does feel like a grieving process that i'm not able to do X or Y or Z anymore, and I have to look at getting somebody else to do it."

- Want HCPs to communicate with each other better rather than working in silos
    - Macquarie health clinic helpful
    - Stephen McMahon's program has "almost fully rehabilitated me"
    - Receive conflicting information from different HCPs

Trial involvement

- 2 injections over a year eliminated pain but still have stiffness

"It [the pain] got so bad I couldn't sleep. I couldn't move because of the pain, it was so bad and along the track I've tried every natural therapy there is, and that never seemed to work and then...We went to a clinical trial...long story short after the first injection my knee was fantastic."

Appendix 4: Themes from JIA Roundtable

- Families can suffer when a child has JIA
    - Children can't play with siblings like they did before

"Her identical twin is impacted as well by her twin having juvenile arthritis and the impact of not being able to do some of the things she did [with her] before [the diagnosis]. So there's a lot of family impact"

    - Parents feel helpless and can't access the information they need

"I could find very little information specifically about JIA"

- Not enough advice and information specific to JIA and the transition to adult arthritis. Instead, info usually mashed together with arthritis types that affect adults only (e.g. RA, OA)

"I think the transition from parents managing the disease to the young adult is a big thing."

"it doesn't stop being juvenile arthritis when you turn 18"

"Maybe a name change is required – while the onset is childhood, it can last a lifetime."

"I'm getting ready for the long haul"

"you end up having to do your own research"

- Accessibility is poor
    - Can't access specialist paediatric rheumatologist easily, nor allied health professionals and nurses that specialise in juvenile rheumatic disease.
        - One participant had her daughter diagnosed at a BBQ by a rheumatologist parent of her child's friend.
        - Can take a long time to get a diagnosis as not getting access to the right people, early

"we're under-resourced from a paediatric rheumatology perspective in Adelaide. We have, well we did have, one specialist for South Australia and the Northern Territory...but she's one person, so when she takes leave, she's away. So you're ringing the hospital and you get bounced around to different registrars and they're doing their best, they're in their placement, so their knowledge could be better"

    - Long waiting times and often need to see clinicians who don't specialise in JIA because there's no one else.
    - Accessibility can also be affected by individual's fatigue or overwhelm with the process of managing their condition

"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"

- Could benefit from having one person that coordinates everything

"like a case manager or a clinical nurse specialist or something who goes 'all you need is this, this, this and this and i'm going to coordinate all that for you.'...they address the needs as they change, as people go through life"

- Hydrotherapy pools are helpful but sessions for people with arthritis run during school time
- Seeing many different health professionals to manage but it would be nice to have a 'one stop shop'
- Medication access

"Access to biologics seems unnecessarily antiquated and causes additional stress. I am hopeful that submissions to the parliamentary inquiry will contribute to this being addressed."

- Community awareness needs to improve
    - People don't know what JIA is and are surprised when they hear that a child has arthritis

"there is a general lack of understanding there among my peers and even my parents' age group and teachers at school, when I was in school."

"[her pain is] often invalidated by others not understanding [JIA] and lacking insight"

- Need to educate people on what JIA is, who it affects and explain what it involves (i.e. not just joint pain but functional limitations, fatigue etc.)

"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.'

- Schools don't understand JIA or the modifications needed for children to perform at their best:

"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 she doesn't want to be explaining that all the time"

"Part of the music education at university [during her teaching degree] was that you had to learn the recorder...I had no hope of playing the recorder [due to JIA in hands] and so they failed me"

- Teachers and parents don't always understand the child's pain experience (might be perceived as trying to get out of something if need to sit down)

"teachers generally will think that if she's sitting down somewhere or needs a chair that she's trying to get out of something"

- Kids don't understand and adults are worse (adults think young people are being ridiculous when complaining about sore knees)
- Need to understand how JIA impacts the ability for children to participate in various activities (e.g being able to play an instrument)
- Also need to improve health professional awareness of JIA for better/faster diagnosis and management
    - Increased awareness of the role for allied health in managing symptoms

"The NDIS has given me a team of allied health professionals that I have never had in my JIA journey."

- o Children can appear healthy on the outside but are in a lot of pain, making it more difficult to explain limitations to others and have adjustments be made for them or be believed

"if you're limping, you're putting it on, you're just asking for attention"

o Books are available to aid understanding of JIA but only targeted towards a young audience

 Poor child/adolescent/young adult specific support for people with JIA

- o Some clinicians treat them like adults with arthritis and don't consider the life of the child when providing advice (e.g. instead of saying absolutely don't drink while on medication, suggesting to still go out with friends but don't overdo it)

"you know, a young person's still a young person, you want to go out clubbing...I don't think doctors consider that"

- o A young adult participant has had a positive experience with her rheumatologist:

"My rheumatologist is actually a pretty cool guy. I remember like telling him about this [issue with balancing wanting to drink alcohol but also manage her condition]. I told him that I was very stressed about alcohol. II was like 'oh my God, I won't even be able to have a drink!' and he's like 'Look, you can have a little bit with food, but drink responsibly, don't have like a drinking session', which definitely made me feel better about it, and I was glad. I felt quite comfortable talking to him. Like, he's particularly interested in the young adult transitions [from paediatric to adult management]. I'm very lucky to have that but it's still really hard to then explain to your friends. Like, I tell my friends 'yeah we can go out for drinks' and I'll have one and need to then say 'oh I don't really drink much...it'll just make me feel ill'.

- Fatigue and brain fog is a big issue in JIA. Need to find a way to manage the fatigue as no known treatment of this and other 'side issues' like itchy scalp.

"It [brain fog] is quite debilitating."

"I was really tired all the time. I'd come to school and I'd be like 'oh my God I'm so tired' and my friends would be like 'Oh, you should just take a sick day, like stay home relax a bit and you can come back when you feel better' and I was like 'If I stayed home every time I felt sick then you would never see me'"

"there's no treatment for it [brain fog]"

- o A participant forgot what she wanted to say during the session:

"this is part of the brain fog, I have forgotten already. I'm so sorry"

- Modifications made for kids can make them stand out and appear different (e.g. badge with old person and walking stick for kids with JIA, have a special key to access lift at school, use laptop instead of handwriting)

"When you're a little kid, you're like 'do I want to wear a badge that tells the whole world that I'm different?' I never wore it".

"Kids ask 'why do you get to go into the special lift?' So there's a lot of peer teasing"

"You don't want to stand out when you're becoming a teenager"

- Grieving loss of function
    - Grief is more apparent for kids diagnosed later who had the opportunity to experience 'normal function'

"I've had arthritis a long time, 43 years i've had arthritis, so I guess it's had a big impact on my life and because it's all i've ever known, basically I don't remember not having arthritis which, I think, in one way, it might be easier "

    - Children need to 'give up' on things (e.g. gymnastics, playing with friends as much as they'd like)

"[he] Just turned 18 and had just been diagnosed [with JIA] and he thought his life was over"

"it's a very big change in your identity. You know, from someone who was super active and super high achieving and suddenly the rug's pulled out from under you"

"I dropped her twin at school and she'd [the twin with JIA] say 'oh mummy, I just hope one day, again, I can play chasey with my friend'. And you're like 'oh...'"

    - Need psychological support
        - Anxiety associated with being sick is amplified by additional stressors (e.g. COVID) and mental health care plan often not enough (only provides some money back and only 10 sessions per year when the psychologist wants to see the patient fortnightly)
        - Parents also struggle

"I dropped her twin at school and she'd [the twin with JIA] say 'oh mummy, I just hope one day, again, I can play chasey with my friend'. And you're like 'oh...'"

    - Function isn't just lost as a child but continues into adulthood

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

    - Need support to find new ways to integrate into the community participate in activities

"You can still have some interactions with sport and all the rest of it"

"my parents got me a keyboard when I was a teenager, and so I did my finger exercises learning the keyboard. I was quite good. Part of the music education at university [during her teaching degree] was that you had to learn the recorder...I had no hope of playing the recorder [due to JIA in hands] and so they failed me"

- Can be stressful for kids and young adults to have to take many drugs and keep on top of the regime

"It has affected my life...having to take daily medication as a child, going to doctors having tests."

"Like, not be being able to drink alcohol. like not that I've been wanting to get really drunk, but like having to be very careful about how much I drink...I know it's very dramatic, but you take methotrexate is like 'oh my God, am I pregnant?' like, yes, that's very stressful for me."

"it's very much a struggle with the relentless nature of it, you know day in, day out and unpredictability of how you're going to feel, not understanding why you feel so terrible today and the invisibility [to others of JIA]"

    - Treatment can often be "trial and error" to find what works

- Fear for teenagers in knowing what they will have to deal with in the future

    - Loss of function

"I travelled while I was young because I knew I wouldn't be able to do it later on...I did a tour of Europe, it nearly killed me, but I have got the memories...you've got to do those things, while you've still got some ability, because it's [JIA] not going to get better"

- Cost of medications

"I wish it wasn't so expensive to be sick"

"I am on a disability support pension. My husband is my carer. The NDIS has been a godsend."

- Can use humour as a coping strategy but also to integrate into the peer group. One young adult explained how she described her condition to her teenage peers

"I'd say stuff like 'My immune system makes me feel sick, like having a hangover and you haven't even gone out and partied. And then every two weeks I inject myself, yep with a needle just just casually in front of the TV'. So I definitely play into the humor of it, it's like my coping mechanism"

- There's a need to increase understanding of the progression of JIA and reduce the fear associated with joint replacements

- Patients need to be partners in decision making

    - Medical professionals changing drugs prescribed without consulting parents first (they only know about it when the pharmacist filled the script) and can have detrimental effects on child's pain and function.

- Adults who have experienced JIA appreciated the benefit of support groups (e.g. arthritis camps, groups at local leisure centre), but many said their children hate the idea (they want to avoid being identified as different or someone with arthritis or 'old')

"I remember going on arthritis camps, I think we went to Western Australia, and so I definitely found that very helpful and I felt like I belonged."

"as an adult [with JIA from a young age], I belong to the young women's arthritis support group, we meet regularly once a month. I find that really helpful...because everyone gets it"

"There seems to be the sort of programs targeted towards young kids [which doesn't suit this young adult]. And then I am a part of a Facebook group but it's mostly older women, and I find that it's not the same issues, necessarily, that we're all experiencing at same time. At different points in your life there's different things that are more or less stressful, or appear in phases."

"She [participant's teenage daughter who has JIA] would sooner swim in the Yarra [a polluted river in Melbourne, Australia] than join a support group. Perhaps if she can guarantee that the support group will be young people like herself, it might be different, but I think she has this view that it's going to be just old people."

- Parent has benefited from a facebook group and Juvenile Arthritis Foundation Australia (JAFA) involvement but need more support and information

"I think that is a big responsibility for parents...there should be some sort of support group for parents."

Appendix 5: Survey questions

Your lived experience of arthritis

1. Please select the statement that best describes you:

- ☐ *I have rheumatoid arthritis*
- ☐ *I have osteoarthritis*
- ☐ *I have juvenile idiopathic arthritis*
- ☐ *I support someone who has arthritis*
- ☐ *I have a different type of arthritis (please write you condition in the box below)*

2. What impact does having arthritis have on your ability to live your life?

- ☐ *No impact*
- ☐ *Low impact*
- ☐ *Medium impact*
- ☐ *High impact*
- ☐ *Other (please specify below)*

3. You are welcome to provide any more comments on the impact of arthritis on your day to day life in the box below.

4. What has been your experience in getting an accurate arthritis diagnosis?

- ☐ *I saw one clinician who diagnosed me with arthritis*
- ☐ *An allied health professional (e.g. physiotherapist, dietician or other) diagnosed me with arthritis*
- ☐ *I had to see multiple clinicians and/or allied health professionals to get an accurate arthritis diagnosis*
- ☐ *Unsure/don't know*
- ☐ *Other (please explain in the box below)*

You are welcome to explain your answer further or provide any examples in the box below.

5. What kinds of treatments have you found effective for your arthritis? You can choose more than one answer.

- ☐ *Traditional arthritis medications*
- ☐ *Physiotherapy*
- ☐ *Exercise management*
- ☐ *Psychological support*
- ☐ *Nutrition and diet modifications*
- ☐ *Other (please specify below)*

6. How have you discovered new ways to manage and treat your arthritis? You can choose more than one answer.

- ☐ *From my GP or specialist*
- ☐ *From an allied health professional (e.g. physical therapist, dietician etc)*
- ☐ *From doing my own research*
- ☐ *From other arthritis sufferers*
- ☐ *From support organisations (e.g. Arthritis Australia)*
- ☐ *Other (please specify below)*

7. Have you ever wanted to access psychological support in relation to your arthritis?

- ☐ *Yes and I was able to easily access psychological support*
- ☐ *Yes and I found it difficult to access psychological support*
- ☐ *No I did not feel this was necessary for me*
- ☐ *Unsure/don't know*

You are welcome to explain your answer further or provide any examples in the box below.

Research to meet the needs of people living with arthritis

8. What research do you think is needed to improve your life living with arthritis? You can choose more than one answer.

- ☐ Better medication options
- ☐ More mental health support
- ☐ Research into the role of exercise and physical activity
- ☐ Research into the cause of arthritis
- ☐ Research into surgical intervention
- ☐ Other (please specify below)

9. Do you have any more comments on the research you think is needed to improve your life living with arthritis?

10. If you could change up to three things today that would make your life living with arthritis easier, what would they be?

1 –

2 -

3 -

11. If there was research into arthritis that might be able to assist you would you be willing to be involved in helping design it? (Answering 'yes' does not mean we will contact you.)

- ☐ Yes
- ☐ No
- ☐ Unsure/don't know

You are welcome to explain your answer further or provide any examples in the box below.

Clinical Trials

Clinical trials test new treatments to find better ways to prevent, detect or treat disease. More information on clinical trials in Australia and how to search for clinical trials to participate in can be found on the Australian Clinical Trials website www.australianclinicaltrials.gov.au

12. Do you know what a clinical trial is?

☐ Yes

☐ No

13. Have you ever participated in a clinical trial in relation to your arthritis?

☐ Yes

☐ No

☐ I am unsure

Note: Only respond to Q14 if you answered 'no' or 'I am unsure' to Q13.

14. If there was a suitable trial in relation to your arthritis, would you be willing to participate? Responding 'yes' does not mean you will be invited to participate in a trial.

☐ Yes

☐ No

☐ It depends (please provide a short reason why below)

Appendix 6: Themes from survey

The survey highlighted vital concerns of people living with arthritis and the impacts the condition has on their lives. Respondents commented on the impacts of living with arthritis, with a large majority noting that the condition has a high impact on their every-day lives. One respondent commented that *"this [arthritis] has had the worst impact on my life. I went from dancing twice a week and hiking to not even being able to work"*. Another central theme highlighted was the chronic pain endured by the respondents, with many wanting research into pain management and prevention of arthritis. One respondent commented, *"I am suffering severe relentless pain in my hips, pelvis, elbows, knees, and feet. I can't exercise; I am in constant pain and struggle to walk or even sleep. I am really getting upset. I would like to find out treatments and pain management,"* whilst another commented that *"chronic pain limits my day to day activities and impacts my mood and social engagement"*. Living with arthritis also significantly affects respondents' everyday lives as they have difficulties doing tasks and activities, such as house chores, walking, opening jars, and sitting down. One respondent commented that *"it [arthritis] pretty much impacts on everything I do on a daily basis."*

Respondents expressed concerns about the impact that arthritis has on their mental health. Chronic pain, fatigue and inability to complete required tasks and responsibilities impacts the mental health of those living with arthritis. A respondent commented that *"when my arthritis symptoms are not under control I have significant pain and fatigue. My mental health is also impacted."* Another respondent commented that *"my life has gradually gone down the gurgles, and I am getting my affairs in order because I am losing the will to live."* Mental health was noted as important by many respondents. However, the high price and long-waiting times to access psychological help were also noted, as 24.62% found it difficult to access support. One respondent commented that *"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"*. Another commented on the benefits of psychological support, saying that *"my support coordinator from NDIS recommended it as did my husband. From actually having the appointment, I have found it beneficial in coming to terms with my diagnosis."*

Another theme captured throughout the survey results was brain fog and fatigue. Respondents commented on how arthritis has produced brain fog, fatigue and lack of quality sleep. For example, one respondent commented, *"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 with autism."* Others commented that *"research particular into the chronic fatigue side of arthritis"* is needed; *"night pain disrupts sleep; affects mood; regular cramping also affect sleeping"*, *"I experience ongoing extreme fatigue that is unpredictable and difficult to plan for"*, and *"sleeping is disturbed through knee pain."*

The survey results also expressed the lack of knowledge and understanding held by GPs and specialists. Respondents commented the following *"I felt something was wrong, but the first GP I saw completely disregarded my symptoms and insisted it was a sports injury"*, *"I am appalled at the lack of knowledge with RA specialist and lack of diagnostic aids"*, *"First GP –* "it's only arthritis" *– he is no longer my GP"*, *"I had long term (20 years +) intermittent episodes of severe fatigue that most GPs I saw were not interested in investigating"*, and *"most GPs are not interested and neither are the physios...the government care plans seem to be a money-making exercise for most GPs and are quite useless as I am still out of pocket considerable amounts of money even with the rebate"*. Others commented on the the positive works of GPs, with one saying that they have *"an outstanding GP who knows me very well. He listened to my vague descriptions and acted on them quickly."*

Other additional issues were also noted. Respondents noted the use and effectiveness of CBD oil, saying that *"I've had great pain relief from CBD oil. Research is needed to identify long term issues and side effects"*, whilst another said *"currently using CBD oil as topical application to hands and fingers. The pain had 95% diminished. Very difficult, but finally found a GP who would prescribe CBD, which I have had dispensed by a Compounding Pharmacist."* Concerns on the impact on biome was also raised, with respondents saying that research on biome and its impact is needed.

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