What do culturally appropriate arthritis education resources look like for Aboriginal and Torres Strait Islander peoples?

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Abstract

I acknowledge the Wurundjeri and Yamaji peoples as the Traditional Custodians of the lands where new knowledge detailed in this thesis has been collaboratively created. Thank you also to the community members who participated in this research for sharing their stories.

Background: Arthritis conditions (osteoarthritis [OA], gout, and rheumatoid arthritis [RA]) result in considerable pain and suffering, and disproportionately impact Aboriginal and Torres Strait Islander peoples (respectfully, hereafter referred to as Indigenous peoples), who are more likely than non-Indigenous people to have an arthritis condition and to experience a higher burden of disease. Access to culturally appropriate health information supports the health and wellbeing of Indigenous peoples. Responding to community-identified needs, and priorities outlined in Australia's National Strategic Action Plan for Arthritis (2019), the aim of my thesis was to inform the co-design of culturally appropriate arthritis education resources for Indigenous peoples.

Methods: Adopting a community-based participatory action research (PAR) framework, Indigenous peoples with lived experience of arthritis conditions were recruited from metropolitan and regional settings in two Australian states – Western Australia (WA) and Victoria (VIC). These individuals participated as co-researchers via two reference groups to prioritise Indigenous voices and knowledge systems.

A four-phase participatory research process was undertaken: 1) Establishment of two community reference groups (CRG); 2) Exploration of beliefs, knowledge, health information needs and preferences of Indigenous peoples living with arthritis through research yarns (culturally appropriate interviews); 3) Synthesis of recommendations in high-quality clinical practice guidelines (CPG) on arthritis care; 4) Integration of the lived experience of people with arthritis conditions and CPG recommendations to inform the development of culturally appropriate arthritis education resources.

Findings: Eight CRG members (VIC n=4, WA n=4) met on four occasions over the course of the project. CRG members represented different locations, including metropolitan (n=2) and regional areas (n=2) in VIC and a regional area in WA (n=4) with a range of ages (22–68 years old), and

conditions (osteoarthritis n=4; gout n=2; rheumatoid arthritis n=1; and mixed n=1). Thirty people participated in research yarns. The sample included people from different locations (VIC n=9; WA n=21) with a range of ages (22–75 years), and conditions (osteoarthritis n=19; gout n=4; rheumatoid arthritis n=5; and mixed n=2). This data was collected and analysed to give insight into the experiences and informational needs and preferences of Indigenous peoples with arthritis conditions (research yarn themes). Following a comprehensive search, 57 CPGs were identified, of which 30 were assessed as high quality and provided management recommendations for arthritis conditions. Eighteen CPGs included education recommendations, and these were integrated with research yarn themes. Synthesis of the two datasets resulted in the following recommendations for the content of education resources: information describing the impact of arthritis on health and wellbeing, when/how to access care, management options (e.g., benefits/risks) and disease knowledge (e.g., prognosis, addressing misconceptions), alongside positive lived experience stories, Indigenous symbols (e.g., flags) and colourful, local art. Recommendations for delivery of education resources included using formats such as brochures, videos and/or yarning circles facilitated by health professionals, family and/or Indigenous community members. These recommendations were used to co-design three information brochures, one for each arthritis condition (OA, gout and RA), and four videos featuring the lived experiences of four Indigenous people.

Conclusions: Development of these education resources can support Indigenous peoples to better manage their arthritis conditions. Findings can also assist health professionals in delivering high-quality arthritis care and tailored education for Indigenous peoples. Additionally, the robust, community-engaged approach used to generate education recommendations can serve as a template for the creation of other health education resources for Indigenous peoples.

Declaration

This is to certify that:

i) The thesis comprises only my original work towards the Doctor of Philosophy (PhD), except where indicated in the preface;

ii) Due acknowledgement has been made in the text to all other material used; and

iii) The thesis is fewer than 100,000 words in length, exclusive of tables, bibliographies and appendices.

Signed,



Brooke Conley

30 May 2024

Preface

This thesis follows The University of Melbourne guidelines for a thesis with publications and contains four original manuscripts (three review articles [published] and one original research study [submitted, under review]); details below. All four manuscripts arose during my PhD candidature. I was the primary author for each publication, leading the writing of the manuscripts, from initial drafting to the final revisions and contributed to at least 70% of the planning, study design, data collection, data analysis and interpretation of results for all publications included in this thesis. Full details of other author contributions for published manuscripts are outlined in the preface to each relevant chapter.

The publication status of each study in this thesis is as follows:

Chapter 4 (Study 1): Published in *Arthritis Care & Research* in February 2023.

Chapter 5 (Study 2): Published in *BMC Rheumatology* in June 2023.

Chapter 6 (Study 3): Published in *Clinical Rheumatology* in June 2023.

Chapter 7 (Study 4): Under review in *The Lancet Rheumatology*. Feedback has been received from five reviewers, and a response is planned following submission of this thesis.

Publications

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Presentations

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I would like to acknowledge the Traditional Custodians on whose land I live, work and continue to learn on. This thesis was written on the lands of the Wadawurrung peoples, and data included throughout was collected on the lands of the Wurundjeri and Yamaji peoples; acknowledging that sovereignty was never ceded on these lands. I pay my respect to their Elders past and present and recognise their ongoing connection to cultural, spiritual and educational practices, alongside their enduring self-determination with regard to health and wellbeing. I thank them for their invaluable teachings through sharing of knowledges and stories, specifically for arthritis conditions that span generations and offer profound insights into navigating these health challenges. Further, I acknowledge all Indigenous peoples and communities across this continent now known as Australia. Always was, always will be Indigenous lands.

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Abbreviations

ABS	Australian Bureau of Statistics
AGREE	Appraisal of Guidelines for Research and Evaluation
AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
CPG	Clinical practice guidelines
CRG	Community reference groups
DMARDs	Disease-modifying antirheumatic drugs
EAG	Expert Advisory Group
NHMRC	National Health and Medical Research Council
OA	Osteoarthritis
PAR	Participatory Action Research
RA	Rheumatoid arthritis
SMSS	Staying Moving, Staying Strong
SLE	Systemic Lupus Erythematosus
TJR	Total joint replacement
VIC	Victoria
WA	Western Australia

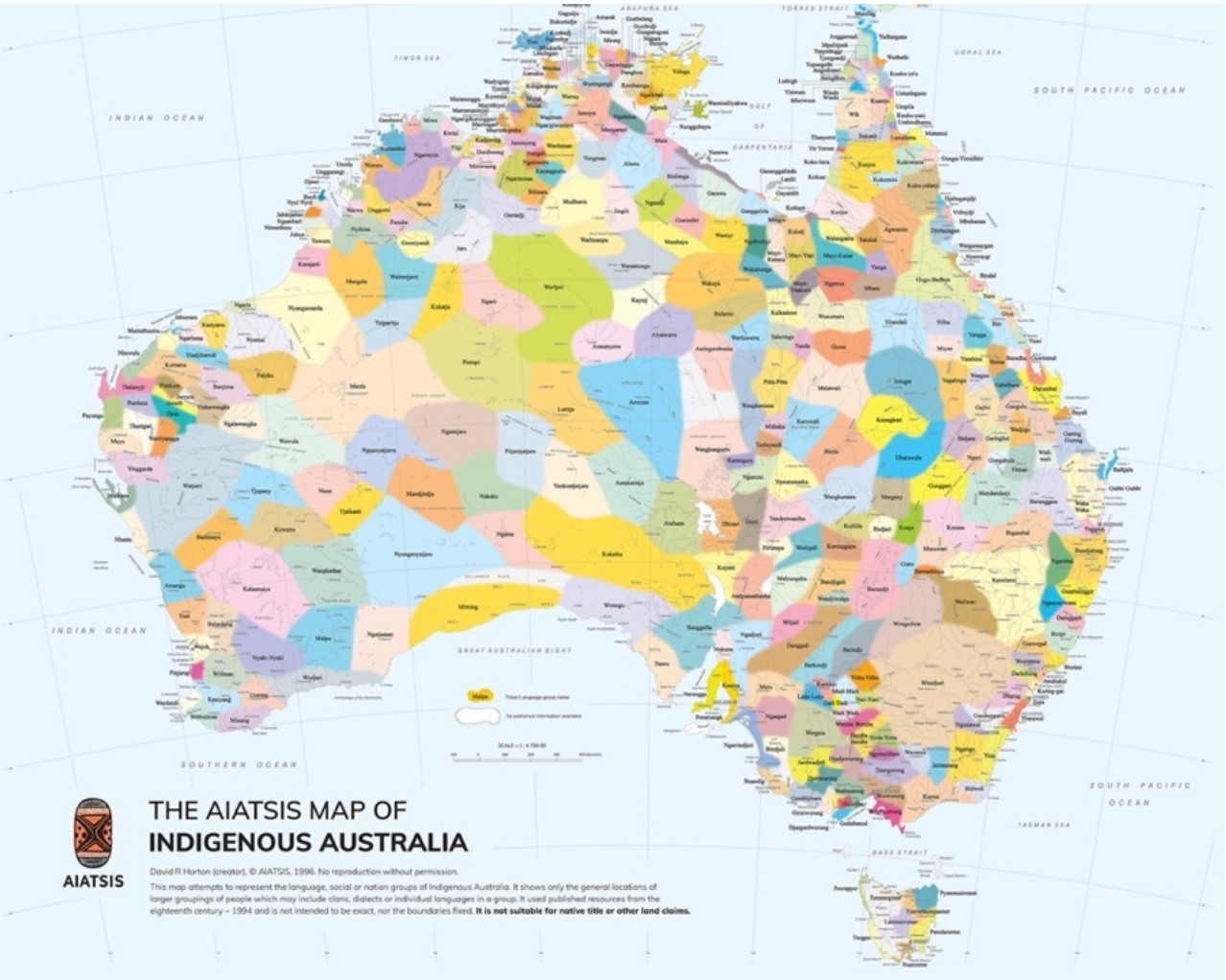
Terminology

Indigenous and First Nations Peoples and Communities

In this thesis, within the Australian context, I utilise the terminology ‘Indigenous’ hereafter to encompass both Aboriginal and Torres Strait Islander peoples. The intent behind this language choice is to ensure equitable inclusion of both Aboriginal and Torres Strait Islander peoples thereby avoiding the harmful impacts associated with using language that may exclusively acknowledge Aboriginal people [1]. However, when discussing the CRGs in Chapters 3 and 7, and my project’s qualitative findings (research yarns) in Chapter 7, I specifically use the term ‘Aboriginal’. This distinction is made because no Torres Strait Islander peoples participated in either the CRGs or the research yarns. While discussing the global context, I applied the terminology of ‘First Nations’.

In recognition of diversity among both Indigenous and international First Nations peoples and communities, I have intentionally employed the plural form of the term "people." Through this choice, I highlight that these populations encompass many distinct and unique sub-groups, and that combining all these sub-groups into a single overarching category would neglect this rich diversity. In the Australian context, this diversity is demonstrated by the many language groups seen in Figure 1.1.

Figure 1.1 Map of Indigenous Language Groups in Australia



David R Horton (creator), © AIATSIS, 1996. No reproduction without permission [2].

This map attempts to represent the language, social or nation groups of Aboriginal Australia. It shows only the general locations of larger groupings of people which may include clans, dialects or individual languages in a group. It used published resources from the eighteenth century to 1994 and is not intended to be exact, nor the boundaries fixed. It is not suitable for native title or other land claims.

People with Lived Experience

Throughout this thesis I adopted terminology of ‘people with lived experience’ to encompass any knowledge holder who is either a patient (has already sought health care) and/or a community member (yet to seek health care) and has experience of living with a particular a condition. In the context of my PhD project these conditions included OA, gout and/or RA. Importantly, this definition

had the potential to extend beyond the individual to include their family and community members. In instances where I am speaking about CPGs and/or certain healthcare contexts, I adopted the terminology of ‘patients’ as it is commonly used within health literature [3].

Staying Moving, Staying Strong Project

My PhD thesis was embedded in a larger study titled, Staying Moving, Staying Strong (SMSS). The SMSS project, described in Appendix A, aimed to develop education resources for Indigenous peoples and communities who experience OA, gout, RA and systemic lupus erythematosus (SLE) [4]. My PhD project and its findings have informed the creation of these education resources, which can be found in Appendix B. Three key differences between my PhD project and the SMSS project included: 1) The SMSS project produced education resources for SLE, however due to time constraints my PhD project did not conduct a systematic review of SLE CPGs or publish on research yarns with Aboriginal peoples living with SLE. 2) The SMSS project included two additional phases: creation of the educational resources (phase 5) and the evaluation of the educational resources (phase 6). Phase 5 was completed by all members of the SMSS team (listed below) and phase 6 will be conducted by another member of the SMSS project team and completed after the conclusion of my PhD candidature. Finally, 3) The SMSS project had oversight by an expert advisory group (EAG) which included Aboriginal people with lived experience of arthritis conditions, Aboriginal health researchers, health professionals (including a rheumatologist and orthopaedic surgeon) and a representative from the National Aboriginal Community Controlled Health Organisation.

Staying Moving, Staying Strong Project Teams' Positionality

The wider research team for the SMSS project consisted of Aboriginal researchers, non-Indigenous researchers and Aboriginal community members. Aboriginal researchers and community members represented diverse cultural backgrounds which included: Noongar (Wardandi) man (Jonathan Bullen), Gumbaynggirr woman (Jane Linton), Badimaya, Wajarri, Wilunyu woman (Charmaine Green), Ngoonooru Wajarri woman (Wanda Flanagan), Whadjuk, Balladong, Gnarla Karla Boodja Nyoongar man (Trevor Pickett) and Aboriginal people with lived experience of OA, gout and RA: Worimi man (Ryan Prehn), Yorta Yorta woman (Janet Bromley), Gija/Bardi woman (Nola Gregory). Additionally, these people had varied life experiences and educational backgrounds including roles as creative writers, poets, artists, storytellers, health professionals and academics. The

remaining SMSS members (Ivan Lin, Samantha Bunzli, Penny O'Brien, Jennifer Persaud) were non-Indigenous and added diversity through their educational backgrounds of physiotherapy and social sciences. These individuals (both Aboriginal and non-Indigenous) were experienced in research areas of Indigenous health and wellbeing (e.g., mental health) and musculoskeletal conditions (e.g., OA), in addition to research methods (e.g., research yarning) applied in this project. Between the SMSS project members, there was a balanced mix of genders, and representation from states across Australia – WA, VIC, New South Wales and Queensland. By having a diverse team, we were able to integrate each person's unique positionality, which included their beliefs, assumptions, interests and working practices. This ultimately enhanced the project, and its outputs [5].

Chapter 1 Introduction and Structure

1.1 Introduction

Prevalence and incidence of OA, gout and RA are increasing, representing a significant and widespread global health issue [6-8]. Osteoarthritis is the most prevalent arthritis condition worldwide, affecting 595 million people [6]. Gout is the most common inflammatory arthritis, affecting approximately 53 million people, followed by RA affecting 17.6 million people [7, 9]. Incidence and prevalence data varies internationally due to factors such as socio-economic status, sex, and assessment methods [10]. For example, gout has a higher incidence and prevalence for people living in high- and middle-socio demographic index regions, and for males in comparison to females at a ratio of 3:1; although variations between genders reduce as women reach post-menopausal age [9, 11]. Similarly, higher rates of OA, gout and RA have been reported among First Nations populations globally in comparison to their non-First Nations counterparts [12-14].

Arthritis case numbers are growing, primarily attributed to increasing and aging populations, higher obesity rates, lifestyle factors (e.g., dietary intake) or possibly due to improved diagnostic methods [7, 15-18]. Subsequently, burden of disease has been steadily increasing [9]. Symptoms often vary between people and can include joint pain, stiffness, swelling, reduced range of motion, and muscle weakness, while RA can lead to extra-articular impacts, affecting other organs [7, 11, 19-21]. Associated pain and symptoms impact on all aspects of an individual's health and wellbeing and contribute to personal, wider socioeconomic and healthcare system costs. For example, in Australia total costs associated with arthritis conditions are estimated to be approximately $4.3 billion (OA); $970 million (RA); $230 million (gout) annually, due to direct costs (e.g., hospitalisations, medications, and diagnostic tests) and indirect costs (e.g., lost wages) [22, 23]. Moreover, arthritis conditions frequently coexist with other health conditions such as cardiovascular disease, chronic kidney disease and obesity, which further exacerbates the burden associated with OA, gout and RA [24-27]. Burden of arthritis conditions for Indigenous peoples is widespread, impacting on their ability to participate in daily life, including work, social and cultural activities [28]. Overall, both

prevalence and burden continue to grow at an alarming rate for all populations worldwide including First Nations peoples [6, 7, 9, 12].

Education is a key pillar of evidence-based practice for arthritis conditions and can assist people to better understand and manage their condition yet existing educational materials are largely based on Western ways of knowing, being and doing [29-32]. This means that current arthritis education is likely not delivered in a way that meets the needs and preferences of Indigenous peoples [33]. In contrast, access to culturally appropriate health information supports the health and wellbeing of Indigenous peoples [34]. Responding to a community-identified need, which is also outlined in the National Strategic Action Plan for Arthritis (2019), the overarching aim of my PhD project was to identify culturally informed, evidence-based recommendations to guide the development of education resources [28, 35]. By creating and implementing these resources as part of the wider SMSS project, the objective was to increase uptake of arthritis education and, in turn, reduce the burden of these conditions for Indigenous peoples and communities.

1.2 Thesis Structure

Table 1.1 Overview of Thesis Chapters

Chapter	Title	Content
1	Introduction and Structure	Provides a background on arthritis conditions; arthritis education for Indigenous peoples; aims of my thesis; and explores the positionality of both myself and my supervisory team.
2	Background and Literature Review	Describes demographic profile of Indigenous peoples; historical context of Indigenous health in Australia; OA, gout and RA (arthritis conditions); arthritis conditions for First Nations (including Indigenous Australians) peoples; clinical practice guidelines; patient education; and culturally appropriate education resources.
3	Research Methodology and Methods	Outlines the research methodology used within this thesis: community-based PAR and associated components; ethical guidelines;

Chapter	Title	Content
		CRGs. It also presents, describes and provides rationale for the research methods: integrative multi-methods research, systematic reviews and qualitative research (research yarns).
4	Study 1: Core Recommendations for Osteoarthritis Care: A Systematic Review of Clinical Practice Guidelines.	Reports evidence-based management for OA consistent with current high-quality international CPGs.
5	Study 2: What are the core recommendations for gout management in first line and specialist care? Systematic review of clinical practice guidelines.	Reports evidence-based management for gout consistent with current high-quality international CPGs.
6	Study 3: What are the core recommendations for rheumatoid arthritis care? Systematic review of clinical practice guidelines.	Reports evidence-based management for RA consistent with current high-quality international CPGs.
7	Study 4: Developing arthritis education resources: Integrating evidence from Indigenous peoples' lived experience and clinical practice guidelines.	Explores Aboriginal peoples' beliefs, knowledge and informational needs and preferences for arthritis education resources and synthesises this data with education recommendations from high-quality CPGs.
8	Discussion	Summarises the main findings of this thesis and their implications for research, clinical practice and Indigenous peoples and communities. The strengths and limitations of the thesis are also identified.

1.3 Aims

The aims of my thesis were:

1. Identify current, evidence-based management of OA (Chapter 4), gout (Chapter 5) and RA (Chapter 6).
2. Explore the beliefs, knowledge and informational needs and preferences, of Indigenous peoples with OA, gout and RA (Chapter 7).

3. Synthesise education recommendations from high-quality CPGs for OA, gout and RA (Chapter 7).
4. Integrate knowledge from Indigenous peoples and CPGs to create recommendations that inform the development of OA, gout and RA education resources for Indigenous peoples (Chapter 7).

1.4 Positionality

1.4.1 My Positionality

My positionality is shaped by the intersectionality of being an Aboriginal woman, a physiotherapist and a researcher. First and foremost, I am a proud Ngiyampaa (Wangaaypuwan) woman with maternal lineage to people from Cobar, New South Wales and I have Irish heritage on my father's side. From this I bring cultural knowledge and experiences, not only of myself, but of my family and community, enriching and informing my approach to research. Second, my background as a physiotherapist provides a foundation for my knowledge and skill set relevant to health care, and musculoskeletal conditions. Third, these backgrounds shape my perspective as a researcher, enabling me to recognise the strengths of each, in conducting evidence-based, culturally sensitive research. In navigating the roles, I experienced opportunities and challenges as they can be both complimentary and contradictory in their identities.

The motivation behind my passion for research and exploration of this topic arises from the combination of my two interest areas – Indigenous health and musculoskeletal conditions. As an Indigenous person I can see the impact that these conditions have on Indigenous peoples and communities, and yet this remains an under-prioritised area of research. Research plays a crucial role in generating widespread impacts across various domains, including health promotion, policy development, resource allocation, and creation of healthcare programs. As a physiotherapist, I can see our ability to make a difference in these spaces through drawing on our comprehensive knowledge and skill set, and through providing effective evidence-based treatments, one of which is patient education. As a researcher, a key priority for me was to integrate different aspects of my identity. This theme is evident throughout my thesis where I present both current evidence for arthritis management consistent with Western ways of physiotherapy (Chapters 4–6), but also expand on the existing body

of evidence to ensure Indigenous peoples' stories and experiences are recognised and prioritised (Chapter 7). I have learnt to draw upon and apply my cultural lens and my physiotherapy practice to bring a unique perspective and strength to my work.

This PhD journey has not been without its challenges. The perspectives and experiences of being an Indigenous person, a physiotherapist and researcher can often conflict. Intersectionality among Indigenous researchers working in academic institutions has been discussed widely. An Australian Indigenous academic stated, 'They (universities) want all our knowledge but do not want it to impact on the structure or the power and the people who hold it' [36]. This summarises the constant struggle to embed our ways of knowing, being and doing in spaces where colonial legacies, systematic biases and power imbalances still exist. This reality is reflected within my own university, as evidenced in The University of Melbourne's truth-telling and justice initiative, which is a component of the Indigenous strategy (2023–2027) titled, 'Murmuk Djerring' [37, 38]. Personally, I have encountered each of these challenges firsthand, through instances of culturally unsafe practices, the constant pressure to teach and advise, experiences of power imbalances (e.g., lack of autonomy) and attempting to conform to academic norms (e.g., adopting their language and adhering to their practices). Unfortunately, these experiences are not unique and are shared by many, if not all, Indigenous scholars. It highlights the urgent necessity for meaningful change within academic institutions. We must work towards creating environments that embrace diversity, respect Indigenous knowledge systems and dismantle the systemic barriers that perpetuate inequity.

Similarly, as both a physiotherapist and a researcher, I encounter unique challenges. While my passion for improving health and wellbeing outcomes is a common thread between both roles, I have noticed that in physiotherapy, change typically happens promptly, whereas research progresses at a slower pace. For example, with the SMSS project, it has taken several years to reach the stage of development and distribution of the educational resources. Furthermore, it will take additional time for these resources to have a tangible impact on Indigenous peoples and their communities. Throughout this journey, I have come to recognise the importance of allocating ample time to create a rigorous, culturally respectful project that is built on strong relationships with Indigenous peoples and communities. Additionally, I have realised the importance of translational research in bridging the gap

between research findings and practical application in real-world settings, and that this process can take time.

I recognise that there are both strengths and challenges associated with being an Indigenous person, a physiotherapist and a researcher. I will continue to explore and learn on this journey of navigating the world of academia.

1.4.2 My Supervisory Teams' Positionality

My original supervisory team consisting of Samantha Bunzli (SB), Ivan Lin (IL) and Jonathan Bullen (JB) already had existing relationships in place, and a common agenda of improving Indigenous health and wellbeing outcomes. These supervisors were included based on their involvement in establishing the SMSS project (SB, IL; both non-Indigenous) or to provide Indigenous leadership and guidance to the research, and to myself as the PhD Candidate (JB, Noongar (Wardandi) man). Collectively, the supervisory teams' approach is highly relational, and they aim to work in ways that foreground Indigenous methodologies and practices, while also navigating the integration of non-Indigenous approaches. They represent a variety of perspectives, with all experienced in research related to my topic area, either Indigenous health and/or musculoskeletal conditions. Additionally, they demonstrated methodological expertise in systematic reviews of CPGs, qualitative and integrative multi-methods research. The majority came from a physiotherapy background (SB, IL), while JB is an Indigenous health researcher. Throughout my candidature, Rachel Toovey (non-Indigenous) was added as an additional supervisor and brought her expertise as a researcher in participatory research and qualitative methods together with her physiotherapy background.

Chapter 2 Background and Literature Review

2.1 Demographic Profile for Indigenous Australian Peoples

In Australia, 983,700 people identified as Indigenous in the last census (2021), representing 3.8% of the total population [39]. Most of these people identified as Aboriginal (91.7%), while the remaining identified as either Torres Strait Islander (4%) or both Aboriginal and Torres Strait Islander (4.3%) [39]. Approximately 79,000 and 120,000 Indigenous peoples live in VIC and WA respectively, with the majority living in metropolitan areas, followed by inner and outer regional areas [39, 40]. The median age throughout Australia for Indigenous peoples is 24 years, and there is an almost equal representation of genders nationally [39].

2.2 Historical Context of Indigenous Health in Australia

> 'For many Indigenous Australians our knowledge of our sovereignty, our connection to land, our people and our culture has been unbroken since time immemorial… Our stories of Country have been handed down for thousands of generations. We are still here, we have never ceded.' – Aunty Charmaine Clarke (Gunditjmara) [41].

Australian Indigenous peoples have a strong and rich history as the oldest living culture in the world, with evidence indicating occupation of our traditional lands for more than 65,000 years [42, 43]. The cultural and historical context of Indigenous peoples is essential to understanding present-day health outcomes [44]. Prior to colonisation, there were greater than 250 languages spoken, including around 800 dialects, with each language group encompassing its own unique culture, kinship system, beliefs and practices [45, 46]. At this time, Indigenous peoples were known to be healthy, but colonisation and its ongoing impacts has led to the development of health inequities [47]. On 26 January, 1788, the First Fleet arrived on the shores of the Eora Nation in Warrane (Sydney), establishing British colonisation of what is now known as Australia [48]. Despite widespread resistance from Indigenous peoples, the years that followed saw dispossession of land, massacres, introduction of disease, imprisonment, slavery, ongoing oppression, racism and marginalisation [49].

These actions were systemic and were often sanctioned or supported by the Australian Government, such as policies associated with the *Aborigines Protection Act 1909*, which separated Indigenous children from their families, communities and culture, or Indigenous peoples being excluded from the Constitution from 1901 until after the successful 1967 referendum, which furthered racial prejudice and marginalisation [50, 51].

This invasion marked the beginning of multidimensional impacts on Indigenous peoples' health and wellbeing which has resulted in a significant gap in health status between Indigenous and non-Indigenous peoples [52, 53]. Disparities are now evident across the majority of political, social, health and economic outcomes experienced by Indigenous peoples, when compared to non-Indigenous peoples [54]. These inequities are attributed to the social determinants of health, which are interrelated and include factors such as education, employment and housing [52, 55, 56]. Additional Indigenous-specific indicators have been identified at a systemic level (e.g., sovereignty), societal level (e.g., land rights and access) and individual level (religion and spirituality) to reflect our holistic view on health and wellbeing [57, 58]. These determinants are influenced by colonisation and can be either a barrier or enabler to health and wellbeing. For example, colonisation involved land theft, which led to a loss of traditional food sources for Indigenous peoples and in some instances, labour was compensated with refined sugar [59]. As a result, a low proportion of Indigenous peoples currently meet the recommended intake of healthy food sources such as fruit (39%) and vegetable serves (4%), and a high proportion (71%) consume sugar sweetened or diet drinks at a population level [60]. Conversely, connection to Country is recognised as a key component of living well, and has shown to provide access to healthy food sources [61, 62]. Beyond that, connection to Country can also strengthen identity and support spiritual (e.g., connection to ancestors or to the land), social (e.g., connection with family), psychological (e.g., reduce stress), and emotional (e.g., foster a sense of feeling grounded) wellbeing [63].

Disparities in social determinants of health contribute to higher mortality and morbidity rates for Indigenous peoples in comparison to non-Indigenous peoples. Life expectancy for Indigenous peoples is 8.8 years lower at 71.9 years for Indigenous males, and 8.1 years lower at 75.6 years for Indigenous females in comparison to their non-Indigenous counterparts [64]. Experiences of chronic

conditions are considered the primary cause for this mortality gap [65]. Data from the most recent National Aboriginal and Torres Strait Islander Health Survey (2018–2019) suggests almost 50% of Indigenous people report having one or more chronic conditions, with this value increasing since previous surveys in 2012–2013 (40%) [60]. Cardiovascular disease, cancer and musculoskeletal conditions are the leading contributors to burden, alongside injuries (e.g., falls) and mental health and substance use disorders (e.g., anxiety) [66]. The majority of people (79%) living with a musculoskeletal condition, specifically an arthritis condition, experience at least one of these other comorbidities [67]. Proposed mechanisms linking arthritis conditions with these comorbidities include chronic inflammatory pathways and/or certain pain management approaches (e.g., non-steroidal anti-inflammatory drugs) associated with arthritis conditions, which have been linked to an increased risk of chronic conditions such as cardiovascular disease and cancer [68]. Additionally, pain and disability can limit physical activity and/or lead to weight gain, which are known risk factors for chronic disease [68]. Relatedly, these individual health risk factors are common for Indigenous peoples, with 89% of people aged 15 years and older not meeting the physical activity guidelines and 71% overweight or obese [60]. Overall, chronic conditions, particularly arthritis conditions, are a serious threat to the health and wellbeing of Indigenous peoples and communities throughout Australia. These higher disease rates, and the burden experienced by Indigenous peoples, are attributed to inequities in the social determinants of health which are a direct result of the ongoing impacts of colonisation.

2.3 Osteoarthritis, Rheumatoid Arthritis and Gout (Arthritis Conditions)

2.3.1 Osteoarthritis

Historically, OA was described as a ‘wear and tear’ disease, caused by aging and overload of a joint that resulted in cartilage loss [69]. However, it is now understood that OA has a complex pathophysiology, and is viewed as a ‘whole person’ condition that involves biological, psychological and social factors [70, 71]. Biological impacts involve changes in joint tissues and structures, including cartilage loss, degeneration of ligaments and tendons, bone changes (e.g., remodelling and osteophyte formation) and a chronic inflammatory response; while psychological factors can include depression and anxiety or pain catastrophising, and social factors can include fear avoidance

behaviours such as withdrawal from physical, social, or work activities [72-75]. The exact cause of OA is unknown but the likelihood of developing OA, and its progression, can be influenced by modifiable (e.g., trauma, obesity, lack of exercise) and non-modifiable risk factors (e.g., aging, genetics) [19, 76]. While it can affect any joint, it most commonly occurs in the knee, hand, hip, and spine [77, 78].

2.3.2 Gout

Gout involves distinct stages, starting with a 'gout flare', before progressing to 'intercritical gout' and 'chronic gouty arthritis' [79]. A gout flare is triggered by sustained hyperuricemia as defined by an elevated serum uric acid over the saturation threshold, greater than 6.8mg/dL [79, 80]. This can be caused by either an increased production (e.g., due to consumption of dietary purines found in meats and seafoods) or, more commonly, renal under-excretion of serum uric acid (e.g., due to genetic factors) [11]. Additional risk factors include aging, gender (more common in males, aged 60–64 years), lifestyle factors (e.g., alcohol intake), use of certain medications and presence of comorbidities [18, 81].

If sustained, hyperuricemia leads to the formation and deposition of monosodium urate crystals in the joints and their surrounding tissues resulting in a subsequent immune response, triggering a gout flare [82]. A gout flare is often characterised by a sudden and intense onset of pain, typically occurring at night, is usually monoarticular in nature affecting joints within the foot, specifically the great toe [83, 84]. Chronic gouty arthritis is associated with poor disease control [85]. In cases of chronic gouty arthritis people will experience recurrent attacks, often resulting in persistent inflammation, joint damage and tophi formation [11]. As the disease progresses, recurrent attacks are more likely to be polyarticular and may occur in any joint, particularly the knee, ankle, wrist, finger and elbow joints [83, 86]. Asymptomatic periods either after or between gout flares despite the presence of monosodium urate crystals are defined as intercritical gout [79].

2.3.3 Rheumatoid Arthritis

Rheumatoid arthritis is a systemic autoimmune condition characterised by chronic inflammation that affects the synovial tissue, cartilage, tendons, ligaments and bone initially [20, 87,

88]. Typically, RA impacts bilateral small joints of the hands and feet (such as metacarpophalangeal, metatarsophalangeal, proximal interphalangeal, and wrist joints) [89]. As the disease progresses it can extend to larger joints such as the ankle, knee, elbow and shoulder and beyond to impact extra-articular organs, including the heart, kidney, lung, digestive system, eye, skin and nervous system [20, 21, 89]. The exact cause of RA is unknown but it is believed to involve a combination of genetic and environmental factors (e.g., cigarette smoking, air pollutants, and occupational) [20, 88]. Additional risk factors include age and gender, with RA more likely to affect women and people aged 75–79 years [20, 90].

2.4 Osteoarthritis, Gout and Rheumatoid Arthritis (Arthritis Conditions) for First Nations Peoples

2.4.1 Prevalence

Internationally, the prevalence of OA [14, 91], RA [12, 91, 92] and gout [91] has been reported to be higher among First Nations peoples in comparison to non-First Nations peoples with the exception of gout being lower among First Nations Canadian populations [93]. In Australia, prevalence data has been reported by national statistical agencies such as the Australia Bureau of Statistics (ABS) and throughout the literature with rates being higher for Indigenous peoples in comparison to non-Indigenous peoples [94-98]. Data published by the ABS from the most recent survey (2018–2019) reported that 85,600 Indigenous people experience arthritis conditions, at a prevalence rate of 17% in comparison to 13% among non-Indigenous peoples [99]. Notably, these rates are likely subject to under-reporting, also acknowledged for other health-related data for Indigenous peoples, as they rely on correct reporting of the condition and identification of Indigenous people [100, 101]. Factors that influence reporting of Indigenous status are well documented and include systems and processes (e.g., data information systems, standard protocols), health service and health professional capability (e.g., staff training) and individual barriers (e.g., presence of biases and discrimination) [102]. Accurate, appropriate and comprehensive data is needed to measure the health gap between Indigenous and non-Indigenous peoples and to inform equitable systems, services, and

policies [103]. Further research is needed to improve the quality and quantity of prevalence data collected for Indigenous people with arthritis conditions.

2.4.2 Burden of Disease

Internationally, First Nations peoples experience a higher prevalence of arthritis conditions, but often have lower access to health care compared to non-First Nations peoples, exacerbating the burden of disease. A systematic review found that First Nations peoples in Australia, Canada, New Zealand and the United States had fewer general practitioner visits and surgeries when compared to their non-First Nations counterparts [104]. In that review, arthritis experiences and outcomes were often poorer for First Nations peoples indicating a higher burden of disease. For example, First Nations peoples were more likely to develop RA at an earlier age and experience greater disease severity, such as extra-articular features and comorbidities [105]. Alongside this, there was less improvement in measures of disease activity and patient-reported outcomes following treatment [105].

Globally, the burden of OA, gout and RA has been acknowledged, and the lived and healthcare experiences of First Nations peoples with these conditions is an emerging area of research. Internationally, researchers have found that arthritis conditions impact on physical, social, emotional and cultural domains of health and wellbeing such as attending the marae for Māori peoples, or feelings of frustration, anger, sadness and shame noted among a Mexican Mayan community [106, 107]. Further, physical and mental impacts of living with an arthritis condition can extend beyond the person to affect family members [106]. Similar to international findings, O'Brien et al., (2023) found that osteoarthritis burden impacted on all aspects of one's life including physical (e.g., sleep, reduced mobility), social (e.g., withdrawal from events/activities) and emotional (e.g., depression, anxiety, stress) [28]. Currently, there are no qualitative studies investigating Indigenous peoples' experiences of living with RA or gout in Australia and further qualitative research is warranted [108].

2.4.3 Management of Arthritis Conditions

Globally, limited research has explored non-pharmacological, pharmacological and surgical management options for OA, gout and RA among First Nations peoples and Indigenous peoples.

Despite the small number of studies, a variety of Western and traditional approaches to care have been reported, and an evidence–practice gap has been identified.

2.4.3.1 Non-pharmacological Management

First Nations peoples with OA, gout and RA report employing evidence-based non-pharmacological management options such as exercise and dietary changes [28, 106, 109]. However these strategies remain underutilised, for reasons which have not been explored [106]. Additionally, a comprehensive range of traditional practices to address the social, emotional and cultural impacts of arthritis have been documented. For example, implementing community support groups, mindfulness strategies (e.g., positive thinking, meditation) and cultural practices such as smudging and praying and the use of traditional healers [28, 109, 110].

2.4.3.2 Pharmacological Management

Pharmacological managements have been explored for First Nations peoples, particularly those experiencing gout and RA, and implementation barriers to both prescription and adherence of medications have been reported. For example, within Australia, prescription of subsidised recommended medications (DMARDs) for RA is limited by strict criteria, including close monitoring by a rheumatologist [111]. Yet barriers to accessing specialists care are well documented and include cost, geographical distance and long wait-times ranging from 22–575 days in VIC [112, 113]. Further, Indigenous peoples have identified issues with specialists communication or lack of time in consultations that resulted in healthcare disengagement [28]. Similarly, urate-lowering therapy has been proven as essential for effective gout management [30]. Despite this, inequitable prescription of urate-lowering therapy was noted for Māori peoples, with urate-lowering therapy being prescribed more frequently for older people than younger people, overlooking the fact that Māori peoples typically experience an earlier onset of gout than their non-Indigenous counterparts [13, 114]. Failure to implement timely, equitable, evidence-based care can have detrimental results for First Nations peoples such as low rates of remission of RA or a higher frequency of gout flares [115, 116]. Once prescribed, First Nations peoples may face challenges with medication adherence, and non-adherence can accelerate arthritis progression [109, 117]. Qualitative studies with First Nations peoples

identified that medication adherence can be influenced by: trust and relationships with patients and health professionals; individual and family members perceptions of medication efficacy or side effects; fear/stigma of drug dependency; understanding of the mechanism of action; administration mode; and a medication's affordability and availability [109]. Of these factors, concerns about potential adverse effects are widely reported [106]. Alternatively, traditional medicines have been used and/or recommended by First Nations peoples in Canada, Aotearoa (New Zealand) and Australia [28, 118, 119]. In Australia, these are commonly termed 'Bush Medicines' , which are recognised for their anti-inflammatory properties (a known contributor to the pain response), and have demonstrated low toxicity and costs in comparison to synthetically produced pharmaceuticals [120-122].

2.4.3.3 Surgical Management

Surgical management has been explored for First Nations peoples, and Indigenous peoples with OA. Total joint replacement (TJR) surgery is recommended as an effective end-stage option to manage OA [29]. Benefits of these procedures are well established and include reducing pain, disability and use of healthcare services, and improving quality of life [123]. Yet, internationally First Nations peoples continue to report low rates of TJR surgery, with this being attributed to availability, affordability and acceptability of health care [104, 124]. Similarly, in Australia, Indigenous peoples with OA experience reduced access to and uptake of TJR surgery when compared to non-Indigenous peoples [125-127]. They are less than half as likely to have TJR surgery or to seek primary care for knee or hip OA [126]. In Victoria, O'Brien et al., (2022) identified that Indigenous peoples undergo TJR surgery at a younger age, and are more likely to exhibit OA risk factors such as being overweight or obese or having multiple comorbidities [125]. Despite this, O'Brien et al., (2022) found no differences for surgical characteristics (e.g., type of arthroplasty) and surgical outcomes (e.g., discharge destination, rates of complications) and minimal difference in patient-reported outcomes [125]. These findings indicate that when Indigenous peoples are provided with recommended care (e.g., uptake of TJR at end-stage OA), positive health outcomes can be achieved.

Future qualitative and quantitative research is needed to explore the use of all management options (Western and traditional) for First Nations peoples with OA, gout and RA internationally, and

especially for Indigenous peoples in Australia; this is essential due to the lack of research in the Australian context. In particular, research must identify facilitators and barriers to bridge the evidence–practice gap in the context of First Nations arthritis care. Further robust, First Nations-led exploration of how traditional management strategies can be utilised to improve arthritis outcomes is needed.

2.4.4 Addressing the Gap

While there has been significant investment in Indigenous health and wellbeing research over the last few decades, there has been a distinct lack of commitment to investigating and addressing the impact of arthritis conditions for Indigenous peoples in the Australian setting [128, 129]. The rising prevalence and burden of arthritis conditions, combined with their frequent coexistence with other chronic conditions, highlights the urgency for further research to be conducted to measure and improve arthritis care for Indigenous peoples [6-8, 25-27]. Similarly, national arthritis strategies are only just beginning to acknowledge the need for tailored arthritis interventions for Indigenous peoples [35, 130]. Strategies have been developed for OA, and for arthritis conditions as a collective [35, 130]. These strategies provide generalised approaches to address the impact of arthritis conditions such as increasing the Indigenous health workforce, delivering cultural safety training for non-Indigenous staff, or highlighting the need for access to equitable and culturally appropriate healthcare [35, 130]. Implementing, and building upon these strategies, alongside developing and delivering other arthritis-specific initiatives, is crucial (e.g., providing culturally adapted arthritis self-management programs in collaboration with Aboriginal Community Controlled Organisations (ACCOs). These efforts would not only contribute to reducing the burden of arthritis conditions on Indigenous peoples and communities but would have overall positive effects on their health and wellbeing more broadly.

2.5 Clinical Practice Guidelines

Clinical practice guidelines provide a means to bridge the gap between policy, evidence-based practice, local contexts and patient preferences [131]. They consist of healthcare recommendations that are formulated through the review of scientific literature and the consensus of

an expert panel [132]. By providing recommendations, CPGs can support health professionals in decision-making, especially in cases of uncertainty due to limited evidence or multiple treatment options [133]. This aims to enhance the efficiency and quality of health care by reducing disparities in clinical practice, to ultimately improve patient outcomes [131]. However, CPG uptake varies, with key barriers including inconsistent recommendations among CPGs and poor CPG quality, due to a lack of clear or sufficiently rigorous approaches [132, 134]. Low-quality CPGs and conflicting recommendations have been observed for arthritis conditions [135]. Reaching agreement among high-quality CPG recommendations is important to promote the delivery of high-quality care that aligns with the current evidence base.

2.6 Patient Education

A central tenet of CPGs for arthritis care is patient education [29-31]. Patient education can comprise educational activities such as individual counselling, strategies such as cognitive behavioural therapy, sharing of experiences among peers, and written and visual materials among other approaches [136]. Regardless of the modality, patient education is designed to increase a person's knowledge, behaviour, skills and attitude to encourage self-management and improve their quality of life; and has no known adverse side effects [137-139].

In Indigenous contexts, education can be a significant contributor to producing, practicing and maintaining Indigenous knowledge, culture and kinship ties [140]. By providing education on chronic conditions, it can improve health literacy and promote self-management, which has been found to improve quality of life and life expectancy for Indigenous peoples [141]. Internationally, arthritis education for First Nations peoples has been explored, revealing several common themes. Firstly, studies in Australia, Canada, and Aotearoa (New Zealand) identified knowledge gaps in participants' understanding of what their arthritis condition is, and available treatment options [28, 106, 142, 143]. From this, participants were concerned about their prognosis, and exhibited misconceptions and often described their condition using unhelpful language of 'bone on bone' or 'wear and tear' [28, 69, 106]. Secondly, studies have investigated the modes of education delivery used and the participants' preferences. These included health professionals and community educators

(e.g., learning and support from peers or health-navigator roles) and educational resources– written and online (e.g., social media) [142-144]. First Nations arthritis- navigator roles have been introduced in Canada to provide a culturally relevant form of case management [145]. The scope of these positions can be broad, ranging from medical aspects (e.g., facilitating communication between the person and the health professional) to personal support of the individual, their families and communities [145]. Finally, studies in Aotearoa (New Zealand) have examined peoples' preferences for education content provided by health professionals. Topics included non-pharmacological management options such as dietary advice, exercise, weight loss, and pharmacological management such as common medications, side effects, dosages, natural remedies [143, 144]. To date, no research has explored the arthritis educational needs of Indigenous peoples in Australia or for First Nations peoples regarding surgical managements.

2.7 Culturally Appropriate Education Resources

One means to improve arthritis outcomes for Indigenous peoples is to address current challenges relating to the appropriateness and acceptability of health education resources [34]. Despite extensive education resources being produced by peak Australian consumer bodies such as Arthritis Australia and Musculoskeletal Australia, and state- and territory-based arthritis organisations, current resources have not been developed in collaboration with Indigenous peoples [146-148]. As such, existing resources are unlikely to meet the needs and preferences of Indigenous peoples regarding acceptability, health literacy, or cultural relevance [34]. Arthritis education resources should be designed or adapted to align with existing knowledges and practices for Indigenous peoples, rather than imposing a Western model of health care [149]. For example, Western models can utilise binary concepts relating to health status such as 'well/not well' that emphasise biological aspects of health and wellbeing while overlooking social, cultural and political factors that are important domains in Indigenous models [33, 57]. This approach would require recognition and understanding of the differences in Indigenous peoples' beliefs, attitudes, language, context and/or behaviours in comparison to non-Indigenous peoples, and between Indigenous communities [150]. In 2019, a National Strategic Action Plan for Arthritis was launched by the Australian Department of Health

[35]. This identified a need for tailored, culturally appropriate arthritis information and education resources for Indigenous peoples [35]. To ensure appropriateness of educational resources, Indigenous peoples and communities should be involved in all stages of their development [34]. This can elicit a sense of connection and ownership, and thus facilitate uptake [34, 151]. Further education resources should be culturally responsive. Common strategies include 'surface level' considerations such as utilising suitable pictures and incorporation of local language words, or participant stories [152, 153]. Whereas 'deep level' considerations include, for example, offering training for respected Indigenous community members to deliver an intervention, or ensuring materials are available entirely in local languages (where appropriate) [152, 153]. These considerations have been applied to create culturally adapted resources for other chronic conditions such as diabetes, cancer and stroke, and have seen benefits for Indigenous peoples such as increased access to health care [151, 154, 155]. However, at present, there are no evidence-based, culturally adapted, education resources for Indigenous people experiencing arthritis conditions.

Chapter 3 Methods

3.1 Research Methodology and Methods

3.1.1 Community-based Participatory Action Research

Community-based PAR adopts a social constructivism view contrasting with many traditional research paradigms that embrace a positivist scientific view [156]. Unlike conventional research approaches that treat individuals as passive participants or subjects of the research, community-based PAR recognises the experiences, knowledge and contributions of participants [156, 157]. Through collaboration between people with lived experiences and researchers, this approach aims to produce knowledge and enable positive action that is directly relevant to that group of people [158, 159]. To achieve this, community-based PAR emphasises building relationships based on trust and respect, focuses on sharing of power, and prioritises self-determination of the participants [160, 161]. These aspects are particularly significant given the historical context of research involving Indigenous peoples, which has often been characterised by power imbalances and exploitation [162, 163]. Since its development, community-based PAR has been increasingly used in both Indigenous and health-research contexts, and can complement the inclusion of Indigenous methods [158, 164]. Applying this participatory approach has the capacity to produce research that is culturally appropriate and meaningful to the lives of Indigenous peoples [165].

3.2 Applying Community-based Participatory Action Research in My Project

3.2.1 Ethics

Ethical considerations are essential for community-based PAR and broader research efforts that involve Indigenous peoples and communities [5]. To date, extensive Indigenous health research has been undertaken in Australia, and yet Indigenous peoples' health and wellbeing outcomes remain largely unchanged [166]. Moreover, the harms caused from researchers and their practices have been well documented such as instances of a lack of reciprocity or consent [167]. Consequently, Indigenous-specific guidelines, such as The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) code of ethics and National Health and Medical Research Council

(NHMRC) ethical guideline, have been developed to provide direction to researchers and to address issues among current research practices with Indigenous peoples and communities [168, 169].

The SMSS project was approved by the Western Australian Indigenous Human Ethics Committee (HREC1018) on 6 October 2020 and the St Vincent's Hospital Melbourne Human Research Ethics Committee (HREC 224/20) on 4 November 2020 (Appendix C). Alongside this, the project adhered to the AIATSIS code of ethics for Indigenous research [168]. The AIATSIS code was created in consultation with the NHMRC, the Australian Research Council and the National Indigenous Australians Agency and offers guidance on values and ethics when working with Indigenous peoples and communities [168]. Key principles of the AIATSIS guidelines are outlined in Figure 3.1. Details of how AIATSIS principles were applied in my research project are presented in Table 3.1. Responsibilities that were less applicable to the context of this research were not reported (e.g. Indigenous land and waters).

Figure 3.1 Australian Institute of Aboriginal and Torres Strait Islander Studies Ethical Principles [169]

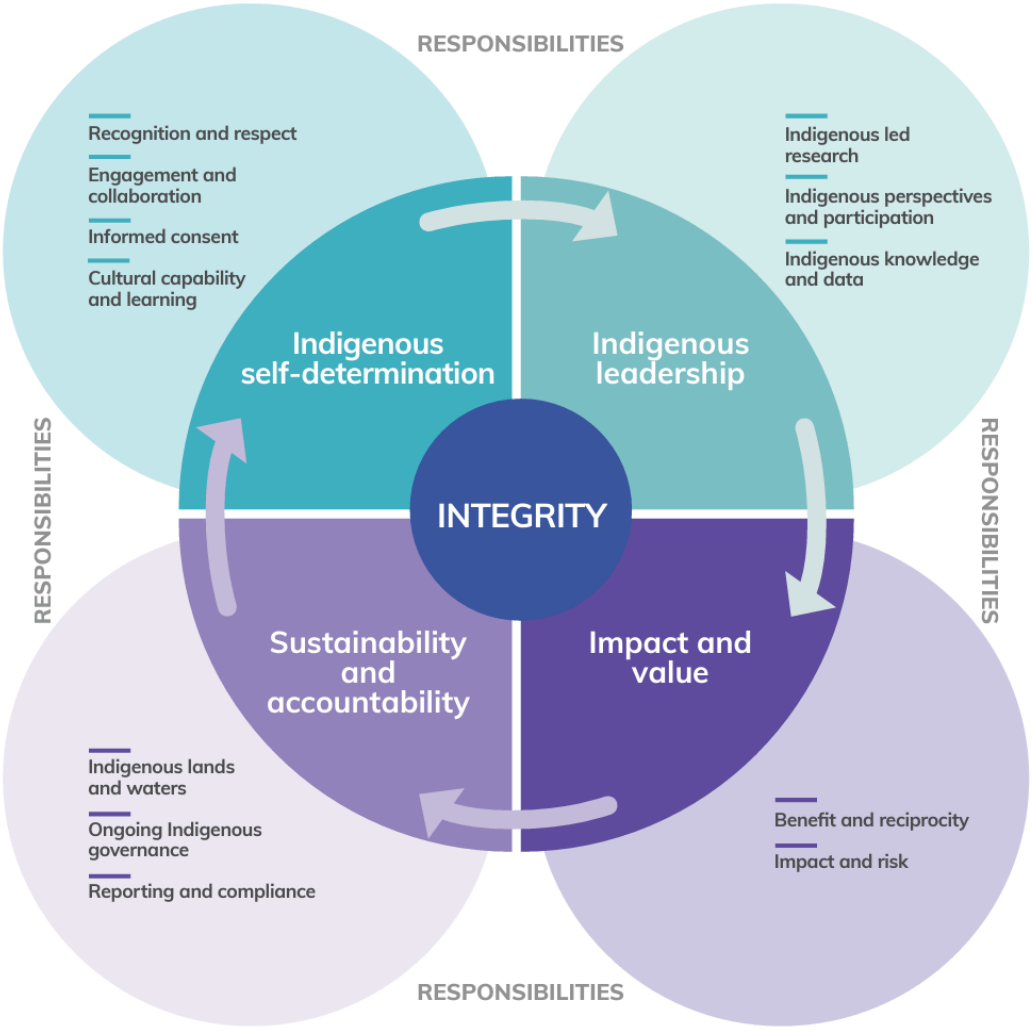


Table 3.1 Australian Institute of Aboriginal and Torres Strait Islander Studies Ethical Principles in this Project

Principle 1. Indigenous self-determination		
RESPONSIBILITIES		
Recognition and respect		
	How this principle was applied in the research	**How the principle was not applied in this research project**
1.1	Understanding of Indigenous peoples' self-determination, consistent with the definition provided by the United Nations Declaration on the Rights of Indigenous Peoples [170] was demonstrated consistently throughout the project and is reflected in this table. This research was undertaken with the aim to promote self-determination through educating Indigenous peoples and communities on how to best manage their arthritis conditions. Individual, group and collective rights, responsibilities and ownership were outlined in the project documentation such as the Terms of Reference and project contracts (e.g., artwork IP) (See Appendix D. Terms of Reference).	
1.2	Diversity was recognised and incorporated by: • Multiple Indigenous researchers from different Mobs[1]: - Ngiyampaa woman (Brooke Conley), Noongar (Wardandi) man (Jonathan Bullen), Gumbaynngirr woman (Jane Linton), Badimaya, Wajarri, Wilunyu woman (Charmaine Green), Ngoonooru Wajarri woman (Wanda Flanagan), Whadjuk, Balladong, Gnarla Karla Boodja Nyoongar man (Trevor Pickett) and Indigenous people with lived experience of arthritis conditions (Ryan Prehn, Janet Bromley, Nola Gregory) (See Staying Moving Staying Strong Project) • Inclusion of positionality statements (See Staying Moving Staying Strong Project1) • Recruitment for the research yarns and community reference groups (CRG) included Indigenous peoples from diverse locations in VIC and WA, from different Mobs and of various genders, ages and conditions (See Chapter 7).	

[1] Mob – 'is a colloquial term identifying a group of Aboriginal people associated with a particular place or country. It is used to connect and identify who an Aboriginal person is and where they are from. Mob can represent your family group, clan group or wider Aboriginal community group' [171].

	• Inclusion of statements to highlight that these findings are not transferable to all Indigenous peoples and further research in particular contexts would need to be conducted to determine applicability (See Chapter 7). • Shared experiences of Indigenous communities were acknowledged such as impacts of colonisation (See Chapter 2).	
1.3	Indigenous knowledges, practices, science, innovations and cultural expressions were respected, protected and maintained as follows: • Indigenous knowledges were included through the advisory mechanism of the CRGs, and the sharing of knowledges in the research yarns (See Chapter 7). • Indigenous practices were included in methods (e.g., research yarning), and in the research itself (e.g., inclusion of statements such as 'Bush Medicines can be used in conjunction with other treatments') and cultural expressions (e.g., weaving) (See Chapter 3; Chapter 7). • For the most part, specific cultural knowledge was not disclosed or published. To protect cultural knowledge in relation to traditional healing practices and also to reflect diversity of Mobs; e.g., no specific Indigenous Bush Medicines were named in this thesis (See Chapter 7). This information (knowledges, practices, cultural expressions), contributed to the development of the first arthritis education resources for Indigenous peoples (innovation), and offered insight into future research directions.	Intellectual property of project outputs varied. In some cases it involved legally binding contracts, such as those related to project artwork. In other instances, such as ownership of the education resources, this resided with funding bodies and the university institutions of the researchers.
1.4	Policies, procedures and templates, where under the control of the research group, remained flexible to respond to the rights and interests of Indigenous peoples. For example, the Terms of Reference listed a two-way knowledge exchange between the research group and Indigenous peoples and communities as a key aim. This supports their right and interests to co-producing research (e.g., through research yarning), and accessing research outputs (e.g., development and dissemination of a Community summary page) (See Appendix D Terms of Reference; Chapter 3).	At times, institutional-level barriers prevented flexibility in processes. For example, strict funding timelines made it difficult to hold group meetings for the CRG at the end of the SMSS project. Instead, because of scheduling constraints, the final meeting was held one-on-one between the chair and individual CRG members.

Engagement and collaboration		
1.5	Meaningful engagement was demonstrated by: Modes of engagement • The Terms of Reference outlined the preferred modes of engagement, as determined by the CRGs. Specifically, Zoom videoconferencing was chosen for engagements in VIC while face-to-face meetings were favoured in WA. The selection of the mode was influenced by geographical distribution of CRG members. In WA, all members resided in the same regional town, whereas in VIC, members were located in different towns and cities. Additionally, the decision to opt for an online mode in VIC was made in response to COVID-19 restrictions (See Appendix D. Terms of Reference; Chapter 7). Intensity of engagement • The Terms of Reference included intensity of engagement, which was originally proposed to be a meeting every 3–6 months, for two years, however this ended up occurring bi-annually for two years, supplemented by communications between meetings including phone calls and emails, in accordance with the preferences of CRG members (See Appendix D. Terms of Reference) Protocols and processes for decision-making • Decision-making within the CRGs was collaborative and involved discussions among all members. In CRG meetings, the chair would seek Elder[2] input on a given item before consulting other group members as a sign of respect, and to adhere to cultural protocol. • Researchers remained flexible in their approaches to accommodate local protocols. For example, advice from local Elders was sought on appropriate terminology to include in the education resources regarding Bush Medicines.	
1.6	Trusting relationships were built and maintained as follows:	Collaborative consultation with CRGs regarding the project aims, methods and benefits of the research were not completed in the planning

[2] Elder – There is no universally accepted definition of who constitutes an Elder. In this thesis, I define an Elder as someone who identifies as an Elder and is highly respected within the communities they are from, or in which they live or work, for their wisdom, cultural knowledge and community service [172].

	• The project outcome of producing an educational resource was predetermined. However, the specific form, content and other aspects were decided through exchange of ideas in the research yarns, and in collaboration with the CRGs (See Appendix A. Staying Moving Staying Strong Protocol) • Before participating in the project, all potential participants were given a participant information consent form (PICF) (See Appendix E. Participant Information Consent Form). This document outlined the project's objectives, methods, potential implications, and anticipated outcomes, ensuring that participants were fully informed before deciding to take part. • Multi-staged consultation with CRGs such as co-design of the resources and discussing distribution strategies (See Chapter 7).	stages due to the requirement of obtaining ethical approval prior to recruitment of community members. Input from Indigenous researchers was considered in this preliminary stage.
1.7	A written agreement (Terms of Reference) was developed for this project to reflect the collaboration between the research group and the CRG. This document was drafted by a member of the research team and presented to the CRG in the initial meeting (for verbal feedback) and circulated to the CRGs via email (for written feedback) before being finalised (See Appendix D. Terms of Reference). Appropriate time was given through all project stages for people to consider as follows: • Participation in the research yarns – by providing the PICF approximately one week in advance of participation. • Participation in the CRGs – by offering the option to participate at the end of the research yarn, with the CRG's first meeting being convened several weeks later. • Feedback on the project by the CRGs – by outlining in the Terms of Reference that: i) CRG members would be expected to fulfil individual roles and responsibilities in a timely manner, and ii) that CRG members could expect a reasonable timeframe in which to make decisions. A specific timeframe was not given, however this was usually two weeks. Templates and project materials (e.g., Terms of Reference, recruitment flyer) were created based on previous Indigenous health projects conducted by group members, rather than a university template (See Appendix D. Terms of Reference; Appendix F. Recruitment Flyer). The Terms of Reference included details to support collaborative decision-making, and expectations of creating a safe space:	This agreement lacked detail on the process for managing Indigenous knowledges and intellectual property and did not include a formal process for resolving disagreements or disputes. The Terms of Reference was not legally binding and no other agreements were created as part of this project.

	• 'The CRG will adopt an informal consensus decision-making processes to reach agreement at meetings. This will involve a collaborative, transparent approach in which all members have the opportunity to voice their opinions. Members of the group should feel safe and respected to voice their concerns in meetings.' The Terms of Reference included an independent complaints process: • 'We recognise that at times members may not feel comfortable to raise concerns. In these circumstances, members will be able to confidentially contact the Chair or Co-Chair out of session. For sensitive topics the CRG may consider an anonymous decision-making process, for example using a paper ballot system.' The CRG meetings were chaired by Brooke Conley (VIC) or Ivan Lin (WA). Although the option of CRG members to serve as the chair and co-chair was proposed, the CRG preferred that these roles be filled by researchers and the decision was made not to appoint a co-chair.	
1.8	Information and data were not collected in the early phases of the project. The design process was documented in a protocol, at which point ethics approval was granted for both sites (VIC and WA) (See Appendix A. Staying Moving Staying Strong Protocol).	
	Informed consent	
1.9	Free informed consent was obtained prior to participation, either verbal (research yarns, CRGs) and/or written (research yarns) on an individual basis rather than a community approach (See Appendix E. Participant Information Consent Form).	
1.10	Researchers were responsible for understanding the definition of free, prior and informed consent, and followed a standard process for seeking consent that was approved by both ethics committees (VIC and WA) (See Appendix C. Human Research Ethics Committees Approval Letters). The PICF detailed the proposed research and its implications (See Appendix E. Participant Information Consent Form).	
1.11	Collective consent was not obtained, only individual consent. Researchers were aware of particular ethical issues in relation to Indigenous peoples' data (See Chapter 2). For example, we considered protocols and individual preferences regarding Sorry Business when producing the Staying Moving, Staying Strong (SMSS) video outputs. Each person was required to complete a form designed by the SMSS project team, indicating their preferences for the use of the videos in the event of their passing. Consent for the use of secondary data was not required in this project.	

1.12	The participant information and consent form (PICF) included a form to withdraw consent, and detailed this could occur at any point throughout the project. The process was predetermined as part of the ethics application and included notifying the researcher and completing the withdrawal of consent form. However, this was not required, as no participants withdrew their consent (See Appendix E. Participant Information Consent Form).	

Cultural capability and learning		
1.13	Non-Indigenous researchers were responsible for their own professional development and ongoing cultural learning. From my perspective, as an Indigenous person, all researchers demonstrated an appropriate level of cultural competency and a commitment to ongoing learning. Experience appropriate to the research project varied, but included knowledge and expertise in Indigenous community engagement and Indigenous methods. Researchers' positionality was discussed at the beginning of the first CRG meeting and included in the relevant publication (See Chapter 7) and research yarns mentioned aspects of the researchers' standpoints, usually within the social yarn component. Further, the research team welcomed discussion and questions from Indigenous participants regarding their qualifications and experience.	
1.14	The university is responsible for providing training to researchers in Indigenous research ethics and methods. No members of the research team had formal training in Indigenous research ethics and methods. The university provided opportunity for the PhD candidate to develop capacity and experience: • I completed the Professional Certificate of Indigenous Research and the Graduate Certificate of Indigenous Research and Leadership together with methods coursework: the Qualitative Research Methods Course delivered by the research centre.	Institutional responsibilities are outside of the project's scope.
1.15	Approval by human research ethics committees (HREC) was obtained in both sites. In WA, this was an Indigenous-specific human research ethics committee – The Western Australian Aboriginal Health Ethics Committee. In VIC, this was a local hospital human research ethics committee, as no Indigenous human research ethics committees currently exist (See Appendix C. Human Research Ethics Committees Approval Letters).	HREC's responsibilities described in this section were outside of the projects scope.
Principle 2. Indigenous leadership		
RESPONSIBILITIES		
Indigenous-led research		
	How this principle was applied in the research	**How the principle was not applied in this research project**
2.1	Mechanisms were created to ensure decision-making was Indigenous led, as described below.	

2.2	Indigenous members of the research team took the lead in decision-making responsibilities, and input from the CRGs was highly valued and considered. This included participation in, and guidance throughout, data collection and analysis, interpretation of findings and communication of results. For example, the preliminary findings were presented to the CRGs for feedback, and dissemination of resources was discussed at CRG meetings.	Non-Indigenous researchers conceptualised the project and secured project funding.
2.3	The research topic was determined in response to Indigenous people's priorities. An early catalyst for the inception of the project was a funding opportunity. However this responded to a body of previous work highlighting this as a priority for Indigenous peoples living with these conditions, with reports of both a higher prevalence and burden, and a lower access to care [129, 173, 174], and opportunities and challenges to improving musculoskeletal care [175]. Project outcomes (education resources) were intended to benefit Indigenous peoples at a state level.	
2.4	The project involved multi-level Indigenous community engagement and collaboration throughout the research process (detailed above, Indigenous self-determination principle).	
Indigenous perspectives and participation		
2.5	Engagement with Indigenous perspectives, worldviews and ways of operating, was achieved as follows: • First Nations academic research and literature was included in all relevant chapters of my thesis (See Chapters 1–3, 7, 8). For community Indigenous research (See Chapter 7). • Adoption of First Nations decolonising methodologies, such as community-based PAR and methods such as research yarning (See Chapter 3). • Indigenous authors and voices were included in the analysis process and communication of research results. • For example, peer checking within the research group of interpretation of research yarn findings included multiple Indigenous peoples (See Chapter 7).	Indigenous researchers were involved in the initial development of the project design, but not other Indigenous community members.
2.6	Meaningful engagement was demonstrated as follows: • Indigenous (and non-Indigenous) peoples were appropriately acknowledged in accordance with specified authorship criteria outlined in University of Melbourne's policy [176]. Authorship was offered and documented with explicit consent. Authorship was considered and agreed on whilst completing the relevant publication. The final authorship list was confirmed on the completion of this publication to reflect contributions (See Chapter 7).	

	• Findings were communicated transparently in outputs (e.g., community summary or conference presentations), including acknowledgement statements to recognise Indigenous peoples' involvement in the CRGs, research yarns and the wider research project (e.g., Indigenous artists and graphic designer). • Acknowledgement of Country statements were added to relevant publications, this thesis and any other project outputs (e.g., conference presentations, project website) (See Acknowledgement of Country section; Chapter 7).	
	Indigenous knowledge and data	
2.7	• Indigenous peoples were involved in the data collection and analysis/interpretation: - Chapters 4–6 (Brooke Conley, Jonathan Bullen). - Chapter 7 (Brooke Conley, Jonathan Bullen, Jane Linton, Charmaine Green, Wanda Flanagan, Trevor Pickett, Ryan Prehn, Janet Bromley, Nola Gregory). • Use of data was consistent with research agreements (e.g., ethics, cultural IP contracts for artwork) and was negotiated with relevant Indigenous stakeholders (e.g., Indigenous health services, Indigenous artists). • Ownership and management of the research data were consistent with university practices: data is stored on password-protected computers and not shared beyond the research team (See Appendix A. Staying Moving Staying Strong Protocol). • A dissemination strategy to communicate research findings was designed in consultation with the CRG and involved community summary, publications, conference presentations, website and the education resources.	A written agreement regarding the process for data ownership, management (including access) and use (including distribution) was not completed.
2.8	Indigenous peoples' knowledge, resources and data were acknowledged: • Indigenous researchers had access and control of research data and their contributions were appropriately acknowledged. • Research results were published in standard academic outputs (e.g., publications, presentations) and community-based outputs (e.g., a project summary).	Ownership and ongoing access is dependent on intellectual property agreements; with the university institutions and/or funders often exhibiting ownership.
2.9	Researchers were aware of and applied the international data principles, and national principles published by Miam Nayri Wingara [177] where possible. For example, data was contextual and disaggregated, available in a demographics table (See	University institutions and the funding organisation are responsible for upholding Indigenous Data

	Appendix J.3). Information on where data was collection (e.g., metropolitan, regional) and states was mentioned in the relevant publication (See Chapter 7).	Sovereignty and Governance principles which were adhered to in some instances but not others. For example, intellectual property of project outputs was shared between the universities and the funders rather than the Indigenous researchers, CRGs or individuals/communities that were involved.
Principle 3. Impact and value		
RESPONSIBILITIES		
Benefit and reciprocity		
	How this principle was applied in the research	**How the principle was not applied in this research project**
3.1	The primary focus was consistently on ensuring benefits for Indigenous peoples at a state level, specifically for those who participated in the project and others in community who may be affected by OA, gout and RA. This included tangible benefits, such as: • Financial compensation for participant involvement in the research yarns ($50) and/or the CRG ($100 per meeting), with the amounts determined based on past research [178]. • Co-authorship on relevant publications. • Employment for certain project staff (Trevor Pickett, Penny O'Brien, Wanda Flanagan). • A community summary that included research results was circulated to all CRG members and research yarn participants. • Education resources disseminated via health services (Aboriginal and mainstream), researchers' networks and arthritis organisations (e.g., Arthritis Australia).	

	And intangible benefits, such as: • Improved quality of education for arthritis conditions. Benefits were outlined in project materials (See Appendix D. Terms of Reference; Appendix F. Recruitment flyer; Chapter 7).	
	Impact and risk	
3,2	This project aimed to have a positive impact for Indigenous peoples who are living with OA, gout and RA.	
3.3	To ensure a shared understanding by all participating in the research, potential impacts and risks were described in project materials. • These were included in the PICF, (See Appendix E. Participant Information Consent Form) and in documents related to this thesis (e.g., PhD pre-confirmation report). A contingency plan was provided for all risks in the latter document. • Risks were written in lay language and were honest, achievable and aligned to the SMSS project's objectives and outputs (See Appendix E. Participant Information Consent Form). • Adequate time was provided to review the PICF and for participants to ask the research team members any questions. Project impact will be monitored over time through website analytics and evaluation of the education resources.	
	Principle 4. Sustainability and accountability	
	RESPONSIBILITIES	
	How this principle was applied in the research	**How the principle was not applied in this research project**
	Indigenous land and waters	
4.1	N/A	
4.2	N/A	
	Ongoing Indigenous governance	
4.3	Indigenous peoples exercised the right to manage (See Chapter 7): • The creation of data (Indigenous research yarn participants) and collection of data (Indigenous researchers)	

	• Data analysis, interpretation and dissemination (Indigenous researchers and the CRGs) • Data management, storage, access, re-use and disposal data (Indigenous researchers). As previously discussed, data that may have cultural significance or value remained unexplored or was protected and unpublished. For example, specific cultural knowledge regarding Indigenous Bush Medicines including their preparation. Control of storage and access of data was consistent with university processes (See Appendix A. Staying Moving Staying Strong Protocol).	
	Reporting and compliance	
4.4	Reporting to all stakeholders remained transparent and included: • Annual reports to human research ethics committees at each site. No additional ethical considerations arose and were therefore not reported. • A community summary which was reviewed by Indigenous researchers and determined to be in a form that is culturally appropriate, useful and informative. PICF detailed institutional processes for reporting on breaches to the relevant human research ethics committee. (See Appendix E. Participant Information Consent Form). Deviations from the protocols were necessary and were described in relevant chapters (See Chapter 3 for protocol deviations regarding Chapter 7's publication; and Chapters 4–6 for systematic review deviations).	

3.2.2 Implications of Australian Institute of Aboriginal and Torres Strait Islander Studies Principles

The AIATSIS guideline served as a framework to guide this research. Although most of the AIATSIS principles and their responsibilities were addressed throughout the SMSS project, there were several areas that were not covered. These were lack of: 1) Indigenous community collaboration at the beginning of the project (e.g., conceptualisation of the project, its aims and objectives); 2) comprehensive and legally binding project documentation (e.g., missing detailed information on intellectual property; Indigenous Data Sovereignty and Governance), and 3) flexibility due to institutional barriers (e.g., funding body and university timelines). Failure to adequately address these areas may have affected the project quality and outcomes. For example, the lack of community input at the early stages of the project may lessen the translational impact of this research. From my perspective as a new researcher, I understand that both institutional and practical factors can influence the ability to adequately adhere to all of the AIATSIS principles, such as appropriate funding associated with community-engagement activities, research timelines, and additional research burden on Indigenous peoples and communities. I acknowledge these areas for improvement and efforts will be made to mitigate these in future projects. This will include efforts to secure funding early; engagement of advisory groups to co-design the project from its inception; creation of detailed project documentation; and personally pursuing training opportunities to expand my knowledge and skill set related to Indigenous Data Sovereignty and Governance.

3.2.3 Community Reference Groups

Consistent with the ethical principles of AIATSIS and a community-based PAR approach, two CRGs were created to provide Indigenous governance to this project. Indigenous peoples who were living in VIC or WA and who experience OA, RA, gout and/or SLE, were eligible to be included to reflect the wider SMSS project's inclusion criteria [4]. The decision for selecting these two Australian states (VIC and WA) was based on the location of the researchers, and the selection of individuals to participate in this group was determined by who the research was intended to benefit. In the context of this project, this was Indigenous peoples living with arthritis conditions, who represented diversity in age, gender, condition, geographical location (e.g., metropolitan, regional,

rural) and cultural backgrounds/mobs (e.g., Yamaji). Recruitment to the CRG occurred either before or during participation in the research yarns. Meetings were conducted through an online teleconferencing platform in VIC or in-person in WA, with either myself or Ivan Lin (PhD co-supervisor) serving as the chairs. Full details of the CRG's role can be found in Chapter 7. Briefly, the CRGs advised on the research process (e.g., recruitment), research findings (e.g., feedback on data analysis) and SMSS project outputs (e.g., education resources, website and logo design).

Eight Indigenous people were involved in the CRGs (VIC n=4; WA n=4). The majority of CRG participants were female (75%) and ages ranged between 22 and 68 years. CRGs included individuals with OA (n=4), gout (n=2), RA (n=1), and both OA and RA (n=1). All participants were located in either metropolitan VIC (n=2) or regional VIC (n=2) and regional WA (n=4). Outcomes of the CRG are discussed in Chapter 7.

3.3 Research Methods

3.3.1 Integrative Multi-Methods Approach

Multi-methods approaches involve combining data collection and analysis techniques from two or more methodological traditions and have been extensively applied in health research contexts [179][180]. However, to my knowledge, there is no existing research that describes how to integrate and interpret findings from research yarns and systematic reviews. Within an overarching PAR approach, this project followed a physiotherapy-based multi-methods framework as described in Skamagki et al., (2022) [181]. This process involves four steps: 1) Create a joint display, 2) Link findings, 3) Establish relationships between datasets, and 4) Interpret and report findings [181]. Broadly these steps were followed, however this framework allows for flexibility in the way these are achieved. Through discussion with members of the research team, different options of data integration were trialled before opting to present findings in a figure that was created by myself and an Indigenous researcher on the SMSS project team (JL) in collaboration with other SMSS project team members (SB, IL, JB, RT) and the CRGs (**Error! Reference source not found.**). From this, links between datasets were made, and relationships were identified, including areas of overlap (convergence), variation (divergence) or where one dataset provided additional insights (expansion)

[182]. These findings were further interpreted and reported on (See Chapter 7). Ultimately, integrative multi-methods research and specifically this approach, was selected to centre Indigenous voices (through research yarn findings) rather than solely CPG education recommendations in this project. This decision aimed to challenge traditional research practices in which evidence is developed by dominant cultural groups without explicit involvement of Indigenous peoples, thus contributing to the decolonisation of Westernised research practices. Ontologically, this approach acknowledged that reality is subjective and multiple, recognising that each persons' experience of their arthritis condition is valid and unique. Epistemologically, it challenged the notion of a single objective truth, instead this approach embraced a constructivist perspective where knowledge was co-created through individual stories and interpretations. Ethically, through prioritising lived experience honoured the diversity of human perspectives and ensured that participants voices were heard, respected and valued in the research process.

3.3.2 Systematic Reviews

The integrative multi-methods approach involved three systematic reviews. Systematic reviews follow a rigorous and transparent methodology that involves: definition of a research question; a coordinated search of the literature with predefined inclusion and exclusion criteria; extraction, appraisal and interpretation of the selected studies [183]. This method is arguably deemed to be the highest form of research evidence [184]. Benefits of systematic reviews include providing an efficient and comprehensive summary of the best available evidence, which is necessary given the growing number of health-related studies published each year and their questionable quality [185, 186]. A significant limitation of systematic reviews is that they are rarely conducted in a participatory manner. For example, they often do not require ethics committee or institutional review, and patient and/or public involvement remains sparse [187, 188]. The latter is a common criticism of Western scientific methods and their use in Indigenous research contexts [189]. Systematic reviews have been used to report on the quality of CPGs for arthritis conditions and to synthesise CPG recommendations, although there were no recent systematic reviews that reported on both the quality of CPGs and their recommendations for OA, gout and RA [135, 190, 191]. In this project, systematic reviews were used to summarise existing literature on management options used for OA, gout and RA, including patient

education (Chapters 4–6). Detailed description of the systematic review methodology can be found in Chapters 4–6.

3.3.3 Research Yarning

The systematic review findings were combined with a participatory approach of research yarning to incorporate expertise from Indigenous peoples with lived experience. Research yarning draws upon oral traditions of storytelling for Indigenous peoples to centre Indigenous knowledge systems, practices, values, and perspectives [192, 193]. This data collection technique is an increasingly used and validated method in Indigenous research contexts [194]. Consistent with the PAR approach, research yarning equalises the power balance inherent in the researcher–person with lived experience relationship and aims to build trust and accountability [192, 194]. Further research yarning facilitates collaboration by remaining flexible and providing participants with the opportunity to actively engage and communicate with the researchers [195]. Applying a collaborative method such as research yarning can foster a sense of cultural safety and agency throughout the research process [194, 196, 197]. Research yarning has been used in the creation of education resources for Indigenous peoples, resulting in materials that were considered suitable and widely adopted [151]. In this project, research yarning was used to summarise Indigenous peoples' stories on their beliefs, knowledge, informational needs and preferences for OA, gout and RA (Chapter 7). A detailed description of the methodology applied to conduct and analyse the research yarns can be found in Chapter 7. This includes a description of strategies to enhance rigour such as cross coding of data, involvement of CRG members in data interpretation, and presentation of raw quotes to demonstrate how interpretations were grounded in raw data.

3.4 Staying Moving, Staying Strong Project Protocol Deviations

The study described in Chapter 7 differed from the original planned protocol of the SMSS project [4]. Phases 1–3 of the SMSS project adhered to the protocol. Phases 4 and 5 originally proposed a modified nominal group technique to culturally adapt key recommendations, and to develop the recommendations to inform the education resources [4, 198]. Briefly, these phases would have involved a group discussion among the CRG members to develop and rank both ideas and

recommendations for the resources [4]. Instead, these phases were adjusted to be one-on-one research yarns to accommodate for CRG members' availability and project deadlines.

Chapter 4 Core Recommendations for Osteoarthritis Care: A Systematic Review of Clinical Practice Guidelines

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American College of Rheumatology
Empowering Rheumatology Professionals

Core Recommendations for Osteoarthritis Care: A Systematic Review of Clinical Practice Guidelines

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Objective. To evaluate the quality of clinical practice guidelines (CPGs) for interventions in management of osteoarthritis (OA) and to provide a synthesis of high-quality CPG recommendations.

Methods. Five databases (OvidSP Medline, Cochrane, Cumulative Index to Nursing and Allied Health Literature [CINAHL], Embase, and the Physiotherapy Evidence Database [PEDro]) and 4 online guideline repositories were searched. CPGs for the management of OA were included if they were 1) written in English and published from January 2015 to February 2022, focused on adults age ≥18 years, and met the criteria of a CPG as defined by the Institute of Medicine; and 2) were rated as high quality on the Appraisal of Guidelines for Research and Evaluation II (AGREE II) instrument. CPGs for OA were excluded if they were available via institutional access only, only addressed recommendations for the system/organization of care and did not include interventional management recommendations, and/or included other arthritic conditions.

Results. Of 20 eligible CPGs, 11 were appraised as high quality and included in the synthesis. Of interest were the hip, knee, hand, and glenohumeral joints and/or polyarticular OA. Consistent recommendations were that care should be patient centered and include exercise, education, and weight loss (where appropriate). Nonsteroidal antiinflammatory drugs and surgical interventions were recommended for disabling OA that had not improved with nonsurgical care. Hand orthoses should be recommended for patients with hand OA.

Conclusion. This synthesis of high-quality CPGs for OA management offers health care providers with clear, simple guidance of recommended OA care to improve patient outcomes.

INTRODUCTION

Osteoarthritis (OA) is a degenerative joint disease that can affect any joint, but it most commonly occurs in the hip, knee, and hand (1,2). Symptoms often include joint pain, stiffness, and reduced range of movement (2). OA affects 303 million people worldwide, with prevalence expected to increase with aging populations and rising obesity rates globally (3,4). OA is a leading cause of pain and disability among adults worldwide and inflicts a significant burden on the individuals affected, including activity limitations and reduced quality of life (5,6). OA is associated with substantial direct health care costs due to health care visits, diagnostic procedures, medications and surgery, and indirect costs related to lost workplace productivity (4,6).

Clinical practice guidelines (CPGs) are a set of health care recommendations developed by reviewing scientific literature and consensus from an expert panel (7). The aim of CPGs is to guide health care decision-making, thereby reducing practice variability and improving patient outcomes (8,9). Several global CPGs have been published in recent years for the management of OA

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Table 4.1 Clinical Practice Guidelines (CPGs) Selection Criteria

SIGNIFICANCE & INNOVATIONS

- Eleven clinical practice guidelines for osteoarthritis (OA) were appraised as high quality.
- Consistent recommendations were that care should be patient centered and include exercise, education, and weight loss (where appropriate). Nonsteroidal antiinflammatory drugs and surgical interventions are recommended for disabling OA that had not improved with nonsurgical care. Hand orthoses should be recommended for patients with hand OA.
- To implement recommendations in practice, future priorities include identifying core skill sets and competencies among health care workers, developing training/education resources, and creating a framework to improve quality of OA care.

(10–29). These typically include nonpharmacologic (e.g., exercise and education), pharmacologic (e.g., acetaminophen and nonsteroidal antiinflammatory drugs [NSAIDs]), and surgical options such as total joint replacement (10–29). However, uptake of recommendations from CPGs into practice is variable, especially for first-line, nonpharmacologic treatments such as exercise (30). Gaps between evidence and practice may in part be due to a lack of clarity about what is being recommended and conflicting recommendations across different CPGs, a situation exacerbated when CPGs for OA are not developed rigorously and their recommendations are less trustworthy (30–36). As CPGs are costly to develop, this is an inefficient use of resources and further adds to the confusion for clinicians (37). To encourage the uptake of evidence and delivery of appropriate OA care, clinicians require clear, consistent management recommendations (31).

The purpose of this systematic review was to evaluate the quality of the CPGs for the management of OA and to provide a synthesis of high-quality CPG recommendations. By synthesizing recommendations across high-quality CPGs, the aim was to offer health care providers with clear, simple guidance of recommended OA care to improve patient outcomes.

MATERIALS AND METHODS

Search strategy and eligibility criteria. This systematic review was registered on the Open Science Framework (DOI 10.17605/OSF.IO/UB3Y7) and followed the Preferred Reporting Items for Systematic Reviews (PRISMA) guidelines. A database search of Medline, Cochrane, CINAHL, Embase, and the Physiotherapy Evidence Database (PEDro), and a further search of 4 online guideline repositories (Guidelines International Network, National Health and Medical Research Council, Agency for Health Care Research and Quality, and the National Institute for Health and Care Excellence) was conducted to identify all relevant CPGs. The search strategy was developed in consultation with a reference librarian. Medical subject headings and key words associated with CPGs (e.g., guideline*.mp. or Practice Guideline/ or Guideline/) and OA were used (see Supplementary Appendix A, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101). Other arthritis conditions were included in the search terms as this systematic review is part of a wider body of work to inform arthritis management. Eligibility criteria are presented in Table 1. The search included CPGs published between January 2015 and December 2020 and was updated to include CPGs published between December 2020 and February 14, 2022. This cutoff date was selected as CPGs >5 years old may be out of date (7).

Protocol changes. In the original protocol, CPGs addressing 1 treatment modality (e.g., medication prescribing) were excluded. To improve comprehensiveness, the scope was expanded during the study selection phase to include all OA management options. Due to time that has elapsed since the original search, the original timeline (January 2015 and December 2020) was extended to include CPGs published up until February 2022.

Study selection. After importing search results into EndNote (Clarivate), duplicates were removed and titles/abstracts were uploaded into Covidence systematic review software (Veritas Health Innovation; available at www.covidence.org). Titles and abstracts were screened by 2 independent reviewers (BC and TG or IL); any disagreements were resolved through consensus discussion with a third reviewer. Following this, full texts were uploaded into Covidence and screened through the same process.

Data appraisal (quality assessment of guidelines). The Appraisal of Guidelines for Research and Evaluation II (AGREE II) instrument was used to assess CPG quality (38). This is an internationally validated tool that has been widely applied in CPG research (38,39). It consists of 23 items grouped into 6 domains: 1) scope and purpose; 2) stakeholder involvement; 3) rigor of development; 4) clarity of presentation; 5) applicability; and 6) editorial independence. Seven reviewers (BC, SB, JB, PO, JP, TG, and IL) were

Table 1. Clinical practice guidelines (CPGs) selection criteria

Inclusion criteria
Published between January 2015 and February 14, 2022
For the interventional management of osteoarthritis
For adults (individuals age ≥18 years)
Published in the English language or has a complete English language version available
Is a CPG, as defined by inclusion of a systematic review of the literature, and developed by an expert multidisciplinary panel (33)
Represents an original body of work, i.e., not solely an adaptation or systematic review of existing guidelines
Exclusion criteria
Does not include interventional management recommendations
Includes other arthritic conditions
Only addresses recommendations for the system/organization of care
Unavailable via institutional access, i.e., requires additional payment

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Table 4.2 Recommendation Classification, Definition and Examples of Terminology for Each Classification

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provided with the AGREE II user manual and undertook the online AGREE II practice exercise to participate in CPG quality appraisal (38,40). In accordance with the AGREE II manual, each item was rated independently by 2 reviewers using a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree) (38). To calculate scores for each domain, the following formula was used: obtained score – minimum possible score / maximum possible score – minimum possible score (38). There is no uniform criterion for overall quality; the AGREE II developers recommend that research teams define their own criteria based on their own study context (38). For the purposes of this review, and consistent with previous reviews in musculoskeletal pain management, the authors defined a quality cutoff score of ≥60% of the maximum possible score in 3 domains deemed the most important for validity: stakeholder involvement (domain 2); rigor of development (domain 3); and editorial independence (domain 6) (36,37,41,42). CPGs that did not meet this definition were excluded.

Interrater agreement. The domain percentages and overall quality rating (%) were independently calculated for each reviewer. We defined acceptable interrater agreement as excellent with intraclass coefficient values of ≥80 and domain percentages and an overall quality rating of ≤20% difference between reviewers (43,44). Where variation of ≥20% between scores existed, a consensus discussion took place with a third reviewer engaged when necessary to agree on a rating (see Supplementary Table 1, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101).

Data extraction. Data extraction was performed by the first author (BC) using a purpose-designed Excel (Microsoft) spreadsheet. Extracted data comprised CPG characteristics (e.g., title, country of publication), methodology, and guideline topic target users (see Supplementary Table 2, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101). From each CPG, extracted recommendations were ranked as either "should do," "could do," "do not do," or "uncertain" (see Supplementary Table 3, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101). Recommendation ratings were consistent with language used in the CPGs and definitions from a previous musculoskeletal systematic review of CPGs (36) (Table 2). Language among the CPGs varied, although recommendations were ranked according to the same criteria, either the Grading of Recommendations Assessment, Development and Evaluation (GRADE) method (10,12,13,20,22,26,29), Oxford Centre for Evidence-Based Medicine standards (13,24), or PEDro scores (17). Extracted data and recommendation rankings were checked by 2 authors (SB and IL), and any discrepancies were resolved by consensus discussion between the 3 reviewers while consulting the original citation.

Narrative summary. A narrative summary was drafted by the first author (BC) and then reviewed and refined by 2 authors (SB and IL). The summary detailed how many CPGs reported on an intervention, what the recommendations involved, and how consistent/inconsistent recommendations were across CPGs regarding OA interventions (see Supplementary Table 4, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101).

Table 2. Recommendation classification, definition, and examples of terminology for each classification*

Recommendation classification	Definition (37)	Examples of terminology from CPGs
Should do	"Should do" recommendations were those that the authors determined should be applied in all circumstances unless there is a rationale not to. These were based on strong evidence, for example, multiple high-quality studies reporting clinically relevant positive effects, benefits that outweigh risks, or when in the opinion of CPG development group members the benefits were unequivocal.	"Should do" (18) and "strongly recommend" (11)
Could do	"Could do" recommendations were those that the authors determined could be applied depending on the circumstances of individual patients. They were usually based on consistent evidence from multiple lesser-quality studies or 1 high-quality study and where benefits outweigh harms.	"Could be used" (18), "may be beneficial" (9,18), "can" and "consider" (26)
Do not do	"Do not do" recommendations were those for which the authors determined that there was strong evidence of no benefit and/or harms outweighing benefits.	"Are not recommended" (18), "do not recommend" (11), and "do not offer" (26)
Uncertain	"Uncertain" recommendations were those for which the authors determined that there was no recommendation for or against a practice because of incomplete or inconsistent research findings. Not all CPGs provided uncertain recommendations.	"Cannot recommend for or against" (9) and "unable to recommend either for or against" (11)

* CPG = clinical practice guideline.

Figure 4.1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020

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RESULTS

Characteristics of included CPGs. Twenty CPGs met the eligibility criteria, and 11 were CPGs appraised as high quality and included (11–13,17–19,21,24,25,27,29) (Figure 1). Most CPGs were developed by medical societies (n = 9, 82%), while the remaining were developed by an expert panel (n = 2, 18%). Five CPGs were published by medical societies or expert panels in the US (10,11,19,25,29), 4 in Europe (13,21,24,27), 1 in Canada (17), and 1 in Australia (12). Of interest were the hip (n = 6), knee (n = 7), hand (n = 4), and glenohumeral (n = 1) joints and/or polyarticular OA (n = 1). Target users included health professionals, decision/policy makers, patients, their families, the pharmaceutical industry, health insurance companies, and those responsible for commissioning care (see Supplementary Table 2, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101).

Quality of CPGs. The AGREE II quality assessment scores for each CPG are provided in Supplementary Table 1, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101. The quality assessment results of each guideline included in the systematic review are provided in Table 3. Those that were excluded based on not achieving a high-quality cutoff score are presented in Supplementary Table 1. The quality of the included CPGs was assessed across the following 6 domains: scope and purpose (range 75–100%); stakeholder involvement (range 58–89%); rigor

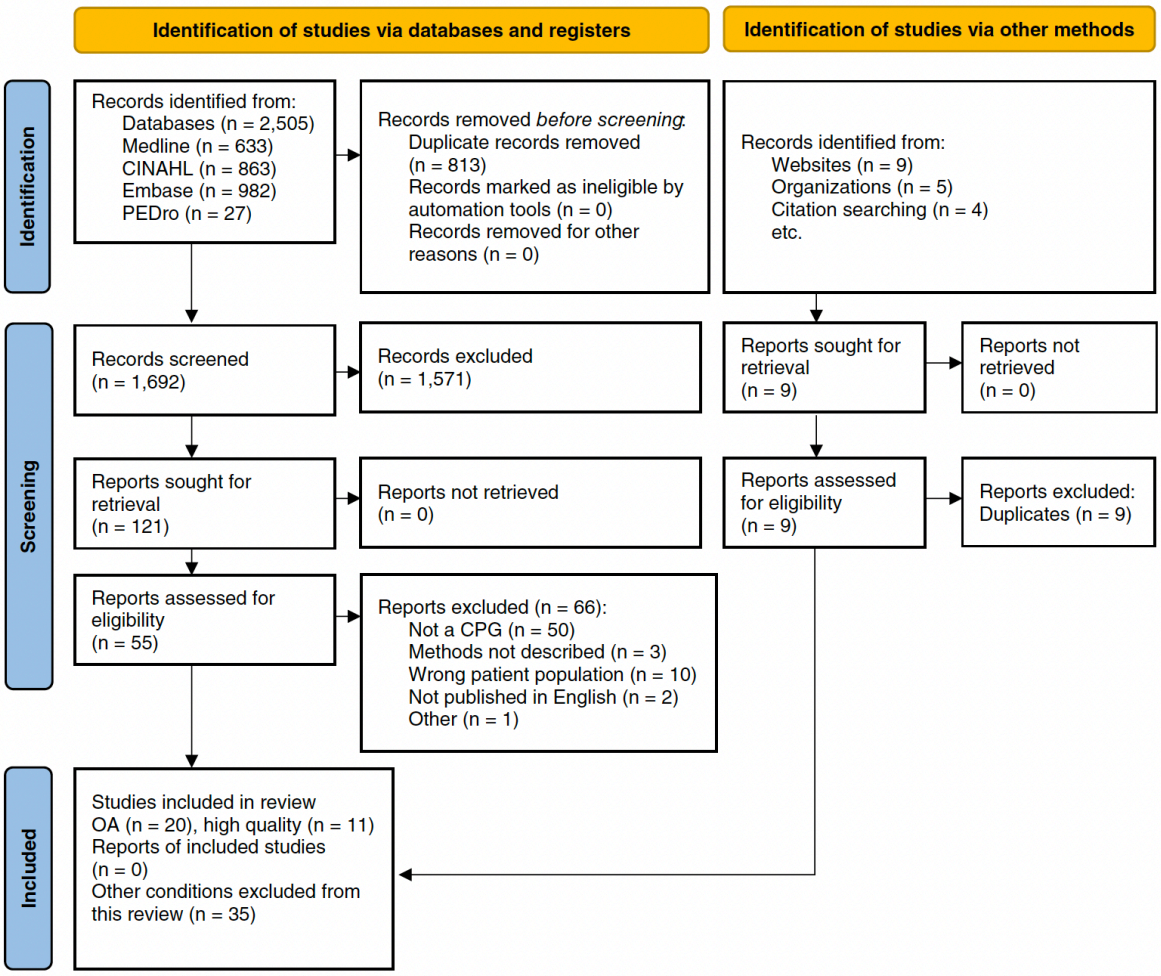


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 flow diagram for new systematic reviews that included searches of databases, registers, and other sources. CINAHL = Cumulative Index to Nursing and Allied Health Literature; CPG = clinical practice guideline; OA = osteoarthritis; PEDro = Physiotherapy Evidence Database.

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of development (range 59–96%); clarity of presentation (range 53–100%); applicability (range 2–42%); and editorial independence (range 33–100%). The mean ± SD AGREE II scores for each item, domain, and overall scores across all guidelines are displayed in Supplementary Table 5, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101. The domain with the lowest mean ± SD score was applicability (21.14% ± 15.0%), and the highest mean ± SD score was for scope and purpose (88.77% ± 9.8%).

Consensus recommendations ("should do"). After synthesis (see Supplementary Table 4, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101), 7 "should do" recommendations were identified. The following recommendations were all found in at least 2 CPGs, where the majority strongly recommended the intervention.

Exercise. Eight CPGs strongly recommended strengthening, aerobic exercise, and tai chi exercise therapy for management of knee, hip, polyarticular, and/or hand OA (12,13,18,19,21,24,25,27). CPGs recommended several modes of exercise therapy, acknowledging that there is currently no consensus on the type of exercise that elicits the greatest benefit (12). Programs should be individualized and progressively overloaded with frequency, duration, and intensity consistent with the patient's preference and capability and the availability of local facilities (12,13).

Education. Five CPGs strongly recommended patient education for managing knee, hip, hand, and polyarticular OA (13,19,21,24,25). They recommended that education be an ongoing intervention that is patient centered and include information to enhance understanding about OA, its management options, education and training in exercise therapy, ergonomic principles, and pacing and assistive devices (13,21,24).

NSAIDs. Five CPGs strongly and 2 CPGs conditionally recommended the use of oral NSAIDs for people with knee, hip, hand, and/or polyarticular OA unless contraindicated (11–13,19,21,24,25). CPGs recommended that clinicians prescribe a low dose for a short period of time and discontinue if not effective, monitoring for side effects or adverse events (12,24).

Four CPGs strongly recommended the use of topical NSAIDS for knee, hip, and/or hand OA (13,19,24,25). Two CPGs conditionally recommended topical NSAIDS for patients with hand, knee, hip, and/or polyarticular OA and some comorbidities (21,25). One CPG was unable to recommend for or against the use of topical NSAIDS for people with knee and/or hip OA (12). However, the authors stated that it might be reasonable to trial topical NSAIDs for a short period and then discontinue use if not effective. Topical NSAIDs are seen to be safe and effective and should be recommended for older adults (>75 years) with only a few symptomatic joints (13). Clinicians should monitor for side effects or adverse events (12,21).

Weight loss. Four CPGs strongly recommended weight loss or management for people who are either overweight (body mass index [BMI] ≥25 kg/m^2) or obese (BMI ≥30 kg/m^2) with hip and/or knee OA (12,13,19,25). People with OA should be educated about the importance of maintaining a healthy body weight, while those who are overweight or obese should be encouraged to achieve a minimum weight loss target of 5.0–7.5% of body weight, with greater weight loss being linked to symptomatic benefits (12).

Hand orthosis. Three CPGs strongly recommended the use of a hand orthosis for OA of the carpometacarpal joint and conditionally recommended it for OA of other hand joints (13,24,25). Two CPGs stated that hand orthoses are suitable for both short-term and long-term use as they provide symptom relief, improve function, and prevent progression of degenerative changes (13,24).

Patient-centered care. Two CPGs strongly recommended that care be patient centered for people with OA of the knee, hip, and/or hand (13,24). This included shared decision-making between the patient and health professional and care that is individualized to the patient's circumstances.

Surgery. Two CPGs strongly recommended considering surgery for people with hip, knee, and hand OA in certain circumstances (13,24). The patient should have radiographic evidence of OA, marked disability, and reduced quality of life, and other treatment modalities should have been unsuccessful in relieving pain (13,24).

Consensus recommendations ("could do"). The following recommendations were found in at least 2 CPGs in which the majority conditionally recommended (or where there was an even number of strongly and conditionally recommended recommendations) that these could apply in a given patient's circumstances: balance exercises; yoga; weight management and exercise; cognitive behavioral therapy; assistive devices; ultrasound-guided injections; duloxetine; and glucocorticoid injections for knee and hand OA. In surgical contexts, preoperative physical therapy and postoperative physical therapy or exercise can be recommended after joint replacement surgery. General and neuraxial anesthesia and tranexamic acid could be considered during surgery (see Supplementary Table 4, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101).

Consensus recommendations ("do not do"). After synthesis (see Supplementary Table 4), 5 "do not do" recommendations were identified (Table 4). The following recommendations were found in at least 2 CPGs, where the majority recommended against the intervention.

Therapeutic ultrasound and pharmacologic interventions (bisphosphonates, colchicine, methotrexate, diacerein). Three CPGs recommended against the use of therapeutic ultrasound for people with knee, hip, and/or polyarticular OA (12,21,27). Two CPGs recommended against the use of bisphosphonates, colchicine, hydroxychloroquine, and methotrexate in people with knee, hip, and/or hand OA (12,25). Similarly, 1 CPG recommended against the use of biologic disease-modifying

Table 3. Clinical practice guidelines included in the systematic review*

Author, year (ref.)	Title/type	Domain 1, scope and purpose	Domain 2, stakeholder involvement	Domain 3, rigor of development	Domain 4, clarity of presentation	Domain 5, applicability	Domain 6, editorial independence	Over all assessments core	Domains 2,3, and 6 combined value
RACGP, 2018 (12)	RACGP	97	58	81	89	35	79	83	73
Bannuru et al, 2019 (21)	OARSI	89	72	59	89	8	100	58	77
Kolasinski et al, 2020 (25)	ACR	97	89	85	86	21	63	75	79
AAOS, 2020 (10)	AAOS (GH joint)	94	61	90	69	15	92	75	81
AAOS, 2017 (11)	AAOS (hip OA)	97	61	92	53	42	71	75	75
Ariani et al, 2019 (13)	ISR	81	64	65	72	2	67	58	65
Kloppenburg et al, 2019 (24)	EULAR	78	81	77	81	6	79	67	79
Van Doormaal et al, 2020 (27)	–	75	67	81	75	42	33	58	60
Brosseau et al, 2018 (17)	OTTAWA	75	61	75	56	6	92	92	76
AAOS, 2015 (29)	AAOS (knee OA surgical)	100	81	96	100	21	100	92	92
AAOS, 2021 (19)	AAOS (knee OA non-arthroplasty)	94	61	96	100	35	92	92	83

* Values are the domain scores in % on the Appraisal of Guidelines for Research and Evaluation II (AGREE II) instrument. AAOS = American Academy of Orthopaedic Surgeons; ACR = American College of Rheumatology; GH = glenohumeral; ISR = Italian Society for Rheumatology; OA = osteoarthritis; OARSI = Osteoarthritis Research Society International; OTTAWA = Ottawa Panel; RACGP = Royal Australian College of General Practitioners; Ref. = reference.

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Table 4.4 Consensus Recommendations

antirheumatic drugs for people with hand OA (24). Two CPGs recommended against the use of diacerein for people with knee and/or hip OA (12,21).

Glucosamine and chondroitin combined. Two CPGs recommended against the use of glucosamine and chondroitin for knee, hip, and polyarticular OA (12,21). One CPG was unable to recommend for or against their combined use in people with OA of the glenohumeral joint (10). Moreover, 1 CPG conditionally recommended this intervention for people with knee OA, noting that further research is warranted to determine structural effects, patients' suitability, and cost-to-benefit ratio (13).

Postsurgical continuous passive motion (CPM) and postsurgical cryotherapy devices. Two CPGs recommended against the use of CPM after total joint replacement for patients with knee and/or hip OA, as research found no improvement in outcomes (27,29). One CPG recommended against the use of cryotherapy devices for patients after total knee arthroplasty (TKA) (29). In contrast, 1 CPG conditionally recommended the use of cryotherapy or cold packs following total shoulder replacement while acknowledging that this decision was based on the opinion of the working group and not strong/reliable evidence (10).

Table 4. Consensus recommendations*

Should do
Exercise therapies (strengthening, aerobics, and/or tai chi)
Education
Weight loss
Hand orthosis
Patient-centered care
Nonsteroidal antiinflammatory drugs (oral and topical)
Surgery
Could do
Balance exercises
Yoga
Assistive devices
Weight management and exercise
Cognitive behavioral therapy
Glucocorticoid injection (knee and hand OA)
Ultrasound-guided injections
Duloxetine
Preoperative physical therapy
Tranexamic acid
Neuraxial anesthesia
Pre- and postoperative physical therapy
Do not do
Therapeutic ultrasound
Bisphosphonates
Colchicine
Methotrexate
Diacerein
Glucosamine and chondroitin combined (hip and polyarticular OA)
Postsurgical continuous passive motion and cryotherapy devices
No consensus
Aquatic therapy
Balneotherapy
Manual therapy
Acupuncture
Massage therapy
Dry needling
Heat and cold therapy
Electrotherapy
Taping and braces
Shoe orthotics
Footwear
Topical capsaicin
Glucocorticoid injection (hip and polyarticular OA)
Intraarticular hyaluronic acid injections
Platelet-rich plasma injections
Stem cell injection
Acetaminophen
Oral opioids
Glucosamine and chondroitin, individually or combined (GH joint OA)
Nutraceuticals

* GH = glenohumeral; OA = osteoarthritis.

Recommendations with no consensus. The following were conflicting recommendations found in at least 2 CPGs: aquatic therapy; balneotherapy; massage therapy; manual therapy; acupuncture; dry needling; heat and cold therapy; electrotherapy; taping and braces; shoe orthotics; footwear; opioids; injections; topical capsaicin; glucosamine and chondroitin individually or combined for OA of the glenohumeral joint; acetaminophen; and nutraceuticals (see Supplementary Table 4).

DISCUSSION

Following quality assessment, 9 CPGs were rated as low quality, and 11 CPGs were high quality and included in the final synthesis. Overall, CPGs recorded the highest score for the AGREE II domain "scope and purpose" and the lowest score for the domain "applicability." This is consistent with the findings of similar systematic reviews (37,45). The AGREE II "applicability" domain assesses whether CPGs provide advice and/or tools for how to apply the guideline in practice, considers the facilitators, barriers, and resource implications, and includes monitoring and/or auditing criteria (38). Poor applicability has been identified as a barrier to the uptake of CPG recommendations into practice (37). Given that developing CPGs is expensive, development of fewer, higher-quality CPGs that focus on implementation (as reflected in higher scoring in the applicability domain on the AGREE II tool) is recommended.

Recommendations from 11 high-quality CPGs were that first-line care should be patient centered and include exercise therapy, patient education, and weight loss (if appropriate). These interventions can be beneficial in reducing pain and in improving function, performance, and quality of life outcomes (46–49). This should be followed by pharmacologic strategies such as NSAIDs in oral or topical form before considering surgical interventions as second- and third-line care. For people with hand OA, orthosis should be used for symptom relief and improved function and to prevent progression of degenerative changes (13,24). This synthesis of recommendations provides evidence-based guidance for clinicians on what should be delivered for best practice in OA care. These recommendations could also be used as a minimum

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standard for health services to assess OA care and to provide the basis for clear consumer information about recommended OA management.

We identified a substantial number of recommendations that were inconsistent between CPGs, which may contribute to confusion among clinicians and to varied management. For example, manual therapy recommendations were inconsistent across the CPGs, with a majority recommending against, yet these are still widely used in clinical practice (50). Similarly, the majority of CPGs recommended against opioids, although 2 CPGs recommended that opioids can be considered in particular circumstances, when pain is severe or if patients do not respond, are intolerant, or contraindicated to NSAIDs, or when other alternatives have been exhausted (13,25). Despite this, opioids are often prescribed for persistent musculoskeletal pain conditions, including OA, and opioid-related harms are of increasing concern (51,52). Additional conflicting recommendations included acupuncture/dry needling, shoe orthotics, taping/braces, glucosamine and chondroitin, and injection therapies, e.g., platelet-rich plasma, stem cell, and intra-articular hyaluronic acid (for a comprehensive list of conflicting recommendations, see Supplementary Table 4, available at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101).

Many of these recommendations are routinely utilized in clinical care. Further high-quality trials are needed to determine their efficacy and/or their suitability for certain subgroups of individuals with OA in order to guide clinicians' practice. CPG recommendations vary, potentially due to differences in evidence included based on the year of CPG publication, assessment of evidence quality, and involvement of expert panels or societies members. For example, 1 CPG recommended against heat therapy, while another CPG recommended that it can be considered as an adjunctive management option for people with hip and/or knee OA (12,27). Both CPGs acknowledged limited evidence supporting this intervention; however, interpretation of evidence by the respective guideline development groups led to conflicting recommendations.

While exercise, weight management, and education were supported across the CPGs and have been recommended as first-line interventions for almost 2 decades, translation into practice remains an issue (53). In Western health care settings including Australia, Europe, the UK, and the US, a majority of patients do not receive care consistent with CPGs (54). Conservative management interventions are often overlooked in favor of pharmacologic and surgical care despite being associated with higher financial costs and risks (e.g., medication side effects or surgical complications) (6,30,55,56). Globally, utilization of exercise and education is low, while pharmacologic therapy and surgical referrals are common (54,57). In Australia, joint replacement surgeries are a substantial cost to the health care system, estimated at between $19,000 and $30,000 (Australian; between $13,000 and $20,600 US dollars) per patient for total knee or hip replacement, resulting in an expenditure of $1.2 billion (Australian) annually on both public and private hospital services (58–60); similar findings have been documented in the UK and the US (61,62). Surgery is a successful and cost-effective intervention for people with end-stage hip and knee OA, although overuse of surgery in patients who could benefit from conservative care remains a challenge (63–66).

Implementation of high-value care such as exercise and weight loss is needed (67). One way is through OA management programs such as OA models of care that operationalize what and how recommended care should be delivered (68). In order to achieve better care, priorities include training/education of OA health care workers, identifying core skill sets and competencies, developing resources, and creating a framework to improve quality of care (69). Outcomes from models of care suggest that this has been an effective way to translate evidence into practice, although definitive evidence for OA management is currently lacking (70). Structured exercise therapies, with or without education and dietary interventions, are cost effective and clinically effective (71). Implementation research that operationalizes recommended care, especially for populations who experience a higher burden of OA, including low- and middle-income countries and First Nations people, is a pressing future priority (72,73). We excluded CPGs that were not published in the English language and that addressed assessment and/or diagnosis of OA without management or treatment recommendations. It is possible that we may have overlooked other CPGs containing recommendations related to OA care. To mitigate this risk, all authors checked the list of full-text CPGs to augment the search process, including authors who are expert clinician researchers in the field of OA (MMD and PC).

Strengths of this systematic review include the involvement of a multidisciplinary team and the use of the AGREE II tool. The research team defined high-quality CPGs as ≥60% in the 3 domains of interest on the AGREE II instrument. These domains are consistent with other high-quality musculoskeletal reviews (36), while 60% is supported by other arthritis and osteoporosis reviews (41,42). Grading of interventions and consensus statements (e.g., "should do," "could do," "do not do," or "unsure") were based on the language used in CPGs and required interpretation by the research team. Consensus statements were cross-checked by 2 authors (SB and IL) to mitigate the risk of misinterpretation. It is important to acknowledge that the majority of the literature regarding OA management is based on hip and knee OA, often neglecting OA in other joints. For transparency, we have listed the affected joint for each recommendation in Supplementary Tables 3 and 4, available on the *Arthritis Care & Research* website at http://onlinelibrary.wiley.com/doi/10.1002/acr.25101.

In conclusion, 7 consistent "should do" recommendations were identified across the 11 CPGs. Exercise therapy, education, and weight loss (if relevant) should be recommended for people with OA before considering pharmacologic or surgical

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interventions, with care being patient centered. Hand orthosis should be considered for those with hand OA. These core tenets of OA care can be used by health care providers to improve consistency and quality of OA care.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Ms. Conley had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study conception and design. Lin.

Acquisition of data. Conley, Gunatillake.

Analysis and interpretation of data. Conley, Bunzli, Bullen, O'Brien, Persaud, Gunatillake, Dowsey, Choong, Lin.

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Chapter 5 What are the core recommendations for gout management in first line and specialist care? Systematic review of clinical practice guidelines

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What are the core recommendations for gout management in first line and specialist care? Systematic review of clinical practice guidelines

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Abstract

Background Gout is the most common inflammatory arthritis, increasing in prevalence and burden. Of the rheumatic diseases, gout is the best-understood and potentially most manageable condition. However, it frequently remains untreated or poorly managed. The purpose of this systematic review is to identify Clinical Practice Guidelines (CPG) regarding gout management, evaluate their quality, and to provide a synthesis of consistent recommendations in the high-quality CPGs.

Methods Gout management CPGs were eligible for inclusion if they were **(1)** written in English and published between January 2015-February 2022; focused on adults aged ≥ 18 years of age; and met the criteria of a CPG as defined by the Institute of Medicine; and **(2)** were rated as high quality on the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument. Gout CPGs were excluded if they required additional payment to access; only addressed recommendations for the system/organisation of care and did not include interventional management recommendations; and/or included other arthritic conditions. OvidSP MEDLINE, Cochrane, CINAHL, Embase and Physiotherapy Evidence Database (PEDro) and four online guideline repositories were searched.

Results Six CPGs were appraised as high quality and included in the synthesis. Clinical practice guidelines consistently recommended education, commencement of non-steroidal anti-inflammatories, colchicine or corticosteroids (unless contraindicated), and assessment of cardiovascular risk factors, renal function, and co-morbid conditions for acute gout management. Consistent recommendations for chronic gout management were urate lowering therapy (ULT) and continued prophylaxis recommended based on individual patient characteristics. Clinical practice guideline recommendations were inconsistent on when to initiate ULT and length of ULT, vitamin C intake, and use of pegloticase, fenofibrate and losartan.

Conclusion Management of acute gout was consistent across CPGs. Management of chronic gout was mostly consistent although there were inconsistent recommendations regarding ULT and other pharmacological therapies.

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Table 5.1 Clinical Practice Guidelines (CPGs) Selection Criteria

This synthesis provides clear guidance that can assist health professionals to provide standardised, evidence-based gout care.

Trial registration The protocol for this review was registered with Open Science Framework (DOI https://doi.org/10.17605/OSF.IO/UB3Y7).

Keywords Evidence-based care, Gout, Practice guidelines, Evidence-based Medicine.

Background

Gout is the most common inflammatory arthritis, estimated to affect 1–4% of people worldwide [1]. The annual incidence of gout is 2.68 per 1000 persons and its prevalence is increasing with risk factors including dietary, genetic, and socioeconomic factors, presence of sustained hyperuricaemia or comorbid conditions [1–3]. Gout is a considerable burden for both people living with the condition and health care systems [4]. Per person, direct costs of USD $18,362 and indirect costs of USD $4,341 per annum are reported [5]. Cost and burden of gout are compounded by the high prevalence of comorbidities in people with gout, such as hypertension, diabetes mellitus, ischaemic heart disease, kidney disease and obesity [6].

Gout is both a metabolic urate accumulation disease and an autoinflammatory arthritic disease [7]. A gout flare is characterised by the onset of a painful, swollen, hot and red joint(s) [8]. After the first gout flare, recurrent flares can occur and gout may become tophaceous and/or erosive [9]. Optimal management of gout requires management of both gout attacks (autoinflammatory) and the metabolic pathway management (urate lowering treatment). Of the rheumatic diseases, gout is the best-understood and potentially most manageable condition, with complete control possible with safe, effective, and inexpensive pharmacological treatment when prescribed at the correct dosage and maintained long-term [2]. However gout frequently remains untreated or poorly managed [10]. Inconsistent recommendations across gout CPGs can result in confusion amongst health care practitioners, potentially contributing to sub-optimal gout management [11–13].

Clinical practice guidelines include recommendations intended to optimise patient care based on evidence and expert opinion [14]. Several CPGs have been published in recent years regarding the management of gout, albeit with variable quality and heterogenous recommendations [12, 15]. The purpose of this systematic review is to identify CPGs regarding gout management, evaluate their quality, and to provide a synthesis of consistent recommendations in the high-quality CPGs. By synthesizing these recommendations, healthcare providers such as general practitioners and rheumatologists will be supported in informed decision-making regarding gout management.

Table 1 Clinical Practice Guidelines (CPGs) selection criteria

Inclusion criteria
• Published between January 2015 –February 14th, 2022.
• For the interventional management of gout.
• For adults (people aged ≥ 18 years).
• Published in the English language or in which a complete English language version is available.
• Developed using a systematic process that is a guideline based on a systematic review of the literature and developed by an expert, multidisciplinary panel [14].
• Represents an original body of work i.e., not solely an adaptation or systematic review of existing guidelines.
Exclusion criteria
• Does not include interventional management recommendations.
• Includes other arthritic conditions.
• **Only** addresses recommendations for the system/organisation of care.
• Required additional payment to access.

Methods

Search strategy and eligibility criteria

This systematic review was registered on the Open Science Framework (DOI https://doi.org/10.17605/OSF.IO/UB3Y7) and followed the Preferred Reporting Items for Systematic reviews guidelines [16]. A search strategy was developed for relevant terms related to CPGs (e.g., guideline*.mp. or Practice Guideline/ or Guideline/) and Gout. The full search strategy is available in Appendix 2. As this is part of a series of systematic reviews on arthritis management, search terms included other conditions and CPGs related to gout were identified from the articles yielded. The search was applied to the following databases: OvidSP MEDLINE, Cochrane, CINAHL, Embase and Physiotherapy Evidence Database (PEDro). A second search was conducted of four guideline repositories: Guidelines International Network, National Health and Medical Research Council, Effective Health Care from Agency for Health Care Research and Quality, and the National Institute for Health and Care Excellence. The search included CPGs published between January 2015 to February 14th, 2022 to reflect up-to-date research evidence (see Table 1). The list of included CPGs was reviewed by two rheumatologists who are clinician-researchers (MN and RG), to identify if any CPGs were missing to their knowledge.

Protocol changes

The original protocol excluded CPGs that addressed one treatment modality only e.g., medication prescribing. However, to improve comprehensiveness of the review, CPGs addressing single interventions were included as they were considered important for gout management. This decision to widen the scope was made during the study selection phase of the review. The timeframe proposed in our original search strategy was between January 2015 and December 2020 but was extended to include published CPGs up until February 14th 2022.

Study selection

Search results from the databases were aggregated in Endnote™ and duplicate records removed. Records were imported to the Covidence software program (Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org). Titles and abstracts were screened independently by two reviewers (BC and TG or IL) and assessed for eligibility according to criteria. Full texts articles were then screened, and final inclusion of articles was agreed on by consensus between the two reviewers or where necessary, consultation with a third reviewer (SB).

Data appraisal: Quality assessment of guidelines

Clinical practice guidelines were assessed for quality using the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument [17]. The AGREE II is an internationally validated, widely used tool to assess the quality of CPGs in any disease area [17, 18]. Seven members of the research team undertook the online AGREE II practice exercise and were provided with the AGREE II user manual [17, 19]. Clinical practice guidelines were independently appraised by pairs of the reviewers (BC, JB, JP, PO, SB, TG). The AGREE II instrument consists of 23 individual items grouped in six domains: scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability, and editorial independence. Consistent with the AGREE II manual, each item was independently rated by two reviewers to increase the reliability of the assessment using a 7-point Likert scale from 1 (strongly disagree) to 7 (strongly agree) [17]. Domain scores were calculated, using the following formula: (Obtained score - minimum possible score / maximum possible score - minimum possible score) [17]. The AGREE II developers do not provide uniform criterion for overall quality and recommend research teams determine criteria based on their own circumstances [17]. Authors determined a cut-off score equal to or greater than 60% of the maximum possible score in three domains we believed were most important for validity. These were: rigour of development (domain 3), editorial independence (domain 6) and stakeholder involvement (domain 2). The three domains of interest are consistent with a previous review of CPGs in musculoskeletal pain management, and a value of 60% for 'high quality' is similar to other reviews [20–22].

Inter-rater agreement

Domain percentages and overall assessment rating (%) for each reviewer were independently calculated. Our criteria for acceptable inter-rater agreement were domain percentages and overall scores that were less than or equal to 20% difference between reviewers (BC, JB, JP, PO, SB, TG) as intraclass coefficient values of 80 or above are considered either excellent or almost perfect [23, 24]. In instances where there was a variation of greater than 20% between scores, reviewers met to discuss the ratings and a rating was determined by consensus, involving a third reviewer if consensus was not achieved. Fifteen domains required consensus across six reviewers (BC, JB, JP, PO, SB, TG).

Data extraction

Data were independently extracted by the first author (BC) using a purpose-designed Excel spreadsheet, adapted from a previous musculoskeletal review [21]. This comprised of CPG characteristics (e.g., title, country of publication), methodology, guideline topic target users (Appendix 4). Recommendations were extracted from CPGs and ranked as either 'should do', 'could do', 'do not do' or 'uncertain' (Appendix 3). Recommendation ratings were consistent with language used in the CPGs and a grading system of a previous musculoskeletal systematic review of CPGs [21]. While CPGs used variable language, their recommendations and quality of evidence were based on the same criteria GRADE [25–28], Oxford Centre for Evidence-Based Medicine standards [25, 29, 30] or an adaption of these tools [31]. In the CPGs a 'should do' meant that the recommendation was based on a high level of evidence and benefit unequivocal and a strong consensus from the development group. A 'could do' meant that consistent evidence from multiple lesser quality studies or one high quality study and where benefits outweigh harms and/or based on strong consensus with the development group. A 'do not' recommendation was based on either high- or low-quality studies where the harms outweigh the benefits. Whilst an 'uncertain' recommendation was stated if only poor-quality evidence was available, and the development group couldn't recommend for or against. Three authors (SB, MN, RG) independently checked tables and interpretation of recommendations, any discrepancies were identified and resolved by discussion between the authors and rechecking data against the original citation.

Figure 5.1 PRISMA 2020 Flow Diagram for New Systematic Reviews Which Included Searches of Databases, Registers and Other Sources

Narrative summary

The narrative summary was developed initially by one author (BC) and then reviewed and refined by four authors (SB, IL, MN and RG). The summary included a description of the number of CPGs that reported on an intervention, what the recommendations involved and highlighted areas where recommendations were consistently similar in their details or where there were inconsistencies (Appendix 7). Recommendations that were considered consistent between CPGs, were described as 'consensus' (see Appendix 1 Process of defining consensus between CPGs on individual recommendations).

Results

Data extraction

Ten CPGs were identified. Six CPGs met the eligibility criteria [25–27, 29, 31, 32] and four were rated low quality on AGREE-II and excluded [33–36] (Fig. 1). All six high quality CPGs were developed by medical/professional societies, two societies were based in the United States of America [26, 27], three in Europe [25, 29, 32] and one in the United Kingdom [31]. Target users included health professionals [25–27, 29, 31, 32], people with gout [25, 26, 29, 31, 32] and their families [32], policy makers and those responsible for commissioning care [29, 31] (Appendix 4).

Quality of CPGs

The AGREE II scores for each CPG are provided in Appendix 6. AGREE II results for included CPGs are provided in Appendix 6.1 with CPGs rated low quality on AGREE II and excluded presented in Appendix 6.2. Quality was assessed across six domains: scope and purpose (range: 67-94%), stakeholder involvement (range: 50-92%), rigor of development (range: 68-82%), clarity of presentation (range: 78-94%), applicability (range: 21-92%), and editorial independence (range: 25-100%). The mean (SD) AGREE II scores for each item, domain and overall scores across all guidelines are displayed in Appendix 5. The mean overall scores for all CPGs were 77% (SD=12.4). The domain with the lowest mean score was 'applicability' (45%, SD=24.8), and the highest mean score was for 'clarity and presentation' (89%, SD=6.8).

Consensus recommendations (Fig. 2; Appendix 7)

Treatment of gout flare

Recommendations with 'Should do' consensus

The following recommendations were strongly recommended by two or more CPGs: non-steroidal anti-inflammatories (NSAIDs), colchicine and/or corticosteroids should be commenced as first-line medications [25–27, 29, 31, 32]. Patients should be provided with education on non-pharmacological and pharmacological

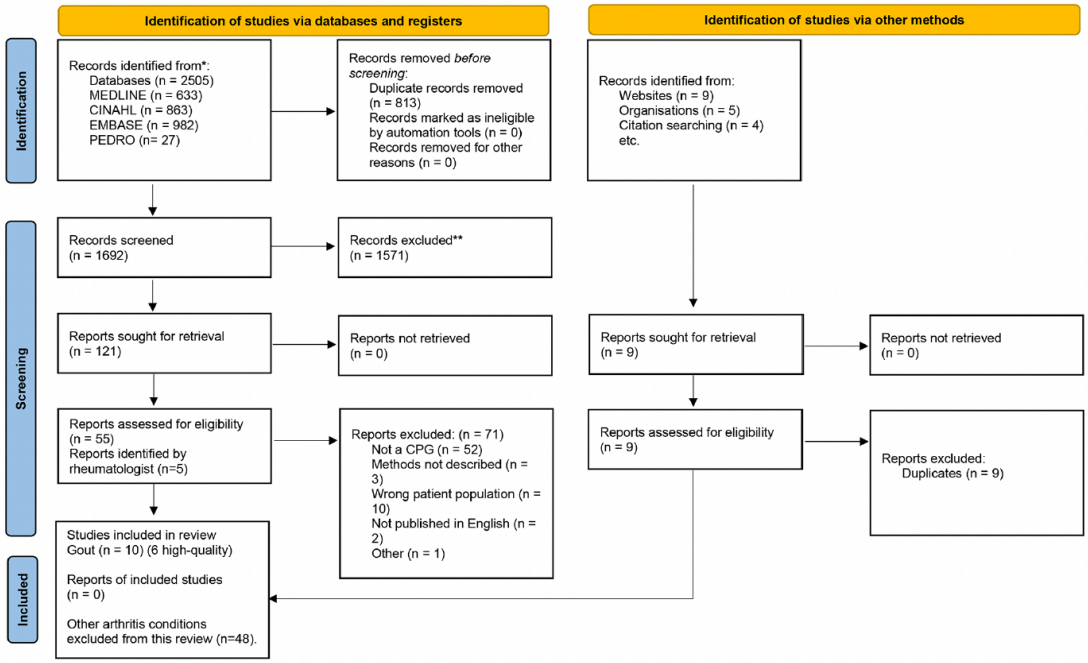


Fig. 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources

Figure 5.2 Gout Management from Synthesis of Six CPGs

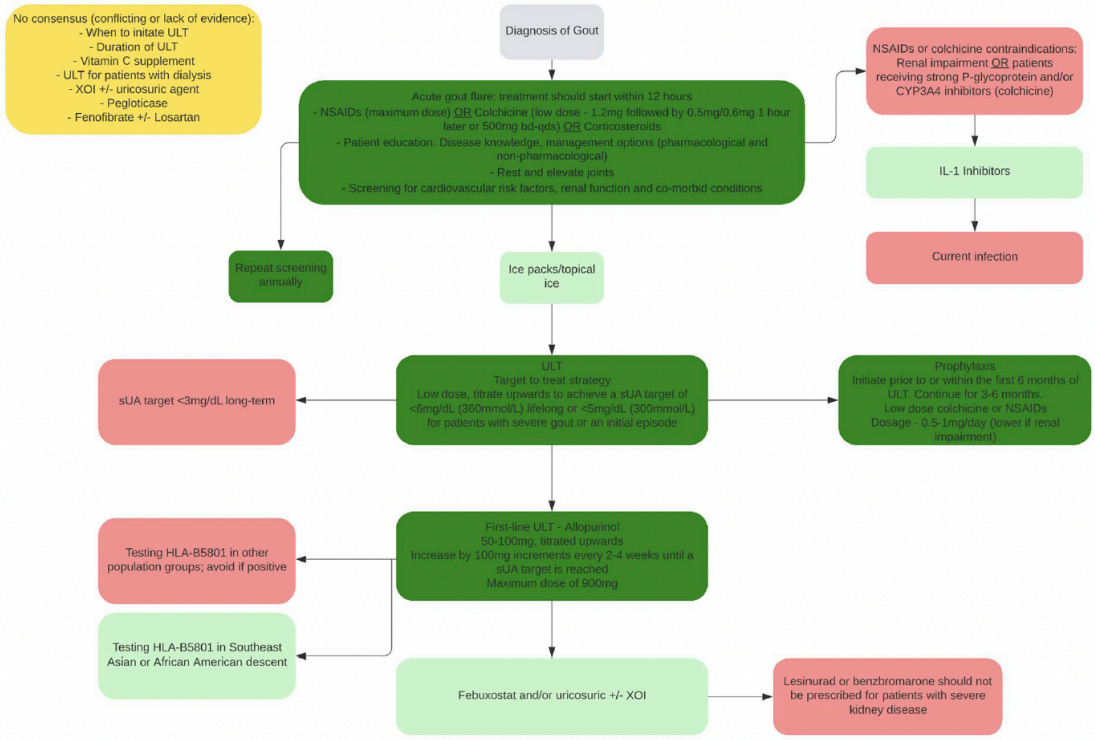


Fig. 2 Gout management from synthesis of six CPG's:
Key: Dark green: Should do consensus recommendations. Light green: Could do consensus recommendations. Red: Do not do consensus recommendations or contraindicated. Yellow: No consensus recommendations.
Abbreviations: sUA – serum uric acid; IL-1 – Interleukin-1; ULT – urate-lowering therapy; XOI – xanthine oxidase inhibitor.

management options and advice on elevating and resting the affected joint(s) [25–27, 29, 31]. Education should also include dietary advice and ULT [25, 27, 29, 31], weight loss for patients who are overweight or obese [25, 26, 29, 31], exercise advice for all patients, and (if applicable) smoking cessation [29]. Clinical practice guidelines did not report how to implement education topics specifically [25, 26, 29, 31]. Screening for cardiovascular risk factors (e.g., coronary heart disease, heart failure, stroke, peripheral arterial disease, renal impairment, obesity, hyperlipidaemia, hypertension, diabetes mellitus, and smoking) should be conducted and repeated annually [25, 29, 31]. Prophylaxis should be recommended prior to or within the first six months of initiating ULT and continued for at least 3–6 months with colchicine being the preferred treatment at a dosage of 0.5-1 mg/day followed by NSAIDs, or COX-2 inhibitors and low-dose glucocorticoids if the other options are contraindicated, not tolerated, or ineffective [25, 26, 29]. Patients with renal impairment should receive a reduced dose of prophylaxis [25].

Recommendations with 'Could do' consensus

The following recommendations were conditionally recommended by two or more CPGs, or equally conditionally and strongly recommended: Cold therapies e.g. ice packs, could be used in combination with other evidence-based therapies [26, 31]. Interleukin-1 (IL-1) inhibitors can be considered for people with acute gout or who have frequent flares, who have contraindications or have not responded adequately to standard treatment of colchicine, NSAIDs and corticosteroids [25, 26, 29, 31].

Recommendations with 'Do not do' consensus

The following recommendations were recommended against by two or more CPGs: IL-1 inhibitors should be avoided if the patient has a current infection [25]. NSAIDs should not be recommended for people with gout and severe renal impairment, who are experiencing an acute gouty attack [25, 29]. Similarly, colchicine should be avoided for patients with renal impairment or for patients who are receiving strong P-glycoprotein and/

or CYP3A4 inhibitors such as cyclosporin or clarithromycin [25, 29, 31].

Chronic gout management

Recommendations with 'Should do' consensus

The following recommendations were strongly recommended by two or more CPGs: Serum uric acid (sUA) levels should be monitored and ULT should be based on a treat-to-target strategy and adjusted to achieve a sUA target < 6 mg/dL (360 mmol/L) lifelong or sUA < 5 mg/dL (300mmol/L) for patients with severe or tophaceous gout [25, 29, 32] with one CPG recommending this target can be considered for all patients with gout, based on expert opinion only [31]. Allopurinol should be recommended as a first-line ULT starting at 50-100 mg daily (no greater than 100 mg) and lower in patients with chronic kidney disease [25, 26, 29, 31, 32]. Allopurinol dose should be increased by 100 mg increments every 2–4 weeks or 4 weeks until sUA target is reached, with a maximum daily dose of 900 mg [25, 29, 31, 32].

Recommendations with 'Could do' consensus

The following recommendations were conditionally recommended by two or more CPGs, or equally conditionally and strongly recommended: Febuxostat can be used as an alternative second-line xanthine oxidase inhibitor (XOI) for patients who have renal impairment and/or chronic kidney disease, where allopurinol is contraindicated or has not been effective in achieving the therapeutic sUA target [26, 29, 31, 32]. A low dose should be prescribed initially of 80 mg-<100 mg daily, increasing the dosage after 4 weeks to 120 mg daily, if necessary to achieve therapeutic target and lower for patients with chronic kidney disease [26, 31]. Uricosuric agents either in combination with a XOI or as monotherapy can be considered for patients who have a poor response, are intolerant or have an adverse reaction to XOI's [29, 31, 32].

IL-1 inhibitors can be considered if a patient has contraindications or hasn't responded to standard treatments for inflammation of gout such as: colchicine, NSAIDs and corticosteroids [25, 26, 29, 31]. If diuretics are being used to treat hypertension and the hypertension is controlled, other anti-hypertensive agents should be considered instead [25, 26, 31].

Recommendations with 'Do not do' consensus

The following recommendations were recommended against by two or more CPGs: A sUA level < 3 mg/dL should be avoided long-term, due to the possibility of adverse effects that may be associated with a very low sUA [29, 31]. Allopurinol should be avoided in patients who have the HLA-B*5801 allele [32]. Uricosuric agents, lesinurad or benzbromarone should not be prescribed for patients with severe kidney disease [32]. Lesinurad should be avoided if a patient has experienced a vascular event in the last 12 months [32]. Measuring urinary uric acid and alkalinizing urine while using uricosuric treatment was recommended against, based on expert opinion [26]. The guideline development group concluded that uricosuric use is infrequent, there is a lack of evidence to support alkalinizing agents for patients with gout and challenges with regular testing such as, inaccurate results from diet [26]. IL-1 inhibitors should not be considered if the patient has a current infection [25]. Patients who are not of Southeast Asian descent (e.g., Han Chinese, Korean, Thai) or African American should not be tested routinely for HLA–B*5801 [26, 32].

Recommendations with no consensus

Inconsistent recommendations were reported for when to initiate ULT, duration of ULT, vitamin C intake, pegloticase, fenofibrate and losartan [25, 26, 29, 31, 32]. Clinical practice guidelines varied on when to initiate ULT, ranging from at their first presentation, following diagnosis [25, 29, 31] to after a flare has settled [31], taking into consideration particular criteria [25, 26, 29, 31] (For full details, see Appendix 7). Duration of ULT varied from short term < 12 months [27] to indefinitely [26]. There were conflicting recommendations regarding the use of vitamin C with one CPG conditionally recommending for [31] and one against the use in managing gout [26], fenofibrate and losartan were recommended against [26, 31] although, one CPG conditionally recommended for their combined use in In treating comorbid hypertension or dyslipidaemia in people with gout [31]. Consensus recommendations are presented in Fig. 2.

Discussion

Six of the ten CPGs identified were assessed as high quality on the AGREE II instrument. Quality scores were higher than in previous reviews [12, 15]. This may be due to the inclusion of more recent CPGs that are of higher quality, or because different criteria to define quality were used. The AGREE II domain 'Applicability' was frequently rated lower than other domains, suggesting developers paid limited attention on how CPGs are translated into practice.

There are consistent recommendations for acute gout management which are patient education, medication to treat inflammation (NSAIDs, colchicine, or corticosteroids) and screening to identify comorbid conditions such as cardiovascular and renal diseases. These anti-inflammatory medications report a similar high-level of efficacy and choice of treatment should be based on the presence of comorbidities and patient preference [37, 38]. Clinicians can be confident that by following these recommendations, they are offering high quality care,

as these findings align with recent gout management reviews and have been supported for over two decades [2, 7, 37, 39].

Clinical practice guidelines recommended clinicians take on an educative role with patients around pharmacological management and lifestyle modifications such as, weight loss and dietary changes. However, implementation of education into practice remains an issue. People with gout report rarely receiving clear guidance on these topics possibly due to a lack of detail and clarity of these recommendations [40, 41]. The CPGs included in this review grouped dietary recommendations together, leading to a lack of clarity in the strength of recommendations for individual dietary choices. Similarly, CPGs recommended clinicians provide advice on other non-pharmacological interventions such as rest/elevation of affected joints, exercise and smoking cessation, although reported insufficient detail on how to apply these interventions in practice [25, 29, 31]. Future CPGs should provide further guidance on these educational topics and look to separate dietary recommendations based on their level of evidence. Individualised dietary advice should consider personal, social and cultural factors including comorbid health conditions, preferences and availability or access to food [42]. Clinicians, particularly general practitioners, have reported a lack of time in consultations as a barrier to effectively educating patients with gout [43]. Involvement of a multi-disciplinary team approach to care, can help address time concerns for limiting education and has been shown to be effective in lowering sUA levels [44–46]. In conjunction with face to face education, providing patients with informational materials such as written materials or web-based resources with content tailored to the patient, may improve uptake of behaviour change [45, 47]. Patient adherence to medical advice remains an issue. Providing clear, jargon-free instructions, at a level that can be understood by the patient and using pictures where appropriate, can facilitate uptake of education and advice [48]. Furthermore, development of therapeutic relationships and equipping patients with the skills and motivation to be adherent with their treatment is needed, is needed, as evidenced by the success of a nurse-led intervention for gout [6, 49, 50].

Urate lowering remains the mainstay of the long-term management of gout with a lack of adherence being recognised as the main cause of gout management failure [2, 51]. Adherence to ULT is low, varying from 20 to 70% [52]. This may be due to misconceptions about what gout is and how best to manage it such as: patients believing that gout is an acute disease which does not require ongoing management; concern about ULT side effects; and/or lack of confidence in ULT effectiveness due to experiencing a gout flare following initiating ULT [2, 43, 47, 53]. Clinical practice guidelines are very clear that education on gout medical management is critical to address a patients' understanding of optimal management. Clinicians should explain the importance of taking ULT regularly and continually to prevent gout attacks and discuss possible side effects such as the risk of flares once commencing ULT [29, 31, 45, 54]. While it is important to educate people about dietary and lifestyle modifications, on their own these modifications do not lead to significant urate reduction, therefore education about the pharmacological management of gout is essential [4, 7, 37].

Clinician level barriers to effective medical management include a lack of referrals between primary and specialist's care, knowledge gaps, conflicting recommendations from CPGs and similar misconceptions to patients such as: general practitioners treating gout as an acute condition only [12, 15, 43, 55]. Appropriate training, development of CPG consensus statements, clearly defined roles amongst healthcare practitioners and strengthening of networks between health professionals can help to address barriers [56]. While CPG can address care of individual people with gout, they do not usually address how to optimise health systems in the delivery of that care. In New Zealand multi-component interventions to reduce barriers to prescribing of ULT and enhance access to ULT have been successful in improving quality of gout care [49]. In the United Kingdom, nurse-led care gout care has been shown to increase the proportion of patients reaching target-serum urate and is cost effective [50]. It seems likely that addressing health systems and care delivery will be integral to achieving better health outcomes for people with gout.

Clinical practice guidelines were consistent in recommending ULT (preferably allopurinol) and prophylaxis for managing chronic gout. Allopurinol was recommended at a low dose of 50-100 mg daily (no greater than 100 mg) and titrated upwards [25, 26, 29, 31]. Research has shown that approximately 400mgs daily or above is often needed achieve sUA target [37]. Sub-optimal use of allopurinol is common, ULT is often underutilised by clinicians, or when it is initiated is often prescribed at a fixed dose, therefore underdosing [11, 54, 57]. Underdosing may be due to fear of kidney damage, which has not been supported by evidence or allopurinol hypersensitivity, a rare yet highly fatal adverse reaction [4, 58–60]. Clinicians should be aware of potential side effects and prescribe ULT in accordance with CPGs guidance, titrating dose as required.

Clinical practice guidelines were inconsistent in their recommendation of when to commence ULT, varying from immediately following diagnosis, to only being indicated in certain clinical scenarios, based on an individual patients' circumstances [25, 26, 29, 31]. This discrepancy could be due to no internationally agreed upon

criteria, and this decision of when to commence ULT being based on the individual patients' circumstances. One CPG did not provide a recommendation on this topic, and reported no clear guidance on ULT in general, sUA target and sUA monitoring [27, 61]. Clinical practice guidelines are divided as to whether it can or cannot be considered whilst the patient is experiencing a gout flare. Historically, it was thought that starting ULT during a gout flare could worsen or prolong the flare, however this has since been questioned [6]. Similarly, heterogeneity existed between CPGs of how long to continue ULT, with one CPG recommending to continue indefinitely and another recommending shorter durations (<12 months) due to a lack of research investigating the long-term benefits of ULT for people with single or infrequent gout (<2 attacks per year) [26, 27]. The American College of Physicians CPG recommendation to avoid long-term ULT use has been heavily criticised for its lack of clear, detailed guidance and for ignoring key ULT considerations such as the presence of tophi [61]. Differences in recommendations have been attributed to their interpretation of the literature by the development group, which included physicians, and reflects the common belief amongst the medical community that gout is an intermittent condition that does not require ongoing management [61]. Despite this recommendation, it is widely accepted that effective gout management requires long-term adherence to ULT, to achieve an optimal sUA target [54]. If CPGs report varying recommendations on when to commence and how long to continue ULT for, this could lead to either delayed commencement and/or failure to prescribe long-term ULT, contributing to the poor long-term management reported in gout patients.

Further areas of research

Further research is needed to understand why gout CPGs differ in their recommendations and to determine recommendations on the current areas with no consensus: when to initiate ULT and length of ULT, vitamin C intake, pegloticase, fenofibrate and losartan. While developing high-quality CPGs is important, this alone is insufficient to improve health outcomes for people with gout [62]. Further research should focus on implementation strategies to encourage uptake of CPGs recommendations in clinical practice.

Strengths and Limitations

Strengths of this systematic review include the use of AGREE II tool as a systematic approach to synthesis [17], and selection of a high-level quality cut-off value. Additionally, we involved a multi-disciplinary team, including rheumatologists (RG, MN), physiotherapists (IL, SB, JP, BC), an Aboriginal health researcher (JB), orthopaedic surgeon (PC), nurse and epidemiologist (MD) and social scientists (TG, PO). The review was conducted according to the published protocol, with only two minor amendments to expand the inclusion criteria so that CPGs on single aspects of gout management could be included and to update the search strategy. The AGREE II instrument reflects methodological processes, not necessarily content, and scores may reflect reporting rather than methodological quality. The research team defined high quality as 60% in the three domains of interest (domain 2, 3 and 6), similar to other reviews [21, 22]. Grading of interventions and consensus recommendations (e.g., 'should do', 'could do', 'do not do' or 'unsure' recommendations) were based on the language used in CPGs. However, CPGs differ in their use of language and recommendations may be based on expert opinion without strong evidence to support this decision. To improve confidence in our interpretations, consensus statements were developed by three authors (BC, SB and IL) and reviewed by the expert clinicians (RG and MN).

Conclusions

This synthesis of current high-quality CPGs provides guidance for health care providers, on recommended gout care. Recommendations from six CPGs were that acute gout flare management should include anti-inflammatories, education, screening, and rest/elevation of the affected joints. Established gout should be managed with ULT and continued prophylaxis to prevent further gout flare and manage tophaceous and erosive gout. CPGs disagreed on when to initiate ULT and length of ULT, vitamin C intake, pegloticase, fenofibrate and losartan. This synthesis of recommendations is relevant to healthcare providers and can be implemented in clinical practice to standardise high-quality care and optimise patient outcomes.

Abbreviations

AGREE	Appraisal of Guidelines for Research and Evaluation
CPGs	clinical practice guidelines
GP	general practitioner
NSAIDs	non-steroidal anti-inflammatory
sUA	serum uric acid
IL-1	Interleukin-1
ULT	urate-lowering therapy
XOI	xanthine oxidase inhibitor

Supplementary Information

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Supplementary Material 1. Appendix 1.

Supplementary Material 2. Appendix 2.

Supplementary Material 3. Appendix 3.

Supplementary Material 4. Appendix 4.

Supplementary Material 5. Appendix 5.

Supplementary Material 6. Appendix 6.

Supplementary Material 7. Appendix 7.

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Authors' contributions
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Data Availability
All data generated or analysed during this study are included in this published article [and its supplementary information files].

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
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Chapter 6 What are the Core Recommendations for Rheumatoid Arthritis Care? Systematic Review of Clinical Practice Guidelines.

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REVIEW ARTICLE

What are the core recommendations for rheumatoid arthritis care? Systematic review of clinical practice guidelines

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Abstract
Systematic review to evaluate the quality of the clinical practice guidelines (CPG) for rheumatoid arthritis (RA) management and to provide a synthesis of high-quality CPG recommendations, highlighting areas of consistency, and inconsistency. Electronic searches of five databases and four online guideline repositories were performed. RA management CPGs were eligible for inclusion if they were written in English and published between January 2015 and February 2022; focused on adults ≥ 18 years of age; met the criteria of a CPG as defined by the Institute of Medicine; and were rated as high quality on the Appraisal of Guidelines for Research and Evaluation II instrument. RA CPGs were excluded if they required additional payment to access; only addressed recommendations for the system/organization of care and did not include interventional management recommendations; and/or included other arthritic conditions. Of 27 CPGs identified, 13 CPGs met eligibility criteria and were included. Non-pharmacological care should include patient education, patient-centered care, shared decision-making, exercise, orthoses, and a multi-disciplinary approach to care. Pharmacological care should include conventional synthetic disease modifying anti-rheumatic drugs (DMARDs), with methotrexate as the first-line choice. If monotherapy conventional synthetic DMARDs fail to achieve a treatment target, this should be followed by combination therapy conventional synthetic DMARDs (leflunomide, sulfasalazine, hydroxychloroquine), biologic DMARDS and targeted synthetic DMARDS. Management should also include monitoring, pre-treatment investigations and vaccinations, and screening for tuberculosis and hepatitis. Surgical care should be recommended if non-surgical care fails. This synthesis offers clear guidance of evidence-based RA care to healthcare providers.
Trial registration The protocol for this review was registered with Open Science Framework (https://doi.org/10.17605/OSF.IO/UB3Y7).

Keywords Evidence-based care · Rheumatoid arthritis · Practice guidelines · Evidence-based medicine · Systematic review

Abbreviations

AGREE	Appraisal of guidelines for research and evaluation
bDMARDs	Biologic disease-modifying anti-rheumatic drug
CHF	Congestive heart failure
CPG	Clinical practice guideline
csDMARDs	Conventional synthetic disease-modifying anti-rheumatic drug
DMARD	Disease-modifying anti-rheumatic drug
HCQ	Hydroxychloroquine
LEF	Leflunomide
MTX	Methotrexate
NSAIDs	Non-steroidal anti-inflammatory drugs
RA	Rheumatoid arthritis
SSZ	Sulfasalazine
TB	Tuberculosis
TNF	Tumor necrosis factor inhibitor
tsDMARDs	Targeted synthetic disease-modifying anti-rheumatic drugs

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Table 6.1 Clinical Practice Guidelines (CPGs) Selection Criteria

Introduction

Rheumatoid arthritis (RA) is a systemic autoimmune disorder affecting 0.1–2.0% of most populations [1]. It is a long-term condition characterized by joint inflammation, with potential for joint damage and extra-articular manifestations [2]. RA can significantly impact physical, mental, and social health and can increase morbidity and mortality [3, 4]. Economic costs, including direct (e.g., drug costs) and indirect costs (e.g., absenteeism and work disability) are estimated to range from US$2,408 to US$83,845 annually [5].

The last 30 years have seen many substantive changes in RA management including expansion in options for pharmacological management, introduction of instruments for clinical monitoring of disease activity and impact, and increased focus on patient-centered care and support for self-management [6, 7]. The pharmacological management options have expanded from conventional synthetic disease-modifying anti-rheumatic drugs (csDMARDs) to biologic DMARDS (bDMARDs) and more recently targeted synthetic DMARDS (tsDMARDS). There are also multiple treatment strategy trials to be considered alongside local medication availability [8]. The evidence underpinning these management approaches are often summarized for clinicians in clinical practice guidelines (CPG).

The aim of CPGs is to support evidence-based clinical decision-making, improve consistency of care and optimize patient outcomes [9]. Robust CPGs comprise a set of management recommendations, created from a systematic review of the literature and consensus by an expert panel [10]. While CPG production has increased in recent decades there are some concerns about quality and implementation into practice [11-13]. Low quality CPGs do not improve care, and conflicting recommendations between CPGs can lead to clinician confusion [11, 14]. To date, systematic reviews have either appraised CPG quality [15], or provided a narrative summary on RA management options [16], or reported on both CPG quality and content, but were only specific for certain management options (e.g., physiotherapy interventions [12], Chinese medicine [17]). To the best of the authors knowledge, currently no systematic review has appraised CPG quality and synthesized recommendations from high-quality CPGs for all management options. By summarizing high quality CPG recommendations, we can offer healthcare providers clear, simple guidance on evidence-based RA care.

The aims of this systematic review were to (1) evaluate the quality of the CPGs for the management of RA and (2) to provide a synthesis of high-quality CPG recommendations, highlighting areas of consistency and inconsistency.

Materials and methods

This systematic review is reported according to the Preferred Reporting Items for Systematic reviews guidelines and the protocol registered on the Open Science Framework (https://doi.org/10.17605/OSF.IO/UB3Y7) [18, 19]. For full details of methods, see Conley et al. [20]. Briefly, five databases (OvidSP MEDLINE, Cochrane, CINAHL, Embase, and Physiotherapy Evidence Database (PEDro) and four guideline repositories were searched from January 2015 to April 1st, 2023. Online Resource 1 provides the details of the search strategy. Search results were exported into Endnote™ and duplicates removed electronically and manually checked before importing titles/abstracts into Covidence systematic review software (Veritas Health Innovation, Melbourne, Australia. Available at www.covidence.org). Two independent authors (BC and TG or IL) screened the titles and abstracts to identify relevant studies. Then full texts were then screened for eligibility (Table 1). Any discrepancies were resolved by a third reviewer. Deviations from the original protocol included updating the search twice and inclusion of CPGs that addressed one treatment modality (e.g.,

Table 1 Clinical practice guidelines (CPGs) selection criteria

Inclusion criteria
• Developed between January 2015 and April 1st, 2023
• For the interventional management of rheumatoid arthritis
• For adult populations (aged ≥ 18 years)
• Published in the English language or in which a complete English language version is available
• Developed using a systematic process that is a guideline based on a systematic review of the literature and developed by an expert, multidisciplinary panel [2]
• Represents an original body of work, i.e., not solely an adaptation or systematic review of existing guidelines
Exclusion criteria
• Does not include interventional management recommendations
• Includes other arthritic conditions
• Only addresses recommendations for the system/organisation of care
• Unavailable via institutional access, i.e., requires additional payment

Table 6.2 Recommendation Classification, Definition and Examples of Terminology for Each Classification

medication prescribing) which were originally excluded based on their narrow scope.

The Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument was used to assess CPG quality [21]. This is a valid, reliable tool that is widely used in CPG appraisal, including those for RA management [11, 12, 15, 22, 23]. Pairs of reviewers (from SB, PO, JB, JP, TG, IL, BC) independently rated each CPG against the AGREE II items using a 7-point Likert scale, from 1 (AGREE II criteria not addressed) to 7 (all AGREE II criteria addressed). Individual reviewer domain scores were calculated and expressed as a percentage. We defined acceptable inter-rater agreement as domain scores of 80% or above, consistent with excellent intraclass coefficient values [24, 25]. If the two reviewer's domain scores varied equal to or greater than 20%, reviewers met to discuss discrepancies and a third reviewer was consulted to resolve any disagreements on the final rating. The AGREE II developers do not provide criteria for CPG quality, rather, they suggest this is at the discretion of the researchers [21]. Consistent with a previous musculoskeletal review, the authors of this study considered the following domains most important when screening high quality RA CPGs: stakeholder involvement (domain 2); rigor of development (domain 3); and editorial independence (domain 6) [13]. Arthritis reviews implementing the AGREE II instrument established an threshold for high quality as equal to or greater than 60% [12, 26]. We decided that CPGs that did not meet this definition were excluded (Online Resource 3).

The first author (BC) independently extracted and recorded CPG data on a bespoke Microsoft Excel spreadsheet, based on a previous musculoskeletal review [13] (Online Resource 2). CPG recommendations were extracted and ranked as either a "should do," "could do," "do not do," or "uncertain" (Online Resource 4). Recommendations were classified into these four categories based on language used in the CPGs (Table 2), consistent with a previous musculoskeletal systematic review of CPGs [13]. Two authors (SB and IL) cross-checked the extracted data and recommendation rankings, any inconsistencies were resolved through discussion among the three authors (BC, SB, IL) while referring to the original CPG.

Recommendations were categorized based on the type of intervention (non-pharmacological, pharmacological, and surgical) and then further divided into individual interventions within these categories (e.g., patient education). Narrative summaries were developed for individual interventions and identified which CPGs included a recommendation within that category; and areas of consistency and inconsistency between CPG recommendations (Online Resource 5). The research team developed a consensus process (Fig. 1), to describe the consistency of recommendations between CPGs, providing a global consensus recommendation on the individual interventions.

Results

Twenty-seven CPGs were identified (Fig. 2). Eleven were excluded as they did not meet criteria of high quality [38-48]. Three CPGs identified earlier in the search period were excluded as two guideline development groups published

Table 2 Recommendation classification, definition, and examples of terminology for each classification

Recommendation classification	Definition [13, 20]	Examples of terminology from CPGs
"Should do"	"Should do" recommendations were those that the authors determined should be applied in all circumstances unless there is a rationale not to. These were based on strong evidence, for example, multiple high-quality studies reporting clinically relevant positive effects, benefits that outweigh risks or when in the opinion of CPG development group members that the benefits were unequivocal	"Should" [8, 27-34], "strongly recommended"[35]
"Could do"	"Could do" recommendations were those that the authors determined could be applied depending on the circumstances of individual patients. They were usually based on consistent evidence from multiple lesser quality studies or one high quality study and where benefits outweigh harms	"May" [8, 28-30, 34], "could" [27], "can" [28, 30, 31], "consider" [32, 33], "conditionally recommended" [35], suggest offering [36]
"Do not do"	"Do not do" recommendations were those for which the authors determined there was strong evidence of no benefit and/or harms outweighing benefits	"Not recommended"[27, 30, 37], "recommend against" [36]
"Uncertain"	"Uncertain" recommendations were those for which the authors determined there was no recommendation for or against a practice, because of incomplete or inconsistent research findings. Not all CPGs provided uncertain recommendations	"It is not possible to recommend" [27]

Figure 6.1 *Creating the Consensus Recommendations*

Figure 6.2 *PRISMA 2020 Flow Diagram for New Systematic Reviews Which Included Searches of Databases, Registers and Other Sources*

Fig. 1 Creating the consensus recommendations

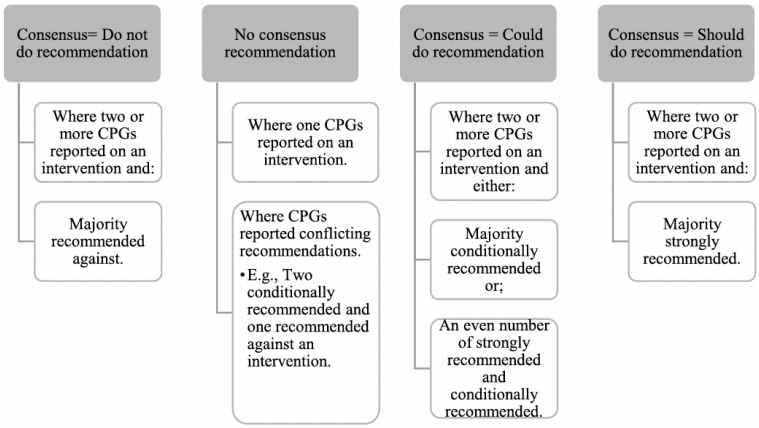
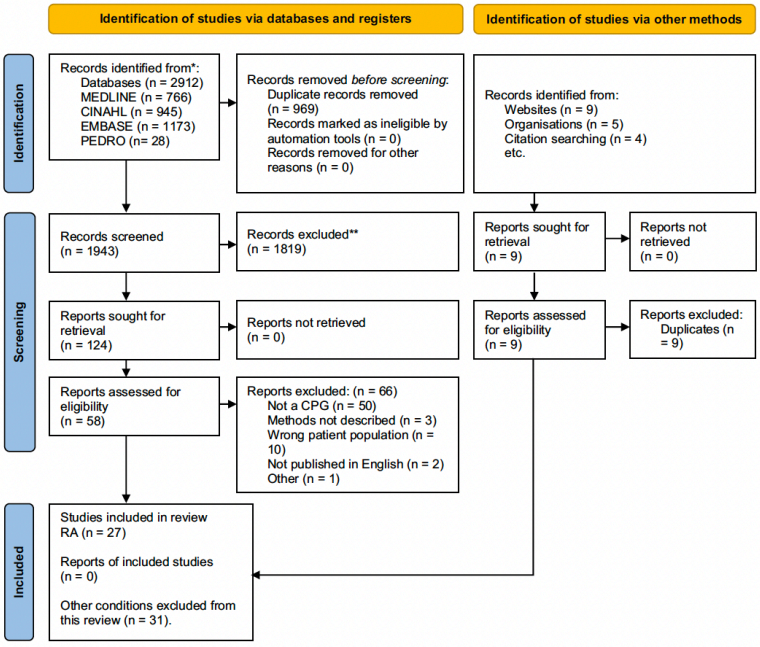


Fig. 2 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers, and other sources



an updated CPG within our search period [49-51] (Online Resource 3). Thirteen CPGs met the eligibility criteria [4, 8, 27-37]. Six were published in European countries [4, 8, 27, 31, 32, 34], two were published in the USA [33, 35], one in the UK [37], one in Brazil [28], one in Malaysia [29], one in Canada [36] and one internationally (Australia, India, Japan, and New Zealand) [30]. Most CPGs were developed by medical societies (77%) [4, 27-30, 32-36], some by an expert panel (15%) [8, 31] and one was a government report (8%) [37]. Target users were stated as: rheumatologists ($n=8$) [4, 8, 27, 28, 30, 31, 34, 36]; and other health professionals who manage patients with RA ($n=13$) [4, 8, 27-37]; patients ($n=7$) [4, 27, 29, 34-37], their families/carers ($n=3$) [27, 29, 37]; decision or policy makers ($n=3$) [4, 29, 36]; those responsible for commissioning care ($n=3$) [4, 34, 37]; and professional societies ($n=1$) [29] (Online Resource 2).

Table 6.3 CPG AGREE II Domain Scores and Quality Assessment (%) Included Studies

Table 3 CPG AGREE II domain scores and quality assessment (%) included studies

	Domain 1 Scope and Purpose	Domain 2 Stakeholder involvement	Domain 3 Rigour of development	Domain 4 Clarity of presentation	Domain 5 Applicability	Domain 6 Editorial independence	Overall assessment score	Domain 2,3,6 combined value
Included based on high-quality (13)								
ACR (2021) [35]	92	94	74	83	27	100	78	89
APLAR (2015) [30]	75	72	61	83	52	75	58	70
BSR [28]	78	42	65	83	38	75	67	60
CRA [36]	97	91	76	72	85	79	83	82
EULAR (2023) [34]	72	67	71	86	42	63	75	67
ISR [4]	72	97	76	69	21	92	83	88
MaHTAS [29]	94	69	51	69	50	58	58	60
NICE [37]	92	72	90	92	65	67	83	76
*Peter et al. [33]	64	69	70	67	23	92	64	77
*Santos et al. [32]	83	61	64	56	19	71	59	65
SER (2019) [27]	97	86	63	86	69	58	75	69
*Tenten-Diepenmaat et al. [31]	78	64	45	81	21	71	58	60
TLAR [8]	39	42	56	83	33	96	50	65

*First author given where there is no stated organisation; *ACR* American College of Rheumatology, *APLAR* Asia Pacific League of Associations for Rheumatology, *BSR* Brazilian Society of Rheumatology, *CRA* Canadian Rheumatology Association, *EULAR* European League Against Rheumatism, *ISR* Italian Society of Rheumatology, *NICE* National Institute for Health and Care Excellence, *SER* Spanish Society of Rheumatology, *TLAR* Turkish League Against Rheumatism

Table 3 shows the AGREE II scores for each CPG. Quality was assessed across six domains: scope and purpose (range: 39–97%), stakeholder involvement (range: 42–97%), rigor of development (range: 45–90%), clarity of presentation (range: 56–92%), applicability (range: 19–85%), and editorial independence (range: 58–100%).

Consensus recommendations

Following synthesis, twenty-two common/consistent "should do" recommendations, seven common/consistent "could do" recommendations, two common/consistent "do not do" recommendations and four "no consensus" recommendations were identified (Fig. 3; Online Resource 5).

Recommendations with "Should do" consensus

The following care elements were strongly recommended by two or more CPGs:

Non-pharmacological

Patients and clinicians should adhere to a shared decision-making process and care should be tailored to the patient and their circumstances [8, 28, 30-32, 34, 35, 37] (e.g., considering disease activity [8, 34] and comorbidities [8, 30, 34]). All patients should receive education [27-29, 31-33, 37]. Patient education should include information about the disease and its management options [32, 33, 37] including joint specific care where relevant [29, 31] (e.g., advice on footcare and hygiene). Clinicians should explain the benefits and risks of management options [31, 37]. Clinicians should discuss the importance of healthy lifestyle habits (e.g., exercise, decreasing stress, and fatigue), providing advice on how this can be achieved and maintained [28, 33]. Exercise therapy should be recommended [29, 31-33, 37], with modalities including "general" exercise therapy [31, 32], hydro-kinesiotherapy [32], and joint-specific programs e.g., hand and wrist programs [29, 37] or foot and ankle programs [31]. Foot orthoses [31, 32]/ functional insoles or therapeutic footwear [37] should be recommended for people with RA with abnormal foot function, when adequate over-the-counter shoes are insufficient in reducing foot pain or symptoms. A multi-disciplinary team approach to care should be recommended [8, 28, 29, 31, 32, 37] and should include a rheumatologist [8, 28, 29, 31, 34, 37], nurse [27, 29, 31, 37], physiotherapist [33, 37], and/or psychological support [32, 37] where appropriate.

Pharmacological

Treatment target and monitoring Treatment should focus on assisting patients in maximizing their overall quality of life and participation through optimized control of disease activity and maintaining physical function [30, 32]. The treatment goal should be to achieve clinical remission or if that is not possible, low disease activity [8, 28-30, 34, 37]. Validated instruments to measure disease activity were recommended [35], and include disease activity score 28 joints (DAS28) [4, 8, 29, 30, 37], simplified disease activity index (SDAI)

Figure 6.3 Treatment Pathway

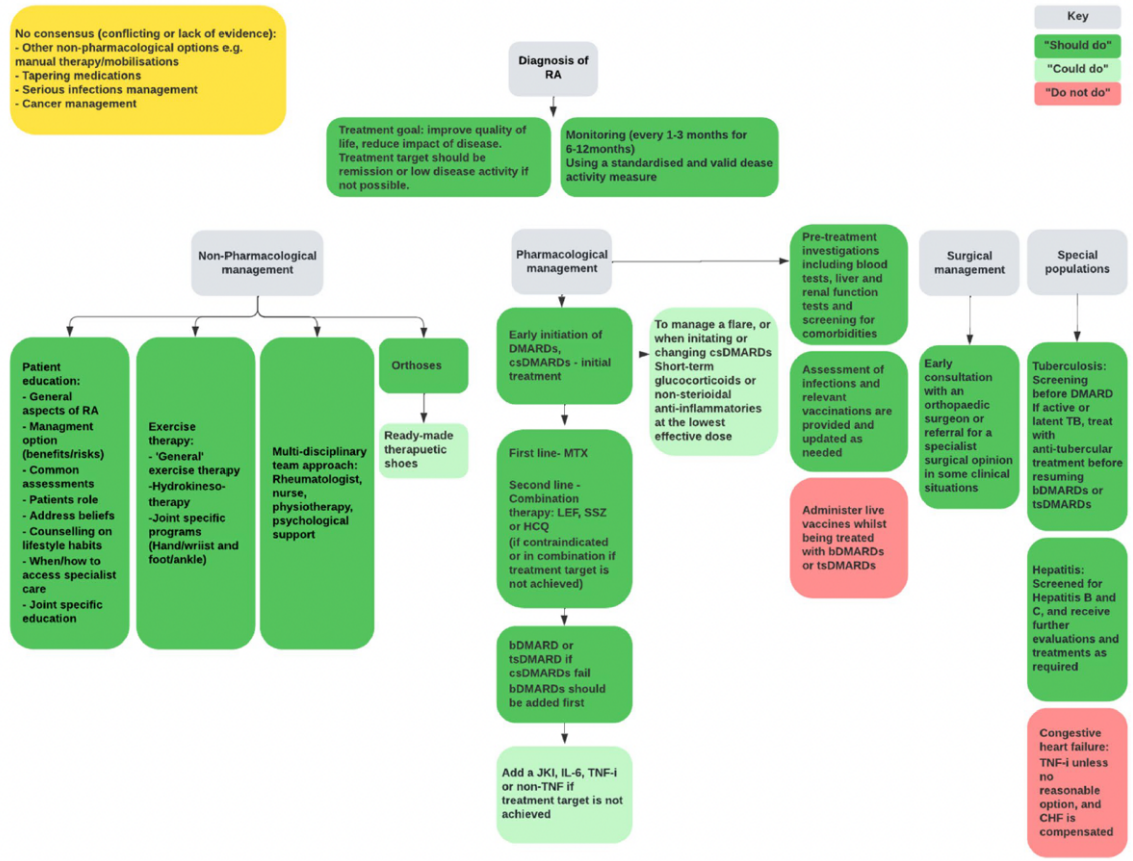


Fig. 3 Treatment pathway

[4, 8, 27, 29, 30], clinical disease activity index (CDAI) [4, 8, 27, 29, 30], or other measures such as ACR-EULAR criteria [28-30, 34]. Several CPGs did not describe a preferred instrument or provide a definition of remission/low disease activity [31-33, 35, 36]. Disease activity should be monitored every 1–3 months after diagnosis or if changing treatment strategies until the treatment target is achieved [30, 34, 35]. Once target disease control is reached, patients can be monitored every 3–6 months if disease remains stable, with a review at 6 months [30, 37]. If the treatment target is not achieved by 6 months, therapy should be adjusted [34, 37].

Disease-modifying antirheumatic drugs (DMARDs) Early initiation of DMARDs, "soon after" RA diagnosis [8, 34] is recommended with initial treatment with csDMARDs [4, 8, 27-30, 34, 35, 37]. Methotrexate (MTX) is the preferred csDMARD in all CPGs that reported on pharmacological management [4, 8, 27-30, 34, 35, 37]. If MTX is contraindicated, the patient has intolerance to MTX or does not achieve treatment target using MTX, the csDMARDS, leflunomide (LEF), sulfasalazine (SSZ), or hydroxychloroquine (HCQ) should be recommended [4, 8, 27, 28, 30, 34, 35, 37]. CPGs often failed to report suggested dosages for MTX LEF, SSZ, and HCQ within the recommendations. Two CPGs reported on dosage for MTX, although differed from least 10 mg/week [27] to at least 15 mg/week [35]. bDMARDs or tsDMARDs should be added in conjunction with csDMARDs if treatment target is still not reached [4, 8, 27-30, 34] with bDMARDs being recommended in the first instance [8, 28, 29, 34, 39].

Pre-treatment investigations and vaccinations Patients should undergo investigations before commencing treatment [29, 30]. These can include screening for comorbidities, pregnancy, chest radiography, blood tests, renal, and liver function tests [29, 30]. All patients should be assessed for infections and vaccinations (particularly live vaccinations) should be provided ideally 4 weeks prior to bDMARD

or tsDMARD therapy and updated as needed [4, 28, 30]. Killed or recombinant vaccines can be administered before initiating or during csDMARD, bDMARD, or tsDMARD therapy [4].

Special populations All patients should be screened for tuberculosis (TB) infection before commencing bDMARD or tsDMARD therapy [4, 30]. If a patient has active or latent TB this should be adequately treated before commencing bDMARDs or tsDMARDs [4, 30]. Patients should be screened for hepatitis B virus or hepatitis C virus infections and if positive, receive further evaluation and treatment [4, 30, 35].

Surgical

Referral for surgical opinion Surgery should be considered when medical management has not been successful, and the patient meets evidence-based criteria for surgery (Online Resource 5) [31, 37].

Recommendations with "Could do" consensus

The following recommendations were conditionally recommended by two or more CPGs, or had an equal number of conditionally and strongly recommendations:

Ready-made therapeutic shoes can be considered for patients with RA in certain clinical circumstances, when custom-made shoes are not indicated [31, 37]. If csDMARD therapy fails, janus kinase inhibitor [4, 27, 28, 30, 34], tumor necrosis factor inhibitor (TNF) [4, 8, 28, 34], or non-TNF therapy [4, 27] can be added in conjunction with csDMARDs, while IL-6 inhibitors [8, 27, 34] can be recommended if bDMARDs fail. Non-steroidal anti-inflammatories (NSAIDs) can be added [29, 30, 37] in combination with DMARDs [29]. This includes traditional NSAIDs (+/− a proton pump inhibitor (PPI) or cox II selective inhibitors [30, 37]. This could be taken orally [8, 37], at the lowest effective dose for the shortest duration [30, 37] to reduce pain and inflammation [8, 29]. Glucocorticoids can be [8, 27-29, 31, 34, 35, 37] considered in response to a patient experiencing a flare/to control active RA [4, 37] or in combination when initiating or changing csDMARDs [4, 8, 27, 29, 30, 34, 37]. Glucocorticoids can include different dose regimens and routes of administration [8, 34], e.g., oral, intramuscular, or intra-articular injections [37]. Injections could be considered for the relief of local symptoms of inflammation [4, 31]. The chosen glucocorticoid should be administered at the lowest dose [4, 28-30, 37] and only used for short-term periods; being tapered when clinically feasible [4, 8, 27, 28, 30, 34] to avoid adverse effects [4, 8]. Definitions of short-term varied among CPGs from < 3 months [29] to < 6 months [4]. Dosage of prednisone recommended varied from ≤ 7.5 [8, 30], ≤ 10 mg once daily [29], or 10–30 mg/day [27].

Recommendations with "Do not do" consensus

The following were specifically recommended not to be done by two or more CPGs:

TNF inhibitor should not be recommended in persons with a history of congestive heart failure, unless there is no other reasonable option, and the congestive heart failure is compensated [4, 35]. Live vaccines should not be administered while a patient is being treated with bDMARDs or tsDMARDs [4, 30].

Recommendations with no consensus

CPGs reporting conflicting recommendations for:

Non-pharmacological treatments such as manual therapies (e.g., thermotherapy, massage, dry needling, passive mobilisations [32, 33]) and recommendations for patients with RA and serious infections [27, 30, 35] or cancer [4, 27]. For example, one CPG recommended bDMARDs, with no specific treatment over another [27] while the other CPG recommended csDMARDs for previous low-grade melanoma or non-melanoma skin cancer or lymphoproliferative disorder or standard care for previously treated solid organ malignancy [4]. For full details of conflicting recommendations, see Online Resource 5.

The majority of CPGs suggested pharmacological tapering should or could be considered, occurring after 6 [27, 30, 35, 36] or 12 months [30, 37]; Four CPGs did not advise on a time frame [4, 8, 28, 34]. If a patient is in remission, DMARD treatment could be tapered, in the following order: glucocorticoids, bDMARDs and tsDMARDs and lastly, csDMARDS in certain clinical circumstances [4, 8, 27, 28, 30, 34-37]. However, one CPG recommended against tapering if the patient does not have rapid access to care or will experience difficulty re-establishing access to medications [36].

Discussion

Clinicians should be aware of and utilize high-quality CPGs to inform decision-making. We determined sixteen of the twenty-seven CPGs were high quality on the AGREE II instrument. CPGs are costly and time-consuming to develop and the significant number of low-quality CPGs is an inefficient use of resources [52]. Local adaption of contemporary high-quality CPGs that includes relevant updates in evidence and a section for area-specific recommendations/considerations such as, availability or cost of treatments may be a more efficient use of resources than development of several original CPGs within a similar time period.

Development of high-quality CPGs are important, although this does not guarantee translation of recommendations into practice [53]. Studies have reported sub-optimal adherence

to CPGs, varying from 22 to 100% for rheumatologists with findings being similar across most health disciplines and internationally [54, 55]. The AGREE II instrument measures CPG implementation within the "applicability" domain, which was the lowest scored domain across CPGs (Table 3); consistent with previous systematic reviews for RA management [15, 56-58]. This highlights the need for CPG developers to focus on addressing implementation in future guidelines. Inclusion of economic evaluations, treatment algorithms and monitoring and auditing criteria can facilitate translation of recommendations into practice [21]. A variety of individual, health system and contextual barriers to CPG implementation have been identified by Correa et al. [59], which include insufficient high quality evidence, contradictory CPG, and patient and physician factors [59]. While clinicians may choose to use treatment recommendations developed by local peak bodies, systematic reviews such as ours are important to address concerns about the quality of recommendations, and conflicting recommendations. By applying these recommendations, clinicians in any setting can be confident that they are offering high quality care that is supported by robust evidence.

Recommendations across CPGs were relatively consistent for non-pharmacological, pharmacological, and surgical care. Non-pharmacological interventions should include patient education, patient-centered care, shared decision-making, exercise, orthoses, and a multi-disciplinary approach to care. Pharmacological interventions should include csDMARDs, with MTX as the first-line choice. Followed by csDMARDs as combination therapy (LEF, SSZ and HCQ), bDMARDS, and tsDMARDS to achieve a treatment target. Other aspects of medical management consistently recommended included monitoring, pretreatment investigations and vaccinations, and screening for tuberculosis and hepatitis. Surgical care should be recommended if non-surgical care fails. TNF inhibitors should not be used in persons with a history of congestive heart failure, unless there is no other reasonable option, and the congestive heart failure is compensated. Live vaccines should be avoided while patients being treated with bDMARDs or tsDMARDs.

Despite the majority of recommendations being consistent across CPGs, they often lacked sufficient detail to guide practice. For example, physiotherapy, psychology, nursing, and rheumatology are professions which provide a range of care options; however, in some CPGs these were broadly classified as interventions. Distinct recommendations for interventions provided by these professions are needed in future CPGs [56]. Similarly, pharmacological recommendations neglected important information needed for implementation into clinical practice such as medication dosage. Dosage for csDMARDs and other medications were often not included with only two CPGs reporting on dosage for MTX, differing from least 10 mg/week to at least 15 mg/week [27, 35]. While dose variation could be attributed to different disease states and consideration of potential side effects, inconsistent dosages, or not including medication dosages are likely barriers to implementation [60]. CPGs often agreed on monitoring frequency [30, 34, 35, 37], and instruments to measure disease activity [4, 8, 27-30, 37, 51] although recommendations on blood monitoring were vague. Medication management is a large component of RA care, and these medications can be associated with adverse effects such as fatigue, nausea, cytopenia, among others [61]. Furthermore, the presence of side effects can prompt changing of treatments. Future CPGs should focus on providing clear, detailed recommendations to improve consistency of care.

No consensus recommendations could be developed due to conflicting recommendations for certain non-pharmacological interventions such as: thermotherapy, recommendations for tapering medications and recommendations for patients with RA and cancer or serious infections. For example, one CPG recommended specific csDMARDs or standard care for patients with RA and certain cancers [4], while the other CPG recommended bDMARDs on a case-by-case basis for patients with RA and cancer [27]. Differences might be attributed to their varied definitions of cancer, either defining it broadly [27] or stating specific cancer types [4]. Guideline development groups interpretation of evidence can influence recommendations [16]. Both CPGs included relevant health professionals in the guideline development group such as rheumatologists and methodological experts, although varied at times for other members, e.g., one CPG included a biostatistician [4] while the other included patients [27]. Another potential reason for the difference could be their methodological process of determining evidence quality, which varied from using either Scottish Intercollegiate Guidelines Network and Osteba critical appraisal tools [27] or the Oxford Levels of Evidence [4].

Our synthesis identified several areas for further development/investigation. Data related to medication tapering is emerging [62]. As such, not all CPGs reported on tapering and those that did differed on timeframes of when to begin tapering. CPGs recommended tapering from 6 [27, 30, 35, 36] or 12 months [30, 37], or did not advise on a time frame [4, 8, 28, 34]. It is important that future CPGs include recommendations on tapering as increasingly people are diagnosed early with RA and treated earlier and the potential issues with long term immunosuppression such as increased likelihood of developing infections [63, 64]. Further research is warranted to explore when tapering should occur and to inform CPGs through quantifying risk of flare with treatment tapering. tsDMARD evidence is an emerging area of research, with JAK-inhibitors have been supported in a recent CPG [34, 65]. Benefits of JAK-inhibitors include their effectiveness and safety, that they can be administered orally and are associated with a lower production cost in comparison to bDMARDs [2]. This highlights the importance of CPGs being updated every 5 years to reflect advances in medicine [10].

Strengths and potential limitations

Strengths of this systematic review include the use of AGREE II tool as a systematic approach to synthesis [21], and selection of a high-level quality cut-off value, that was based on other reviews in the field [12, 26]. Additionally, we involved a multi-disciplinary team, including rheumatologists (RG, MN, CB), physiotherapists (IL, SB, JP, BC), and social scientists (TG, PO, JB).

The AGREE II instrument examines CPG methodology, not necessarily content and scores can be influenced by authors' reporting rather than methodological quality [20]. Our search strategy may have failed to identify all relevant CPGs in relation to RA care as non-English language CPGs and CPGs that addressed assessment and/or diagnosis of RA without management or treatment recommendations were excluded. To reduce the likelihood of CPGs being missed, a medical reference librarian assisted in the development of the search strategy and all authors checked the list of full-text CPGs to determine if any were missing to the best of their knowledge. Authors were required to interpret the language used in CPG recommendations, to provide grading of interventions (e.g., "should do" and "could do"). To improve confidence in our interpretations, consensus statements were developed by three authors (BC, SB, and IL) and reviewed by the expert clinicians (MN, RG, CB). The process of interpretation is clearly reported in the methods, and in previous reviews [20].

Conclusion

Sixteen of the twenty-seven CPGs were identified as high quality on the AGREE II instrument.

Thirteen CPGs met the eligibility criteria, and their recommendations were synthesized. Non-pharmacological care should include patient education, patient-centered care, shared decision making, exercise, orthoses, and a multidisciplinary approach to care. Pharmacological care should include csDMARDs, with MTX as the first-line choice. If monotherapy csDMARDs fail to achieve a treatment target, this should be followed by combination therapy csDMARDs (LEF, SSZ, HCQ), bDMARDS, and tsDMARDS. Management should also include monitoring, pre-treatment investigations and vaccinations, and screening for tuberculosis and hepatitis. Surgical care should be recommended if non-surgical care fails. This synthesis can provide clear, simple guidance of evidence-based RA care to healthcare providers.

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Declarations

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Chapter 7 Developing Arthritis Education Resources: Integrating Evidence from Indigenous Peoples' Lived Experience and Clinical Practice Guidelines.

Chapters 4–6 identified recommendations from CPGs to inform the arthritis education resources. However, in each of the systematic reviews there was no indication of participation from Indigenous peoples, either within the guideline development group, or as external reviewers. This means that the recommendations from the CPGs alone may not align with the needs and preferences of Indigenous peoples, potentially limiting the suitability and feasibility of the education resources within Indigenous communities [199, 200]. To ensure that arthritis education resources are relevant and useful for Indigenous peoples it is important to actively involve Indigenous peoples in their development [151]. Therefore, this chapter explored Indigenous peoples lived experience of OA, gout and RA, specifically their beliefs, knowledge, informational needs and preferences. These insights were then integrated with the education recommendations from arthritis CPGs to guide the development of culturally informed, evidence-based education resources.

The authors declare the following contributions to this study: Conceptualisation (BC, JB, IL, RT, SB); Methodology (BC, JB, IL, RT, SB; JL); Supervision (SB, IL, JB); Acquisition of data (BC, IL, TP, LP, CG, WF); Analysis and interpretation of data (all authors); Writing – original draft preparation (BC); Writing – review and editing (all authors); All authors approved the final version of the manuscript.

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Title: Developing arthritis education resources: Integrating evidence from Aboriginal peoples' lived experience and clinical practice guidelines.

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Abstract

Background: Globally, arthritis conditions (osteoarthritis, rheumatoid arthritis, and gout) result in considerable pain and suffering and disproportionately impact First Nations peoples, who are more likely than non-First Nations peoples to have an arthritis condition and experience a higher burden of disease. Access to culturally appropriate health information supports the health and wellbeing of First Nations peoples. The aim of this study was to identify evidence-based, culturally appropriate recommendations to inform the development of arthritis education resources for Aboriginal and Torres Strait Islander peoples (First Nations peoples in Australia).

Methods: A integrative multi-methods study utilising community-based participatory action research involved three phases: 1) Interviews (research yarns) with Aboriginal peoples to explore their informational needs and preferences for arthritis education resources, 2) Systematic review and synthesis of education recommendations from high-quality arthritis clinical practice guidelines (CPGs), 3) Integration and interpretation of datasets from phase one and two.

Findings: Thirty Aboriginal peoples participated in research yarns, and education recommendations from 18 CPGs were included. Synthesis of the two datasets generated the following recommendations for education resources: education content should include the impact of arthritis on health and wellbeing, when/how to access care, management options (e.g., benefits/risks), and disease knowledge (e.g., prognosis, addressing misconceptions). In addition, education resources should be jargon-free, include positive lived experience stories, flags and colourful local art and be delivered by health professionals, family and/or Aboriginal Community members in the form of brochures, videos and/or yarning circles.

Interpretation: These recommendations will inform the development of arthritis education resources for Aboriginal peoples. Findings can support health professionals to deliver evidenced-based arthritis care to Aboriginal peoples. A Community based participatory action research approach can be applied to develop information resources for First Nations peoples elsewhere.

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Key words

First-Nations, Aboriginal, arthritis, education, health resources.

Abbreviations

ACCO – Aboriginal Community Controlled Organisation; AI – Artificial Intelligence; Appraisal of Guidelines for Research and Evaluation – AGREE; CPGs – Clinical practice guidelines; OA – Osteoarthritis; PAR – Participatory Action Research; RA – Rheumatoid arthritis; WA – Western Australia.

Putting research into context

Evidence before this study: First Nations peoples internationally experience a higher prevalence and burden of arthritis conditions. Yet there has been limited research to address this beyond a 'deficit-lens', focusing on the prevalence/burden gap between First Nations peoples and non-First Nations peoples. In Australia, there is very little research exploring the experiences of First Nations peoples living with arthritis conditions and no studies have identified their arthritis educational needs and preferences. Research is needed that is strengths-based and bridges the gap by engaging First Nations Communities to translate evidence into community-identified solutions.

Added value of this study: This study reports the needs and preferences of First Nations Australians (specifically Aboriginal peoples) related to arthritis information for the first time. These findings will guide culturally informed, evidence-based arthritis education resources for Aboriginal peoples in Australia and can contribute to addressing this large and unacceptable burden of arthritis.

Implications of all available evidence: Health professionals may benefit from insights on tailoring education for Aboriginal peoples seeking care such as considering the multidimensional impact of arthritis. Authentic participatory processes can be applied by researchers creating health education resources for Aboriginal peoples (and First Nations populations globally) as well as groups developing clinical practice guidelines. Such processes may improve acceptance and sustainability of education resources and facilitate the dissemination and implementation of clinical practice guidelines, ultimately leading to better arthritis outcomes for Aboriginal peoples.

Introduction

We acknowledge the Wurundjeri and Yamaji peoples as the Traditional Custodians of the land where new knowledge has been collaboratively created.

Osteoarthritis (OA), rheumatoid arthritis (RA), and gout (arthritis conditions) are often characterised by pain, swelling, reduced joint mobility, muscle weakness, and instability, significantly impacting the individual, and resulting in wider social and economic burden [1]. Arthritis conditions are common globally, with a worldwide prevalence of 527.8 million for osteoarthritis, 53.8 million for gout and 18.5 million for rheumatoid arthritis [2]. First Nations populations in Canada, the United States of America, Aotearoa and Australia experience these conditions at higher rates in comparison to non-First Nations peoples [3]. In Australia, Aboriginal and Torres Strait Islander peoples experience a higher prevalence of arthritis conditions compared to non-Aboriginal and Torres Strait Islander peoples (17% and 13% respectively) [4]. Arthritis conditions adversely impact all domains of health and wellbeing for Aboriginal and Torres Strait Islander peoples (e.g., physical and emotional), affecting their ability to perform activities of daily living and engage in work, social and cultural activities [5].

Patient education is the pillar of evidence-based arthritis care, recommended by clinical practice guidelines (CPGs) [6]. Education is critical to increasing individuals' disease knowledge, and changing attitudes, beliefs, and behaviours to facilitate effective self-management [7]. Failure to meet peoples' health informational needs, preferences and values can result in poor uptake of recommended care and suboptimal health outcomes [8]. The Australian Department of Health, and peak bodies such as Arthritis Australia, have identified a lack of culturally appropriate arthritis information developed with and by Aboriginal and Torres Strait Islander peoples [9]. To help address this gap, the aims of this study were to:

1) Explore the informational needs and preferences of Aboriginal peoples with OA, RA and gout.
2) Synthesise the education recommendations from high-quality CPGs for OA, RA and gout.

3) Integrate the findings from Aims 1 and 2 to generate recommendations that will inform the development of culturally appropriate OA, RA and gout education resources.

Materials and methods

Ethical approval

Ethical approval for this study was obtained from the Western Australian (WA) Aboriginal Human Ethics Committee (HREC1018) and the St Vincent's Hospital Melbourne Human Research Ethics Committee (HREC 224/20).

Research team

Our personal experiences and cultural backgrounds inform our perspectives and engagement with this research. The research team is led by first author, Ngiyampaa woman (BC) and comprises other Aboriginal researchers: Gumbaynngirr woman (JL), Badimaya, Wajarri, Wilunyu woman (CG), Ngoonooru Wajarri woman (WF), Whadjuk, Balladong, Gnarla Karla Boodja Nyoongar man (TP) and Noongar (Wardandi) man (JB) and Aboriginal people with lived experience of OA, RA and gout (RP, JBr, NG). The remaining authors (IL, SB, RT, PO, JP) are non-Aboriginal researchers with experience in Aboriginal and Torres Strait Islander health and/or musculoskeletal pain research including arthritis. A number of authors are also practicing physiotherapists (BC, JL, IL, JP).

Study settings

This research took place in two Australian states – Victoria and Western Australia (WA). This decision was based on the location of members of the research team and enabled the recruitment of study participants that represented both geographical diversity (e.g., metropolitan, and regional participants) and cultural diversity of different Aboriginal peoples[3] and communities (e.g., Yamaji, Yorta Yorta). Recruiting participants from diverse geographical and cultural backgrounds

[3] In this paper, the term 'Aboriginal peoples' is intentionally employed when referencing this study, due to no Torres Strait Islander peoples being involved in the reference groups and interviews.

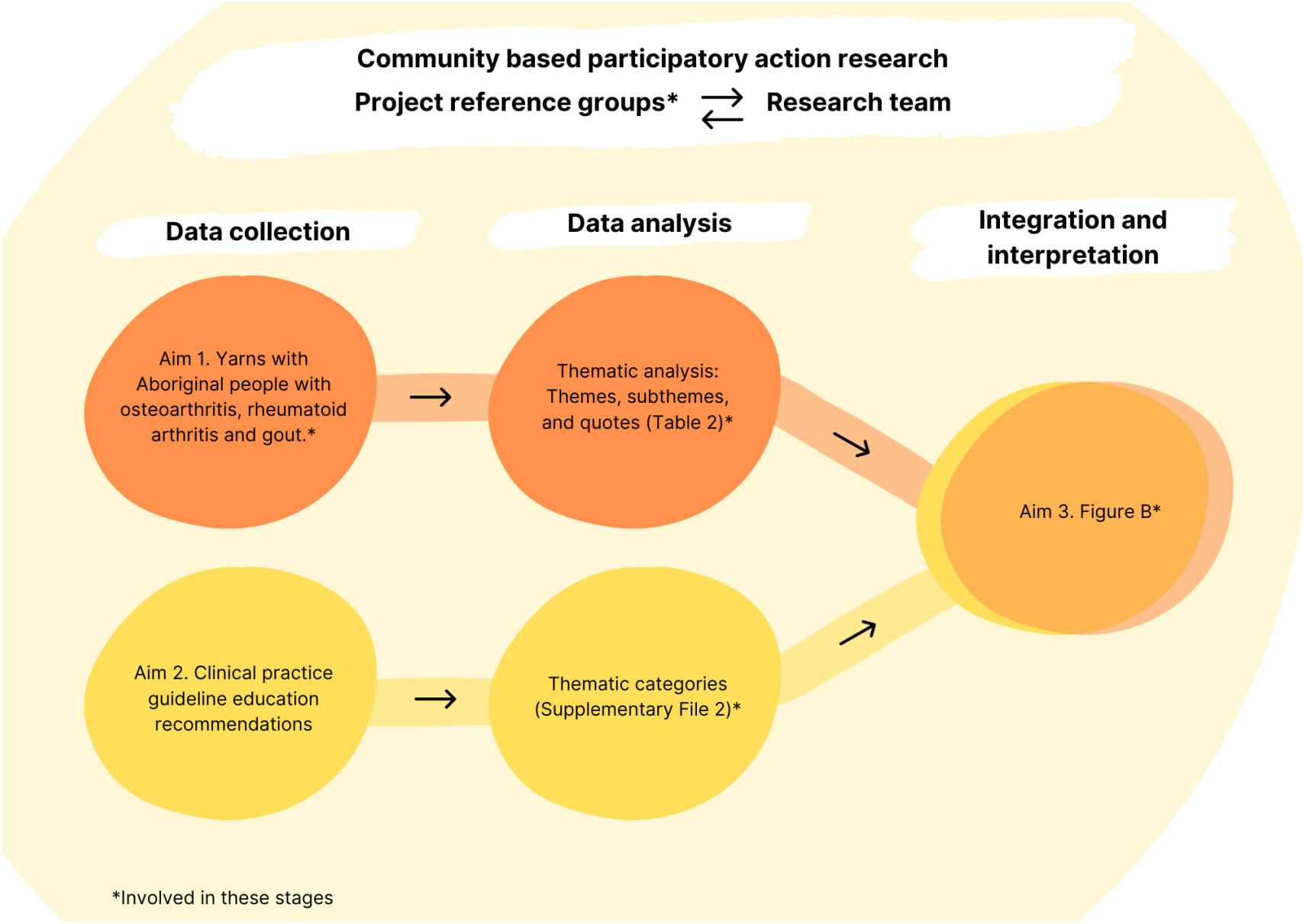
acknowledges the heterogeneity that exists within Australia, for example, varying levels of access to care/services, or differences in cultures, values, beliefs and practices amongst Aboriginal communities.

METHODOLOGY

Integrative multi-methods

This study utilised an integrative multi-methods approach, that involved simultaneous data collection and analysis of: 1) Research yarns (culturally appropriate interviews) with Aboriginal peoples with OA, RA and gout; and 2) CPG education recommendations; followed by 3) Integration and interpretation of both datasets [10] (Figure 7.1).

Figure 7.1 *Project Phases*



Community-based participatory action research

This interactive multi-methods study was underpinned by Community-based Participatory Action Research (PAR) [11]. Combining multiple methods, and PAR approaches can produce research of high scientific rigour whilst prioritising community and individuals priorities, needs and voices [11]. Community-based PAR is critical from a cultural, ethical and practical standpoint as it enables deep cultural insights and learning about health-related issues by recognising Aboriginal and Torres Strait Islander peoples' unique Indigeneity, knowledge systems and ways of working [11, 12]. Ethically, it facilitates the reclaiming of power, by involving stakeholders as co-researchers, which historically hasn't been prioritised in research with Aboriginal peoples [11]. Practically, it allows co-production of knowledge to create research that is directly useful to a group of people for which the research is intended to benefit, and can enable community-led actions [11]. In this study, PAR involved cyclical review, collaboration and reflective processes with community reference groups, within the research team, and culturally appropriate research methods were utilised to engage Aboriginal people with arthritis in the project.

Community Reference Groups

Two Aboriginal community reference groups were established, one in each site (Victoria and WA), to recognise diversity of Aboriginal peoples and Communities. These groups comprised of Aboriginal peoples with lived experience of OA, RA and gout. Potential reference group members were identified either before or during the research yarns (Figure 7.1). Individuals who represented diversity in age, gender, condition and geographical location, were invited to be involved at key points throughout the study. Meetings were held online via a teleconferencing platform in Victoria, or in-person in WA and chaired by authors (BC or IL). The groups' role was to oversee the research process, provide guidance and support into each study phase, including: subsequent recruitment for the research yarns, feedback on data analysis and input into interpretation of findings (Figure 7.1).

Research Yarning

The qualitative component of this study utilised a culturally appropriate method commonly used in Aboriginal and Torres Strait Islander health research, research yarning. This is a culturally safe approach to qualitative data collection that includes of four parts: a social yarn, research topic yarn, collaborative and therapeutic yarns [13]. Social yarning is an informal, unstructured discussion that aims to build connection and rapport between the participant and the researcher [13]. Research yarning focuses on collecting information related to the research topic through participants' stories [13]. Collaborative yarning refers to sharing information to create new learnings in relation to the research topic [13]. Finally, therapeutic yarning occurs if participants share deeply personal and emotional information when recounting their stories [13]. In this situation, the researcher assumes the role of a listener and provides support and affirmation to the participant and their story [13].

Aboriginal leadership

As described in our positionality statement, this study was led by an Aboriginal researcher, and included a team of Aboriginal and non-Aboriginal researchers and community members as collaborators. Aboriginal leadership was demonstrated throughout all phases of the research project, including providing guidance and support with study design, data collection, data analysis and feedback on the recommendations for the education resources (e.g., content and format).

RECRUITMENT AND DATA COLLECTION

Research Yarns – Participant recruitment

Aboriginal and Torres Strait Islander peoples with OA, RA and gout, aged ≥18 years and living in Victoria or WA were eligible. In Victoria, recruitment of participants was conducted through distribution of a project flyer through social media and Aboriginal Community Controlled Organisations (ACCOs) networks. In WA, patients within an ACCO were identified by searching clinical records for OA, RA or gout diagnostic codes. An ACCO is an Aboriginal run organisation that delivers holistic, high-quality cultural and clinical care, specific for Aboriginal and Torres Strait Islander peoples. Networks of the research team also facilitated recruitment at both sites. People were

then contacted and invited to participate. The sampling strategy was designed to recruit people from both sites with representation from all conditions, a range of ages, genders, and cultural backgrounds to ensure diverse perspectives were captured. Participation was voluntary and all participants provided prior verbal informed consent. Throughout the process of data collection and analysis, sampling was adjusted based on missing perspectives. These parallel processes enabled us to identify when sufficient patterns had been observed in the data to answer the research question, at which point recruitment ceased.

Research Yarns – Data collection

Research yarns were conducted by an Aboriginal researcher (BC) or an Aboriginal researcher (CG, WF, TP) and non-Aboriginal researcher (IL) between June 2021 – November 2022. A yarning guide was developed to explore: Understanding of arthritis condition and its management, experiences of seeking or receiving information, informational needs, and preferences (Online Supplementary File 1). The yarning guide remained open to follow people's storytelling and explore new questions as they arose during each yarn and through the parallel process of data analysis. General demographics were also collected including location, gender, and age. Research yarns were held at a mutually agreed upon location, either face-to-face, over telephone or via teleconferencing platform. Participants were remunerated with a $50 voucher for their participation.

Research Yarns – Data analysis

All research yarns were audio recorded, transcribed and imported into NVivo12 Plus (QSR International Pty Ltd, Version 12.3.0.599) to support data analysis. Data were analysed using reflexive thematic analysis [14]. Two authors (BC and JL) familiarised themselves with the data by independently reading a sample of the transcripts (n=5) and then generated initial codes using an inductive (data-driven rather than a priori) approach. They then met to discuss the codes and agree on an initial coding framework with two authors experienced in qualitative research (IL and SB). This process was repeated until the code book stabilised (e.g., no new codes were added/collapsed through the process of coding subsequent transcripts). Authors (BC and JL) then independently coded the

remaining transcripts, meeting regularly to discuss emerging interpretations and define sub-themes and themes with other authors (SB, IL, JB, RT). Sub-themes were based on the codes derived from the data, before being grouped together and summarised to create the themes. Sub-themes, themes and interpretations of the data were presented to the reference groups for feedback.

CPG education recommendations – Data collection

Systematic reviews exploring the management of OA, RA and gout CPGs were conducted. Detailed methods have been reported previously [15-17]. In summary, four guideline repositories and five databases were searched: OvidSP MEDLINE, Cochrane, CINAHL, Embase and Physiotherapy Evidence Database (PEDro). Eligibility criteria is presented in Table 7.1.

Table 7.1 Clinical Practice Guidelines (CPGs) Selection Criteria

Inclusion criteria • Published between January 2015 – April 1st, 2023. • For the interventional management of osteoarthritis, rheumatoid arthritis and gout. • For adults (people aged ≥18 years). • Published in the English language or in which a complete English language version is available. • Developed using a systematic process that is a guideline based on a systematic review of the literature and developed by an expert, multidisciplinary panel. • Represents an original body of work i.e., not solely an adaptation or systematic review of existing guidelines.
Exclusion criteria • Does not include interventional management recommendations. • Includes other arthritic conditions. • **Only** addresses recommendations for the system/organisation of care. • Required additional payment to access.

*Previously published in [15-17].

CPGs that met the inclusion criteria were assessed for quality using the Appraisal of Guidelines for Research and Evaluation (AGREE) II instrument by two independent reviewers [18]. Individual domain percentages and overall assessment ratings (%) were calculated by each reviewer. If there was a deviation of more than 20% in scores between reviewers, a discussion was held to reach a consensus, and if consensus couldn't be reached, a third reviewer was included. Final domain percentages rated equal to or greater than 60% in domains two, three and six were considered high-quality, and included in the analysis. CPG data was extracted by the first author (BC), using a purpose-designed Microsoft Excel™ spreadsheet. Data comprised of CPG characteristics (e.g., title, country of publication), methodology, guideline topic, target users. CPG recommendations were also extracted and ranked as either a “should do”, “could do”, “do not do” or “uncertain” based on language used in the CPGs. At least two authors cross-checked the extracted data and recommendation rankings, any inconsistencies were resolved through discussion amongst the three authors while referring to the original CPG. This study specifically focused on the education recommendations which were extracted and are presented in Online Supplementary File 2.

CPG education recommendations – Data analysis

The initial data analysis process is published in three systematic reviews [15-17]. Briefly, a narrative summary for all CPG management options was created initially by first author (BC) and then reviewed and refined by at least two authors. The summary contained information about the number of CPGs that recommended a particular management option, outlined the content of these recommendations and highlighted instances of similarities or discrepancies amongst the recommendations. In this study, recommendations related to education were grouped into key overarching thematic categories (Online Supplementary File 2) through consensus discussion among three authors (BC, JL, SB) and checked by additional authors (JB, RT, IL).

Integration phase

Thematic categories identified in the CPG education recommendations were mapped to sub-themes identified from the research yarns by first author (BC), and checked by two authors (SB, JL).

Integrated insights from the synthesis of both datasets were developed through group discussion between six authors (BC, JL JB, RT, IL and SB) and presented to the reference groups for feedback, before being summarised into “recommendations for the resources”. Authors were open to the possibility of CPG thematic categories not aligning with yarn sub-themes. In this case, CPG thematic categories or yarn sub-themes were presented independently within the integration phase, ensuring their inclusion in the recommendations irrespective of alignment.

Results

Reference groups

Eight individuals accepted the invitation to join the two groups and met on four occasions over the course of the project. Preliminary data analysis (yarn sub-themes, and CPG thematic categories) was summarised and presented to the reference groups to test/challenge emerging interpretations. Feedback included but was not limited to: the format of the resources (e.g., brochures and videos) and the content (e.g., questions for health professionals, presentation/layout advice). Full details of the reference groups feedback can be found in Table 7.2.

Table 7.2 Analysis of Research Yarns

Theme	Subthemes	Description and supporting quotes, indexed by participant number (e.g., Participant 9, P9) and condition (OA, RA, Gout).
Impacts of arthritis	Individual experiences	Experiences of arthritis conditions varied from minimal impact: "I haven't had a full blown (experience) for a long, long time" (P25, Gout) to pain being constant: "I'm in pain all the time" (P21, OA) and widespread: "Every bone in my body aches" (P20, OA). Participants mentioned triggers are individualised too: "But specific foods, you know, you hear of ones that are apparently really bad… I haven't found any consistency in that information, not that fits with my experience anyway" (P1, Gout).
	Impact on all aspects of health and wellbeing	Most participants reported arthritis symptoms impacted on their physical capacity, often resulting in limited mobility: "I couldn't stand up and I could hardly walk, I just lay on the bed crying" (P12, OA). This in turn impacted on the ability to work: "I've had to give up working. That was really hard because I was a major breadwinner in the family" (P14, OA) or to participate in social activities: "You just lose your enthusiasm to do anything" (P26, Gout). Many participants reported being in pain affected their mood: "I was just really, really down because I was in so much pain" (P29, RA). Interconnections between physical, emotional, social, cultural domains of wellbeing were emphasised with participants recognising that not feeling good in one domain could impact the other domains: "So you know, your mind is not feeling good, so your body's not feeling good" (P12, OA). Arthritis conditions also impacted on kinship roles and responsibilities: "For those ten years, I've been rushing around doing this. I've been sick. I've had a lot of pain, but I've put that all on the back burner because I've had to look after him" (P20, OA).
	Worries and fears for the future	Participants exhibited worries/fears for their future, believing arthritis would further impact on their health and wellbeing, through limiting cultural activities: "It worries me with my hands about the weaving… I don't want to lose the ability to be able to do those things" (P8, RA/OA); their mobility and independence: "I think the worst thing for me is the pain and worrying about whether I'm going to end up in a wheelchair or not… I still want to be independent" (P14, OA); and their social wellbeing: "Am I going to get to a point where I actually can't, you know, pick them (grandkids) up?" (P4, OA). At times doctors/health professionals re-enforced these worries/fears: "He (general practitioner, GP) said yes, it could you could very well end up in a wheelchair" (P14, OA).
	Suffering in silence	Despite the impacts arthritis is having on participants, some reported they didn't seek care: **"**I've just given up on it" (P30, RA); "Just learn to live with it" (P12, OA) and some were unsure on care pathways: "A lot of people now who are suffering with arthritis but they doing it silently because they don't know where to go" (P16, OA); "I don't know if in (town) the have a specialist in osteoarthritis or rheumatoid arthritis, do they have a specialist for that?" (P10, OA), leaving people feeling lost: "You see, how lost I am, aren't I? I'm so far from knowing what I'm doing (P21, OA).
	Multi-disciplinary approach to care	For participants who sought care, they would often present to GPs in the first instance for diagnosis: "It was the GP I believe that diagnosed the rheumatoid arthritis" (P6, RA) and management: "I was put on to my dosage (of Allopurinol) initially at the Aboriginal Community Controlled Organisation" (P1, Gout). Referrals to other health professionals were often completed by GPs, most frequently to specialists' care (e.g., rheumatologists and orthopaedic surgeons): "No, he's been really good doctor, (name)…He's always sent me to a specialist" (P14, OA). Allied health referrals (e.g., dieticians, physiotherapists and exercise physiologists) were completed less frequently: "Nothing else, and I don't know about diet. I've never been told or directed to a dietician" (P12, OA). Whilst others presented to GPs and were not referred elsewhere. No participants reported being educated on when or how to access care, and most didn't receive education on health professionals' roles/areas of expertise: "Yeah, if there is osteoarthritis specialist in (Town name), I'd probably go and see em and ask what sort of exercises I can do with bad knees and bad hips?" (P14, OA).
Experiences of education – delivery	"In the dark"	Those who sought care often recalled receiving a lack of education from health professionals: "They just say, oh you've got osteoarthritis and that's it. In the dark" (P15, OA) and wanted more information on how to manage: "Just given the basics would be better than nothing" (P6, RA).
	Health professionals	Health professionals were seen as trusted sources of knowledge: "The GP and the rheumatologist you can trust" (P26, Gout). **Facilitators** Positive encounters were those in which health professionals took time to understand the individual and what they were going through: "She's good, she'll yarn with you" (P10, OA), acknowledge the individual as an expert in their own lived experience: "The GP said to me, you do what you think is best, she said, because you are the one in the pain" (P17, OA) and provided tailored information: "Because like for me, like 22 years old now living with osteoarthritis, that's very different from someone who's 90 and living with osteoarthritis" (P9, OA). Other facilitators included, a therapeutic relationship between the health professional and the

		individual: “I've got a really great relationship with my local GP… she'll explain things clear to me and I'm quite comfortable” (P13, OA); “So I’ve been with him for 21 years. He knows my condition really well” (P14, OA); or between the health professional and Community: “They're known through the community, so it makes it easier for people to go to” (P2, Gout). **Barriers** Sometimes gaps in evidence-based understanding of arthritis conditions and their management appeared to be perpetuated by health professionals communication/language either explicitly: “He goes, you’re buggered mate… you know that’s how he said, he’s pretty dry” (P21, OA) or implicitly, for example, through the use of medical jargon that was difficult to understand: “I don’t think it’s explained in a way a lot of the time where people can actually understand it” (P8, RA/OA); “Health professionals and you know they like talking in their big lingo” (P7, OA); "Medically terminology… I don't understand it” (P6, RA). Other barriers included: a lack of time: “Doctors these days, like they just don't have time to like, sit down in a consultation and go through these things with you” (P3, RA); racism/discrimination: “He wouldn't give me a pain killer but anyway that was life back in the old days. Discrimination everywhere you went” (P2, Gout); access: “He's (rheumatologist) not coming to (town) anymore” (P29, RA); financial burden: “On a pension you just can't (afford to access care)” (P15, OA). Some participants reported health professionals making decisions, without their input: “They've already made their decision anyway, so, you don't really get a sort of, chance to say anything really” (P7, OA) and wanted to be recognised for their lived expertise: “They're not the ones going through the pain and suffering. I mean they might be experts of what they know. And what they've studied you know their particular thing that I know, but I'm the one who's an expert in my pain and what I'm feeling” (P9, OA).
	Family and Community shared experiences, knowledge and social support.	Family and Community members were also trusted sources of knowledge: “I learned from some of the old people as well, you know, when they talk about their experiences” (P13, OA); “You’ve shared that experience” (P25, Gout); “Yeah, somebody else has used and tested it” (P28, RA/OA). They also provided social support: “I'm always talking to her. She understands” (P20, OA); “I suppose it doesn't make you feel as alone?” (P30, RA) and improved adherence to management strategies: “I stopped walking because I had no grannies with me to come… to make me laugh…if my grannies were there, I'd be right” (P11, OA). Participants acknowledged that education still needs to be tailored when sharing information amongst Community: **“**Yeah it might work for you, but it doesn't work for me” (P26, Gout).
	Online/Self-education	A lack of education from health professionals resulted in some taking matters in their own hands: “When I am in them flare ups, that isn't a lot, there's no magic pill to help me. So then just starting to find strategies to help me cope throughout them times. No one gave me that advice I've searched for it” (P3, RA). Although, many found it difficult to find trustworthy sources: “You try to pick out the good ones from the bad. But yeah, you know, it's hard, it is hard to do that” (P1, Gout). Several participants said that they were more likely to trust information from universities or government websites: “If something has a dot vic dot gov at the end of it, then I feel safe... pdfs will come up from universities, then I go, right, OK… I'll definitely read them like I trust that” (P3, RA).
Experiences of education – content	Knowledge gaps (what is arthritis, what causes arthritis and how do I manage arthritis)	Participants reported a lack of understanding about their arthritis condition, and its management, they perceived this was from a lack of education being provided by health professionals: “Just deal with it was their (rheumatologist) answer” (P6, RA). Participants were unsure about what to ask health professionals: “They (specialists) don’t give you all the information you want to know unless you ask for it and sometimes you don’t know what you’re asking for” (P16, OA). During the course of the research yarns, knowledge gaps were revealed, including gaps about what arthritis is: “I think your bones get fragile” (P16, OA), its causes: “I don’t know what causes that build-up of uric acid” (P26, Gout), prognosis: “With the arthritis, does it go away?” (P30, RA) and how to effectively manage: “He (GP) said that you can't do anything about arthritis” (P8, RA/OA).
	Misconceptions	Misconceptions (beliefs that were not aligned with the evidence base) were observed among some participants, such as misconceptions about causes: “Old peoples disease” (P23, OA) and “Disease of kings” (P1, Gout). While misconceptions about management could lead to unhelpful behaviours and coping responses, for example Participant 21 who stopped walking because they believed it would damage their joint: “I used to walk heaps, but I’m just all.. It’s just, I know it’s too far gone now, you know? But that was the problem. I was doing more damage than good wasn’t I” (P21, OA).
	Management options	**Evidence-based management VS non-evidence-based** While some participants were told about evidence-based management: “(GP name) said to me, he said, I really need to lose weight to make it easier on my body” (P10, OA)”, many were not: “I had a TENs machine I think it was called, like an ultrasound and I've purchased one myself” (P6, RA). **More options**

		A range of management options were often not provided to participants: “I guess for me and, it would be more about having other options” (P7, OA), and participants wanted additional self-management strategies, particularly non-pharmacological management strategies for OA participants: “We need information on how to cope with it” (P5, OA); “Non-medical ways to manage it” (P4, OA). **Benefits and risks of management options** Benefits of treatments were often vague, generalised statements: “I was told they were to help my bones” (P24, OA); “I said, why do I have to take them (medication). Yeah, that's for your osteo” (P18, OA). Participants explained knowing the benefits of management options would improve adherence: “Make me more likely to follow that information if I know why it helps” (P1, Gout). Risks of pharmacological management were rarely discussed, and some participants experienced incorrect high doses of medications, withdrawals, alongside other side effects: “It (Targin) wasn't a safe drug to be on. Yeah. But withdrawing was a killer… Tell you what, it was very hard. I was very sick for three months” (P5, OA). **Cultural recognised in management** Participants drew strength from traditional healing practices: “I really believe in our culture of our healing people, you know, and back when I was younger, when I didn’t have this disease or anything that our people were still alive, you know, that could help” (P20, OA). In addition, many participants reported benefits from bush medicines: ‘Heal from the inside’; “It’s a bush medicine oil that’s not from the shops. It’s from my own culture… fixes up all your insides” (P18, OA). Health professionals often lacked recognition of culture in management: “It's really interesting, because every time I've gone to a doctor, and said about the arthritis. Well, since I've been up here, and I say I'm a weaver, ‘Oh we'll have to do something about that’ then they've never done anything about it” (P8, RA/OA).
Participants drew on these experiences to come up with recommendations for education resources…		
Impact of arthritis	Positive stories of lived experience	To address participants individual experiences of arthritis and relatability, they recommended including positive lived experience stories, avoiding deficit language into the resources: “Some positive encouragement as well. So not only the negative stories…coming from people who've been there”; “Having others, other people around, you know, and what their journey is, that's really important… that's relatable to other Aboriginal people” (P8, RA/OA). Reference groups supported including quotes from people with lived experience. They also suggested a story/journey approach of the information in the brochure. Reference groups recommended positive language throughout, including statements such as: “There are a range of things you can do to manage”.
	Information on how arthritis impacts all aspects of health and wellbeing	To address arthritis impacting on all aspects of health and wellbeing, participants recommended including information such as: “Maybe some information about your mental state as well?” (P29, RA). Reference groups recommended including statements to recognise the impact of arthritis on all aspects of health and wellbeing.
	Information on prognosis	To address the worries and fears for the future, participants recommended including information on prognosis: “What it's going to be like in the future?” (P30, RA).
	Information on when/how to access care	To address suffering in silence, participants recommended information on care pathways: “You know, see your doctor, see your physio” (P23, OA); and including questions to ask your doctor: “I think that's really important, when making information for people with OA that it's, they know what questions to ask” (P9, OA). Reference groups recommended including statements such as: “Don’t be shame about asking questions” and including a list of common questions to ask health professionals. They also recommended including links or information for health services/support services.
Education experiences – delivery	Format: brochures, videos and yarning circles	Videos, brochures and yarning circles were recommended as preferred formats, with videos and yarning circles reflecting Aboriginal and Torres Strait Islander practices of storytelling: “Our messages are passed down verbally” (P2, Gout); “Telling each other their stories” (P10, OA), whilst brochures were helpful as you can refer back to the information: “Look back on it” (P16, OA). Reference groups recommended both brochures and videos as the preferred formats.

	Language (jargon free, words we use)	To address communication barriers, participants recommended that the resources are jargon-free and accounts for varying health literacy levels: "I think for Indigenous people, I think something a bit more simplified for some people who don't understand and can't read or write properly" (P34, RA) and using "Everyday words we use" (P2, Gout). Including images: "Both pictures and words" (P14, OA). Reference groups recommended to reduce the amount of text and incorporate images into the resources. They also recommended the following accessibility considerations: Bold headings, dot-points for information, adequate spacing and delivery options to reflect a variety of health literacy levels.
	Delivered by a trusted source(s)	To address trust/mistrust, participants recommended that the resource is delivered by trusted sources, these can include health professionals, family and Aboriginal Community members and some online sources. Reference groups recommended including advice to yarn with/see your doctor for education on arthritis and its management.
	Created by Blak fellas	To address the current gap of culturally appropriate resources, participants reported a Community approach to education: "There's nothing out there for Community… and that's why, you know, I'm interested in doing these things to get more information out to Community" (P5, OA). These resources should be created by Aboriginal and Torres Strait Islander peoples or people working in Aboriginal health settings: "I reckon it be done by Blak fellas or a non-Aboriginal person that has worked with Aboriginal people" (P23, OA).
Education experiences – content	Comprehensive information on disease knowledge topics (e.g., causes), and management options	To address the lack of information on disease knowledge topics (e.g., causes) that led to subsequent knowledge gaps, participants recommended comprehensive education such as: "What caused it… how I can manage it" (P17, OA). Reference groups recommended to include information about triggers for Gout and RA.
	Information to address misconceptions	To address common misconceptions, participants recommended statements such as: "You say it affects everyone regardless of age…Dispel that myth…it's not old people's disease" (P23, OA). Reference groups recommended addressing common misconceptions e.g., The belief that increased alcohol intake is the main cause of gout.
	Information on holistic management options (including culture)	To address arthritis impacting on all aspects of health and wellbeing, participants recommended taking a holistic approach to management: "Holistic perspective though I think that, you know, messaging about drinking plenty of water and, you know, avoiding the booze and, you know, good diet" (P1, Gout). Alongside recognition of bush medicines, and their benefits: "Emu oil…I can rub that on there that stops the pain instantly" (P20, OA). Reference groups recommended evidence-based management options, alongside recognising cultural practices e.g., advice to seek education from an Elder, Cultural healer or cultural practitioner and use of bush medicines in conjunction with other treatments. Reference groups recommended inclusion of a range of management options and encouraging people to be active, in a way that is achievable e.g., Going bush for a walk, a walk around the shops or the block as opposed to attending a gym. Hydrotherapy was also supported as a management strategy for OA reference group members.
	Information on treatment benefits and risks	To address the lack of information on treatment benefits and risks, participants recommended information on what management options were helpful or harmful: "What you can do, what you can't do" (P28, RA/OA).
	Colourful local art, flags	To include elements of culture, participants recommended including Aboriginal and Torres Strait Islander flags and artwork: "As soon as they sit and see a flag or an Aboriginal painting or something they go and have a look at it" (P2, Gout); "Indigenous art is always nice it just brings you straight to comfort" (P3, RA); "Colourful artwork" (P29, RA). Including the artists story was recommended to relate to the resources: "I would like look to see who the artist is, you know, and like where the mobs from… you like relate to it" (P3, RA).

GP – General Practitioner; OA – Osteoarthritis; RA – Rheumatoid arthritis.

Research yarns

Thirty yarns were completed in Victoria (n=9) and WA (n=21), with participants recruited from regional (n=18), rural (n=1) and remote (n=2) WA and either metropolitan (n=3) or regional Victoria (n=6). All participants identified as Aboriginal, and no participants identified as Torres Strait Islander. Participants were recruited from the researchers' networks (n=14) or ACCOs (n=16) (Online Supplementary File 3). Participant ages ranged from 22-75 years, and conditions included OA (n=19), RA (n=5), Gout (n=4) and a combination of two of these conditions (n=2). Average yarn time was 50 minutes. Yarns were either face-to-face (n=19), over telephone (n=4) or via teleconferencing platform (n=7). Themes (n=3: Impact of arthritis, education content and education delivery), subthemes and supporting quotes are presented in Table 7.2.

CPG education recommendations

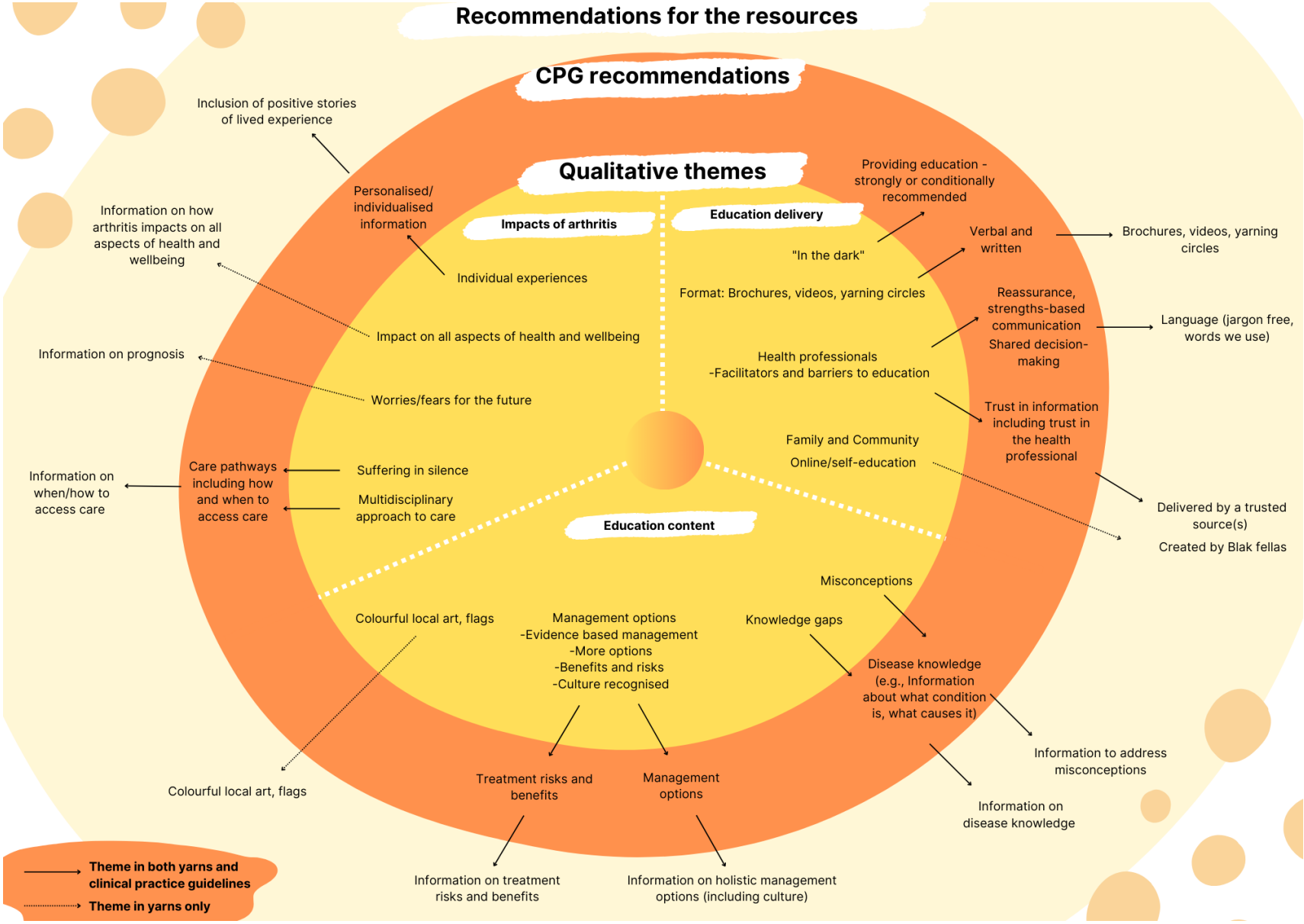
Eighteen CPGs were rated as high-quality on the AGREE II tool and included an education recommendation: OA (n=6), Gout (n=5) and RA (n=7). Education recommendations from CPGs were grouped into nine thematic categories: Disease knowledge, management options, treatment benefits and risks, care pathways, providing education, personalised/individualised information, shared decision making, reassurance/positive communication, and trust in information. Individual education recommendations and thematic categories are available in Online Supplementary File 2.

Integration phase

Research yarn themes e.g., “Individual experiences”, and CPG thematic categories e.g., “Personalised/individualised information” were broad in scope, allowing them to be mapped against each other. However, research yarns produced additional sub-themes that were unique, such as: family and Aboriginal community members as education providers. Overarching recommendations for education resources identified based on this synthesis are outlined in Figure 7.2. These were: Education resources should include information on the impact of arthritis on health and wellbeing, when/how to access care, management options (e.g., benefits/risks), and disease knowledge (e.g., prognosis, addressing misconceptions). Education resources should be jargon-free and include

positive lived experience stories, colourful local art and Aboriginal and Torres Strait Islander flags and be delivered by health professionals, family and/or Aboriginal Community members in the form of brochures, videos and/or yarning circles.

Figure 7.2 *Recommendations for the Resource*



Discussion

This study is the first to describe the informational needs and preferences of Aboriginal peoples with OA, RA and gout. The synthesis of qualitative and CPG data resulted in recommendations that can inform development of culturally informed, evidence-based arthritis education resources.

While recommendations from Aboriginal peoples and CPGs were broadly congruent, participants identified unique recommendations to better meet cultural needs. Participants perceived that health professionals were a trusted source of arthritis information, although also identified family, Aboriginal Community members and selected online sources. Similar findings are reported amongst First Nations peoples internationally, with Māori participants seeking arthritis information from family and friends and First Nations Canadian participants identifying a need for a First Nations Community facilitator to provide arthritis education, to increase their disease understanding and support management [19, 20]. The role of family and community members in providing information to Aboriginal peoples with arthritis conditions warrants further exploration. Increasingly people with arthritis are obtaining information from online sources [21]. Often websites contain accurate information, but can lack essential details such as references and author credentials/affiliations or provide contradicting information, which could potentially result in mistrust of content [19, 21]. Future research exploring factors contributing to trust of online resources for Aboriginal peoples with arthritis conditions is needed.

The participants in this study preferred resources in the form of either a brochure, video and/or a yarning circle. Brochures and videos are commonly recommended patient education formats as they provide consistent delivery of information that can complement clinical encounters and act as a memory aid [22]. Group education sessions are frequently used in existing arthritis management programs [23]. Yarning circles are a form of group education that is consistent with Aboriginal and Torres Strait Islander cultural practices [24]. Yarning circles involve a focussed, directed discussion that aims to remove positions of power by encouraging collaborative communication and sharing of knowledges [13, 24]. Further, yarning circles can evoke a sense of belonging, community and safety

within the group [25]. Reflecting cultural protocols, the participants in this study suggested that yarning circles should be delivered by Aboriginal people, for example Aboriginal health workers, or potentially adopt a co-delivery model with a non-Aboriginal health practitioner. Currently, there is a lack of research describing this approach in the context of arthritis and future research is warranted. Overall, a combination of modalities is recommended including visual, verbal and/or written education. This is supported by evidence that education delivered in any mode can result in sustained improvements in disease knowledge and decisional conflict [26].

It is widely accepted that Western biomedical constructs of health commonly used to inform existing evidence-base (e.g., CPGs) often differ from Aboriginal peoples beliefs on health and wellbeing [27]. Participants in this study recognised the need to address non-physical health impacts (e.g., social and emotional), and relevant management such as, psychological or social interventions which are increasingly being included in CPGs [28]. Participants also shared knowledges of Bush Medicines and their benefits, suggesting their use in combination with other management strategies. This theme is emerging internationally, for example in Canada, researchers have recognised the need to integrate First Nations traditional healing practices into mainstream arthritis care [20]. Relatedly, participants in this study recommended inclusion of local artwork and Aboriginal and Torres Strait Islander flags in the resources to express identity and culture, and inclusion of these, may potentially facilitate the uptake of education resources.

The participants emphasised the importance of appropriate language (“words we use”) in education resources. For written and visual materials, replacing jargon with lay language can improve readability and increase patient attention, comprehension, recall and adherence [29]. Further, the use of negative, deficit-focussed language is not uncommon in reference to Aboriginal and Torres Strait Islander health and is identified as a barrier to improving health outcomes [30]. Incorporating strengths-based language into health education resources (and adoption of strengths-based communication by health professionals) is recommended and can assist in shifting this deficit-

discourse examples include incorporating positive lived-experience stories of self-management into the resources [30].

Design considerations

The backgrounds/perspectives of the multi-disciplinary research team, including both Aboriginal and non-Aboriginal researchers, shaped the study from design to interpretations, for example, influencing the choice of methodology and culturally safe research methods that prioritised Aboriginal knowledges and voices.

The authors acknowledge that "Aboriginal" is a broad term encompassing many language groups with diverse cultures. As such, the findings of this study may not be transferrable to all Aboriginal and Torres Strait Islander peoples across Australia, or First Nations peoples' and communities globally. We attempted to recruit from diverse geographical locations, genders, and conditions however all participants identified as Aboriginal and therefore, Torres Strait Islander peoples were not represented in this study. Likewise, no women who experience gout were able to be recruited, and only one male with RA was interviewed. Conversely, there was over-recruitment of participants with OA, due to the higher prevalence in comparison to RA and Gout [2]. Despite this variation, thematic saturation was able to be reached with the included participants and similar themes were found across conditions, genders, and geographical locations.

Conclusions

Using a robust, integrative multi-method approach, this study generated novel recommendations to inform the development of culturally informed, evidence-based arthritis education resources for Aboriginal peoples. The research approach and recommendations generated may be relevant for other research groups seeking to develop culturally appropriate education resources in other First Nations health contexts.

Contributions

BC, JB, IL, RT, SB were responsible for the concept and design of this project. BC, IL, TP, LP, CG, WF were responsible for data collection. All authors were responsible for data analysis and integration. BC led and drafted the first version of this manuscript. All authors provided significant contribution and feedback on drafts and have read and approved the final version of this manuscript for submission.

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Competing interests

The authors declare that they have no conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Chapter 8 Discussion

The overall aim of my thesis was to create recommendations that informed the development of OA, gout and RA education resources for Indigenous peoples. To achieve this aim, an integrative multi-methods research design was adopted. Findings from the systematic reviews (Chapters 4, 5, 6) on the current evidence-based management of OA, gout and RA were synthesised with findings from research yarns (Chapter 7) on the beliefs, knowledge, information needs and preferences of Indigenous peoples living with OA, gout and RA.

8.1 Key Findings – Systematic Reviews

Three main findings emerged from the systematic reviews (Chapters 4–6). Firstly, 30 out of the 57 eligible CPGs were classified as low-quality across the three systematic reviews, revealing that many low-quality CPGs continue to be published [29-31]. Secondly, across high-quality CPGs included in the reviews, the Appraisal of Guidelines for Research and Evaluation (AGREE) II domain that scored the highest varied between: 'Scope and purpose' [29], 'Clarity and presentation' [30], or 'Editorial independence' [31]. However, the lowest domain was consistently 'Applicability', highlighting that CPGs are lacking consideration of implementation factors including detail on barriers and facilitators, resource implications, monitoring and auditing criteria, and advice or tools to support translation into practice. Finally, for the most part, high-quality CPGs often reported consistent recommendations, although discrepancies were evident for certain management options for OA, gout and RA either due to conflicting recommendations or a lack of evidence [29-31].

8.2 Key Findings – Research Yarns

Chapter 7 explored Aboriginal peoples' beliefs, knowledge and educational needs and preferences related to arthritis conditions. The key findings highlight that arthritis conditions impact physical, emotional, social and cultural wellbeing. Participants identified a need for comprehensive education to address knowledge gaps, misconceptions, and worries/fears. They also expressed a desire for culturally inclusive management, additional non-pharmacological management options, a multi-disciplinary approach to care, and clearer care pathways. Participants emphasised that education

should be delivered in a variety of formats and by trusted sources such as health professionals, family and community members and that communication barriers and facilitators between health professionals and people living with arthritis conditions should be addressed.

8.3 Key Findings – Multi-Methods Integration

Chapter 7 showed that education recommendations identified from the systematic reviews of CPGs and Aboriginal peoples' arthritis educational needs and preferences were largely congruent. Similarities included that education should be delivered by health professionals, using jargon-free, strengths-based language in either verbal or written materials (e.g., videos and brochures). Education content should include information on when/how to access care, management options (e.g., benefits/risks), and disease knowledge (e.g., prognosis, addressing misconceptions). However, research yarns generated additional recommendations for tailoring education delivery and content to incorporate Aboriginal cultural considerations. For example, recommendations for education delivery included sharing information through: 1) storytelling; 2) involving family and community members; and 3) utilising yarning circles. Recommendations for education content included: 1) integrating beliefs of the multi-dimensional impact and holistic management of arthritis conditions; 2) respecting cultural practices such as the use of Bush Medicines in management; 3) inclusion of familiar language and terms; and 4) making resources identifiable to Indigenous peoples by using Indigenous-specific symbols (e.g., flags) and artwork.

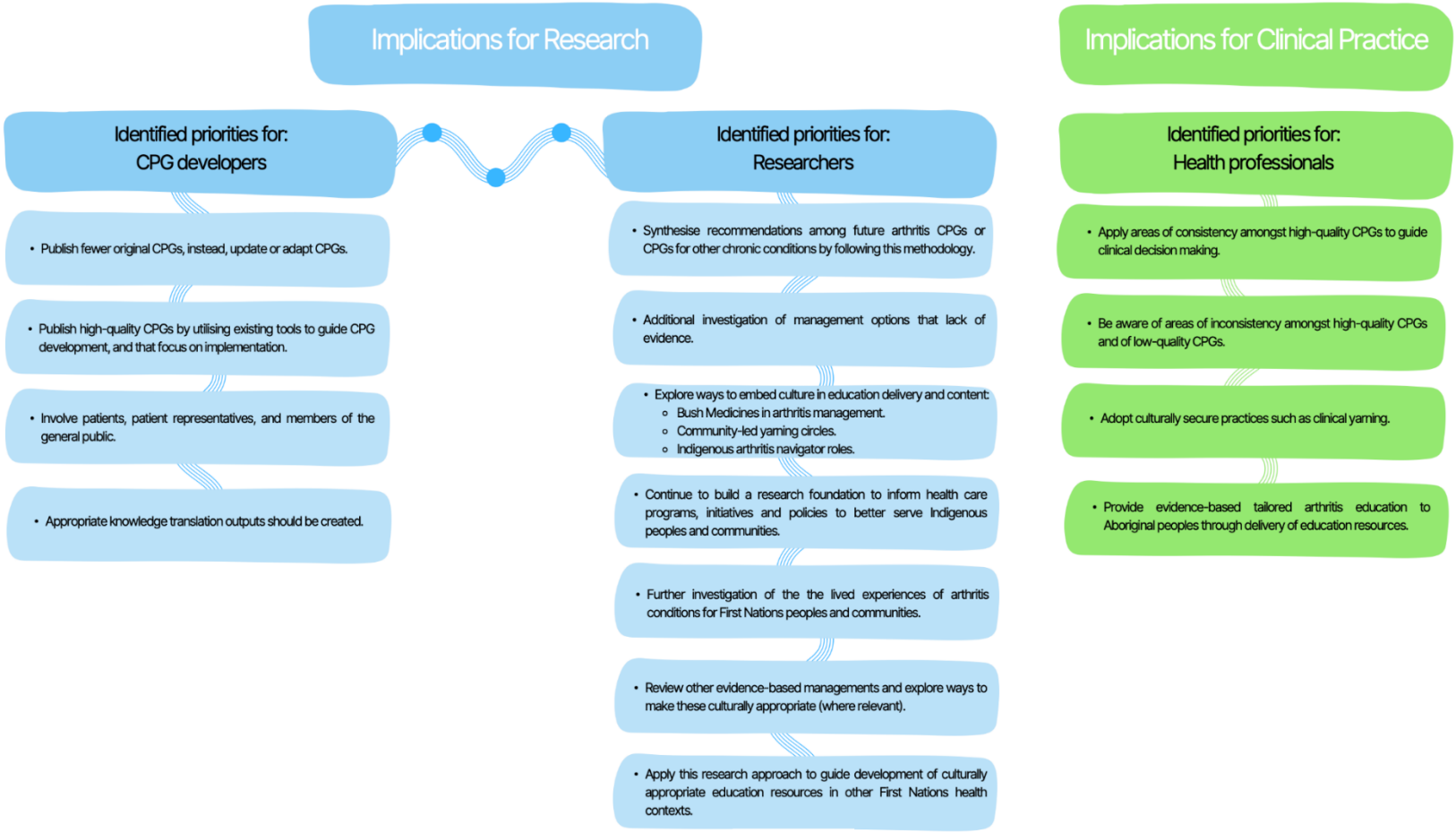
8.4 Education Resources

My PhD project provided recommendations to guide the development of the first evidence-based, culturally informed education resources for Aboriginal people living with OA, gout and RA in VIC and WA. These education resources (Appendix B) have been disseminated to health services (Indigenous and mainstream) throughout Australia, and to researchers' networks and arthritis organisations (e.g., Arthritis Australia). Evaluation of these resources is currently underway to determine their effectiveness.

8.5 Future Implications

These findings have future implications for research and clinical practice (Figure 8.1).

Figure 8.1 Implications for Research and Clinical Practice



8.5.1 Research Implications

The systematic review findings highlighted several priority areas for CPG developers internationally, including publishing fewer, high-quality CPGs that focus on implementation and include adequate involvement of patients, patient representatives (e.g., caregivers, advocates) and/or members of the public. In the last few decades, there has been a significant increase in the number of CPGs being produced [131]. Ongoing production of low-quality CPGs remains an issue, with ≥50% of arthritis CPGs being reported as low-quality [190, 201, 202]. This represents an inefficient use of resources in both developing CPGs and in providing care through delivery of harmful, or unnecessary management [190]. CPG developers should only create a new CPG in cases where there have been significant changes to the evidence base [131]. Instead, CPG developers should focus on updating content to reflect current evidence, and/or adapting existing CPGs to local context [131]. For example, tailoring a CPG to suit local circumstances may include obtaining feedback from local stakeholders and consideration of available resources, policies and cultural variations [203]. Several frameworks exist to support these processes although gaps have been identified, such as how to adapt CPGs to varying socioeconomic environments and health systems or settings [131, 204]. Additional guidance on how to update or adapt CPGs is needed [131].

In response to the widespread issue of variations in CPG quality, over 20 appraisal tools (e.g., AGREE II) have been developed [205, 206]. These tools provide a standardised way to measure rigour and transparency of CPGs to determine their suitability to guide clinical practice [207]. While it is important to assess CPG quality, the production of high-quality CPGs alone may not necessarily mean that recommendations are trustworthy [208]. Originally, when CPGs were introduced in the 1970s, recommendations were based on expert opinion and were often criticised for their lack of evidence [209, 210]. Although this approach is less common now, assessment tools have been developed to provide transparency of evidence used to inform recommendations (e.g., grading of recommendations, assessment, development and evaluations) and to determine the quality of CPG recommendations (e.g., AGREE-REX) [211, 212]. Appraisal tools that measure both the internal validity (e.g., AGREE II) and external validity (e.g., AGREE-REX) can identify if CPGs and their

recommendations are credible and implementable, and should be used to guide CPG development [205, 212, 213].

The 'Applicability' domain of the AGREE II tool scored consistently low across the CPGs included in the systematic reviews, prompting the need for future arthritis CPG developers to prioritise implementation [29-31, 214]. CPG recommendations are often not translated into practice, as indicated by a recent systematic review of physiotherapists and their treatment choices for musculoskeletal conditions (e.g., OA) [215]. Zadro et al., (2019) revealed that only 63% of physiotherapists provided recommended care, 27% of physiotherapists offered treatments that CPGs recommend against and 45% provided treatments that lacked evidence [215]. Similar findings have been noted among other healthcare professions in arthritis care, such as rheumatologists, with CPG adherence ranging from 22–100% [216]. Future CPG developers should focus on addressing the 'Applicability' domain of the AGREE II tool to improve translation of CPGs into practice.

Involving patients, patient representatives (e.g., caregivers, advocates) and/or members of the public is now recognised as an important component in the creation of CPGs [217]. Their participation can take various forms, such as inclusion in the guideline development group, or through consultation at various stages of CPG development (e.g., external review for public comment, focus groups, surveys) to obtain feedback from a wider audience [217]. Active involvement of patients and relevant stakeholders has been found to enhance both CPG quality and implementation by reflecting their needs and preferences to produce a more meaningful and useful CPG and improving the likelihood of uptake [200, 214, 218, 219]. Recently, involvement of First Nations peoples has been advised as necessary for future arthritis CPGs to reflect cultural differences [220]. For example, gout CPGs have recommended dietary advice be provided as part of patient education, including limiting seafood intake [30]. Yet research has shown seafood has great cultural significance for Māori people living with gout and recommending Māori people not to eat such foods, at best, has little impact on their gout severity and at worst, demonstrates cultural insensitivity [83, 144]. Thus, inclusion of a diverse range of people should be common practice in the development of CPGs, with appropriate representation from First Nations peoples.

The systematic reviews can provide First Nations and Indigenous peoples and communities with an understanding of high value arthritis care that should be provided by health professionals. However, CPGs typically cater to a readership of health professionals rather than patients or the general public [233]. Various factors restrict patient or general public use of CPGs, such as a lack of awareness, presence of complex language/medical jargon, or the absence of translational resources [233]. To facilitate knowledge translation, these barriers should be addressed, and outputs suitable for the general public (particularly, Indigenous peoples and communities) should be created and disseminated appropriately. These might include multimedia tools (e.g., videos, and television), creative methods (e.g., theatre, dance, artwork), storytelling and written materials [234].

For researchers, the systematic reviews identified areas where there was no consensus either due to conflicting recommendations or a lack of evidence to support those management strategies. Discrepancies in CPG recommendations can create confusion among users and complicate decision-making [221]. For example, the systematic review for OA management highlighted that most CPGs advised against opioid usage, yet there were two who recommended its use in specific circumstances (such as in cases of severe pain or when patients do not respond, exhibit intolerance or have contraindications to non-steroidal anti-inflammatory drugs) [29]. Adverse effects associated with opioid use are well documented and include an increased risk of dependency, falls and death [222]. Despite these harmful impacts, doctors continue to prescribe opioids at more than twice the rate for Indigenous people compared to non-Indigenous peoples, and as a result Indigenous peoples are three times more likely to experience a fatal overdose than non-Indigenous peoples [222, 223]. Future research can follow the methodology used in these systematic reviews to establish agreement among new arthritis CPGs, thereby mitigating confusion and preventing prescription of harmful interventions such as opioids. Similarly, this methodology can be applied in other conditions to synthesise CPG recommendations. In cases where evidence is lacking to recommend for or against a particular management strategy (e.g., dry needling for OA) it may lead to variations in practice [29]. Additional investigation is necessary to provide clarity on the use of these management options, for example, conducting robust randomised controlled trials to determine efficacy.

The research yarns were the first qualitative project to explore the experiences of Indigenous peoples living with OA, gout and RA collectively. Several areas for how content and delivery of arthritis education can better align with Indigenous culture were identified, including the need for further investigation of traditional medicines, community-led yarning circles, and First Nations arthritis-navigator roles. Moreover, this study established a research foundation for Indigenous peoples with OA, gout and RA, and highlighted the need for a more comprehensive evidence base, both nationally and internationally.

Incorporation of cultural practices such as the use of Australian traditional medicines (Bush Medicines) in both arthritis education content and as an adjunctive management option requires further exploration. Types of Bush Medicines and their use vary greatly across Australia [224]. Research on specific plants and their benefits in arthritis symptom management is growing [122, 225, 226]. Future studies should investigate the use of common Bush Medicines in arthritis management in Australia and determine their benefits and any possible risks. This research would have the potential to contribute to the evidence informing CPGs, which typically report from a Western biomedical lens and neglect traditional medicines [227]. Expanding the research base will also allow for policy changes to further encourage their incorporation into standard practice. For example, in Canada, traditional healing practices including medicines have been recognised in the Truth and Reconciliation Commission of Canada's 94 Calls to Action [228]. Health professionals such as rheumatologists have since expressed a willingness to incorporate the First Nations traditional healing approaches into arthritis management to support patient self-determination and patient-centred care [229]. Internationally, research should focus on implementing these practices and evaluating patient outcomes.

Similarly, cultural practices that prioritise community-led delivery of arthritis education, such as yarning circles and First Nations arthritis-navigator roles, warrant additional research. Coordinating trials and evaluations of both initiatives represents a crucial next step to enhance arthritis education delivery and to improve arthritis care more broadly. When yarning (previously discussed in Chapter 3) is applied in the context of multiple people, and underpinned by cultural protocols, this can be termed as a yarning circle. Yarning circles have been applied in health education contexts for

Indigenous peoples and have shown positive effects on program adherence and patient outcome measures [230]. However, education delivered through yarning circles is usually a component of a broader treatment plan alongside other modalities such as exercise programs, making it difficult to attribute benefits solely to education [230]. Currently, no research has been conducted to investigate this approach for delivering arthritis education. Additionally, yarning circles can also be applied in the research context to collect information regarding arthritis education. This offers an opportunity to engage with Indigenous peoples via a method they are familiar with and reiterates principles of community-based PAR. Involvement of family and community members can be achieved through either participation in yarning circles or by implementing Indigenous arthritis patient-navigator roles in Australia. Indigenous patient-navigator roles have been applied in chronic conditions and have seen benefits including increased access to health care and adherence to treatment, although patient experiences, clinical outcomes and cost effectiveness still require further exploration [231]. In Canada, First Nations arthritis-navigator roles have been piloted and participants reported improved trust, communication and continuity of care [145]. The navigators and other health professionals observed that they promoted the use of available resources, and facilitated the initiation of treatment plans [145]. Currently there have been no comparable studies conducted in Australia for arthritis conditions.

This novel research lays the foundation for future studies to build upon to improve arthritis care for Indigenous peoples. Participants in this study highlighted the multi-dimensional impacts of arthritis on all aspects of health and wellbeing (e.g., social and cultural). Yet, to date, investigating the impact of arthritis conditions for Indigenous peoples has not been a priority in research, unlike other chronic conditions such as cancer and cardiovascular disease [28]. Future qualitative research should explore beliefs surrounding these themes for Indigenous peoples and communities, particularly Torres Strait Islander peoples or Aboriginal peoples from Australian states and territories other than VIC and WA. While in the international context, OA, gout and RA have been explored among First Nations populations, research is still lacking in certain areas, such as rheumatoid arthritis for Māori peoples. Greater exploration of how arthritis conditions affect First Nations peoples can lead to much needed research investments aimed at findings local ways to address this burden.

While education resources offer one avenue to address this burden, another approach is to implement and evaluate other evidence-based arthritis management strategies such as exercise programs to deliver comprehensive arthritis management. These interventions may require local cultural adaptation if deemed as a priority by First Nations communities. However, cultural adaptations may not be relevant or feasible in all contexts such as resource constrained environments.

The community-led approach of the research yarns centred the voices of Aboriginal people with OA, gout and RA for the first time and promoted self-determined arthritis research. By building a research evidence base that is driven by community this can inform different aspects of arthritis care, including healthcare programs, initiatives and policies to better serve Indigenous peoples and communities and improve health outcomes [232]. In addition, this research amplified their stories including the impact of these conditions which can assist in raising community awareness of arthritis conditions.

The PAR approach and integrative multi-methods design, which incorporated evidence from different sources (research yarns and CPGs), can be used in other First Nations health contexts to guide development of culturally appropriate education resources for other chronic conditions. Additionally, Peake et al., (2019) emphasised the importance of prioritising collaborative relationships, community ownership, evaluation, cultural sensitivity and health literacy when developing education resources for Indigenous peoples [34]. In the absence of extensive literature, the study seen in Chapter 7 plays a vital role in guiding the development of future education resources.

8.5.2 Clinical Practice Implications

The systematic reviews highlighted areas of consistency among CPGs providing health professionals with clear guidance to assist clinical decision-making. They also identified CPGs that were deemed as low-quality, and areas of inconsistency among high-quality CPGs, which can inform health professionals of CPGs, and management options that should not be used to guide their clinical practice. This work has broad implications for all health professionals as OA, gout and RA care typically involve a multi-disciplinary approach [31]. Of particular interest to my professional discipline, (physiotherapy) is the guidance on the use of non-pharmacological treatment modalities as this is within our scope of practice. Whereas other health professionals such as general practitioners,

rheumatologists, surgeons and nurses may benefit from the pharmacological and surgical recommendations (see Chapters 4–6). Presently, there is opportunity to enhance health professionals' adherence to CPGs, and the provision of clear recommendations can help facilitate this process [215, 216].

The research yarns provided an understanding of the experiences of Aboriginal peoples living with arthritis, as well as their informational needs and preferences highlighting the cultural differences in education. These findings can assist health professionals when tailoring education for their Aboriginal patients. To facilitate culturally sensitive education in clinical practice, clinical yarning can serve as a valuable tool. Adapted from research yarning, clinical yarning involves three phases: social, diagnostic and management yarns, and focuses on building a trusting therapeutic relationship through reciprocal sharing of information, active listening and application of patient-centred care [192, 235]. Evaluation of clinical yarning among diverse health professionals (such as doctors, nurses, allied health) and university students, in various contexts (such as persistent pain clinics and health education settings) and states (Queensland, WA) has shown improvement in self-assessed communication skills, ability, confidence and knowledge after completing the program [236, 237]. In addition to health professionals adopting culturally secure practices such as clinical yarning, health-service environments where education is often provided should also promote culturally secure practices. The research yarn findings showed that inclusion of familiar language and terms, and Indigenous symbols and artwork can assist in making resources identifiable and improve uptake. Relatedly, the presence of Indigenous symbols (e.g., flags) and artwork within healthcare settings can elicit a sense of safety, acceptance and confidence from Indigenous people seeking health care in both the service and providers [238]. At times, these environments can be perceived as unwelcoming by Indigenous peoples and communities [239]. However, it is important to note that cultural safety extends beyond these environmental changes and requires individual and institutional knowledge, skills, attitudes and competencies to deliver optimal health care for Indigenous peoples [240]. Ultimately, the level and quality of cultural safety is up to the Indigenous person to determine [241]. Health professionals should utilise findings from the research yarns and culturally secure practices such as clinical yarning when providing tailored arthritis education to Indigenous peoples and

communities. Health services should implement environmental changes that align with research yarn findings to encourage a culturally safe environment for education delivery.

The project outputs are directly relevant to clinical practice and should be integrated as resources into clinical care. Recent studies have shown that health professionals can lack the confidence or knowledge to provide evidence-based arthritis education, and cite limited resources as a barrier to providing education that is consistent with CPGs in practice [242, 243]. Moreover, it is widely-documented that patients exhibit a low recall of information following a consultation with a health professional. Research suggests that 40–80% of information is forgotten instantly and almost half the information retained is inaccurate [244]. Providing education resources to reinforce and/or augment verbal information may improve concordance with care recommendations [138]. Compounding the problem of low recall, health professionals and healthcare settings frequently provide arthritis information in a way that does not take into account cultural needs and preferences for First Nations peoples [143, 144]. These resources, informed by my research, present an opportunity to address these gaps in the context of arthritis education in Australia.

Indigenous peoples and communities can use these education resources to be further informed about their arthritis condition and potential management strategies in a culturally appropriate manner. Providing culturally appropriate health information (e.g., information on Bush Medicines; links to ACCOs) will support health and wellbeing outcomes and ultimately reduce the burden of arthritis conditions [34].

8.6 Design Considerations

The strengths and limitations of each study have been discussed in their respective chapters. Therefore, this section will provide an overview of the entire PhD project, rather than emphasising the key strengths and limitations of each study.

8.6.1 Strengths

This thesis demonstrated several strengths, including alignment with most of the AIATSIS principles as described in Table 3.1. For example, recognition and respect for Indigenous self-determination were evident through Indigenous leadership both in my PhD project, and the wider SMSS project. As an Indigenous PhD candidate, I led the first Indigenous-led arthritis project in Australia, working in collaboration with the CRGs and the SMSS research team. Collectively, we had representation of a multi-disciplinary team comprising both Indigenous and non-Indigenous researchers and health professionals including rheumatologists and physiotherapists. Additionally, Indigenous-led research was exemplified through the use of Indigenous methods such as community-based PAR and research yarning. These approaches resulted in the collection of unique data regarding the experiences, needs and preferences of people with lived experience and, as such, offered new insights to improve arthritis management specific to Indigenous peoples. Moreover, these methods were rigorously applied in the design and completion of the publications, including but not limited to: the use of the AGREE II tool to define high-quality CPGs; cross coding of qualitative data; and involvement of the CRGs in interpretation of synthesis findings. The overall approach of this thesis, utilising community-based PAR and an integrative multi-methods framework, facilitated the development of a transcultural model that bridges Indigenous approaches with Western research methodologies. In a health research context, this model ensures cultural relevance while maintaining scientific rigor and contributes to the growing body of literature by demonstrating how participatory, culturally appropriate methods can enhance healthcare initiatives for Indigenous peoples. This model can be applied in various contexts, including but not limited to the development of health education resources, the creation of CPGs and the design of evidence-based chronic disease health programs and initiatives for Indigenous peoples, and First Nations peoples internationally.

As part of the SMSS project, engagement with Arthritis Australia facilitated advocacy efforts with the Australian Commonwealth Government to promote greater recognition and funding to address existing gaps. Alongside this, extensive dissemination of project outputs was achieved with a dedicated launch, communications through key policy and health organisations such as National Aboriginal Community Controlled Health Organisation, conference presentations, a community summary and media outputs, all of which have generated significant interest.

8.6.2 Limitations

Not all AIATSIS principles were addressed in this research as identified in Table 3.1. Specifically, further project documentation could have been developed, such as project agreements, and institutional/system level barriers prevented flexibility and sharing of intellectual property in certain situations. In saying that, several project materials were developed in consultation with CRGs (e.g., Terms of Reference) and, where possible, the research group remained adaptable and responsive to community needs, for example, extended recruitment timelines to allow for competing demands. Additionally, transferability of research findings may be limited due to a lack of representation from all communities, and geographical areas other than VIC and WA, or specific gender/condition combinations. For example, no women who experience gout were able to be recruited and no participants identified as Torres Strait Islander in the CRGs or the research yarns. Representation of these groups are in part due to demographic disparities, such as the predominance of Aboriginal peoples in comparison to Torres Strait Islander peoples, and that males are three times more likely to experience gout than women [18, 39]. Through the application of purposive sampling, thematic saturation was achieved, with consistent themes identified from the sample comprised of people with different arthritis conditions, genders and from different geographical locations. Relatedly, the SMSS was a project aimed to develop statewide educational resources (VIC and WA), rather than for a local community context. Local engagement and contribution are important to ensure relevance of education resources [34, 245]. Further research is warranted among these populations to obtain data from missing perspectives, and educational resources may need to be tailored for local context. Finally, my PhD project was completed during the COVID-19 pandemic, during which VIC endured more stringent and prolonged lockdown measures than WA, such as restrictions on travelling beyond

a 5 km radius of one's residence. As a result, various research stages were affected. For example, the original recruitment strategies for the research yarns and the CRGs (e.g., attending community events and meeting face to face with local ACCO staff), were adapted to account for the travel restrictions within VIC (e.g., phone and online meetings, and social media flyers). This affected the ability to build relationships and understandably both Indigenous community members and ACCOs had limited capacity for research activities at this time. In turn, recruitment was lower for VIC (9 participants) in comparison to WA (21 participants).

8.7 Conclusions

Employing a comprehensive integrated multi-methods and participatory approach this thesis formulated recommendations that guided the development of culturally informed, evidence-based arthritis education resources for Indigenous peoples living with OA, gout and RA. These research findings have implications for future research involving Indigenous peoples with OA, gout and RA, for clinical practice of health professionals caring for Indigenous peoples with OA, gout and RA, and for arthritis management for Indigenous peoples and communities. Furthermore, project findings may have relevance internationally for arthritis research, clinical practice and First Nations peoples and communities.

Overall, this research has provided the foundation for future research in this space and enabled me to address an important aspect of arthritis care and contribute to tackling the burden of OA, gout and RA on Indigenous peoples and communities throughout Australia. I hope that Indigenous peoples and communities can use these education resources, and be further informed about their arthritis condition and potential management strategies to achieve self-determination in their arthritis care journey. Moving forward, I remain committed to advocating for the needs and priorities for our communities in improving musculoskeletal care. I will continue to apply Indigenous-led solutions to foster positive and sustainable change for our health and wellbeing.

Appendices

Appendix A. Staying Moving, Staying Strong Protocol

PLOS ONE

STUDY PROTOCOL

Staying moving, staying strong: Protocol for developing culturally appropriate information for Aboriginal people with osteoarthritis, rheumatoid arthritis, lupus and gout

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Abbreviations: AGREE II, Appraisal of Guidelines for Research Evaluation II instrument; AMS,

Abstract

Introduction

Addressing disparities in arthritis care is an important yet unmet health need for Aboriginal and Torres Strait Islander people in Australia (respectfully Aboriginal people herewith). Despite the significant prevalence and burden of arthritis within Aboriginal communities, access to care for arthritis is low. One means to reduce existing disparities in health care is to address current challenges relating to the appropriateness and acceptability of health care information resources for Aboriginal people. Health information sources can help to empower patients and their families to have greater involvement in their care and to engage in self-management of their condition. Despite an extensive range of arthritis information resources being available, currently no resources have been culturally adapted and developed in collaboration with Aboriginal consumers with arthritis. This paper outlines the processes that will be undertaken within the *Staying Moving, Staying Strong* project. This project aims to develop culturally secure arthritis information for Aboriginal people with osteoarthritis, rheumatoid arthritis, lupus and gout.

Methods and analysis

The overarching principle guiding this project is cultural security, referring to the incorporation of processes such that the research will not compromise the cultural rights, values and expectations of Aboriginal people. This project will prioritise partnerships, community engagement, community benefit, sustainability, transferability, and capacity building and therefore uphold the cultural rights and values of Aboriginal people. In this six-phase project we will; 1) Establish a community reference group and advisory committee; 2) Explore the health information needs and preferences of Aboriginal people with arthritis; 3) Synthesise

Aboriginal Medical Service; CRE, Australian National Health and Medical Research Council Centre for Research Excellence; DALY, Disability-Adjusted Life Years; ECCO, The Enhancing Equity, Collaboration and Culturally secure Osteoarthritis care for Aboriginal Australians collaboration; Lupus, Systemic lupus erythematosus; OPUS, Centre for Research Excellence in Total Joint Replacement—OPtimise oUtcomes, equity, cost effectiveness and patient Selection for people with osteoarthritis; NHMRC, Australian National Health and Medical Research Council.

the existing key recommendations in high quality clinical practice guidelines on arthritis care; 4) Culturally adapt key clinical recommendations; 5) Develop culturally appropriate arthritis resources and; 6) Qualitatively evaluate the developed resources.

Introduction

Ensuring timely access to equitable, high quality health care for all populations within society is an integral component of the right to health and is a goal of Australia's universal health care system [1, 2]. Barriers to access arise within health care when cultural factors are not acknowledged, respected and prioritized [3]. Cultural security describes a commitment to providing health care services that do not compromise the cultural rights, values, beliefs, knowledge systems and expectations of Aboriginal and Torres Strait Islander people (respectfully Aboriginal people herewith) and must be considered in the development and delivery of meaningful patient education and information resources [3, 4].

Addressing the burden associated with musculoskeletal conditions experienced by Aboriginal people is an emerging priority in Aboriginal health care and research [5–7]. The Australian Department of Health National Strategic Action Plan for Arthritis recommends providing information, education and support to people with arthritic conditions so that they can effectively self-manage their symptoms [8]. This includes prioritising the development of comprehensive health promotion resources and expanding and tailoring existing resources for Aboriginal people [8]. Few culturally adapted health information resources have been designed to meet the needs of Aboriginal people living with arthritis and those that have been developed have not been robustly evaluated [9]. This study aims to address these issues by reviewing existing patient information resources available for arthritic conditions, including osteoarthritis, rheumatoid arthritis and systemic lupus erythematosus (lupus) and gout. Working in partnership with Aboriginal community members, Aboriginal health researchers, and arthritis experts, we will develop culturally appropriate information resources so that they are accessible, appealing, and empowering for Aboriginal people with arthritic conditions to allow better self-management of their symptoms.

Arthritis and disparities in health care

Arthritis is an umbrella term used to identify a collection of over 100 musculoskeletal conditions, including osteoarthritis, rheumatoid arthritis, lupus and gout [10]. These conditions are leading causes of pain and disability, impacting 15% of the population or 3.6 million Australians [10]. Compared to the general population, people 45 years or older who experience arthritis are twice as likely to describe their health as poor, and twice as likely to report very high levels of psychological distress and also report experiencing moderate to very severe pain [10]. Like many chronic conditions, the impact of arthritis is heightened in populations that experience greater burden of disease as a result of health inequity, such as Indigenous populations [11].

Impact of arthritis on Aboriginal communities

Arthritis is highly prevalent in Indigenous communities in Australia, Canada, New Zealand and the United States of America [5–7, 12]. In Australia, the prevalence of osteoarthritis in Aboriginal people is between 1.2 and 1.5 times higher than non-Aboriginal people [13] and the burden of disease is greater (31 Disability-Adjusted Life Years [DALY] per 1000 people for

Aboriginal people versus 22 per 1000 people for non-Aboriginal people) [14]. The prevalence of lupus in Aboriginal people is 52.0–92.8 cases per 100 000 population compared to 19.3–39.0 cases per 100 000 population for non-Aboriginal people [15]. The burden of rheumatoid arthritis in Aboriginal people is 4.8 DALY per 1,000 people compared to 3.5 DALY per 1,000 for non-Aboriginal people [14].

Despite an increased prevalence and burden of arthritis within Aboriginal communities, the utilisation of care for arthritis is low. For example, Aboriginal people with hip or knee osteoarthritis access primary care services at half the rate based on incidence [16, 17]. Cultural barriers for Aboriginal people when accessing health care have been recognised since the 1970s [18] yet, Aboriginal people continue to report feeling unsafe, experience racism and difficulties in understanding or being understood by service providers [19, 20]. For Aboriginal people seeking care for arthritis, ineffective communication with health practitioners, lower levels of health literacy and experiences of stigma are further barriers to care [5]. One way to address these barriers is through improving access to culturally appropriate information tailored to the needs of Aboriginal people [5, 21, 22]. This is an essential step in building an accessible, culturally secure program of arthritis care that is required to address the current higher prevalence of arthritic conditions experienced by Aboriginal people.

Evidence based management of arthritis and the role of patient information resources

Patient education and information resources such as booklets, factsheets and websites can be stand-alone or provided within health care consultations to reinforce verbal teaching and facilitate meaningful communication [23]. They aim to educate patients, families, and the public in an effort to increase health knowledge [24, 25] and in turn improve health literacy [26] and comprehension [27]. In doing so, patient education and information resources empower patients and their families to have greater involvement in decisions about care, to engage in self-management [28, 29] and adhere to medication and physical activity programs [30], positively impacting health outcomes [31, 32].

Peak national bodies such as Arthritis Australia, and State and Territory based arthritis organisations such as Arthritis and Osteoporosis Western Australia, provide an extensive range of arthritis management resources such as information sheets and booklets, patient education tools and programs and support services. Typically, these resources address beliefs and knowledge about arthritis and encourage patients to proactively self-manage their condition through pain management strategies, staying active and engaging in exercise and physical activity. Despite the availability of such resources, there are currently no arthritis resources that have been developed for Aboriginal people or involving input from Aboriginal consumers who experience arthritis. Aboriginal people need to be involved in the development of resources, as governance of the process is more likely to lead to resources which are meaningful and relevant to Aboriginal people with arthritis. This is likely to increase uptake of advice and recommendations made within the resources [9, 33].

The Staying Moving, Staying Strong project

This paper outlines research that will be undertaken within the *Staying Moving, Staying Strong* project, an implementation project that aims to develop, implement and evaluate culturally secure arthritis information for Aboriginal people with osteoarthritis, rheumatoid arthritis, lupus and gout. This protocol relates to the first phase of research in which we will co-develop arthritis resources with community members through a six-stage study involving a systematic

review and robust qualitative research methods. The outcome will be culturally secure information resources ready for implementation.

Materials & methods

The overarching principle underpinning this project is cultural security, referring to the incorporation of processes such that the research will not compromise the cultural rights, values and expectations of Aboriginal people [3]. Such processes include privileging Aboriginal voices, and multilevel and ongoing Aboriginal community engagement to guide methodological and cultural aspects of this project. This will ensure responsivity to community needs as they are identified. We will also build the capabilities of Aboriginal researchers and clinicians to work in musculoskeletal health and non-Aboriginal researchers and clinicians to work within culturally secure research paradigms.

In this six-phase project (see Table 1), we will adopt a qualitative approach using the culturally secure research method of research *yarning* [34]. Senior researchers in the project team

Table 1. Overview of project activities.

Phase	Objective	Project activities
Phase 1	To establish a community reference group and advisory group.	• Establish community reference group comprised of a diverse group of Aboriginal people who experience arthritis. • The community reference group will provide governance and oversight of the project activities, to advise on the strategic direction, cultural security, interpretation and dissemination of the research findings. • Establish an advisory group comprised of Aboriginal health researchers, health service providers, clinicians and health service researchers, Aboriginal consumers, and stakeholders. • The advisory committee will provide guidance on the methodological aspects of the study.
Phase 2	To explore the health information needs and preferences of Aboriginal people with arthritis.	• Qualitative study involving interviews with Aboriginal participants who have osteoarthritis, rheumatoid arthritis, lupus and gout. • Interviews explore participants' experience of engaging with health resources, their informational needs in relation to arthritis and preferences regarding the format of health information. • Inclusion criteria: Aged 18 years or older, identify as Aboriginal and/or Torres Strait Islander, experience one or more of osteoarthritis, rheumatoid arthritis, lupus and gout, English speaking, able to provide informed consent and willing to participate. • Exclusion criteria: Requires an interpreter to participate, experience cognitive impairment preventing participants from providing meaningful responses to interview questions, psychological illness that may put researchers or interviewers at risk of harm.
Phase 3	To identify and synthesise key recommendations from high quality clinical practice guidelines on arthritis care.	• Literature review to identify contemporary clinical practice guidelines on osteoarthritis, rheumatoid arthritis, lupus and gout. • Quality appraisal of clinical practice guidelines using the Appraisal of Guidelines for Research Evaluation II (AGREE II) instrument. • Synthesis of key recommendations from high quality clinical practice guidelines.
Phase 4	To culturally adapt key recommendations.	• Key recommendations culturally adapted for Aboriginal people through consultation with the advisory group using a modified nominal group technique.
Phase 5	To develop culturally adapted arthritis resources for Aboriginal people.	• Draft arthritis resources will be developed based on the feedback received in phase 4. • Draft resources will be presented to the community reference group using a culturally adapted nominal group discussion. • Resources further adapted based on feedback.
Phase 6	To qualitatively evaluate the culturally adapted arthritis resources.	• Qualitative evaluation using research yarning and adapted think aloud exercises with Aboriginal consumers with osteoarthritis, rheumatoid arthritis, lupus and gout. • Inclusion criteria: Aged 18 years or older, identify as Aboriginal and/or Torres Strait Islander, experience one or more of osteoarthritis, rheumatoid arthritis, lupus and gout, English speaking, able to provide informed consent and willing to participate. • Exclusion criteria: Requires an interpreter to participate, experience cognitive impairment preventing participants from providing meaningful responses to interview questions, psychological illness that may put researchers or interviewers at risk of harm.

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with expertise in research yarning will provide training to all researchers who will be conducting research yarns. Research yarning is acknowledged as a culturally secure approach to qualitative interviews as it privileges the lived experience and cultural context of the participants [35]. Research yarning aligns with Aboriginal ways of knowing and doing, such as the use of storytelling, and ensures interviews and focus groups are informal, relaxed and requires the researcher to build a relationship that is accountable to Aboriginal people participating in the research [34]. The yarning process is made up of difference forms of yarning. In the first phase and prior to the research yarn, the interviewer and participant engages in an unstructured, informal social yarn which aims to develop trust and rapport. Following the social yarn, the researcher may then engage in the research topic yarn, which aims to collect data through the participants' stories within a semi-structured interview format [34]. Data collection and analysis will also be carried out concurrently by Aboriginal and non-Aboriginal researchers working alongside each other.

Ethical considerations

This project follows the Australian National Health and Medical Research Council (NHMRC) guidelines for ethical conduct for research in Aboriginal and Torres Strait Islander People and communities and has been designed with multilevel Aboriginal engagement and consultation. Each of the six core values of spirit and integrity, cultural continuity, equity, reciprocity, respect, and responsibility have been addressed in ethics applications approved by the Western Australian Aboriginal Human Ethics Committee (HREC1018) on the 6th of October 2020 and the St Vincent's Hospital Melbourne Human Research Ethics Committee (HREC 224/20) on the 4th of November 2020. These applications have also addressed the NHMRC Indigenous research excellence criteria: community engagement, benefit, sustainability and transferability and building capabilities.

Patient and public involvement

This project is predicated on meaningful patient and public involvement. We will establish a community reference group and advisory group, both of which will comprise of a diverse group of Aboriginal consumers who experience arthritis. The community reference group and advisory group will have a significant role in guiding the conduct of all phases of this research.

Partnerships

This project involves a national partnership between Arthritis and Osteoporosis Western Australia and the Enhancing Equity, Collaboration and Culturally secure Osteoarthritis care for Aboriginal Australians (ECCO) collaboration, with the support of Arthritis Australia and funding from the Commonwealth Government. The ECCO collaboration is an inter-professional team of Aboriginal and non-Aboriginal health practitioners, health service staff, and research leaders from the University of Melbourne, Geraldton Regional Aboriginal Medical Service, Victorian Aboriginal Heath Service, University of Western Australia, Western Australia Centre for Rural Health, Telethon Kids Institute, and St Vincent's Hospital, Melbourne. ECCO also has established links with local Aboriginal Medical Services (AMSs) in Western Australia and Victoria. This collective was established with support from the NHMRC Centre for Research Excellence (CRE) in Total Joint Replacement which aims to OPtimise oUtcomes, equity, cost effectiveness and patient Selection for people with osteoarthritis (OPUS). Work conducted at the OPUS CRE identified that there is an absence of opportunity for Aboriginal people to access culturally appropriate arthritis information and culturally secure clinical care. The ECCO collaboration was formed to address this gap in musculoskeletal health research

and to build an evidence-based model of arthritis care that addresses the needs of Aboriginal people.

Participants

Participants and participant groups have been described within each of the six phases of this study outlined below.

Methodology and analysis

Phase 1: Establish a community reference group and advisory group

The first phase of this research will be to establish a community reference group and advisory group.

Community reference group. To recruit the community reference group, we will draw on our previously established partnerships and networks to identify Aboriginal community members who experience osteoarthritis, rheumatoid arthritis, lupus and/or gout. We will then use 'snowballing' recruitment to identify suitable community reference group members. We will leverage relationships rather than a formal admission interview process. A face to face or phone yarn will screen potential group members for suitability. Suitable candidates will be willing to participate and comfortable to share opinions and experiences in a group situation. Each arthritic condition, women and men of a range of ages and from different geographical locations (urban, regional, remote Australia) will be represented in the group. The main purpose of the community reference group is to provide governance and oversight of the project activities, to advise on the strategic direction, cultural security, interpretation and dissemination of the research findings. The group will meet bi-annually face-to-face and through a teleconferencing platform where required.

Advisory group. The advisory group will comprise of Aboriginal health researchers, health service providers, clinicians (including a rheumatologist), health service researchers, Aboriginal consumers, and stakeholders. Similarly, we will draw on our existing partnerships and research networks to recruit approximately 12 individuals. The primary aim of this group will be to advise on methodological aspects of the study and will also meet bi-annually through a teleconferencing platform.

Phase 2. Explore the health information needs and preferences of Aboriginal people with arthritis

In the second phase of research we will conduct a qualitative study to explore the health information needs and preferences of Aboriginal people with arthritis. To recruit participants, we will draw on the network of investigators and existing partnerships with local AMSs. Potential participants will be provided a detailed Participant Information Sheet and an Aboriginal research assistant will follow up with phone call to further describe and discuss the study. The Aboriginal research assistant will answer any questions the potential participants may have and seek verbal consent once they are satisfied the participant is fully informed. Participants will be adults over the age of 18, as approaches to providing health information to children would likely differ significantly to the adult population. We will ensure that the sample comprises of a representative number of people with osteoarthritis, rheumatoid arthritis, lupus and gout, and that gender is diversely represented relative to the prevalence of each condition. We will employ maximal variation sampling to ensure that a range of ages and people from diverse geographical locations are included. Data collection and analysis will be conducted in parallel. Through our yarning approach, we anticipate that each interview will generate rich data. The

sample size will be guided by thematic saturation within each group i.e. the point at which no new themes are emerging from the data. To capture a range of voices across diverse urban, regional and rural settings, we will aim to recruit 4–5 participants per condition at each of the two main study sites (Geraldton, Western Australia and Melbourne, Victoria). Thus, we anticipate recruiting approximately 8–10 participants per condition; for a total of 32–40 across all of the included conditions. Individual interviews held over a teleconferencing platform will be conducted by both an Aboriginal researcher and non-Aboriginal researcher with expertise interviewing people with arthritis. Researchers conducting the interviews will seek additional verbal informed consent, ensuring the participant has read and understood the Participant Information Sheet. Verbal consent from both participants and any family members present will be audiotaped prior to the beginning of the interview. Interview questions will explore participants' experience of engaging with health resources in the past, their informational needs in relation to arthritis and preferences regarding the format of health information. Interviews will be audio-recorded and transcribed. Data will be analysed for each condition separately. Thematic analysis [36] of interview transcripts will be led by the two interviewers. To test/challenge emerging interpretations, preliminary findings from the analysis will be discussed with the community reference and advisory group. The outcome will be a set of recommendations about the content and format of health information based on the needs and preferences of Aboriginal people with arthritis.

Phase 3. Synthesise key recommendations from high quality clinical practice guidelines on arthritis care

Adopting a methodology previously described in Lin et al. 2018 [37]; we will undertake a review of the literature and synthesise findings from contemporary clinical practice guidelines on osteoarthritis, rheumatoid arthritis, lupus and gout to identify recommendations related to patient information (See Open Science Framework Protocol Registration: DOI 10.17605/https://osf.io/UB3Y7/). We will select clinical practice guidelines published within the last five years to reflect up-to-date research evidence. Quality of the retrieved clinical practice guidelines will be appraised using the Appraisal of Guidelines for Research Evaluation II (AGREE II) instrument [38]. The AGREE II has been widely used to assess the quality of clinical practice guidelines, with validated cut-off scores for high and low quality. Only clinical practice guidelines scored as high quality on the AGREE II will be included in our synthesis. Data will be synthesised separately for each condition. The synthesis will involve four stages: extracting information; classifying recommendations; developing a narrative summary and describing common recommendations relating to patient information.

Phase 4. Cultural adaption of key recommendations

Key recommendations will be culturally adapted through consultation with the advisory group using a modified nominal group technique [39], a method for arriving at consensus among a group of experts. Members of the advisory group will be proved a detailed Participant Information Sheet and be given an opportunity to ask questions about participating before being involved in the nominal group discussion. All participants will sign a written consent form on the day of the nominal group discussion. The modified nominal group technique will begin with a yarning session about the key recommendations identified in phases 2 and 3. The advisory group will be asked a question such as: "How can we adapt these key recommendations for Aboriginal consumers?" Participants will be encouraged to consider both the content and format of the recommendations. Following this, in a round-robin fashion, each participant will be invited to present one response or idea at a time. The ideas will be recorded on a

whiteboard or virtual whiteboard made visible to all participants. This phase will continue until no new ideas are generated. Participants will then discuss and clarify the ideas before grouping ideas together into themes. In the final step, themes will be ranked and prioritized. Participants will be invited to vote for the themes they deem most important. A rank-order will then be created for listed themes based on total votes. The outcome will be a set of culturally informed and adapted arthritis recommendations.

Phase 5. Develop culturally adapted arthritis resources

Based on the outcomes of phase four, the researchers will draft a cultural adaption of the key recommendations and format them in a way that meets the needs of Aboriginal consumers and is informed by evidence-based frameworks for the development of patient health information [40, 41]. This may take the form of print, video or web-based materials or a combination of all. Principles such as observing, watching and narrative storytelling may be incorporated into the formats chosen and will be guided by the preferences of the participants. A first draft of the resources will be presented to the community reference group using a culturally adapted nominal group discussion as outlined in phase 4. Members of the community reference group will be proved a detailed Participant Information Sheet and be given an opportunity to ask questions about participating before being involved in the nominal group discussion. All participants will sign a written consent form on the day of the nominal group discussion. First, the community reference group members will be given the opportunity to interact with the draft resources. Following this, a structured yarning discussion will be facilitated to determine how well the resources meet the needs of Aboriginal consumers with arthritis. Key themes will be summarised and ranked and the resulting recommendations will be used to refine the resources.

Phase 6. Qualitative evaluation of resources

We will conduct a qualitative evaluation of the resources among Aboriginal consumers. The sample will include a representative number of people with osteoarthritis, rheumatoid arthritis, lupus and gout and men and women who represent a range of ages and come from diverse geographical locations across urban, regional, remote Australia. While the actual sample size will be guided by thematic saturation, we will aim to recruit approximately 6–8 individuals per condition. Recruitment will be facilitated through existing networks and AMSs at each study site and the same informed consent procedures adopted in Phase 2 will be used to ensure participants are fully informed before participating in the evaluation. Employing culturally appropriate research yarning, the qualitative evaluation will involve an adapted think aloud exercise [42] and semi-structured interviews. In the think aloud exercise, participants will be asked to review the culturally adapted resources and 'think aloud' about what they are experiencing while being observed by the interviewer. The interviewer will prompt the participant during the observation such as "Can you describe what you are seeing to me?" and "How does what you are seeing make you feel?" to encourage participants to share their understanding and reactions to the resources. Researchers will pay particular attention to participants non-verbal cues, prompting participants to clarify their behaviour and thought process, for example: "What were you thinking when you stopped at. . .?" The think aloud exercise will be followed by a research yarn to explore how key messages in the resources were taken up by the participants in light of the participants' underlying assumptions (i.e. how the participants pre-existing experiences interact with what parts of the information they give attention to, accept or dismiss). We will consider not only the intended effects of the messages (i.e. on the attitudes, beliefs, intentions of the participants) but also any potential unintended effects of the messages

(e.g. on the physical, mental, social and cultural wellbeing of the participants). Data will be collected and analysed in parallel so that emerging interpretations can be tested and challenged in subsequent interviews. Data will be analysed using a critical approach [43] and the outcome will be categorised into themes describing the participants' experiences of engaging with the culturally adapted arthritis resources.

Data management

All data collected in this project including audio recordings of interviews and focus groups will be stored on a password protected computer kept on secure servers and in a locked facility at University of Melbourne and the University of Western Australia. Only project investigators as approved by the Western Australian Aboriginal Health Ethics Committee and St Vincent's Hospital Melbourne Human Research Ethics Committee will have access to primary data. Transcription of audio data will be outsourced to a trusted Australian transcription company who adhere to strict confidentiality agreements and the Commonwealth Privacy Act. These transcripts will not record any identifying information.

Timelines

Data collection for this project will commence in the first quarter of 2021 with an overall timeline described in Table 2.

Project outcomes

The output will be culturally appropriate health information resources for Aboriginal people with arthritis that can be used in health care and self-management, or as stand-alone consumer information resources.

Discussion

In this project, culturally secure processes will be employed in each step of the development of patient education and information materials to ensure that they are culturally appropriate and relevant to Aboriginal consumers with arthritis. The focus of this research is osteoarthritis, rheumatoid arthritis, lupus and gout, in line with the funding scheme. While other musculoskeletal conditions are beyond the scope of this project, the outcomes of this research will have

Table 2. Project timelines.

	Year 1				Year 2			
Milestone	**Q1**	**Q2**	**Q3**	**Q4**	**Q1**	**Q2**	**Q3**	**Q4**
Project planning: Set up team communication plan & progress meetings								
Project planning: Recruitment of additional Aboriginal and Torres Strait Islander staff in WA & VIC								
Project planning: Develop project implementation document								
Phase 1: Terms of Reference for advisory committees								
Phase 1: Convene Executive Advisory Group and Community Reference Group								
Phase 2: Qualitative investigation of health information needs								
Phase 3: Systematic review of existing arthritis resources								
Phase 4: Modification of key recommendations with Advisory Group								
Phase 5: Draft arthritis resources								
Phase 5: Further cultural adaptation of draft resources with Community Reference Group								
Phase 5: Final resources developed								
Phase 6: Qualitative evaluation of final resources								

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relevance to musculoskeletal conditions more broadly. Adopting culturally secure research methods which prioritise partnerships, community engagement, community benefit, sustainability and transferability and capacity building, the framework we have presented in this protocol paper may also be applied by other groups seeking to develop culturally secure resources in other areas of health.

Foundational to this project will be the formation of a diverse and representative expert advisory committee and Aboriginal community reference group. The advisory group and community reference group will oversee project activities, steering both methodological and cultural aspects of the project, therefore allowing the research team to respond to community identified priorities. Addressing the burden of musculoskeletal health conditions in Aboriginal communities is currently considered an unmet health need [5]. This project will generate new knowledge regarding the lived experience of Aboriginal people with arthritis as well as how Aboriginal people engage with arthritis information resources. This is an essential step to improve patient-practitioner communication within health services and may improve the health outcomes for Aboriginal people living with arthritis [14].

To ensure the sustainability of this project, this team will build on existing partnerships with AMSs, Aboriginal Community Controlled Health Services and major acute health services. Such partnerships will be important sources of dissemination, distribution, and translation of the developed resources into the clinical environment. Key learnings may also be transferable to the development of resources for conditions other than arthritis. By working closely with health services, we will build the capabilities of Aboriginal and non-Aboriginal clinicians to respond to and manage joint pain and arthritis. Further to this, capacity building within the research team is a key element of this project. We will employ two part-time Aboriginal research assistants and appoint an Aboriginal PhD student who will be mentored by experts in musculoskeletal health research and Aboriginal health research.

There are potential limitations in relation to the scope of this study. Firstly, we will only include English speaking participants. More than 150 Aboriginal languages were recorded as spoken at home in Australia in 2016 and many Aboriginal people speak English as an additional language [44, 45]. Although initially only English-speaking participants will be included, the resources may be translated into some Aboriginal languages if recommended by the Aboriginal consumers included in this project. Audio-visual formats will also be available in the development of the resources, as observing/watching may be a more culturally appropriate form of learning than reading. Secondly, the authors acknowledge limitations associated with employing a qualitative evaluation methodology. While inferences made through the testing and evaluation of the developed resources will be limited in their scope, this project provides a robust foundation for which future research can be based upon. Future directions for related research could include a randomized controlled trial to test the efficacy of culturally adapted resources on the knowledge, beliefs, health behaviours and health-related outcomes of Aboriginal people who experience arthritis.

Conclusions

This project outlines one aspect of addressing disparities in musculoskeletal health care available for Aboriginal people. Patient education and information resources can be a powerful tool to address communication challenges, health literacy and health care access for Aboriginal people who experience arthritis and to empower people to be able to self-manage their conditions. Embedded in a larger body of work seeking to develop a culturally secure model of arthritis care, the Staying Moving Staying Strong project will benefit over 85,000 Aboriginal people who are currently living with arthritis in Australia.

Author Contributions

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B.1 Osteoarthritis Brochure

SURGERY

- Most people can look after osteoarthritis without surgery.
- For a small number of people surgery can help.
- Yarn with your doctor or physio to see if surgery is an option for you.

DON'T BE SHAME ABOUT ASKING QUESTIONS

The more you know about your osteoarthritis, the more you can be in charge of your health and wellbeing.

SOME QUESTIONS YOU COULD ASK YOUR DOCTOR:

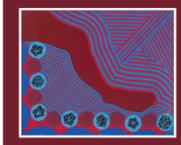
- What can I do to live well with osteoarthritis?
- What is going to happen in the future?
- Where can I go for help?



ABOUT THE ARTIST

THOMAS MARKS – LIVING WITH ARTHRITIS

Thomas 'Marksey' Marks is a proud Wotjobaluk/ Gunaikurnai man from Gippsland. Being one of many Stolen Generations children, he wasn't able to grow up on his traditional Country. As an adult, he is now proudly reclaiming his Aboriginal identity through art. In his artwork 'Living With Arthritis' Thomas tells the story of his struggle with arthritis and the journey he is on to fight back against the pain. It's also a story for others who experience arthritis and go through life followed by this lingering pain.



NICOLE DICKERSON – HEALING TOGETHER

Nicole is a Yamaji Woman from Geraldton Western Australia with connections to the Amangu, Naaguja, Wilunyu and Ngarluma People. Nicole grew up interested in art with her creative ways coming from her Dad. Nicole's art is her form of healing, strength, her words when she cannot speak, and most importantly it's her story. In 'Healing together' Nicole tells the story of how the rain falls on the land, connecting people, cleansing the mind, body & soul, from one place that connects two, to support Healing Together on one land.



WHERE CAN I GO FOR HELP?

If joint pains are stopping you from living well, have a yarn with your doctor, health worker or physio.

If you'd like help finding your local Aboriginal health service have a look at these links:

https://askizzy.org.au
https://www.naccho.org.au/naccho-map

WANT TO KNOW MORE ABOUT OSTEOARTHRITIS?

Scan here

This brochure was developed with funding from the Australian Government and support from Arthritis Australia

STAYING MOVING, STAYING STRONG
OSTEOARTHRITIS

WHAT IS OSTEOARTHRITIS?

- Osteoarthritis is when your joints, such as your knees, hips, back and hands are stiff and sore.
- This can happen for lots of reasons - weak muscles, not enough exercise or sleep, poor diet, smoking or stress.
- You're more likely to get osteoarthritis if it runs in the family, if you are overweight, or if you've had a big injury to the joint in the past.
- People can experience osteoarthritis at any age.
- It's often described as joint 'wear and tear'. But using your joints won't wear them away. Joints need to move to be healthy.

WHAT DOES OSTEOARTHRITIS FEEL LIKE?

- It's common to feel joint aches and pains. Joints can also be swollen or feel stiff.
- There can be good and bad days. Bad days (e.g. when joints are stiff and sore) are called 'flare ups'.
- Often joints feel more stiff and sore in the morning, before you get moving.
- Joint aches and pains can affect your body, mind and spirit.

Everyone with osteoarthritis has a different story.

"I notice I was just getting slower and slower and lots of aches and pains" — Aboriginal woman, aged 67.



HOW DO I KNOW IF I HAVE OSTEOARTHRITIS?

- If you feel joint pain or stiffness, have a yarn with your doctor, health worker or physio.
- A doctor or physio doesn't need an x-ray or scan to diagnose osteoarthritis.
- They will ask you questions about your pain and look at your joints and movement.

HOW CAN I LOOK AFTER OSTEOARTHRITIS?

Some mob reckon there's not much you can do for your osteoarthritis, but with the right plan you can live well with it.

STAYING MOVING, STAYING STRONG

- Staying moving is the best way to look after your osteoarthritis. It keeps your bones, joints and muscles healthy, and is good for your mind too.



"I go to the gym and do stuff to keep me in shape, which helps with my day to day. It's when I stop exercising, that's when my knees play up" — Wotjobaluk/ Gunaikurnai man, aged 52.

- Any movement is better than no movement. Do something you enjoy, like walking with your grannies or on Country or exercising in water.
- It's safe to be active, even if it's a bit sore at the start. Start slow and see a physio or exercise physiologist to make a plan.

MEDICINES

- Medicines can help joint aches and pains.
- Yarn with your doctor before trying medicines.
- Medicines that might help are:
  - Medicines for pain (e.g. paracetamol).
  - Medicines to help swelling (inflammation) (e.g. ibuprofen).

BUSH MEDICINE

- Bush medicines may help alongside Western medicine. Yarn with your local Aboriginal health service or Cultural Elder to find out more.



LIVE HEALTHY

- Eating healthy, being active and looking after your weight can help your osteoarthritis. Talk to your doctor or dietitian about a plan.
- Cut down, or if you can, get off the smokes. This will keep your body healthy and help with your joint pain.
- Osteoarthritis can make you feel down and frustrated. Yarn about your feelings with family, doctor or staff at your Aboriginal health service.

B.2 Gout Brochure

"So I walked around the neighbourhood, run into a few other people walkin their dogs. And that achieves two things, it tests my joints are loose, moving. And you get to see people and you gettin out and about.", — Gomeroi man, aged 66.

- Staying moving keeps your body and mind healthy and keeps your joints healthy too.
- Any movement is better than no movement. Do something you enjoy, like exercising in water or getting out and walking on Country.
- If you're having a flare up, it's ok to rest. Get moving again when you feel better. Using a walking stick or a cold pack can help.
- Joint pains can affect your spirit and can make you feel down and frustrated. Yarn about your feelings with family, your doctor or staff at your Aboriginal health service.

DON'T BE SHAME ABOUT ASKING QUESTIONS

The more you know about your gout, the more you can be in charge of your health and wellbeing.

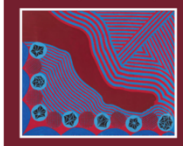
Some questions you could ask your doctor:

- What causes gout?
- Why do I get flare ups?
- What can I do to look after my gout?
- What medications can I take?
- What can be the side effects of these medications?
- How often do I need to see a doctor?
- What is going to happen in the future?

ABOUT THE ARTIST

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Thomas 'Marksey' Marks is a proud Wotjobaluk/Gunaikurnai man from Gippsland. Being one of many Stolen Generations children, he wasn't able to grow up on his traditional Country. As an adult, he is now proudly reclaiming his Aboriginal identity through art. In his artwork 'Living With Arthritis' Thomas tells the story of his struggle with arthritis and the journey he is on to fight back against the pain. It's also a story for others who experience arthritis and go through life followed by this lingering pain.



NICOLE DICKERSON – HEALING TOGETHER

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WHERE CAN I GO FOR HELP?

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WANT TO KNOW MORE ABOUT GOUT?

Scan here

THE UNIVERSITY OF MELBOURNE
THE UNIVERSITY OF WESTERN AUSTRALIA
Arthritis & Osteoporosis Western Australia
Arthritis Australia
Western Australian Centre for Rural Health

This brochure was developed with funding from the Australian Government and support from Arthritis Australia

STAYING MOVING, STAYING STRONG GOUT

WHAT IS GOUT?

- Gout is a type of arthritis that is caused by a natural chemical in the blood called urate.
- Urate is healthy for most people. In gout, urate builds up in the blood, in and around the joints.
- Excessive urate build up in the blood causes swelling (inflammation) in joints. This can be very painful.
- Urate is not a crystal that gets stuck in joints, even though it is common for people to think this!
- Gout can affect any joint. It is most common in the foot.
- Uncontrolled gout can affect organs too such as the kidneys.
- People can get gout at any age.
- You're more likely to get gout if it runs in your family, if you're overweight or if you have other conditions like diabetes or kidney disease.

WHAT DOES GOUT FEEL LIKE?

- It's common for joint pains to come on quickly, over a few hours, and last for a week or so. These are called 'flare ups'.
- Flare ups can be very painful and stop you living well.
- Joints may also feel swollen, red or hot to touch.

Everyone with gout has a different story.

"When it's flared up, everything stops. Yeah, you can't do anything" — Worimi man, aged 32 years



HOW DO I KNOW IF I HAVE GOUT?

- If you feel joint pains or notice swelling, have a yarn with your doctor or health worker.
- They will ask you questions about your pain and look at your joints.
- To diagnose gout, your doctor might ask you to get some blood tests.
- Your doctor may also send you to a specialist doctor called a rheumatologist.

"I haven't had it (gout) fully blown for a long time because I get the signs and I take tablets as soon as I get that tingling" — Badimaya/Noongar man, aged 53

HOW CAN I LOOK AFTER GOUT?

MEDICINES

- Medicines are the most important way of controlling gout.
- Yarn with your doctor. They will help find the right medicines for you.

Medicines that can help are:

- Medicine to lower urate in your blood (e.g. allopurinol). These must be taken every day to prevent flare ups.
- Medicines to help swelling (inflammation) and pain (e.g. paracetamol, ibuprofen, colchicine, cortisone).



Some mob reckon there's not much you can do, but with the right plan you can live well with gout!

BUSH MEDICINE

- Bush medicines may help alongside Western medicine. Yarn with your local Aboriginal health service or Cultural Elder to find out more.



HEALTHY LIVING

- Living healthy will help with your gout.
- Drink lots of water and eat lots of fresh veggies.
- Some foods and drinks can trigger flare ups. If you notice a food or drink is causing flare ups, try cutting it out of your diet.
- Alcohol increases the urate in your blood. Drink less. This can help you manage flare ups.
- Cut down, or if you can, get off the smokes. This will keep your body healthy and help with your joint pain.

B.3 Rheumatoid Arthritis Brochure

HOW CAN I LOOK AFTER RHEUMATOID ARTHRITIS?

- Not sleeping well can make pain worse. Good sleep at night can help your joint pain and keep your mind healthy too.
- Rheumatoid arthritis can make you feel down and frustrated. Look after your moods and stress. Yarn about your feelings with family, your doctor or staff at your Aboriginal health service.

SURGERY

- Most people look after rheumatoid arthritis without surgery. For a small number of people surgery can help.
- Yarn with your doctor to see if surgery is an option for you.

DON'T BE SHAME ABOUT ASKING QUESTIONS

The more you know about your rheumatoid arthritis, the more you can be in charge of your health and wellbeing.

Some questions you could ask your doctor:

- What causes rheumatoid arthritis?
- Why do I get flare ups?
- What can I do to look after rheumatoid arthritis?
- What medicines can help?
- What can be side effects of these medicines?
- What is going to happen in the future?
- Where can I go for help?

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https://askizzy.org.au
https://www.naccho.org.au/naccho-map

WANT TO KNOW MORE ABOUT RHEUMATOID ARTHRITIS?

Scan here

An audio version of the brochure can also be accessed by scanning the QR code or going to **www.stayingstrongwitharthritis.org.au**

THE UNIVERSITY OF MELBOURNE
THE UNIVERSITY OF WESTERN AUSTRALIA
Arthritis & Osteoporosis
Arthritis Australia
Western Australian Centre for Rural Health

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STAYING MOVING, STAYING STRONG
RHEUMATOID ARTHRITIS

WHAT IS RHEUMATOID ARTHRITIS?

- Rheumatoid arthritis is an autoimmune condition.
- This means the body's immune system thinks joints need healing even when they don't. This causes joints to get swollen and sore.
- It can affect any joint, but most often occurs in smaller joints like in the hands and feet.
- It's not known what causes rheumatoid arthritis. But you're more likely to get it if it runs in the family, you're a woman, if you are overweight or smoke.

WHAT DOES RHEUMATOID ARTHRITIS FEEL LIKE?

- It's common for people to feel joint pains. Joints can also be red and swollen (inflamed) or feel stiff.
- People have good and bad days. Bad days (e.g. when joints are sore and swollen) are called 'flare ups'.
- Rheumatoid arthritis can affect your body, mind and spirit.

Everyone with rheumatoid arthritis has a different story.

"I might have been a teenager or early 20s. When, I just woke up one day, everything started swelling"
— Wilunyu/Wajarri/Martuthunira woman, aged 34

HOW DO I KNOW IF I HAVE RHEUMATOID ARTHRITIS?

- If you feel joint pains or notice swelling have a yarn with your doctor, health worker or physio.
- To diagnose rheumatoid arthritis, your doctor might ask you to get blood tests and have an x-ray or scan.
- Your doctor might send you to a specialist doctor called a rheumatologist.



HOW CAN I LOOK AFTER RHEUMATOID ARTHRITIS?

MEDICINES

- Medicines are an important way to control rheumatoid arthritis.
- Yarn with your doctor. They will help find the right medicines for you.

Medicines that can help are:

- Medicines to calm your immune system (called DMARDs – Disease Modifying Anti-Rheumatic Drugs e.g. methotrexate)
- Medicines to help swelling (inflammation) and pain (e.g. paracetamol, ibuprofen or cortisone)
- When starting medicines, check in with your doctor every 1-3 months about how you're feeling.

BUSH MEDICINES

- Bush medicines may help alongside Western medicine. Yarn with your local Aboriginal health service or Cultural Elder to find out more.

SPLINTS

- Splints can help for hand pain and special shoes or inserts can help with foot pain. Yarn with your doctor, physio, occupational therapist or podiatrist to find out more.

LIVE HEALTHY

- Staying moving is a good way to look after rheumatoid arthritis. It keeps your body and mind healthy too.
- Any movement is better than none. Do something you enjoy, like exercising in water or getting out and walking on Country.

"I exercise regularly, like at a gym ... I feel better about myself, I feel better with, like, the fatigue and the pain, in managing it." — Wotjobaluk woman, aged 33

- Starting a gym program can be good. Talk to your Aboriginal health service, physio or exercise physiologist about a plan.
- If you're having a flare up, it's ok to rest. Get moving again when you feel better.
- Cut down, or if you can, get off the smokes. This will keep your body healthy and help with your joint pain.



B.4 Systemic Lupus Erythematosus Brochure

LIVE HEALTHY

- Staying active and eating healthy will help your lupus.
- Cut down, or if you can, get off the smokes.
- Not sleeping well can make pain worse. Good sleep at night can help your joint pain and keep your mind healthy too.
- Look after your moods and stress. Yarn about your feelings with family, your doctor or staff at your Aboriginal health service.



Don't be shame about asking questions

The more you know about your lupus, the more you can be in charge of your health and wellbeing.

Some questions you could ask your doctor:

- What causes lupus?
- Why do I get flare ups?
- What can I do to look after my lupus?
- What is going to happen in the future?
- What medicines can help me?
- What can be side effects of these medicines?
- How often do I need to see a doctor or specialist?

ABOUT THE ARTIST

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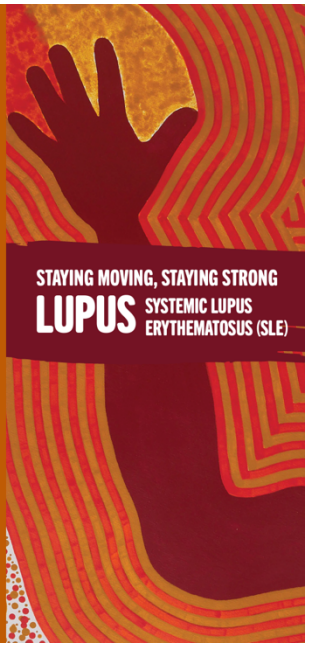
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https://www.naccho.org.au/naccho-map

WANT TO KNOW MORE ABOUT LUPUS?

Scan here

This brochure was developed with funding from the Australian Government and support from Arthritis Australia



WHAT IS LUPUS?

- Lupus, also called systemic lupus erythematosus or SLE, is an autoimmune condition.
- This means the body's immune system thinks that body parts need healing even when they don't. This causes swelling (inflammation) in the body.
- Lupus can affect many parts of the body including joints, skin or other organs like the lungs and kidneys.
- It is not known what causes lupus. But you're more likely to get it if it runs in your family, if you are a woman or have a long period of illness or stress.



WHAT DOES LUPUS FEEL LIKE?

People can have good and bad days. Bad days (e.g. when feeling tired and sore) are called 'flare ups'.

People with lupus can feel:

- Sore and swollen joints
- Tired
- Sad or depressed
- Fevers
- Rashes
- Mouth sores
- Lupus can affect your body, mind and spirit.

Everyone with lupus has a different story.

"People get it inside, people can get it on the outside. I can have butterfly rashes on my face some days and then some days I won't, but I still have pain inside" — Yindjibarndi woman, aged 48



HOW DO I KNOW IF I HAVE LUPUS?

- Have a yarn with your doctor.
- To diagnose lupus, your doctor might ask you to get blood or urine tests.
- Your doctor may also send you to a specialist doctor called a rheumatologist.



HOW CAN I LOOK AFTER LUPUS?

MEDICINES

- Medicines are an important way to control lupus.
- Yarn with your rheumatologist and doctor about the right medicines for you.
- The right medicines depend on how lupus affects you and which body parts are involved (e.g. your joints, skin, organs)

These can include:

- Medicines to calm your immune system, including antimalarials (e.g. hydroxychloroquine, or immunosuppressants e.g. mycophenolate).
- Medicines to help swelling (inflammation) and pain (e.g. ibuprofen, celecoxib, cortisone).
- Medicines to stop blood clots (anticoagulants).
- When starting medicines, check in with your doctor every 1-3 months about how you're feeling. After this, check in every 6 months.
- Tell your doctor if you are pregnant or plan to get pregnant.

"When I was diagnosed I had to start rethinking about my health and changing my lifestyle. Changing my food intake, take all my medications and trying to do a lot of exercise and walking" — Nhanda woman, aged 68

BUSH MEDICINES

- Bush medicines may help alongside Western medicine. Yarn with your local Aboriginal health service or Cultural Elder to find out more.

MANAGING TRIGGERS

- Knowing your triggers can help you avoid flare ups.
- Common triggers are feeling stressed, being sick or having an injury, being pregnant or using some medicines.
- Sunlight can be a trigger and your skin may be extra sensitive. Sun protection is important. Wear sunscreen, cover your skin, wear a hat and sunglasses when outdoors.

B.5 Staying Moving, Staying Strong Videos

https://www.youtube.com/@StayingStrongwithArthritis

Appendix C. Human Research Ethics Committees Approval Letters

C.1 Western Australian Aboriginal Health Ethics Committee Approval Letter



Approval Letter

Date: 06/10/2020

Dear Dr Lin

HREC Reference number: 1018

Project title:

Staying moving, staying strong: Developing culturally appropriate health information resource for Aboriginal Australians with osteoarthritis, rheumatoid arthritis, lupus and gout

Thank you for submitting the above research project for ethics approval. The research project was considered by the WA Aboriginal Health Ethics Committee (WAAHEC) at the meeting held on 05/10/2020 . I am pleased to advise that the WAAHEC has reviewed and approved the following documents submitted for this project:

Document(s):

WAAHEC Application_Stay Moving Stay Strong_e-signed 16092020
Stay Moving Stay Strong_Study Protocol_v1 11092020
Statement addressing values and ethics ECCO_02092020
PICF Phase 6_Evaluation_Interviews v1 08092020
PICF Phase 2_Qual Study_Interviews v1 08092020
GRAMS Letter of Support_15092020

450 Beaufort Street, Highgate WA 6003 / PO Box 8493, Stirling Street, Perth WA 6849
Phone: (08) 9227 1631 **Fax:** (08) 9228 1099 **Email:** ethics@ahcwa.org **Web:** www.ahcwa.org.au **ABN:** 48 114 220 478 **ACN:** 114 220 478

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WAAHEC Western Australian Aboriginal Health Ethics Committee

The WAAHEC has granted approval of this research project from <date of the meeting held>, pending your agreement of the following conditions:

Conditions

- The WAAHEC will be notified in writing, giving reasons, if the project is discontinued before the expected date of completion.
- The Chief Investigator will provide a Progress Report by 30 June each year in the specified format. This form can be found on the AHCWA website (www.ahcwa.org.au).
- The approval for research projects is three years. Research projects should commence and conclude within that period of time. Projects must be resubmitted if extension over three years becomes necessary.
- Information about publications and/or conference presentations may be incorporated into Progress and Final Reports. This enables the WAAHEC to maintain a record of publications. Researchers can contact the WAAHEC if they require support or feedback prior to publication.
- Aboriginal and Torres Strait Islander communities are formally acknowledged for their contribution to this research project.
- If amendments to the research project become necessary, these should be submitted using the form provided on the AHCWA website (www.ahcwa.org.au).

Please contact ethics@ahcwa.org if you have any queries about the WAAHEC's consideration of your project.

The WAAHEC wishes you every success in your research.

Kind regards

Erica Lewin

For, Vicki O'Donnell
Chairperson, WAAHEC

450 Beaufort Street, Highgate WA 6003 / PO Box 8493, Stirling Street, Perth WA 6849
Phone: (08) 9227 1631 **Fax:** (08) 9228 1099 **Email:** ethics@ahcwa.org **Web:** www.ahcwa.org.au **ABN:** 48 114 220 478 **ACN:** 114 220 478

C.2 St Vincent's Hospital Melbourne Human Research Ethics Committee Approval Letter

ST VINCENT'S HOSPITAL
MELBOURNE
A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

St Vincent's Hospital
(Melbourne) Limited
ABN 22 052 110 755

41 Victoria Parade Fitzroy VIC 3065
PO Box 2900 Fitzroy VIC 3065

Telephone 03 9231 2211
Facsimile 03 9231 3399
www.svhm.org.au

4 November 2020

Dr Samantha Bunzli
Department of Surgery
University of Melbourne

Dear Dr Samantha Bunzli

Project ID Number: 68457
St Vincent's HREC Reference: HREC 224/20

'Staying Moving, Staying Strong: Developing Culturally Appropriate Information for Aboriginal Australians with Osteoarthritis, Rheumatoid Arthritis, Lupus and Gout'

I am pleased to advise that the above project has received **Ethical approval** from the St Vincent's Hospital Melbourne Human Research Ethics Committee (HREC)

HREC Approval Date: 4 November 2020

This HREC is accredited by the Office of Health and Medical Research under the single ethical review system. The HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007, updated 2018).

Ethical approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992*, the *National Statement on Ethical Conduct in Human Research 2007 (Including all updates)* and the *Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research (2018).*

Ethical approval is given for this research project to be conducted at the following sites:

- St Vincent's Hospital (Melbourne), VIC

The following documents have been reviewed and approved:

Approved Documents

Document	Version	Date
Victorian Specific Module	-	16 Sept 20
Study Protocol	3.0	19 Oct 20

SVHM PICF – Phase 2 Qual Study	3.0	19 Oct 20
SVHM PICF – Phase 5 Community Focus Group	3.0	19 Oct 20
SVHM PICF – Phase 6 Evaluation Interviews	3.0	19 Oct 20
Research Yarn Guide Phase 2	1.0	04 Sept 20
Research Yarn Guide Phase 6	1.0	04 Sept 20

Acknowledged Documents

Document	Version	Date
HREA - HREC/68457/SVHM-2020-237108(v2)	-	-
CV – Samantha Bunzli	-	-
CV – Ivan Lin	-	-
CV – Michelle Dowsey	-	-
CV – Penny O'Brien	-	-
CV – Tilini Gunatillake	-	-
CV – Brooke Conley	-	-
CV – Peter Choong	-	-
CV – Jennifer Persuad	-	-
CV – Naz Rind	-	-
CV – Jonathan Bullen	-	-
GCP – Samantha Bunzli	-	03 Feb 19

St Vincent's HREC: 224/20
Project ID: 68457
Please quote these numbers on all Correspondence

Approval is subject to:

- **An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the 01 May each year for the duration of the project. Continuation of ethics approval is contingent on submission of an annual report. Failure to comply with this requirement may result in suspension of the project by the HREC.**
- The Principal Researcher is to ensure that all associate researchers are aware of the terms of approval and to ensure the project is conducted as specified in the application and in accordance with the National Statement on Ethical Conduct in Human Research 2007 (including all updates)
- The Principal Researcher is to notify the Research Governance Unit of all significant safety issues in accordance with the *NHMRC Guidance: Safety monitoring and reporting in clinical trials involving therapeutic goods (including all updates)*.
- Submit an Annual Safety Report for the duration of the project.
- Immediate notification of any unforeseen events that may affect the continuing ethical acceptability of the project;
- Notification and reasons for ceasing the project prior to its expected date of completion;
- Submit to the reviewing HREC for approval of any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s, Investigator Brochure and other study materials.

Appendix D. Terms of Reference



Community Reference Group

Terms of Reference

Purpose

The purpose of the Community Reference Group (CRG) is to provide ECCO Collaborative guidance and advice in relation to the Staying Moving Staying Strong Project (SMSS) which aims to create culturally appropriate arthritis education resources for the management of osteoarthritis, rheumatoid arthritis, lupus and gout. The CRG will work in collaboration with the ECCO research team to navigate the research methods, processes, findings and dissemination of outcomes. The overall aim is for cultural security to be upheld in all ECCO research activities which should ultimately benefit Aboriginal and/Torres Strait Islander people who experience arthritis conditions.

Role

Community engagement aims of the CRG are:

- To build meaningful engagement with Aboriginal and/or Torres Strait Islander peoples' which ECCO research aims to serve.
- To represent and give voice to Victoria Aboriginal and/or Torres Strait Islander peoples' who experience arthritis conditions, whilst also acknowledging and celebrating the diversity of culture within Communities.

Research steering aims of the CRG are:

- To act as navigators, drawing on their unique experiences and expertise to guide all cultural and methodological aspects of ECCO research.
- To assist with research priority setting for Aboriginal and/or Torres Strait Islander people who experience arthritis or joint pain.
- To provide advice and direction on how best to ensure that the work of ECCO is conducted in an ethical and culturally safe and secure manner.
- To guide health care services and clinicians in providing musculoskeletal care and achieve positive health and wellbeing outcomes for Aboriginal and Torres Strait islander people who experience arthritis.

Knowledge communication and advocacy aims of the CRG are:

- To ensure that ECCO research findings are appropriately communicated to Community.
- To create a safe space for community members and support a two-way knowledge exchange between ECCO researchers and Aboriginal and/or Torres Strait Islander health services, patients and communities.

Artist: Mick Harding Taungwurrung Elder and belongs to the Yowong-Illam-Baluk clan (Mansfield Region) of the Taungwurrung people.

Authority

The CRG is a reference group. The group will make recommendations to the ECCO research group however does not provide final authority decision making for policies. Final approval rests with the ECCO research team, on consultation with other project leaders. Although the CRG does not have final decision-making authority, the CRG will have a strong input in research steering.

Membership

Composition

The CRG will consist of 4-6 Aboriginal and/or Torres Strait Islander members living in Victoria who will represent diversity in gender, age, geographical location, knowledge and expertise. Members will have a confirmed diagnosis of either osteoarthritis, rheumatoid arthritis, systemic lupus erythematosus and/or gout.

Responsibility

Members of the CRG are expected to:

- Work respectfully, collaboratively and inclusively, acknowledging and respecting all members of the group who represent diverse communities and experiences and allowing all members to voice their opinion.
- Be committed to upholding the principle or cultural security in all functions of the group.
- Demonstrate a commitment to privileging Aboriginal and/or Torres Strait Islander voices.
- Demonstrate a commitment to responding to Aboriginal and/or Torres Strait Islander identified priorities, to improve access to culturally secure musculoskeletal care.
- Attend meetings with an understanding of the forthcoming agenda and matters arising and therefore being able to proactively participate in meetings and respond in reasonable out of session requests.
- Fulfill individual roles and responsibilities in a timely manner.

Expectations

Members of the CRG can expect:

- To be provided with complete and accurate information in a timely manner.
- To receive ongoing and up to date communication through emails.
- To be given a reasonable timeframe to make decisions.
- To feel culturally safe and secure in all meetings and for appropriate channels to be available for members to voice concerns confidentially.

Artist: Mick Harding Taungwurrung Elder and belongs to the Yowong-Illam-Baluk clan (Mansfield Region) of the Taungwurrung people.



Time Commitment

The CRG will be convened every 3-6 months for 2 years duration this will be informed by the intensity of the research projects and the capacity of the members of the group.

Meeting Venue

All meetings will be available to be joined via teleconferencing platform Zoom. Links to Zoom meetings will be circulated with all other meeting documentation via calendar invites and emails.

Sitting fees

All CRG members will be remunerated for their time sitting at the meetings, and reimbursement for any out-of-pocket travel expenses in-line with the OPUS Policy for Reimbursement and Sitting Fees. A sitting fee of $100 per meeting will be offered to members as financial reimbursement. Light refreshments will also be offered if face to face meetings are to be arranged.

Meeting process

Decision making

The CRG will adopt an informal consensus decision making processes to reach agreement at meetings. This will involve a collaborative, transparent approach in which all members have the opportunity to voice their opinions. Members of the group should feel safe and respected to voice their concerns in meetings. We recognise that at times members may not feel comfortable to raise concerns. In these circumstances, members will be able to confidentially contact the Chair or Co-Chair out of session. For sensitive topics the CRG may consider an anonymous decision-making process, for example using a paper ballot system.

Meeting process and documents

The meeting process and agenda follows a standard format in keeping with the agreed purposes of the CRG. The standard format includes the following headings:

- Acknowledgement of Country
- Minutes of the previous meeting
- SMSS project update
- Other business
- Next meeting
- Close

The CRG Secretariat will manage and provide documentation (e.g., agendas and minutes of meetings, relevant project updates, documents for review) relevant to the CRG. The agenda for each meeting and any required additional reading will be provided to CRG members at least one week before each meeting via email.

Artist: Mick Harding Taungwurrung Elder and belongs to the Yowong-Illam-Baluk clan (Mansfield Region) of the Taungwurrung people.

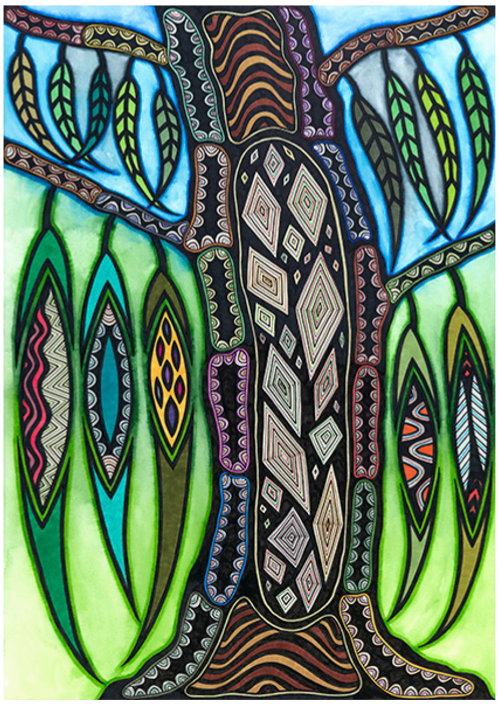
Approval/Review Date

The Terms of Reference will be in place until the end of Brooke's PhD activities (January 2024).

Appendix A.

Our Story in a Painting

Artist Mick Harding tells the story of our research through a scar tree and the diamonds within it, very much focusing on the relationship building and relationships within our musculoskeletal health research. The diamonds represent Liwik (ancestors). Aboriginal and Torres Strait Islander communities around Australia are represented by the designs alongside both sides and the limbs of the scar tree. The wavy lines at the top and bottom of the tree represent the overall journey of the research group and how its research has a ripple effect that influences possible change within our communities. The five colourful gum leaves represent the five difference research streams conducted at OPUS.



Artist: Mick Harding Taungwurrung Elder and belongs to the Yowong-Illam-Baluk clan (Mansfield Region) of the Taungwurrung people.



Appendix B. Definitions

Cultural Security: Cultural security is a commitment to conducting research and providing services that do not compromise the cultural rights, values, beliefs, knowledge systems and expectations of Aboriginal and/or Torres Strait Islander people and is the overarching principle that guides the way we do business at ECCO.

ECCO: The Enhancing Equity, Collaboration and Culturally secure Osteoarthritis care for Aboriginal Australians (ECCO) collaboration. The ECCO collaboration is an inter-professional team of Aboriginal and non-Aboriginal health practitioners, health service staff, and researchers in Victoria, Queensland and Western Australia who are working together to 1) explore the impact of arthritis on Aboriginal and Torres Strait Islander people and 2) develop a culturally safe and secure model of arthritis care for Aboriginal and Torres Strait Islander people in Australia.

OPUS: **OP**timising patient o**U**tcomes by improving equity, cost effectiveness, and patient **S**election. OPUS refers to the Centre for Research Excellence in Total Joint Replacement, funded by the National Health and Medical Research Council and based at the Department of Surgery, University of Melbourne.

Artist: Mick Harding Taungwurrung Elder and belongs to the Yowong-Illam-Baluk clan (Mansfield Region) of the Taungwurrung people.

Appendix E. Participant Information Consent Form

Participant Information Sheet/Consent Form

St Vincent's Hospital Melbourne

Title	*Staying Moving, Staying Strong*
Protocol Number	HREC 224/20
Project Sponsor	*Arthritis & Osteoporosis Western Australia*
Coordinating Principal Investigator/ Principal Investigator	*Dr. Ivan Lin, Dr Samantha Bunzli*
Location	*Melbourne, Victoria*

1 Introduction

We invite you to take part in a project gathering information about how Aboriginal and/or Torres Strait Islander Peoples (respectfully referred to as Aboriginal people herewith) and their families think and feel about health information concerning arthritis. This is because you have told your local health service or health worker that you experience osteoarthritis, rheumatoid arthritis, lupus and/or gout. If you decide to take part in this project, please read the following information sheet. This information sheet will provide you with information about the study and help you decide if you would like to take part in the project. We will ask you to verbally confirm that you understand the information provided and consent to take part in the research project.

Participation in this research is voluntary. If you don't wish to take part, you don't have to. We encourage you to ask questions about anything that you don't understand or would like to know more about. You might also like to talk about it with a family member or friend before you decide if you want to take part.

2 What is the purpose of this research?

We have asked you to take part in this study as you have told your local health service or health worker that you experience an arthritic condition such as osteoarthritis, rheumatoid arthritis, or lupus and/or gout. People with arthritis should be provided with up-to-date, culturally appropriate information about their condition and what they can do about it. However, currently there are no arthritis resources that have been adapted with input from Aboriginal people who experience arthritis.

The aim of this study is to hear about what you think and prefer when accessing health information relevant to your condition. This will help us create up-to-date, relevant, culturally appropriate health information resources suited to your condition.

3 What does participation in this research involve?

Involvement in this study requires participation in an interview either face to face or over the phone at a time and place that is convenient to you. The research team is happy to travel to where you work or live. The interview will be conducted by a non-Aboriginal researcher and/or a male or female Aboriginal researcher.

You will be asked about your thoughts, needs and preferences when it comes to health information about your condition. If you give permission the interview and your verbal consent will be audio-recorded. Everything you say in the interview will be confidential and will not be heard by anyone outside of the research team and no one will be able to identify you in the findings from the study.



- Interviews can take place at a place that is convenient and comfortable to you (either through the telephone, through video conferencing tools (such as; Zoom, FaceTime, Skype), at your health service or community centre, at your home.



- The interview may last up to an hour.



- We will audio tape the interview and your verbal consent on a tape recorder so that we can listen back to your stories.



- A family member can be present if you would like them to be. They should also read and sign this information sheet if you would like them to be present at the time of the interview.

4 What type of questions are we asking?

We are interested in what you understand about your condition, what you do to look after it, what information you have previously been given about it, and your suggestions about information that would be most helpful for you.

5 What do I have to do?

The research team from St Vincent's Hospital will provide you with all the information you require to participate in this study. You should indicate your preferred time and a contact number/email address on the attached sheet. The research team will contact you when a date and time has been decided upon.

6 Other relevant information about the project

This research is being run by a team from the Western Australian Centre of Rural Health, Geraldton Regional Aboriginal Medical Service, Curtin University, Telethon Kids Institute, Arthritis and Osteoporosis Western Australia, The University of Melbourne, and St Vincent's Hospital, in partnership with Aboriginal consumer reference groups in Western Australia and Victoria

This research project is being funded by:

- Arthritis & Osteoporosis Western Australia

This research project has been approved by:

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). This project is approved by St Vincent's Hospital Melbourne HREC.

7 Do I have to take part in this research project?

Taking part in this study is entirely voluntary which means that **you don't have to participate if you don't want to.** You can **withdraw** or stop participating at any time throughout the project, for whatever

reason. If you do decide to leave the project, the researchers would like to keep the information already collected about you. This is to help them make sure that the results of the research can include as many different perspectives as possible. If you do not want them to do this, you should tell them at the time you withdraw from the project.

8 What will the researchers do with the information they collect?

We will use the information we collect to better understand how to meet the needs and preferences of Aboriginal people living with Arthritis. We will also share our findings with the community, as well as write articles in scientific journals. This information will also help inform future research projects. We won't use any names to identify people who participate in this project. If we use a quote, we will use a fake name to protect your identity.

We will keep the audio files and transcriptions of the interviews on the researchers' **password protected computer** at the University of Melbourne for seven years. Any written records will be stored in a locked filing cabinet in the researchers' office.

During that time, we would like to use them to help other researchers and health professionals and for conference presentations. As we will use fake names, you will not be identifiable to any other researchers or health professionals looking at the data. If the information is useful for the future and provides ongoing benefit for Aboriginal Australians, we may ask to keep it for longer.

9 Benefits to you and benefits of the project

There will be no immediate benefit to you from your participation in this research however the results from this study will be used to create culturally appropriate health information for Aboriginal Australians who live with arthritis.

10 Discomforts and risks

We do not anticipate there being any risks from taking part in this study. However, we understand that it might be upsetting to talk about your health problems or experiences. You can bring a family member to make you feel more comfortable and you can stop the interview at any time if you feel upset.

11 Reimbursement for your time participating in the study

You will be reimbursed for your time with a $50 Coles/Myer voucher.

12 Who should I contact if I need more information?

If you would like any additional information or have any questions about the research project you can speak to the Principal Investigator, Dr. Samantha Bunzli or Study coordinator, Ms Brooke Conley.

Dr. Samantha Bunzli

Email: Samantha.bunzli@unimelb.edu.au

Ms Brooke Conley

Email: bccon@student.unimelb.edu.au

Phone: 0492980453

Complaints or concerns:

If you have any concerns or complaints about the research project you can speak with Ms O'Brien on the contact details above. If you would like to talk to a person independent of the research team you may contact the St Vincent's Human Research Ethics committee or a Patient Liaison Officer at St Vincent's Hospital Melbourne:

Reviewing HREC approving this research and HREC Executive Officer details

Reviewing HREC	St Vincent's Hospital Melbourne
HREC Executive	The Executive Officer of Research
Telephone	03 9231 2394
Email	Research.Ethics@SVHM.org.au

Complaints contact person

Position	Patient Liaison Officer at St Vincent's Hospital Melbourne
Telephone	(03) 9231 1954
Email	PLO@svhm.org.au

Study findings:

If you would like information about the study findings, these may be made available to you at the completion of the study by contacting the study coordinator: Ms Brooke Conley, University of Melbourne, St. Vincent's Hospital Melbourne via email: bccon@student.unimelb.edu.au or Telephone: 0492980453.

Consent Form - *Adult providing own consent*

Title	*Staying Moving, Staying Strong*
Project Sponsor	*Arthritis & Osteoporosis WA*
Coordinating Principal Investigator/ Principal Investigator	*Dr Ivan Lin, Dr Samantha Bunzli*
Location	*Melbourne, Victoria*

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please _____

Signature _____ Date _____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher[†] (please print) _____

Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title	*Staying Moving, Staying Strong*
Project Sponsor	*Arthritis & Osteoporosis WA*
Coordinating Principal Investigator/ Principal Investigator	*Dr Ivan Lin, Dr Samantha Bunzli*
Location	*Melbourne, Victoria*

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or St Vincent's Hospital, Melbourne.

Name of Participant (please _____

Signature _____ Date _____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print) _____

Signature _____ Date _____

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.

Appendix F. Recruitment Flyer

ENHANCING EQUITY, COLLABORATION AND CULTURALLY SECURE ARTHRITIS CARE FOR ABORIGINAL AUSTRALIANS

You mob get sore knees, hips or joints?
We want to hear your stories!

What's it all about?

- Many Aboriginal and/or Torres Strait Islander people have aches and pains in their hips, knees or other joints.
- This can cause problems with moving, walking or doing activities. It can stop people from doing the things they want to do.

Who are we?

- We are a group of Aboriginal and non-Aboriginal researchers looking at how aches and pains affect Aboriginal and/or Torres Strait Islander people in Victoria.

Want to get involved?

- If you have **osteoarthritis**, **rheumatoid arthritis**, **lupus** or **gout**, we would love to have a yarn about how it affects you and your family. We can compensate you for your time with a $50 Coles/Myer gift card.

INTERESTED OR WANT MORE INFO?

We'd love to hear from you!

Ryan Prehn
ryan.prehn@unimelb.edu.au
0427789409

Brooke Conley
bccon@student.unimelb.edu.au
0492980453



Mick Harding: Ngarradjarranun Gorong Darrang - Healing Scar Tree

opus-tjr.org.au/ecco/ @ECCO_OPUS_TJR

This project has been approved by the SVHM human research ethics committee please contact the Patient Liaison Officer on 92311945 if you have any concerns regarding this project

Appendix G. Core Recommendations for Osteoarthritis Care: A Systematic Review of Clinical Practice Guidelines: Supplementary Materials

Supplementary Appendix A: Database Search Strategies Undertaken 11/2/2021, updated on 14/2/22.

Medline

1. guideline*.ti,pt,kw.
2. Practice Guideline/ or Guideline/
3. 1 or 2
4. (arthriti* or osteoarthriti* or lupus or gout).mp.
5. exp arthritis/ or exp Lupus Erythematosus, Systemic/ or Gout/
6. 4 or 5
7. 3 and 6
8. limit 7 to (english language and yr="2015 - 2020")

CINAHL

1. MH Practice Guidelines OR TI guideline* OR PT Practice Guidelines
2. MH arthritis+
3. MH Lupus Erythematosus, Systemic+
4. MH Gout
5. (arthriti* or osteoarhriti* or lupus or gout)
6. S2 OR S3 OR S4 OR S5
7. S1 AND S6
8. S1 AND S6 limit to 2015-2020 and english

EMBASE

1. Guideline*.ti,kw.
2. *practice guideline/
3. 1 or 2
4. (arthriti* or osteoarthriti* or lupus or gout).ti,ab,kw.
5. exp *arthritis/
6. exp *systemic lupus erythematosus/
7. *gout/
8. 4 or 5 or 6 or 7
9. 3 and 8

10. limit 9 to conference abstracts
11. 9 not 10
12. limit 11 to (english language and yr="2015 - 2020")

PEDRO

1. Abstract and title: Osteoarthritis
2. Abstract and title: Rheumatoid arthritis
3. Abstract and title: Lupus / SLE
4. Gout

Method	Practice guideline
When searching	Match all terms with and
Published since	2015

G.2 CPG AGREE II Domain Scores and Quality Assessment (%)

CPGs excluded from the systematic review

Title	Domain 1 Scope and purpose	Domain 2 Stakeholder involvement	Domain 3 Rigour of development	Domain 4 Clarity of presentation	Domain 5 Applicability	Domain 6 Editorial independence	Overall assessment score	Domain 2,3,6 combined value
*Zhang, et al. [28]	75	50	51	47	0	75	33	59
PANLAR [26]	44	47	33	78	4	29	33	37
ESCEO [22]	67	42	50	81	27	46	42	46
OTTAWA (Hip OA) [18]	86	64	54	64	4	42	50	53
OTTAWA (Knee OA part 3) [15]	50	42	50	83	13	42	50	44
OTTAWA (Knee OA part 1) [14]	50	56	42	33	0	33	33	44
OTTAWA (Knee OA part 2) [16]	53	56	51	83	15	33	58	47
TLAR [20]	36	17	42	36	2	50	33	36
*Eymard, et al. 2020 [23]	44	42	51	72	2	58	58	50

*First author given where there is no stated organisation; AAOS - American Academy of Orthopaedic Surgeons; ACP – American College of Physicians; ACR - American College of Rheumatology; EULAR - European League Against Rheumatism; ESCEO - European Society for Clinical and Economic Aspects of Osteoporosis and Osteoarthritis; GH JT - Glenohumeral joint; ISR – Italian Society of Rheumatology; KNGF - Royal Dutch Society of Physiotherapy; NICE - National Institute for Health and Care Excellence; OA – Osteoarthritis; OARSI - Osteoarthritis Research Society International; Ottawa – Ottawa Panel; RACGP - Royal Australian College of General Practitioners; UK - United Kingdom; USA - United States of America.

G.3 Description of Clinical Practice Guidelines

Title	Year	Type of developer	Country/ Region of Origin	Format	Informed by CPG quality tool	Accompanying documents accessed	Guideline topic	Target users
RACGP [12]	2018	Medical Society	Australia	Report	No	Technical document	OA interventions, other than joint replacement for adults diagnosed with symptomatic OA of the knee and/or hip across the disease trajectory.	Australian GPs in primary care settings in metropolitan, regional, rural and remote areas. Sport and exercise medicine physicians, rheumatologists, orthopaedic surgeons, physiotherapists, occupational therapists, pharmacists, podiatrists, pain physicians, psychologists, exercise physiologists, dietitians, nurses, chiropractors, and osteopaths.
OARSI [21]	2019	Medical society	International - Europe/ UK/ USA/ Canada/ Japan	Journal Article	No	Supplementary Tables 1-8 Evidence report	Non-surgical management of knee, hip and polyarticular OA and comorbidity heuristics that are common in people with OA and confound its treatment (1) gastrointestinal (GI) comorbidities, (2) cardiovascular (CV) comorbidities, (3) frailty, and (4) widespread pain and/or depression.	Individuals with OA and physicians.

ACR [25]	2020	Medical Society	USA	Journal Article	No	Appendix 1-5 Disclosure summary Project plan	Pharmacologic and non-pharmacologic management of hand, hip, and knee OA.	Health care providers, caregivers, and patients.
AAOS - GH JT [10]	2020	Medical Society	USA	Report	No	e-Appendix 1 e-Appendix 2	Management of glenohumeral joint OA.	Physicians, orthopaedic surgeons, geriatricians, adult primary care physicians, adult medicine specialists, physical therapists, occupational therapists, physician assistants, nurse practitioners and physiatrists. Assist developers of future practice guidelines and treatment recommendations.
AAOS - Hip OA [11]	2017	Medical Society	USA	Report	No	Nil	Management of adult patients with OA of the hip.	Orthopaedic surgeons, physicians, anaesthesiologists, rheumatologists, physiatrists, adult primary care physicians, geriatricians, hospital based adult medicine specialists, physical therapists, occupational therapists, nurse practitioners, physician assistants, emergency physicians, and other healthcare professionals.
ISR [13]	2019	Medical society	Europe	Journal Article	Yes	Nil	Adult patients with suspected or established knee, hip and/or hand OA.	Attending physicians (rheumatologists, physiatrists, geriatricians, internists, orthopaedic surgeons and general practitioners) and health professionals who manage patients with knee, hip and hand OA in primary care and hospital, community and academic practice settings; patients, policy makers and those responsible for

								commissioning care for patients with knee, hip and hand OA in the Italian National Health Service.
EULAR [24]	2018	Medical Society	Europe	Journal Article	Yes	Nil	Management of hand OA.	Rheumatologists, general practitioners, orthopaedic and plastic surgeons, occupational and physical therapists and rehabilitation physicians, patients and students. Pharmaceutical industry, policy makers and health insurance companies.
*Van doormal et al. [27]	2020	Expert Panel	Europe	Journal Article	Yes	Nil	Physical therapeutic assessment and treatment of hip or knee OA.	Physical therapists.
OTTAWA [17]	2018	Expert Panel	Canada	Journal Article	No	Supplementary Figures Supplementary Clinical relevance tables Appendix 1-13	Management of hand OA.	Healthcare professionals (i.e. family physicians, rheumatologists, general practitioners, occupational therapists, physiotherapists) and patients with hand osteoarthritis

AAOS - Knee OA (Surgical) [29]	2015	Medical Society	USA	Report	No	Nil	Surgical management OA of the knee in adult patients.	Orthopaedic surgeons, physicians, anaesthesiologists, rheumatologists, physiatrists, adult primary care physicians, geriatricians, hospital based adult medicine specialists, physical therapists, occupational therapists, nurse practitioners, physician assistants, emergency physicians, and other healthcare professionals. Decision makers and developers of practice guidelines and recommendations.
AAOS Knee OA (Non-arthroplasty) [19]	2021	Medical Society	USA	Report	No	2 x Appendix documents	Non-surgical management of patients with knee OA.	Orthopaedic surgeons, medical practitioners, and other healthcare providers.

*First author given where there is no stated organisation; AAOS - American Academy of Orthopedic Surgeons; ACP – American College of Physicians; ACR - American College of Rheumatology; EULAR - European League Against Rheumatism; ESCEO - European Society for Clinical and Economic Aspects of Osteoporosis and Osteoarthritis; ISR – Italian Society of Rheumatology; KNGF - Royal Dutch Society of Physiotherapy; NICE - National Institute for Health and Care Excellence; OA – Osteoarthritis; OARSI - Osteoarthritis Research Society International; Ottawa – Ottawa Panel; RACGP - Royal Australian College of General Practitioners; UK - United Kingdom; USA - United States of America.

G.4 OA Management Recommendations

Non-pharmacological recommendations

	References										
	RACGP	**OARSI**	**ACR**	**AAOS (GH)**	**AAOS (Hip)**	**ISR**	**EULAR**	**Van Doormaal et al**	**OTTAWA**	**AAOS (Surgical Mx)**	**AAOS (Non-Arthroplasty Mx)**
Management principles											
Exercise therapies											
Strengthening and/or aerobic	✓✓ Knee and/or Hip OA ? Hip OA (specific forms of land-based exercise)	✓✓ Knee, Hip and Polyarticular OA	✓✓ Knee, Hip and/or Hand OA			✓✓ Knee, Hip and Hand OA	✓✓ Hand OA	✓✓ Knee and Hip OA	✓✓ Hand OA		✓✓ Knee OA
Aquatic exercise/ Hydrotherapy	✓ Hip and/or Knee OA	✓ Knee OA with/ without comorbidities ✓ Polyarticular OA widespread pain/depression O Knee OA Frail individuals O Polyarticular or Hip OA with or without comorbidities				✓✓ Knee, Hip and Hand OA					✓✓ Knee OA
Balance exercises		✓✓ Knee, Hip and Polyarticular OA with/without comorbidities	✓ Knee and/or Hip OA								✓ Knee OA

Thai Chi	✓✓ Knee and/or Hip OA	✓✓ Knee OA with/without comorbidities ✓ Hip and Polyarticular OA with/ without comorbidities	✓✓ Knee and/or Hip OA								
Yoga	✓ Knee OA	✓✓ Knee OA with/without comorbidities ✓ Hip and Polyarticular OA with/ without comorbidities	✓ Knee OA								
Balneotherapy		O Knee, Hip or Polyarticular OA with or without comorbidities				✓ Knee, Hip and Hand OA					
Other non-pharmacological interventions											
Education / Self-management programs	? Knee and/or Hip OA	✓✓ Knee, Hip or Polyarticular OA with/without comorbidities ✓ Knee, Hip or Polyarticular Self-mx program	✓ Knee, Hip, and/or Hand OA			✓✓ Hand, Hip and Knee	✓✓ Hand OA				✓✓ Knee OA
Manual therapy	✓ Knee and/or Hip OA	O Knee, Hip or Polyarticular OA with or without comorbidities	O Knee and/or Hip OA			? Knee OA		O Knee and Hip OA			✓ Knee OA
Assistive devices	✓ Hip and/or Knee OA	✓ Knee, Hip or Polyarticular OA with/ without comorbidities	✓ Knee and/or Hip OA			✓ Knee and Hip OA		✓✓ Knee and Hip OA			✓ Knee OA
Acupuncture	O Knee and/or hip	O Knee, Hip, Polyarticular OA	✓ Knee, Hip and/or Hand OA	? GH OA		? Knee and Hip OA					✓ Knee OA

		with or without comorbidities									
Weight management	✓✓ Hip and/or Knee OA	O (Hip OA of any comorbidity subgroup and frail individuals) ✓ (Hip OA + BMI ≥30 kg/m2 or any comorbidity subgroup as a part of a healthy lifestyle regimen) ✓✓ Knee OA ✓ Polyarticular OA with or without any comorbidities	✓ Knee and/or Hip OA			✓✓ Knee and Hip OA					✓✓ Knee OA
Massage therapy	✓ Knee and/or Hip OA	✓ Knee OA with or without comorbidities O Polyarticular or Hip OA with or without comorbidities	O Knee and/or Hip OA					O Knee and/or Hip OA			✓ Knee OA
Cognitive behavioural therapy	✓ Hip and/or Knee OA	✓ Knee and Hip OA with widespread pain/depression with exercises for other comorbidities/ no comorbidities ✓ Polyarticular OA with widespread pain and/or depression	✓ Knee, Hip and/or Hand OA								

		O Polyarticular OA no comorbidities, GI, CV, frail comorbidities									
Weight management + exercise	✓ Knee and/or Hip OA	✓✓ Knee OA ✓ Hip OA no comorbidities or widespread pain and depression O Hip OA with GI, CV or frail O Polyarticular OA frail ✓ Polyarticular no comorbidities or GI, CV or widespread pain/depression									
Dry Needling				? GH OA							? Knee OA
No treatment		✓✓ Hip and Polyarticular OA									
Physiotherapy					✓ Hip OA						
Vocational rehabilitation						✓✓ Hip and Knee OA					
Multi-disciplinary pain management program		✓ Knee, Hip or Polyarticular OA and widespread pain and/or depression									
Cupping				? GH OA							
Heat/cold therapy											

Heat therapy	✓ Knee and/or Hip OA	O Knee, Hip or Polyarticular OA with or without comorbidities	✓ Knee, Hip and/or Hand OA					O Knee and Hip OA			
Therapeutic U/S	O Knee and/or hip	O Knee, Polyarticular OA with or without comorbidities						O Knee and Hip OA			
Cold therapy	O Knee and/or Hip OA	O Hip no comorbidities, frail or widespread pain/depression O Knee Frail or widespread pain/depression	✓ Knee, Hip and/or Hand OA								
Paraffin			✓ Hand OA								
Electrotherapy											
TENS	✓ Hip and/or Knee OA		O Knee and/or Hip OA	? GH OA		✓ Knee and Hip OA		O Knee and/or Hip OA ✓ Severe pain			✓ Knee OA
Pulsed electromagnetic/ shortwave therapy	? Hip and/or Knee OA	O Knee OA with or without comorbidities O Polyarticular OA with GI or CV comorbidities	O Knee OA					O Knee and Hip OA			✓ Knee OA
Other electrotherapy	O Knee and/or hip	✓ Knee OA with GI or CV or frail O Knee OA no comorbidities, widespread pain/depression O Polyarticular OA						O Knee and Hip OA			✓ Knee OA

		with GI or CV comorbidities									
Nerve block therapy		O Knee OA with or without comorbidities									
Radiofrequency ablation			✓ Knee OA								
Iontophoresis			O First CMC Joint OA								
Extracorporeal Shockwave therapy											✓ Knee OA
Braces											
Valgus unloading and patellofemoral braces knee braces	O Knee and Patellofemoral OA	O Knee OA no comorbidities, GI or CV comorbidities	✓ Patellofemoral knee OA								✓ Knee OA
Varus unloading and tibiofemoral knee braces	? Knee OA	O Knee OA no comorbidities, GI or CV comorbidities	✓✓ Knee OA								
Soft brace		O Knee OA no, GI, CV or frail comorbidities									
Taping											
Kinesio taping	O Knee and/or Hip OA		✓ Knee and/or first CMC OA					O Knee and Hip OA			
Bandage taping						✓ Knee OA					
Patella taping	? Knee OA										
Orthosis and footwear											
Shoe orthotics - lateral wedge insoles	O Medial Tibiofemoral Knee OA	✓ Knee OA with or without comorbidities O Polyarticular OA	O Knee and/or Hip OA								O Knee OA

		with or without comorbidities									
Shoe orthotics - medial wedge insoles	? Knee and Hip OA	✓ Knee OA with or without comorbidities O Polyarticular OA with or without comorbidities	O Knee and/or Hip OA								
Footwear	O Knee OA ? Knee and/or hip OA		O Knee and/or Hip OA			✓✓ Knee and Hip OA					
Hand orthosis			✓✓ CMC OA ✓ Other hand joints			✓✓ CMC OA	✓✓ CMC OA				
Treatment considerations											
Patient-centered care						✓✓ Hand, Hip and Knee	✓✓ Hand OA				

✓✓Should do; ✓ Could do; O Do not do; ?Uncertain.

RACGP, The Royal Australian College of General Practitioners; ACR, American College of Rheumatology; AAOS, American Academy of Orthopaedic Surgeons; ISR, Italian Society of Rheumatology; EULAR, European Alliance of Associations for Rheumatology; TENS, transcutaneous electrical nerve stimulation; CMC, carpometacarpal joint; OA, osteoarthritis; GH, glenohumeral; U/S, ultrasound.

Pharmacological recommendations

	References										
	RACGP	**OARSI**	**ACR**	**AAOS (GH)**	**AAOS (Hip)**	**ISR**	**EULAR**	**Van Doormaal et al**	**OTTAWA**	**AAOS (Surgical Mx)**	**AAOS (Non-Arthroplasty Mx)**
Non-steroidal anti-inflammatories (NSAIDs)											
Oral NSAIDs	✓ Knee and/or Hip OA	✓ Knee OA with no and/or GI, CV, widespread pain and/or depression comorbidities O Knee OA Frail ✓ Hip, Polyarticular OA without comorbidities, GI (+PPI), CV, widespread pain/depression O Hip, Polyarticular OA frail, GI (-PPI) ✓ Good clinical practice statement Hip OA at risk inc Frail	✓✓ Knee, Hip and/or Hand OA		✓ Hip OA	✓✓ Low Dose ✓ Higher Dose O Nephropathic patients ✓ CV risk - Naproxen	✓✓ Hand OA				✓✓ Knee OA
Topical NSAIDs	? Knee and/or Hip OA	✓ Knee OA with or without comorbidities ✓ Hip OA GI, CV and frail O Hip OA no comorbidities, widespread pain/depression	✓✓ Knee OA ✓ Hand OA			✓✓ Knee, Hip and Hand OA	✓✓ Hand OA				✓✓ Knee OA

		✓ Polyarticular OA no comorbidities, GI, CV, Frail O Polyarticular OA widespread pain/depression									
Topical capsaicin	? (Hip) O (Knee)	O Knee OA with or without comorbidities	✓ Knee OA O Hand OA	? GH OA		✓✓ Knee, Hip and Hand OA					
Non-selective NSAID		✓ Knee OA with GI, CV or widespread pain/ depression O Knee OA frail O Polyarticular OA with GI comorbidities ✓ Hip OA with or without comorbidities COX inhibitors only GI comorbidities									
Injections											
Corticosteroid injection	✓ Knee and/or Hip OA	✓ Knee with/without comorbidity groups O Hip, Polyarticular OA with or without comorbidities	✓✓ Knee and Hip ✓ Hand - added ✓ in comparison to other injections - added		✓ Hip OA	✓	O Hand OA ✓ Interphalangeal joints				✓ Knee OA
Intraarticular hyaluronic acid injections	O Hip OA	✓ Knee with/without comorbidity groups	O Knee, Hip and/or	O GH OA	O Hip OA	✓					O Knee OA

		O Hip, Polyarticular OA with or without comorbidities	first CMC JT OA								
PRP injection	? Knee and/or Hip OA		O Knee and/or Hip OA	O GH OA		? Knee OA					✓ Knee OA
Stem cell injections	O Knee and/or Hip OA		O Knee and/or Hip OA	O GH OA		? Knee OA					
U/S guided intraarticular glucocorticoid injection			✓✓ Hip OA			✓					
Prolotherapy			O Knee and/or Hip OA								
Intraarticular botulinum toxin injections			O Knee and/or Hip OA								
Other pharmacological											
Paracetamol	? Knee and/or Hip OA	O Knee, Hip, Polyarticular OA with or without comorbidities	✓ Knee, Hip and/or Hand OA			✓✓ Knee, Hip and Hand OA					✓✓ Knee OA
Duloxetine	✓ Knee and/or Hip OA	✓ Knee no comorbidities, frail or widespread pain/ depression O Knee OA GI or CV comorbidities ✓ Hip OA widespread pain/depression O Hip OA no comorbidities, GI, CV or frail ✓ Polyarticular OA no	✓ Knee, Hip and or Hand OA			✓ Knee OA ? Hip OA					

		comorbidities or widespread/depression O Polyarticular OA with GI, CV or frail									
Bisphosphonates	O Knee and/or Hip OA		O Knee, Hip and/or Hand OA								
Colchicine	O Knee and/or Hip OA		O Knee, Hip and/or Hand OA								
Methotrexate	O Knee and/or Hip OA		O Knee, Hip and/or Hand OA								
Diacerein	O Knee and/or Hip OA	O Knee OA with or without comorbidities O Hip OA GI or CV comorbidities O Polyarticular OA with no comorbidities or GI or CV comorbidities									
Doxycycline	O Knee and/or Hip OA										
Strontium ranelate	O Knee and/or Hip OA										
IL-1 inhibitors	O Knee and/or Hip OA										

Fibroblast growth factor	O Knee and/or Hip OA										
Viscosupplementation injection	O Hip OA										
Tumour necrosis factor inhibitors and interleukin-1 receptor antagonists			O Knee, Hip and/or Hand OA								
Boswellia serrata extract	? Knee and/or Hip OA										
Curcuma/curcuminoid	? Knee and/or Hip OA										
Pine bark extract	? Knee and/or Hip OA										
Calcitonin	O Knee and/or Hip OA										
Anti-NGF	O Knee and/or Hip OA										
Dextrose prolotherapy	O Knee and/or Hip OA										
Biological DMARDs							O Hand OA				
Hydroxychloroquine			O Knee, Hip and/or Hand OA								
Opioids											

Oral opioids	O Knee and/or Hip OA	O Knee, Hip or Polyarticular OA no comorbidities	✓ Knee, Hip and/or Hand OA Tramadol opioids O Knee, Hip and/or Hand OA Non-tramadol opioids	O GH OA		✓✓ Weak opioids ✓ Strong					O Knee OA
Transdermal opioids	O Knee and/or Hip OA										
Glucosamine and/or chondroitin											
Glucosamine	O Knee and/or Hip OA		O Knee, Hip and/or Hand OA		O Hip OA						✓ Knee OA
Chondroitin	O Knee and/or Hip OA	O Knee, Polyarticular OA with or without comorbidities O Hip OA GI, CV or frail	O Knee, Hip and/or Hand OA				✓ Hand OA				✓ Knee OA
Glucosamine and chondroitin	O Knee and/or Hip OA	O Knee OA no comorbidities O Polyarticular OA with or without comorbidities		? GH OA		✓ Knee OA					
Nutraceutical											

Vitamin D	O Knee and/or Hip OA	O Knee, Hip or Polyarticular OA with or without comorbidities	O Knee, Hip and/or Hand OA								✓ Knee OA
Avocado Soybean Unsaponifiable	? Knee and/or Hip OA	✓ Knee, Hip OA with or without comorbidities O Polyarticular OA with or without comorbidities									
Methylsulfonylmethane	? Knee and/or Hip OA	O Knee, Hip or Polyarticular OA with or without comorbidities									
Collagen	? Knee and/or Hip OA	O Knee, Hip or Polyarticular OA with or without comorbidities									
Omega-3 fatty acids	O Knee and/or Hip OA										
Fish oil			O Knee, Hip and/or Hand OA								
Boswellia		✓ Hip OA with widespread pain/depression ✓ Knee OA with or without comorbidities O Polyarticular, Hip OA with GI, CV or frail or without comorbidities									

Curcuminoid formulations		O Knee or hip OA with or without comorbidities ✓ Polyarticular OA with or without comorbidities									
Cannabis				? GH OA							
Cannabidiol oil				? GH OA							
Shark cartilage				? GH OA							
Turmeric											✓ Knee OA
Ginger extract											✓ Knee OA

✓✓Should do; ✓ Could do; O Do not do; ?Uncertain.

RACGP, The Royal Australian College of General Practitioners; ACR, American College of Rheumatology; AAOS, American Academy of Orthopaedic Surgeons; ISR, Italian Society of Rheumatology; EULAR, European Alliance of Associations for Rheumatology; NGF - Nerve growth factor; NSAIDs, nonsteroidal anti-inflammatory drugs; OA, osteoarthritis; COX-2, cyclooxygenase-2; NSAIDs, nonsteroidal anti-inflammatory drugs; OA, osteoarthritis; PRP, platelet-rich plasma; IL-1, interleukin-1; GH, Glenohumeral; U/S, ultrasound.

Surgical recommendations

	References										
	RACGP	**OARSI**	**ACR**	**AAOS (GH)**	**AAOS (Hip)**	**ISR**	**EULAR**	**Van Doormaal et al**	**OTTAWA**	**AAOS (Surgical Mx)**	**AAOS (Non-Arthroplasty Mx)**
Pre-operative considerations											
Physical Therapy (PT)				✓ GH OA	✓ Hip OA			✓✓ Knee and Hip OA		✓ Knee OA	
Surgical consideration						✓✓ Knee, hip and hand OA	✓✓ Hand OA				
Grashey view radiographs				✓✓ GH OA							
Exercise therapy								✓ Knee and Hip OA			
Types of surgeries											
Trapeziectomy							✓✓ Thumb base OA				
Arthrodesis or arthroplasty hand							✓✓ Interphalangeal OA				
TSA variations				✓✓ GH OA (TSA vs Hemi-arthroplasty) ✓ GH OA (anatomic or reverse TSA) ✓ GH OA (TSA - subscapularis peel, tenotomy, lesser tuberosity osteotomy)							

TKA variations										✓ Knee OA (TKA vs UKA) ✓ Medial compartment knee OA (UKA- decrease DVT risk and manipulation) ✓ Medial compartment knee OA (UKA or valgus-producing proximal tibial osteotomy) ✓ Knee OA (Bilateral TKA) ✓✓ Knee OA (Delaying TKA)	
Patient specific instrumentation										O Knee OA	
THR - approach exposure					✓ Hip OA						
Other knee surgical options											
Arthroscopic, lavage and debridement, meniscectomy and cartilage repair	O Knee OA										
Denervation therapy											✓ Knee OA
Lavage/debridement											O Knee OA
Partial meniscectomy											✓ Knee OA
Tibial osteotomy											✓ Knee OA
Free floating interpositional devices											O Knee OA
Intraoperative considerations											
Tranexamic acid				✓ GH OA	✓ Hip OA					✓✓ Knee OA	

Anaesthetic types					✓ Neuraxial for Hip OA					✓✓ (Local peri-articular, peripheral nerve blockade) ✓ Neuraxial Knee OA	
Glenoid prosthetic components				✓ GH OA (Pegged or Keeled) O GH OA (Metal-backed cementless) ✓ GH OA (Polyethylene-metal or all-polyethylene) ? GH OA (Non-prosthetic surgical options) ✓ GH OA (Hemiarthroplasty - stems) ✓ GH OA (Cemented components)							
Knee prosthetic components										✓✓ Knee OA (Cemented components) O Knee OA (Antibiotic bone cement) ✓✓ Knee OA (Polyethylene tibial component) Patellar resurfacing: ✓ Knee OA (Reoperations after 5 years) O Knee OA (Patient specific instrumentation)	
Cruciate retraining arthroplasty design										? Knee OA	
Tourniquet										✓ Knee OA (Intraoperative blood loss)	

										O Knee OA (Short-term pain and post-op function)	
Drains										O Knee OA	
Surgical navigation										O Knee OA	
Biceps tenodesis and tenotomy				✓ GH OA							
Supraspinatus tears				✓ GH OA							
Post-operative considerations											
PT				✓ GH OA	✓ Hip OA					✓✓ Knee OA	
Exercise therapy								✓ Knee OA		✓✓ Knee OA during first 2 months post TKA (physical function) ✓ <2 months post TKA (pain) >2months post TKA	
Continuous Passive Motion								O Knee and Hip OA		O Knee OA	
Cryotherapy				✓ GH OA						O Knee OA	
Discharge (same-day)				✓ GH OA							
Multimodal pain management				✓ GH OA							

✓✓Should do; ✓ Could do; O Do not do; ?Uncertain.

TKA: Total Knee Arthroscopy; UKA: Unicompartmental knee arthroscopy; TSA: total shoulder arthroplasty; PT: Physical therapy or physiotherapy; THR: Total hip replacement.

G.5 Narrative Synthesis of CPG Recommendations

This table is a synthesis of Osteoarthritis CPG recommendations. A common consensus recommendation was identified when two or more CPGs reported on an intervention. Consensus recommendations were either: 'should do', 'could do', 'do not do' or 'no consensus'. Where one CPG reported on an intervention, no consensus recommendation was developed (Table 5). Recommendations were grouped into themes (management principles/interventions) and ordered from most frequently recommended to least frequently recommended within each theme.

Non-pharmacological management strategies narrative summary

Management Principles	Narrative Summary
Exercise therapies	**Strengthening and/or aerobic** Eight CPGs strongly recommended strengthening and aerobic exercise for management of knee, hip, polyarticular and/or hand OA [12, 13, 18, 19, 21, 24, 25, 27]. Exercise programs should be implemented in the conservative treatment phase of hip and knee OA[27]. Programs should be individualised and progressively overloaded with frequency, duration and intensity [12, 13, 27], consistent with the person's preference, capability, and the availability of local facilities [12, 13]. Realistic goals should be set and strategies to optimise adherence should be created [12]. Recommendations for modes of exercise varied between CPGs and the arthritic joint they were investigating. Knee OA examples included: aerobic [13] such as walking [12] resistance land-based [12, 13, 21] aquatic exercise [13], mind-body exercise, tai chi [12, 21] and yoga [21]. One CPG reported that type of exercise that elicits the greatest benefit in those with hip OA still remains unknown and recommended clinicians consider land-based exercise, and potential referral to an exercise professional to assist with exercise prescription in some cases and either face-to-face or remote monitoring [12]. One CPG strongly recommended upper limb exercise programs involving the thumb, hand, wrist, elbow and shoulder joints [18]. programs could include strengthening, stretching, range of motion, +/- other modalities such as education and joint mobilisation, performed as either a home program or in the clinic [18]. Consensus: Exercise therapy should be recommended for all patients with knee, hip, polyarticular and/or hand OA. **Aquatic therapy** Two CPGs strongly recommended [13, 19] and two CPGs conditionally recommended [12, 21] aquatic therapy for people with knee, hip, polyarticular and/or hand OA; considering patient preference and availability of facilities [12, 13]. One CPG conditionally recommended aquatic therapy for people with knee OA however they do not recommend it for people with hip and/or polyarticular OA, except those who experience widespread pain or depression due to potential barriers such as: accessibility, uptake, financial burden, and risk of accidental injury [21]. Consensus: No consensus. **Balance exercises**

	One CPG strongly recommended [21] and two CPG conditionally recommended balance exercises for patients with knee, hip and/or polyarticular OA [19, 25]. Neuromuscular exercises included balance, agility and coordination and were recommended to be combined with traditional strength and joint mobility exercises [19]. Consensus: Balance exercises could be included in an exercise program for patients with knee, hip and/or polyarticular OA. **Tai Chi** Three CPGs strongly recommended Tai Chi exercise for patients with knee OA [12, 21, 25] and/or hip OA [25] either as a stand-alone intervention or in combination with interventions [21]. One CPG conditionally recommended Tai Chi for people with hip and polyarticular OA despite a lack of high-quality evidence, the panel considered this intervention to be safe and effective [21]. Consensus: Tai Chi should be offered to patients with knee, hip and/or polyarticular OA, alone or in conjunction with other evidence-based therapies. **Yoga (and/or Hatha yoga)** One CPG strongly recommended yoga for knee OA [21], whilst two CPGs conditionally recommended yoga for knee [25], hip and polyarticular OA [21]. One CPG conditionally recommended offering stationary cycling and/or hatha yoga for some people with knee OA, consistent with their exercise therapy recommendations of progressively overloading the intervention, considering patient circumstances and availability of resources/facilities [12]. Consensus: Yoga (and/or Hatha yoga) could be recommended for patients with knee, hip and/or polyarticular OA. **Balneotherapy** One CPG recommended against the use of balneotherapy for people with knee, hip and/or polyarticular OA [21] whereas one conditionally recommended for those with knee, hip and/or hand OA as it can be effective in relieving symptoms [13]. Consensus: No consensus.
Other non-pharmacological interventions	**Education programs/ self-management programs** Five CPGs strongly recommended education programs and/or self-management programs [13, 19, 21, 24, 25], with the exception of one CPG who conditionally recommend self-management programs [21]. One CPG reported neither for nor against self-management education programs, however this may be attributed to their definition of this recommendation as, formal face-to-face programs [12]. Health professionals should provide ongoing education [21], that is tailored to the individual [13] and includes the following information to enhance understanding about OA: nature and course of the disease/prognosis, its optimal management options [13], self-management principles [24], techniques to promote hope, optimism, and a positive expectation of benefit from treatment [21]. Additionally, one CPG recommended education and training in ergonomic principles, pacing of activity and use of assistive devices should be offered to every patient. Health professionals should discuss long-term and short-term goals with the patient [13]. One CPG described that people with hip and/or knee OA should be taught a regular individualised (daily) exercise regimen and participate in self-management programs, strengthening, low-impact aerobic exercises, and neuromuscular education [13]. Consensus: Health professionals should provide education on OA, its management, and education and training in exercise therapy, ergonomic principles, pacing and assistive devices. **Manual therapy**

	Six CPGs reported on the use of manual therapy techniques such as: stretching, soft tissue and/or joint mobilisation and/or manipulation. Majority recommended against for people with knee, hip and/or polyarticular OA [21, 25, 27]. One CPG was unable either for or against manual therapy for people with knee OA [13]. Whereas two CPGs recommended considering short-term use of manual therapy [12, 19] in combination with other active management strategies, noting therapy cost and access needs to be considered [12]. Consensus: No consensus. **Assistive devices** Four CPGs conditionally recommend the use of assistive devices (e.g. walking stick, crutches [13], cane [19] for some people with knee, hip and polyarticular OA [12, 13, 19, 21], as a management or preventive intervention [13]; taking into consideration a person's preference and capability [12]. Two CPGs strongly recommend gait aids for people with knee and/or hip OA [25, 27], who have disease in one or more joints and a large impact on ambulation, joint stability, or pain [25]. Consensus: The use of assistive devices could be offered for people with knee, hip and/or polyarticular OA. **Acupuncture** Two CPGs conditionally recommend the use of acupuncture for people with knee, hip and/or hand OA [19, 25]. Two CPGs were uncertain on the benefit of acupuncture for people with knee, hip and/or GH JT OA due to a lack of reliable evidence [10, 13]. Two CPGs recommend against offering acupuncture for people with knee, hip and/or polyarticular OA [12, 21]. Consensus: No consensus. **Weight management** Four CPGs strongly recommended weight loss or management for patients who are either overweight or obese with hip and/or knee OA [12, 13, 19, 25]. One CPGs recommendations vary based on the affected joint and/or comorbidities [21]. OARSI strongly recommended weight loss for knee OA, however conditionally recommended for polyarticular OA with or without any comorbidities and against for hip OA; unless their body mass index (BMI) is ≥30 kg/m2 [21]. Similarly, RACGP defines overweight as BMI ≥25 kg/m2 and obese as BMI ≥30 kg/m2 and encourages a minimum weight loss target of 5–7.5% of body weight, with greater weight loss being linked to symptomatic benefits [12]. They encourage education regarding the importance of maintaining a healthy body weight for those within a healthy body weight range [12]. Consensus: Weight loss should be recommended to people with knee, hip OA who either are overweight or obese. Weight loss could be recommended for people with polyarticular OA who either are overweight or obese. **Massage therapy** Three CPGs conditionally recommend short-term massage therapy for people with knee [12, 19, 21] and/or hip OA [12] in combination with active management strategies, considering cost and access. Whereas three CPGs recommend against massage therapy for people with knee [25, 27], hip [21, 25, 27] and/or polyarticular OA [21], due to low quality evidence [25, 27]. Consensus: No consensus. **Cognitive behavioural therapy (CBT)** Three CPGs conditionally recommend the use of CBT for people with hip, knee, hand and/or polyarticular OA with certain comorbidities [12, 21, 25]. RACGP encourages clinicians to consider psychological comorbidities, personal preference, cost and access to determine if it would be appropriate to

	prescribe/deliver [12]. They recommend CBT in combination with exercise to improve outcomes, offering the program as either face-to-face or via online [12]. Consensus: CBT could be offered to people with knee, hip, hand and/or polyarticular OA. **Weight management and exercise** One CPG strongly recommended weight management and exercise [21], whilst one CPG conditionally recommended [12] this for people with knee OA. Both CPGs conditionally recommend this combined intervention for people with hip [12, 21] and polyarticular OA with the exception of those with certain comorbidities e.g., frailty [21]. Consensus: Consider offering exercise and weight management for people with knee, hip and polyarticular OA who are overweight or obese. **Dry needling** Two CPGs were unable to recommend either for or against the use of dry needling for people with GH JT and knee OA [10, 19]. Consensus: No consensus.
Heat and cold therapy	**Heat therapy** Two CPGs conditionally recommend heat therapy (e.g., hot packs) as an adjunctive treatment [12] for people with knee, hip and/or hand OA [12, 25]. Two CPGs recommended against the use of heat therapy for people with knee, hip and/or polyarticular OA [21, 27]. Consensus: No consensus. **Therapeutic U/S** Three CPGs recommended against the use of therapeutic ultrasound for people with knee, hip and/or polyarticular OA [12, 21, 27]. Consensus: Do not offer therapeutic ultrasound for people with knee, hip and/or polyarticular OA. **Cold therapy** One CPG conditionally recommended for the use of local cold application (e.g., ice packs) for people with knee, hip and/or hand OA [25], whilst two CPGs recommended against its use for people with knee and/or hip OA [12, 21]. Consensus: No consensus.
Electrotherapy	**Transcutaneous electrical nerve stimulation (TENS)** Three CPGs conditionally recommended TENS for people with knee and/or hip [12, 13, 19], whilst two CPGs recommended against this intervention [25, 27]. Several CPGs acknowledged that if considered, TENS should be only used for short term pain control [13] if pain is impairing a person's ability to complete exercise therapy [27]. RACGP advises patient self-administered use of TENS can be considered, following clinicians providing sufficient instructions on self-use and considering individual accessibility and affordability [12]. One CPG was unable to recommend either for or against its use for patients with GH JT OA due to lack of reliable evidence [10]. Consensus: No consensus. **Pulsed electromagnetic/ shockwave therapy** Three CPGs recommended against the use of pulsed electromagnetic/shockwave therapy for people with knee, hip and/or polyarticular OA [21, 25, 27]. One CPG was unable to recommend either for or against this intervention for people with knee and/or hip OA [12] and one CPG conditionally recommended for percutaneous electrical nerve stimulation/pulsed electromagnetic field therapy for people with knee OA [19].

	Consensus: No consensus. **Other electrotherapy** Two CPGs recommended against the use of other electrotherapy modalities such as laser therapy [12, 27]. One CPG recommended against the use of electrotherapy for people with knee and/or polyarticular OA with certain comorbidities. Whilst conditionally recommended for people with knee OA and gastrointestinal, cardiovascular comorbidities or who are frail [21]. One CPG conditionally recommended laser treatment for people with knee OA [19]. Consensus: No consensus.
Taping and Braces	**Valgus unloading and patellofemoral braces** Two CPGs recommended against valgus unloading/realignment braces for people with medial tibiofemoral compartment knee OA [12, 21]. Two CPGs recommend against patellofemoral braces for patellofemoral OA [12, 21] whilst one CPG conditionally recommended for these braces in people who have OA in 1 or both knees, where this is causing a sufficiently large impact on ambulation, joint stability, or pain to warrant use of an assistive device [25]. Consensus: No consensus **Varus unloading and tibiofemoral braces** One CPG was unable to recommend either for or against the use of varus unloading/realignment braces for people with lateral tibiofemoral compartment knee OA [12], one CPG recommended against [21], and one CPG strongly recommended for tibiofemoral braces in patients who have OA in 1 or both knees where this is causing a sufficiently large impact on ambulation, joint stability, or pain to warrant use of an assistive device [25]. Consensus: No consensus. **Taping** Types of tape and techniques differed across CPGs. Two CPGs recommend against the use of kinesiology or tape in general for people with knee and/or hip OA [12, 27], whilst others conditionally recommended for kinesiology or bandage tape [13, 25] and one CPG was uncertain of the benefits of patella taping for people with knee OA [12]. One CPG conditionally recommended taping for people with first carpometacarpal joint OA [25]. CPGs argued that taping can benefit those with joint instability [13], patella alignment [12], reduce pain [12, 13] and improve function [12]. Consensus: No consensus.
Orthosis and footwear	**Shoe orthotics - lateral wedge insoles** One CPG conditionally recommended lateral wedge insoles for people with knee OA [21], whilst four CPGs recommend against for people with knee and/or hip OA, in particular those with medial tibiofemoral OA [12, 19, 25] and people with polyarticular OA [21]. Consensus: No consensus. **Shoe orthotics - medial wedge insoles** Two CPGs recommended against the use of medial wedge insoles for people with knee, hip [25] and/or polyarticular OA [21], whilst one CPG conditionally recommended their use for people with knee OA [21]. One CPG is unable to recommend either for or against this intervention for people with lateral tibiofemoral OA and valgus deformity [12]. Consensus: No consensus.

	Footwear Two CPGs recommended against [12, 25] and one CPG strongly recommended for footwear changes for people with knee and/or hip OA [13]. This variation in recommendations may be attributed to the CPGs considering different types of footwear. RACGP recommended against the following shoes: unloading shoes, minimalist footwear, rocker-sole shoes and high-heeled shoes [12]. ACR agreed that modified shoes, that are intended to alter the biomechanics of the lower extremities and the gait pattern. ACR acknowledges 'optimal footwear' is likely to be an important consideration however there is a current lack research to determine what this is for people with knee and/or hip OA [25]. Two CPGs suggests that appropriate and comfortable shoes should be recommended [13], considering shoes with shock absorbing properties [12]. Consensus: No consensus. **Hand orthosis** Three CPGs strongly recommend the use of hand orthosis for carpo-metacarpal joint OA [13, 24, 25] and conditionally recommend for other hand joints OA [25]. Two CPGs state hand orthosis are suitable for both short-term and long-term use as they provide symptom relief, improve function, and prevent progression of degenerative changes [13, 24]. Consensus: Hand orthosis should be recommended for people with hand OA.
Patient Centred Care (PCC)	Two CPGs strongly recommended PCC for people with knee, hip and/or hand OA [13, 24]. One CPG recommended a shared decision-making approach, considering multidisciplinary health professional involvement when necessary [24]. Both CPGs identify elements of PCC including individualising treatment options, considering the patient's comorbidities, condition severity, risk factors (e.g. age, sex, obesity) wishes and expectations [13, 24]. Long-term follow-up was recommended for patients with hand OA [24]. Consensus: Management of knee, hip and/or hand OA should be patient centred. This includes care that is decided on between both the patient and health professional and that is individualised to the patient's circumstances.

ACR – American College of Rheumatology; BMI – Body mass index; CBT – Cognitive behavioural therapy; CPG – Clinical practice guideline; GH JT – Glenohumeral joint; ISR – Italian society of rheumatology; OA – Osteoarthritis; OARSI; Osteoarthritis research society international; PCC – Patient Centred Care; RACGP – The Royal Australian College of General Practitioners; TENS – Transcutaneous electrical nerve stimulation.

Pharmacological management strategies narrative summary

Management Principles	Narrative Summary
NSAIDs	**Oral NSAIDs** Five CPGs strongly [11, 13, 19, 24, 25] and two CPGs conditionally [12, 21] supported the use of oral NSAIDs (such as ibuprofen, diclofenac and naproxen)[13] for people with knee, hip, hand and/or polyarticular OA[12, 21] unless contraindicated [19]. Three CPGs recommended starting at the lowest effective dose for a short period [24] for people who respond inadequately to paracetamol [13], then discontinue use if not effective [12]. If the patient is experiencing severe pain, higher doses may be recommended [13]. Clinicians also need to inform people, monitor, and capture adverse events, especially gastrointestinal, renal and cardiovascular, which may be associated with use of NSAIDs. Patients with increased GI risk, should use NSAIDs in conjunction with a PPI or a selective COX-2 inhibitor [13, 21] or can consider naproxen [13]. In nephropathic patients the use of NSAIDs and COX-2 inhibitors should be avoided [13] Consensus: Oral NSAIDs should be recommended to patients with OA unless contraindicated. **Topical NSAIDs** Five CPGs reported on the use of topical NSAIDs. Four strongly recommend for knee [13, 19, 25], hip [13] and/or hand OA [24]. Two CPGs conditionally recommended for hand, [25] knee, hip and or polyarticular OA with some comorbidities and against for other comorbidities [21]. One CPG was unable to recommend either for or against for people with knee and/or hip OA [12]. However, they stated that it might be reasonable to trial topical NSAIDs for a short period and then discontinue use if not effective [12]. Two CPGs stated topical treatments are safe, effective and the first pharmacological topical treatment of choice especially for mild to moderate pain and when only a few joints are affected [13]. Patients with age >75 years should use topical rather than oral NSAIDs even though the analgesic response decreases after 1 year of use [13]. Clinicians also need to monitor and capture the adverse effects along with its use [12], effects for example: local skin reactions [21]. Consensus: Topical NSAIDs should be recommended to patients with knee, hip and/or hand OA. **Topical capsaicin** Five CPGs reported on the use of topical capsaicin with a notable variation between recommendations and the OA affected joints. Two recommended against [12, 21], one conditionally for [25] and one strongly for its use in people with knee OA [13]. One CPG was unsure [12] whereas one CPG strongly recommended for its use in people with hip OA [13]. One CPG was unsure of its use for people with GH JT OA [10] based on lack of evidence. One CPG recommended against people with hand OA [25], whereas one strongly recommended for [13]. One CPG supported topical pharmacological treatments over systemic treatments, especially in cases of mild to moderate pain and when only a few joints are affected [13]. They advised, topical NSAIDs and capsaicin gel are effective and safe treatments and patients with age >75 years should use topical rather than oral NSAIDs even though the analgesic response decreases after 1 year of use [13]. Consensus: No consensus.

Injections	**Corticosteroid (IACS) injection** Most CPGs reported on the use of IACS injection for patients with OA however recommendations varied. Two CPGs strongly recommended IACS injections for hip [11, 25] and knee OA [25]. Five conditionally recommended this intervention for people with hip [12], knee [12, 19, 21], hand OA [25] and/or patients with painful interphalangeal joints [24], however EULAR didn't support this intervention for patients with hand OA in general [24]. Similarly, one CPG conditionally recommended for IACS injections without specifying the specific joint, stating the injection can provide short-term pain relief in those who suffer painful relapses and who do not respond or have a contraindication to analgesics and NSAIDs [13]. Whereas one CPG recommended against IACS injections for hip and polyarticular OA [21]. Several CPGs mentioned IACS injections can improve function and reduce short-term pain [11, 12], acknowledging that clinicians need to be aware of and consider the potential harms of repeated use [12]. Consensus: IACS injections could be recommended for people with knee and hand OA who are contraindicated to analgesics and NSAIDs. Clinicians need to be aware of potential harms associated with repeated injections. Consensus: No consensus for IACS injections for people with hip and polyarticular OA. **Intraarticular hyaluronic acid (IAHA) injection** Seven CPGs reported on the use of IAHA injections, five recommended against its use in knee, hip, CMC JT and GH JT OA [10-12, 19, 25]. Whereas one conditionally recommended for knee OA and against hip and polyarticular OA [21]. Whilst one CPG conditionally recommended for without specifying which joint, justifying that its use could provide symptomatic relief and reduce NSAID use [13]. Consensus: No consensus. **Platelet-Rich Plasma (PRP) injection** One CPG conditionally recommended PRP injections for people with knee OA [19], whilst two CPG was unable to recommend either for or against for people with knee and/or hip OA [12, 13]. Conversely, two CPGs recommended against or knee, hip and/or GH OA [10, 25]. Consensus: No consensus. **Stem cell injections** Three CPGs recommended against [10, 12, 25], and one was uncertain [13] on the use of stem cell injections for treatment knee, hip and/or GH JT OA. Consensus: No consensus. **Ultrasound (U/S) guided intraarticular glucocorticoid (IAGC) injection** One CPG strongly recommended U/S guided IAGC injection for hip joints [25] whereas one CPG conditionally recommended the use of IAGC injection without specifying the relevant joint, stating it may improve accuracy it is particularly recommended for joints that are difficult to access due to the site itself, degree of deformity or obesity [13]. Consensus: Medical practitioners could use U/S guided IAGC injection for hip joint OA and other joints that are difficult to access.
Other pharmacological interventions	**Paracetamol and acetaminophen** Five CPGs reported on the use of paracetamol. Two CPGs strongly recommended [13, 19] and one CPG conditionally recommended [25] for people with knee, hip and/or hand OA. ISR described a dosage of up to 3 g/day is an effective initial oral analgesic for treatment of mild to moderate pain [13]. In elderly patients it should be preferred because of its relative safety in comparison with NSAIDs [13]. Whereas one CPG was unable to recommend for or against in people with knee and/or hip OA [12]. However, they stated that it may be considered for a short period, if effective, advising that clinicians

	monitor and capture adverse events that may be associated with its use. Conversely, one CPG recommended against for people with knee, hip and polyarticular OA [21]. Consensus: No consensus. **Duloxetine** CPGs conditionally recommended duloxetine for people with knee OA [12, 13, 21, 25], hip OA [12, 21, 25], polyarticular OA and certain comorbidities [21] and hand OA [25]. Whereas one CPG reports an uncertain recommendation for hip OA [13]. Consensus: Duloxetine could be recommended for people with knee, hip, hand and/or polyarticular OA. **Bisphosphonates, Colchicine, Methotrexate, Diacerein** Two CPGs recommended against the use of bisphosphonates [12, 25], colchicine [12, 25], hydrochloroquine [25] methotrexate in people with knee, hip and/or hand OA [12, 25]. Two CPGs recommended against the use of diacerein for people with knee and/or hip OA [12, 21]. Consensus: Do not offer Bisphosphonates, colchicine, hydroxcloroquine, methotrexate or diacerein for people with knee, hip and/or hand OA.
Opioids	**Oral opioids** Four CPGs recommend against oral opioids for people with knee, hip and/or polyarticular OA [10, 12, 19, 21]. One CPG recommended the use of weak opioids in cases of severe pain or if patients don't respond, are intolerant or contraindicated to NSAIDs [13]. Whilst advising that stronger opioids should only be used for the management of severe pain in exceptional circumstances [13]. Whereas one CPG recommended for tramadol and against non-tramadol opioids in patients with knee, hip and/or hand OA, noting that they can be considered circumstances when other alternatives have been exhausted [25]. Consensus: No consensus.
Glucosamine and/or chondroitin	**Glucosamine and Chondroitin individually** Three CPGs recommend against the use of glucosamine in people with knee, hip and/or hand OA [11, 12, 25]. Similarly, three CPGs recommend against the use of chondroitin in people with knee, hip and/or polyarticular OA [12, 21, 25]. Whereas one CPG supports chondroitin sulfate as a form of pain relief and improves function in people with hand OA [24]. Similarly, one CPG conditionally recommended these interventions for people with knee OA [19]. Consensus: No consensus. **Glucosamine and chondroitin combined** Two CPGs recommended against the use of glucosamine and chondroitin for knee, hip and polyarticular OA [12, 21]. One CPG was unable to recommend for or against their combined use of people with GH JT OA[10]. Whereas one CPG conditionally recommended for this intervention for people with knee OA [13], noting that further research is warranted to determine structural effects, patients' suitability and cost to benefit ratio [13]. Consensus: Do not recommend glucosamine and chondroitin for patients with hip and polyarticular OA. Consensus: No consensus for knee or GH JT OA.
Nutraceuticals	**Vitamin D** Three CPGs recommend against the use of vitamin D in people with knee, hip, hand and/or polyarticular OA [12, 21, 25], whilst one CPG conditionally recommended these supplements noting the inconsistent/limited evidence to support its use [19]. Consensus: No consensus.

	Avocado Soybean Unsaponifiables (ASU) One CPG recommended for the use of ASU for people with knee and/or hip OA, however recommended against people with polyarticular OA [21]. One CPG was unable to recommend for or against the use of ASU for people with knee and/or hip OA [12]. Consensus: No consensus. **Methylsulfonylmethane (MSM)** One CPG recommended against the use of MSM in people with knee, hip and/or polyarticular OA [21]. Whereas one CPG was unable to recommend either for or against the use of MSM for people with knee and/or hip OA [12]. Consensus: No consensus. **Collagen** One CPG was unable to recommend either for or against the use of collagen for people with knee and/or hip OA [12]. Whereas one CPG recommended against the use of collagen in people with knee, hip and/or polyarticular OA [21]. Consensus: No consensus.

ASU – Avocado Soybean Unsaponifiables; BDMARDs – biological disease-modifying antirheumatic drugs; CPG – Clinical practice guidelines; EULAR – Eurpopean Alliance of Associations for Rheumatology; GH JT – Glenohumeral Joint; IACS – Corticosteroid injection; IAGC – Intraarticular glucocorticoid injection; IAHA – Intraarticular hyaluronic acid injections; MSM – Methylsulfonylmethane; NSAIDs – Non-steroidal anti-inflammatories; Osteoarthritis; Pcc – Patient centered care; PRP – Platelet-Rich Plasma; U/S – Ultrasound.

Surgical Management narrative summary

Management Principles	Narrative Summary
Pre-operative considerations	**Physical therapy/ Physiotherapy (PT) pre-op** Three CPGs conditionally recommend PT for patients' knee, hip and GH JT OA before surgical intervention, noting that these recommendations are all based on limited evidence [10, 11, 29] . CPGs support supervised exercise or PT pre-surgery might improve pain [29] and physical function after surgery [11, 29]. PT may also benefit select patients with glenohumeral joint osteoarthritis who are not good candidates for arthroplasty e.g. young patients with GH JT OA and concerns for implant survivorship, and older patients who are not surgical candidates due to co-morbidities; reducing pain, and improving mobility and function [10]. One CPG strongly recommended all patients are taught to use a walking aid that will be needed in the postoperative phase [27]. Consensus: PT/ supervised exercise sessions could be offered prior to joint replacement surgery for patients with OA. Health professionals should teach all patients how to use a walking aid that will be needed post-op. **Surgical consideration** Two CPGs strongly recommended surgery should be considered for people with hand, knee and hip OA in certain circumstances [13, 24]. The patient should have radiographic evidence of OA, marked disability, reduced quality of life (QoL) and where other treatment modalities have been unsuccessful in relieving pain [13, 24]. Consensus: Surgery should be considered when the patient has OA, marked disability, reduced QoL and other treatment modalities haven't been effective in relieving pain.
Intraoperative considerations	**Tranexamic acid** One CPG strongly recommended [29], and two CPGs conditionally recommended [10, 11] the use of intravenous or topical tranexamic acid for people who are undergoing THA [11], TSA [10] or TKA [29] to reduce blood loss [10, 11, 29] and reduce the risk of blood transfusion [10, 29]. Consensus: Tranexamic acid could be used for people undergoing TKA, THA or TSA. **Anaesthetic types** Two CPGs reported on the use of several types of aesthetics including neuraxial anaesthesia [11, 29] peripheral nerve blockade [29] and peri-articular local anaesthetic infiltration for knee [29] and hip OA [11]. Both CPGs conditionally recommended neuraxial anaesthesia for people undergoing TKA or THA in comparison to general anaesthesia [11, 29]. One CPG strongly recommended the use of a peripheral nerve blockade and peri-articular local anaesthetic infiltration for people undergoing TKA as it decreases pain and opioid use post-operatively [29]. Consensus: Clinicians could use neuraxial anaesthesia for people undergoing TKA or THA as opposed to a general anaesthesia. Clinicians should use a peripheral nerve blockade and peri-articular local anaesthetic infiltration for people undergoing TKA.
Post-operative considerations	**PT post-op** One CPG strongly recommended PT start on the day of the TKA to reduce length of hospital stay, reduce pain and function in comparison to starting on postop day 1 [29]. Two CPGs conditionally recommend post-operative PT to improve function post THA [11] and TSA [10], despite a lack of reliable evidence [10]. Consensus: PT could be used post-TKA, THA or TSA.

	Exercise therapy One CPG strongly recommended patients complete a supervised exercise program during the first two months post TKA for improving physical function and conditionally recommended this for decreasing pain [29]. Whilst conditionally recommending supports that selected patients might be referred to an intensive supervised exercise program during late stage post TKA to improve physical function despite being based on limited evidence [29]. Similarly, one CPG conditionally recommended exercise therapy post TKR, if they are at an increased risk of delayed recovery and/or if complications occur, considering the FITT principles [27]. They suggest limiting the number of exercises, monitoring technique and ensuring patients can perform them independently [27]. Consensus: Exercise therapy could be used for people post-TKA. **Continuous Passive Motion (CPM)** Two CPGs recommended against the use of CPM after total joint replacement for people with knee and/or hip OA as research found no improvement to outcomes [27, 29]. Consensus: Do not offer CPM to patients post total joint hip or knee replacement. **Cryotherapy devices** One CPG recommended against the use of cryotherapy devices for people post-TKA [29]. In contrast one CPG conditionally recommended for the use of cryotherapy or cold packs following TSA, whilst acknowledging this decision was based on the opinion of the working group and not strong/reliable evidence [10]. Consensus: Do not use cryotherapy devices post-TKA or TSA.

CPM – Continuous passive motion; FITT – Frequency, Intensity, Type, Time; OA – Osteoarthritis; PT- Physical therapy/Physiotherapy; THA – Total hip arthroplasty; TKA – Total knee arthroplasty; TSA – Total shoulder arthroplasty; QoL – Quality of Life.

Non-pharmacological, pharmacological, and surgical interventions, single CPG recommendations.

NON-PHARMACOLOGICAL
Other pharmacological interventions
No treatment One CPG strongly recommended no treatment intervention for people with hip and/or polyarticular OA due to a lack of direct evidence supporting any treatment strategy [21].
Physical Therapy/Physiotherapy (PT) One CPG strongly recommended PT for people with hip OA and mild to moderate symptoms. They concluded that PT could improve function and reduce pain, acknowledging that future research is warranted to identify the optimal dose and type of intervention to elicit the greatest benefit for patients [11].
Vocational rehabilitation One CPG strongly recommended that health professionals provide vocational rehabilitation including counselling on modifiable work-related factors to people who experience hip or knee OA and are at risk of developing a work disability [13].
Multidisciplinary pain management program One CPG specified that patients with knee, hip and/or polyarticular OA who experience widespread pain and/or depression may benefit from a referral to a multidisciplinary pain management program [21].
Cupping One CPG was unable to recommend either for or against the use of cupping for people with GH JT OA [10].
Heat and cold therapy
Paraffin One CPG conditionally recommended the use of paraffin in addition to other heat therapies for patients with hand OA [25].
Electrotherapy
Nerve block therapy One CPG recommended against nerve block therapy for people with knee OA [21].
Radiofrequency ablation One CPG recommended against the use of radiofrequency ablation for people with knee OA [25].
Iontophoresis One CPG recommended against the use of iontophoresis for people with first CMC JT OA [25].
Extracorporeal Shockwave therapy One CPG conditionally recommended the use of extracorporeal shockwave therapy for people with knee OA [19].
Braces

One CPG conditionally recommended knee braces in general for people with knee OA [19].
One CPG conditionally recommended soft braces [21].
PHARMACOLOGICAL
NSAIDs
Non-selective NSAID
One CPG reported on the use of non-selective NSAID +/- PPI/ COX inhibitors recommended for knee and hip OA with certain comorbidities, whilst against for polyarticular OA with GI comorbidities [21].
Injections
Prolotherapy
One CPG recommended against prolotherapy for patients with knee and/or hip OA [25].
Intraarticular botulinum toxin injections
One CPG recommended against intraarticular botulinum toxin injections for patients with knee and/or hip OA [25].
Other pharmacological
Tumor necrosis factor inhibitors and interleukin-1 receptor antagonists
One CPG recommended against the use of tumor necrosis factor inhibitors and interleukin-1 receptor antagonists for people with knee, hip and/or GH JT OA [25].
One CPG reported against or uncertain for several other pharmacological treatment options for patients with knee and/or hip OA.
Doxycycline, strontium ranelate, IL-1 inhibitors, FGF, Calcitonin, NGF, dextrose prolotherapy to people with knee and/or hip OA [12].
Further research is warranted to determine if the following interventions should or should not be recommended for people with knee and/or hip OA: Boswellia serrata extract, Curcuma/curcuminoid, Pine bark extract [12].
BDMARDs
One CPG recommended against the use of BDMARDs for people with hand OA [24].
Opioids
Transdermal opioids
One CPG recommended not offering transdermal opioids with people with knee and/or hip OA [12].
Nutraceutical
Omega-3 Fatty Acids
One CPG recommended against offering omega-3 fatty acids for people with knee and/or hip OA [12].
Fish oil
One CPG recommended against the use of fish oil for people with knee, hip and/or hand OA [25].
Boswellia

One CPG recommended for the use of Boswellia for people with knee and/or hip OA and against for people with polyarticular OA [21]
Curcuminoid formulations
One CPG recommended against the use of curcuminoid formulations for people with knee and/or hip OA, however, conditionally recommend for people with polyarticular OA [21].
Cannabis, cannabidiol oil or shark cartilage
One CPG was unable to determine either for or against the use of cannabis, cannabodiol oil or shark cartilage due to the absence of reliable evidence [10].
Turmeric
One CPG conditionally recommended the use of turmeric for people with knee OA [19].
Ginger extract
One CPG conditionally recommended the use of ginger extract for people with knee OA [19].
SURGICAL
Pre-operative
Grashey view radiographs
One CPG strongly recommended the use of axillary and true AP (Grashey view) radiographs prior to TSA for GH JT OA with further advanced imaging being performed as per the health professional's clinical judgement [10].
Exercise therapy
One CPG conditionally recommended for pre-operative exercise therapy for people with knee and hip OA [25].
Types of surgeries
Trapeziectomy
One CPG strongly recommended considering trapeziectomy for people with CMC JT OA [24].
Arthrodesis or Arthroplasty
One CPG strongly recommended considering arthrodesis or arthroplasty in patients with interphalangeal OA [24].
TSA VARIATIONS
TSA vs hemiarthroplasty
One CPG strongly recommended total shoulder arthroplasty (TSA) in comparison to hemiarthroplasty for the treatment of GH JT OA as this resulted in improve function and pain relief post-surgery [10].
Anatomic or reverse TSA
One CPG conditionally recommended either an anatomic TSA or reverse TSA for people with GH JT OA who have excessive glenoid bone loss and/or rotator cuff dysfunction [10].

TSA - subscapularis peel, tenotomy, lesser tuberosity osteotomy

One CPG conditionally recommended that surgeons can utilise subscapularis peel, lesser tuberosity osteotomy, or tenotomy when performing a TSA [10].

TKA VARIATIONS

TKA vs UKA

One CPG conditionally recommended TKA over UKA to decrease revision surgery risk for medical compartment OA [29]. AAOS conditionally recommend UKA, may be used to decrease the risk of deep vein thrombosis and manipulation under anaesthesia compared to TKA for medial compartment osteoarthritis [29]. Whilst supporting no difference between UKA or valgus-producing proximal tibial osteotomy in outcomes and complications in patients with medial compartment knee osteoarthritis [29].

Bilateral TKA

One CPG conditionally recommended that bilateral TKA can be considered for patients with bilateral knee OA who are 70 or younger or American Society of Anaesthesiologists (ASA) status 1-2 [29]. The ASA is a physical status classification system was created to assess a patient's physical status prior to surgical intervention. A value of 1-2 is considered low risk [29].

Delaying TKA

One CPG strongly recommended an eight-month delay to TKA, as this was found to not worsen outcomes [29].

Patient specific instrumentation:

One CPG recommended not using patient specific instrumentation in comparison to conventional instrumentation for TKA because there is no difference in pain or functional outcomes, transfusions or complications [29].

Approach exposure

One CPG recommended there is no difference in clinical patient outcomes for THA surgical approaches [11].

Other knee surgical types

Arthroscopic, lavage and debridement, meniscectomy and cartilage repair

One CPG recommended against arthroscopic, lavage and debridement, meniscectomy and cartilage repair for people with knee OA unless the person also has mechanical symptoms of a clinically locked knee as per Australian Knee Society's 'Arthroscopy position statement' [12].

Denervation therapy

One CPG conditionally recommended denervation therapy, as it may reduce pain and improve function in patients with knee OA [19].

Lavage/Debridement

One CPG recommended against lavage and/or debridement in patients with a primary diagnosis of knee OA [19].

Partial Meniscectomy

One CPG conditionally recommended a partial meniscectomy for patients with meniscal tears and mild to moderate knee OA when PT and other nonsurgical treatments have been unsuccessful [19].

Denervation Therapy
One CPG conditionally recommended denervation therapy for patients with knee OA [19].

Tibial Osteotomy
One CPG conditionally recommended high tibial osteotomy for patients with unicompartmental knee OA [19].

Free Floating Interpositional Devices
One CPG recommended against the use of free-floating (un-fixed) interpositional devices in patients with symptomatic medial compartment knee OA [19].

Intraoperative considerations

GLENOID PROSTHETIC COMPONENTS

Pegged or keeled
One CPG conditionally recommended that clinicians may utilise either pegged or keeled glenoid components in patients with GH JT osteoarthritis and a well-functioning rotator cuff. Pegged components demonstrate less radiolucent lines, but the effect on clinical outcomes and survivorship are unclear [10].

Metal-backed cementless
One CPG recommended against the use of metal-backed cementless glenoid components for people with GH JT OA [10].

Polyethylene-metal or all-polyethylene
One CPG advises that surgeons can use polyethylene-metal hybrid glenoid components or all-polyethylene components during TSA for people with GH JT OA [10].

Non-prosthetic surgical options
One CPG reported non-prosthetic surgical options may or may not provide short-term benefit for patients with GH JT OA, noting this decision was based on a lack of strong evidence [10].

Hemiarthroplasty – stems
One CPG conditionally recommended clinicians can use either stemmed, stemless or resurfacing prosthesis for patients with GH JT OA undergoing TSA or hemiarthroplasty [10].

Cemented components
One CPG recommended either cemented or cementless stems can be used for patients with GH JT OA, and a well-functioning rotator cuff [10].

KNEE PROSTHETIC COMPONENTS

Cemented components
One CPG strongly recommended the use of tibial component fixation that is cemented or cementless in TKA. Similarly, they also recommend either cemented or cementless femoral or tibial components in TKA. They also recommend the use of either cementing all components or hybrid fixation (cementless femur) in TKA [29].

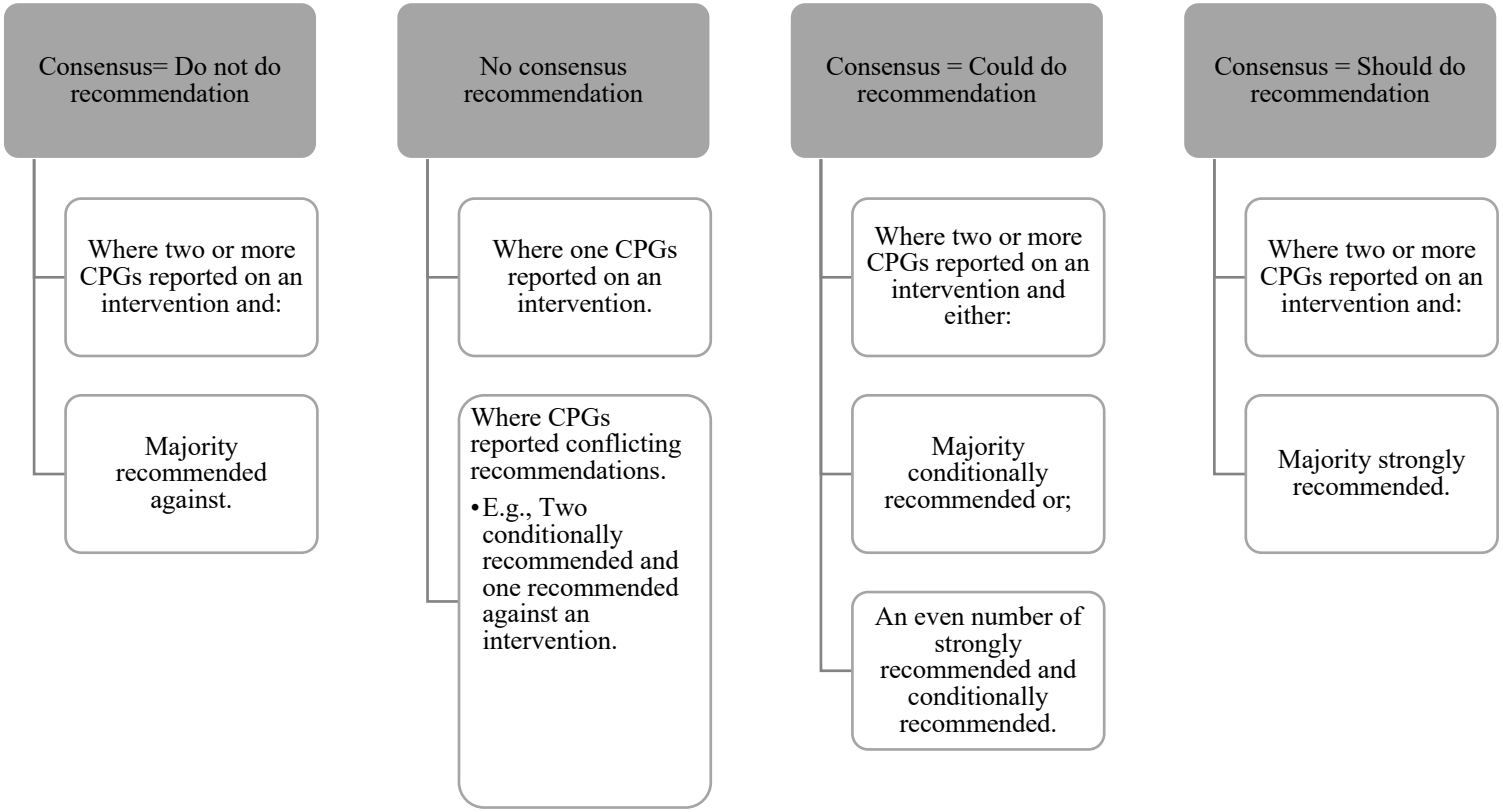
Antibiotic bone cement

One CPG recommended against the use of antibiotics in the cement for primary TKA [29].
Polyethylene tibial component
One CPG strongly recommended the use of either all-polyethylene or modular tibial components in TKA [29].
Patellar resurfacing
One CPG conditionally recommended patellar resurfacing in patients undergoing TKA. They identified no difference in pain or function, however a potential decrease in cumulative reoperations after 5 years for patella resurfacing when compared to no patellar resurfacing [29].
Patient specific instrumentation
One CPG recommended against patient specific instrumentation in comparison to conventional instrumentation for TKA because there is no difference in pain or functional outcomes [29].
Cruciate retaining arthroplasty
One CPG determined no difference in outcomes or complications between posterior stabilized and posterior cruciate retaining arthroplasty designs [29].
Tourniquet
One CPG reported conflicting recommendations for the use of tourniquet based on the outcomes. AAOS supports its use to decrease intraoperative blood loss, however, recommended against its use based on an increase in short term pain and decreased function post-operatively [29].
Drains
One CPG recommended against the use of a drain in TKA, as research shows no difference in complications or outcomes [29].
Surgical navigation
One CPG recommended against the use of intraoperative navigation in TKA, as research shows there is no difference in outcomes or complications [29].
Biceps tenodesis and tenotomy
One CPG conditionally recommended that clinicians may consider concomitant biceps tenodesis or tenotomy during shoulder arthroplasty, despite reliable evidence [10].
Supraspinatus tears
One CPG conditionally recommended that for patients with small isolated, repairable supraspinatus tears, clinicians can perform anatomic total shoulder arthroplasty [10].
Post-operative considerations
Discharge
One CPG conditionally recommended for same-day discharge after shoulder arthroplasty in select patients [10].
Multimodal pain management
One CPG conditionally recommended the use of multimodal pain management strategies or non-opioid individual modalities following TSA [10].

CPG – Clinical practice guideline; GH JT – Glenohumeral joint; PT- Physical therapy/Physiotherapy; QoL- Quality of Life; TKA – Total knee arthroplasty; TSA- Total shoulder arthroplasty.

Appendix H. What Are the Core Recommendations for Gout Management in First Line and Specialist Care? Systematic Review of Clinical practice Guideline: Supplementary Materials

H.1 Defining Consensus Among CPGs Regarding Individual Recommendations



H.2 Database Search Strategies

Medline

1. guideline*.ti,pt,kw.
2. Practice Guideline/ or Guideline/
3. 1 or 2
4. (arthriti* or osteoarthriti* or lupus or gout).mp.
5. exp arthritis/ or exp Lupus Erythematosus, Systemic/ or Gout/
6. 4 or 5
7. 3 and 6
8. limit 7 to (english language and yr="2015 - 2020")

CINAHL

1. MH Practice Guidelines OR TI guideline* OR PT Practice Guidelines
2. MH arthritis+
3. MH Lupus Erythematosus, Systemic+
4. MH Gout
5. (arthriti* or osteoarhriti* or lupus or gout)
6. S2 OR S3 OR S4 OR S5
7. S1 AND S6
8. S1 AND S6 limit to 2015-2020 and english

EMBASE

1. Guideline*.ti,kw.
2. *practice guideline/
3. 1 or 2
4. (arthriti* or osteoarthriti* or lupus or gout).ti,ab,kw.
5. exp *arthritis/
6. exp *systemic lupus erythematosus/
7. *gout/
8. 4 or 5 or 6 or 7
9. 3 and 8
10. limit 9 to conference abstracts
11. 9 not 10
12. limit 11 to (english language and yr="2015 - 2020")

PEDRO

1. Abstract and title: Osteoarthritis
2. Abstract and title: Rheumatoid arthritis
3. Abstract and title: Lupus / SLE
4. Gout

Method	Practice guideline
When searching	Match all terms with and
Published since	2015

H.3 Classification of Gout Recommendations

	BSR [31]	ACP [27]	EULAR [25]	ISR [29]	ACR [26]	SER [32]
Non-pharmacological management						
Education (diet, exercise, weight management, ULT, rest, elevation, cool environment)	✓✓	✓✓	✓✓	✓✓	✓	
Adequate water intake (>2L)	✓✓					
Vitamin C	✓				O	
Nurse involvement						✓✓
Urate-lowering therapies						? Patients on dialysis ✓ Referred to unit with clinical experience
Initiating ULT	✓✓ All patients especially recurring attacks; tophi; chronic; joint damage; renal impairment; a history of urolithiasis; diuretic therapy use; primary gout starting at a young age. ✓ Delayed commencement		✓✓ All patients especially recurrent flares; tophi; urate arthropathy and/or renal stones; young age (<40 years); very high sUA level; and/or comorbidities	✓✓ Patients with recurrent flares; tophi; urate arthropathy and/or renal stones; very high sUA level; and/or comorbidities	✓✓(≥ 1 subcutaneous tophi, radiographic damage, Gout flare >2/year) ✓ (Infrequent flares <2/year, first flare and CKD stage >3, sUA >9 mg/dl, or urolithiasis) O (First flare, asymptomatic hyperuricemia (sUA >6.8 mg/dl with no prior gout flares or subcutaneous tophi) ✓ During a flare	✓✓ ULT w XOI
Aim and monitoring sUA level combined	✓✓ ≤300 mmol/l initial ✓ ≤360 mmol/l		✓✓ 360 mmol/L (<6 mg/dL) ✓ 300 mmol/L (<5 mg/dL) severe gout O <3 mg/dL long term.	✓✓ 360 mmol/L (<6 mg/dL) ✓✓ 300 mmol/L (<5 mg/dL) severe gout	✓✓ 360 mmol/L (<6 mg/dL)	✓ 300 mmol/L (<5 mg/dL) ✓✓ Same for CKD
Dosage of ULT (Titration to reach sUA target)			✓✓		✓✓	✓✓

Length of ULT therapy		✓ Short-term O Long-term			✓	
Acute treatment						
NSAID	✓✓	✓✓	✓✓ O Severe renal impairment	✓✓ O (Severe renal impairment)	✓✓	✓✓
Colchicine	✓✓	✓✓	✓✓ O Colchicine if receiving strong P-glycoprotein and/or CYP3A4 inhibitors O Severe renal impairment	✓✓ O Severe renal impairment	✓✓	
Corticosteroids	✓	✓✓	✓✓	✓✓	✓✓	✓✓
Prevention						
Prophylaxis			✓✓	✓✓	✓✓	
Xanthine Inhibitor					✓✓ CKD stage >3 ✓ switching first XOI to an alternate XOI	✓✓ CKD ✓✓ XOI and uricosuric agents
Allopurinol	✓✓		✓✓ ✓ Renal impairment	✓✓ ✓ Renal impairment	✓✓ All patients including those with CKD stage >3 ✓ Allergy - allopurinol desensitization	✓✓ All patients including those with CKD O HLA-B*58 allele ✓✓ CV event
Febuxostat	✓			✓ Renal impairment	✓✓ ✓ Switching ULT if history of CVD or a new CV event	✓ First-line severe gout ✓✓ CKD ✓ High CV risk, no history of CV event – consider risk/benefits
Uricosuric agents	✓			✓	O Checking urinary uric acid and alkalinizing urine	✓✓ Lesinurad:

						✓✓ Montherapy or + XOI Before benzbromarone O Severe kidney disease O CV event past 12 months Benzbromarone ✓ Poor response to treatment, adverse reactions to XOI or CVD or CKD O Severe kidney disease
Pegloticase			✓ Severe, debilitating, chronic tophaceous gout, poor QoL, failed to achieve sUA target		O First-line therapy and patients who have failed to achieve the sUA target; infrequent gout flares; no tophi. ✓✓ Failed to achieve sUA target; frequent gout flares; non-resolving subcutaneous tophi.	✓ Refractory gout or no other treatment option ✓✓ Severe kidney disease or who do not tolerate well other treatment options
Probenecid					✓	
Fenofibrate +/- Losartan	O Primary ULT ✓ Hypertension or dyslipidaemia				O	
IL-1 inhibitors	✓		✓ O current infection	✓	✓	
Antihypertensive medications	✓		✓		✓	
Stopping aspirin					O	
Two medications with the same mechanism of action						O

Medical vs Surgical				✓✓ Medical intervention ✓ Surgical mx in selected cases e.g. nerve compression, mechanical impingement or infection		
Screening/Monitoring						
Testing HLA–B*5801					✓ (Pt Southeast Asian descent) O (all other populations)	✓ (Asian ethnic groups) O ('white population')
Cardiovascular risk factors and co-morbid conditions	✓✓		✓✓	✓✓		
Radiography						✓✓
Ultrasound						✓✓
Frequency of monitoring						?
Dual-energy computed tomography						?
Special populations						
Solid organ transplant						? safest most effective treatment ✓ Specialist input

✓✓Should do; ✓ Could do; O Do not do; ? Uncertain.

ACP – American College of Physicians; ACR – American College of Rheumatology; BSR – British Society of Rheumatology; CKD – chronic kidney disease; CV – cardiovascular; e.g. – example EULAR – European League Against Rheumatism; ISR – Italian Society of Rheumatology; IL-1 –interleukin-1; NSAID – non-steroidal anti-inflammatories; SER – Spanish Society of Rheumatology; sUA – serum urate levels; ULT – urate lowering therapy; ; XOI – xanthine oxidase inhibitors.

H.4 Description of Clinical Practice Guidelines

Title	Year	Type of developer	Country/ Region of Origin	Format	Informed by CPG quality tool	Accompanying documents accessed	Guideline topic	Target users
EULAR [25]	2016	Medical Society	Europe	Journal Article	Yes	Lay version Supplementary Material Document	Non-pharmacological and pharmacological treatments for gout.	Physicians, rheumatologists, GPs, patients and others.
ISR [29]	2019	Medical Society	Europe	Journal Article	Yes	Nil	Diagnosis and treatment of patients with gout in Italy.	Attending physicians (general practitioners, rheumatologists, internists, nephrologists, cardiologists, geriatricians) and health professionals who manage patients with gout in primary care, and in hospital and community practice settings. Policy makers and those responsible for commissioning care for patients with gout in the Italian National Health Service.
ACR [26]	2020	Medical Society	USA	Journal Article	Yes	Supplementary Appendix 1-10 Disclosure Summary Project Plan	Management of gout.	Health care providers and patients with gout.
ACP [27]	2017	Medical Society	USA	Journal Article	Yes	Full report Appendix: Detailed methods Summary of Methods Systematic review	Management of acute and recurrent gout in adults.	All clinicians.
BSR [31]	2017	Medical Society	UK	Journal Article	No	Supplementary Data Document	Management of gout in the UK patients.	Doctors and allied health professionals who treat and manage patients with gout in primary care and hospital practice. Those responsible for commissioning care for patients with gout in the National Health Service.

SER [32]	2020	Medical society	Europe – Spain	Report	Yes	N/a	Treatment, diagnosing and monitoring Gout.	Rheumatologists, other health professionals working in primary or specialist care, namely, those from the specialities of cardiology, nephrology, urology, family medicine, and nursing, as well as other specialities potentially involved in the care of these patients and patients and family members.

ACP - American College of Physicians; ACR - American College of Rheumatology; BSR – British Society of Rheumatology; EULAR - European League Against Rheumatism; GP – General practitioner; ISR – Italian Society of Rheumatology; SER – Spanish Society of Rheumatology; USA – United States of America; UK – United Kingdom.

H.5 Overall Mean (Standard Deviation) Percentage Scores in each AGREE II Domain and Mean (1–7 Scale/Standard Deviation) for Each Item

	Mean (SD)
Domain 1. Scope and Purpose (%)	**86% (11.3)**
1. The overall objective(s) of the guideline is (are) specifically described.	6.6 (0.5)
2. The health question(s) covered by the guideline is (are) specifically described.	6.0 (1.4)
3. The population (patients, public, etc.) to whom the guideline is meant to apply is specifically described.	5.8 (1.3)
Domain 2. Stakeholder Involvement (%)	**79% (15.8)**
4. The guideline development group includes individuals from all relevant professional groups.	5.8 (0.9)
5. The views and preferences of the target population (patients, public, etc.) have been sought.	5.1 (1.8)
6. The target users of the guideline are clearly defined.	6.1 (1.1)
Domain 3. Rigour of Development (%)	**75% (5.7)**
7. Systematic methods were used to search for evidence.	6.5 (0.7)
8. The criteria for selecting the evidence are clearly described.	6.0 (1.5)
9. The strengths and limitations of the body of evidence are clearly described.	4.9 (1.4)
10. The methods for formulating the recommendations are clearly described.	5.6 (1.4)
11. The health benefits, side effects, and risks have been considered in formulating the recommendations.	6.5 (0.7)
12. There is an explicit link between the recommendations and the supporting evidence.	6.5 (0.9)
13. The guideline has been externally reviewed by experts prior to its publication.	5.2 (1.1)
14. A procedure for updating the guideline is provided.	2.7 (2.0)
Domain 4. Clarity of Presentation (%)	**89% (6.8)**
15. The recommendations are specific and unambiguous.	6.3 (0.8)
16. The different options for management of the condition or health issue are clearly presented.	6.2 (1.2)
17. Key recommendations are easily identifiable.	6.5 (0.9)
Domain 5. Applicability (%)	**45% (24.8)**
18. The guideline describes facilitators and barriers to its application.	2.8 (2.3)
19. The guideline provides advice and/or tools on how the recommendations can be put into practice.	3.8 (2.0)
20. The potential resource implications of applying the recommendations have been considered.	3.8 (1.9)
21. The guideline presents monitoring and/or auditing criteria.	4.3 (2.4)
Domain 6. Editorial Independence (%)	**76% (33.6)**
22. The views of the funding body have not influenced the content of the guideline.	5.0 (3.0)
23. Competing interests of guideline development group members have been recorded and addressed.	6.1 (1.2)
Overall Score (%)	**75% (11.8)**

H.6 CPG AGREE II Domain Scores and Quality Assessment (%)

CPGs included in the systematic review

	Doman 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Overall assessment	Domain 2,3,6
ACP [27]	94	50	74	92	21	100	67	75
EULAR [25]	67	72	70	94	35	42	67	61
ACR [26]	81	83	80	92	31	25	67	63
ISR [29]	92	83	82	83	48	100	83	89
BSR [31]	97	92	74	94	92	100	92	89
SER [32]	83	92	68	78	40	88	75	82

CPGs excluded from the systematic review

	Doman 1	Domain 2	Domain 3	Domain 4	Domain 5	Domain 6	Overall assessment	Domain 2,3,6
*Graf et al. [33]	42	14	34	64	19	0	33	16
APLAR [34]	81	44	69	78	31	17	53	43
FSR – Acute Gout Flare [35]	53	45	41	67	8	46	50	44
FSR – ULT [36]	47	45	41	67	8	46	42	44

*First author given where there is no stated organisation; ACP - American College of Physicians; ACR - American College of Rheumatology; APLAR – Asia Pacific League of Associations for Rheumatology; BSR – British Society of Rheumatology; EULAR - European League Against Rheumatism; FSR – French Society of Rheumatology; ISR – Italian Society of Rheumatology; ULT – Urate lowering therapy.

H.7 Narrative Synthesis of CPG Recommendations

Gout management interventions narrative summary

Management Interventions	Narrative Summary
Non-pharmacological management	
Education	Four CPGs strongly [25, 27, 29, 31] and one CPG conditionally [26] recommended providing education for people with gout. Patients should be supported [29, 31] provided with both verbal and written information [31], including individualised management options, and considering the patients co-morbidities [25, 31], concurrent medications [31] and discussing potential illness perceptions or barriers to care [31]. Content should include education to improve disease knowledge and both non-pharmacological and pharmacological management options. Decision making should be shared between the patient and clinician and be based on a treat-to-target protocol [26]. **Disease knowledge topics** ● The causes and consequences of gout and hyperuricaemia [31]. ● Pathophysiology of the disease [25]. ● The principles of managing acute attacks and eliminating urate crystals through lifelong lowering of serum urate levels (sUA) level below a target level [25]. ● Effective treatments [25]. **Non-pharmacological education topics (diet, exercise, weight management, smoking):** Lifestyle advice including regarding dietary changes should be provided to all people with gout [25, 31]. Patients should be encouraged to well-balanced diet low in fat and added sugars, and high in vegetables and fibre [31] inclusion of low-fat dairy products [25] such as: skimmed milk and/or low-fat yoghurt alongside, soybeans and vegetable sources of protein, and cherries [31]. CPGs recommended to avoid or limit the following: alcoholic drinks [26, 31] (especially beer and spirits) [25], high- purine foods [25, 26, 31] and sugar-sweetened soft drinks [25, 31], high-fructose corn syrup [26], heavy meals and excessive intake of meat and seafood [25]. Three CPGs strongly encouraged dietary modification to achieve a gradual reduction in body weight and subsequent maintenance in people who are overweight or obese [25, 29, 31]. Whilst one CPG conditionally recommended weight loss for overweight/obese patients with gout, regardless of disease activity [26]. Three CPGs strongly recommended to discuss and encourage regular exercise for all patients with gout [25, 29, 31]. One CPG strongly recommended ceasing smoking in patients with gout [29].

	Pharmacological education topics The option of urate lowering therapy (ULT) should be explained to patients following a confirmed diagnosis of gout [31]. Patients with gout should receive full information concerning the use of ULT [25]. Clinicians should explain the rationale [31], aims of its use to target urate levels [31], benefits, harms and costs before initiating ULT [27]. Decision making, including when to commence ULT should consider the individual preferences of the patient [25, 27, 29, 31], with the ULT medication choice being based on the patient factors such as: potential contraindications, past experience of treatments, time of initiation after flare onset and the number and type of joint(s) involved [25]. Clinicians should encourage patients to self-medicate at the onset of symptoms (ideally within 24 hours) during an acute flare [25, 29, 31]. Advice should include continuing any established ULT during and following an attack to prevent the return of symptoms [29, 31]. One CPG strongly recommends gout affected joints during a flare should be rested, elevated, and exposed in a cool environment such as: using ice packs [31]. One CPG conditionally recommends topical ice can be considered [26]. These strategies can be effective as an adjuvant treatment in combination with other therapies [26, 31]. Consensus: Health professions should provide all patients with both written and verbal information including education to improve disease knowledge and both non-pharmacological and pharmacological management options, specifically ULT. Gout affected joints should be rested and elevated. Ice packs or topical ice could be offered to people with gout.
Vitamin C	Two CPGs reported conflicting recommendations on vitamin C supplementation for people with Gout. One CPG conditionally recommended for its use at a dosage of 500-1500mg daily due to its weak uricosuric effect [31], whereas one CPG recommended against for all patients with gout, regardless of disease activity [26]. Consensus: No consensus.
Urate-lowering therapies	
One CPG was unable to develop a recommendation for the use of ULT for patients with dialysis due to a lack of evidence [32]. Instead, they recommended that the patient is referred to a unit that has the appropriate clinical experience [32]. Consensus: No consensus.	
Initiating ULT	Five CPGs strongly recommended initiating ULT in most cases [25, 26, 29, 31, 32], with a xanthine oxidase inhibitor (XOI) as monotherapy [32]. Whilst, one CPG's recommendations varied on disease severity [26]. Three CPGs strongly recommended that ULT should be discussed and offered to all patients who have a diagnosis of gout at their first presentation [25, 29, 31] and can be considered during a flare [26]. Conversely, one CPG suggested delaying commencement until the inflammation has settled; as they believed ULT is better discussed when the patient is not in pain [31]. CPGs provided criteria for when to initiate ULT: ULT should be recommended particularly for patients with: - Recurring attacks [25, 29] (defined as: 52 attacks in 12 months [31] or >2/year [26]). - Radiographic damage (any modality) attributable to gout [26].

	- Tophi [25, 26, 29, 31]. - Chronic gouty arthritis [31]. - Joint damage [31]. - Renal impairment (estimated Glomerular Filtration Rate <60ml/min) [31]. - A history of urolithiasis [31]. - Diuretic therapy use [31]. - Primary gout starting at a young age [31] defined as <40 years [25]. - Urate arthropathy and/or renal stones [25, 29] - People with a very high sUA level (>8.0 mg/dl; 480 μmol/L) and/or comorbidities (e.g. renal impairment, hypertension, ischemic heart disease, heart failure) [25, 29]. ULT can be recommended: - For patients who have previously experienced >1 flare but have infrequent flares (<2/year) or for patients experiencing their first flare and CKD stage >3, sUA >9 mg/dl, or urolithiasis [26]. ULT should not be recommended for: - For patients experiencing their first flare or patients with asymptomatic hyperuricemia (sUA >6.8 mg/dl with no prior gout flares or subcutaneous tophi) [26]. Consensus: No consensus.
Aim and monitoring sUA level	Two CPGs strongly recommended monitoring sUA level [25, 29], frequency of gout attacks and tophi size [29]. Four CPGs strongly recommended maintaining a low target sUA [26, 31, 32] for faster crystal elimination [26, 31]; with the treatment target being an absence of gout attacks and resolution of tophi [29]. sUA target levels vary depending on gout severity. sUA <5 mg/dL (300 mmol/L) is recommended for patients with severe gout (defined by - tophi, chronic arthropathy, frequent attacks) [25, 29, 32], or initial gout episode [31] as a lower sUA target can assist with crystal dissolution [25, 31] and prevent further urate crystal formation [31]. Clinicians can consider increasing the sUA target to <6 mg/dL (360 mmol/L) [25, 26, 29, 31] when the patient has experienced several years of successful treatment, tophi has resolved, and the patient is symptom free [31]. This should be monitored and maintained lifelong [25, 26, 29, 31]. The same target sUA levels should be used for patients who have chronic kidney disease [32]. A sUA level <3 mg/dL is not recommended long-term [29], due to the possibility of adverse effects [29, 31]. Consensus: sUA level should be monitored and maintained to <6 mg/dL (360 mmol/L) lifelong, or sUA <5 mg/dL (300 mmol/L) for patients with severe gout or those experiencing an initial gout episode. A sUA level <3 mg/dL is not recommended in the long term.

Dosage of ULT	Three CPGs strongly recommended delivery of ULT following a treat-to-target strategy [26], that includes starting from a low dose [25, 32] and dose titration [25, 26, 32] upwards to achieve the sUA target [25, 26, 32] of <6 mg/dL (360 mmol/L) [25]. This is preferred over a fixed, standard-dose ULT strategy [26]. Consensus: ULT dosage should be selected based on a target-to-treat strategy and titrated upwards to achieve a sUA target of <6 mg/dL (360 mmol/L) long-term.
Length of ULT therapy	One CPG conditionally recommended continuing ULT indefinitely over stopping ULT [26] whereas one CPG conditionally recommended for ULT in shorter durations, however they recommend against long-term (≥12 months) ULT use in majority of patients after a first gout attack or in patients with infrequent attacks due to lack of evidence [27]. Consensus: No consensus.
Acute treatment	
NSAIDs	All CPGs strongly recommended non-steroidal anti-inflammatories (NSAIDs) [25-27, 29, 31, 32] with two CPGs recommending against for people with gout and renal impairment [25, 29]. Initial combination therapy is an appropriate option for acute [27] gout attack [29] when there are no contraindications [31] and when monotherapy is insufficient [29, 31]. NSAID (+/-plus proton pump inhibitors)[25, 31] at maximum dose [31] should be considered as a first-line treatment option, alongside colchicine [25, 26, 29, 31] or corticosteroids [25-27, 29]. These medications are effective in reducing pain [27], and should be discussed with the patient. Treatment decisions should consider patient factors [26] including patient preference [31, 32], presence of comorbidities [29, 31, 32] e.g. impaired renal function, contraindications, the number and type of joint(s) involved [29]. NSAIDs should be avoided in patients with severe renal impairment who are experiencing an acute gouty attacks [25, 29]. Consensus: NSAIDs should be recommended for people with gout as a first-line treatment, taking into consideration patient factors. NSAIDs should not be recommended for people with gout and renal impairment.
Colchicine	All CPGs strongly recommended colchicine [25-27, 29, 31] as the drug of choice (alongside NSAIDs or corticosteroids) for managing an acute gouty attack when there are no contraindications [31]; avoid for patients with renal impairment [25, 29, 31] or for patients who are receiving strong P-glycoprotein and/or CYP3A4 inhibitors such as cyclosporin or clarithromycin [25]. This should be initiated within 12 hours of flare onset [25], at a low-dose [26, 27]. Dosage varied from 1.2 mg followed by 0.6 mg 1 h later [27] to 1 mg followed 1 hour later by 0.5 mg [25] or 500mg bd-qds [31]. Low doses are seen as effective as higher dosages for reducing pain and are associated with fewer gastrointestinal adverse effects [27]. In patients who cannot tolerate colchicine, a low-dose NSAID or coxib, with gastroprotection can be used as an alternative providing there are no contraindications [31]. These options should be discussed with the patient and treatment decisions should consider patient factors [26] including patient preference [31], presence of comorbidities [29, 31] e.g. impaired renal function, contraindications, the number and type of joint(s) involved [29]. Initial combination therapy is an appropriate option for a severe gouty attack [29].

	Consensus: Colchicine should be recommended for people with gout as a first-line treatment, taking into consideration patient factors. Colchicine should not be recommended for people with gout and renal impairment or who are receiving strong P-glycoprotein and/or CYP3A4 inhibitors.
Corticosteroids	Five CPGs strongly recommended for the use of corticosteroids [25-27, 29, 32], whilst one conditionally recommended for this intervention [31] as a first-line option for an acute gout flare alongside NSAIDs, colchicine [27, 29, 32]; with the choice of treatment depending on patient preferences and comorbidities [32]. For patients who are unable to tolerate NSAIDs or colchicine, a short course of oral corticosteroid [31] or joint aspiration [31] and a single injection of an intramuscular corticosteroid [31] [26, 29], intra-articular or intravenous [26, 29] can be considered. Corticosteroids either an intramuscular injection or short-course orally is considered appropriate for oligo- or polyarticular attacks of gout [31]. Corticosteroids and corticotrophin [29] are recommended over IL-1 inhibitors or adrenocorticotropic hormone [26]. Consensus: Corticosteroids should be offered to patients with acute gout.
Prevention	
Prophylaxis	Three CPGs strongly recommended for the use of prophylaxis for people with gout [25, 26, 29]. Prophylaxis should be fully explained and discussed with the patient [25]. Treatment should be initiated prior to or within the first 6 months of ULT [25, 29] or upon resolution of acute gout [26] and continued for 3–6 months, with ongoing evaluation and continued prophylaxis as needed if the patient continues to experience flare [26]. A dosage of 0.5–1 mg/day is recommended, that should be reduced in patients with renal impairment [25]. Colchicine is recommended as the first choice of prophylactic treatment, followed by a low-dose NSAID [25, 26, 29] or COXIB [25, 29] and lastly low-dose glucocorticoids if the other options are contraindicated, not tolerated, or ineffective [29]. Alternatively to low-dose colchicine or NSAIDs, febuxostat (40 mg/d) and allopurinol (300 mg/d) are equally effective at decreasing sUA levels [26]. Neurotoxicity and/or muscular toxicity risk should be considered, if a patient has renal impairment or is receiving statin treatment [25]. Avoid co-prescription of colchicine with strong P-glycoprotein and/or CYP3A4 inhibitors [25]. Consensus: Prophylaxis should be initiated prior to or within the first 6 months of ULT and continued for at least 3-6 months at a dosage of 0.5-1mg/day. Lower dosage and side effects of colchicine should be considered for people with renal impairment.
XOI	Two CPGs strongly recommended the use of an XOI (allopurinol or febuxostat) for people with chronic kidney disease (CKD) [26, 32] stage >3 [26] as a first-line treatment [26, 32] over probenecid [26] with specific limitations stated in their summary of product characteristics [32]. One CPG recommended that for patients who are taking their first XOI monotherapy at a maximum dose, and who are not achieving target sUA and/or continue to have frequent flares or non-resolving subcutaneous tophi, consider switching to an alternate XOI agent instead of a uricosuric agent [26]. Whereas the other CPG recommended to combine XOI with a uricosuric agent [32]. Consensus: XOI should be recommended for patients with CKD.

Allopurinol	Five CPGs strongly recommended the use of allopurinol as a first-line ULT [25, 26, 29, 31, 32] for people with gout and with normal kidney function [25], including in those with CKD [26, 32] stage >3 [26]. It is recommended to start at a low dose of 50-100mg daily [31] (no greater than 100mg) [25, 26, 29] and lower in patients with CKD [26]. Dosage should be increased by 100mg increments [25, 31] every 2-4 weeks [25] or 4 weeks [31] until sUA target is reached [25, 29, 31, 32], with a maximum dose of 900mg [31]. In patients with renal impairment (any grade), allopurinol may be used, if the initial dosage starts at 50 to 100 mg daily for the lowest levels of renal function [32]. Doses should be gradually increased by smaller increments (50mg [29, 31, 32] – 100mg depending on renal function [32]) and the maximum dose will be lower [31]. Dose should be adjusted to creatinine clearance [25], but target sUA levels should be the same [31]. Clinicians should conduct close monitoring for adverse events and toxicity (e.g., pruritus, rash, elevated hepatic transaminases [29]. If the sUA target cannot be achieved [29] or allopurinol cannot be tolerated, febuxostat [25, 29, 32] or benzbromarone with or without allopurinol can be considered except for patients with estimated glomerular filtration rate <30 mL/min [25]. Febuxostat can be given at a dosage of 40mg/d [26] and/or a uricosuric, can be considered [25, 29]. For patients with a prior allergic response to allopurinol who cannot be treated with other oral ULT, we conditionally recommend using allopurinol desensitization [26]. One CPG recommended that allopurinol should be avoided in patients who are known to have the HLA-B*58 allele (such as those who are transplant recipients or on a transplant programme) [32]. Consensus: Allopurinol should be recommended as a first line ULT at 50-100mg daily and increased 100mg increments every 2-4 weeks until sUA target is reached with a maximum dose of 900mg. Consider febuxostat and/or uricosuric if allopurinol is not effective or contraindicated. Allopurinol should be avoided for patients with HLA-B*58 allele
Febuxostat	Two CPGs conditionally recommended [29, 31], one CPG strongly recommended [26] the use of febuxostat as an alternative second-line XOI where allopurinol has not been effective in achieving the therapeutic sUA target [29, 31] or if renal impairment prevents allopurinol dose escalation [31]. It can be considered as a first-line therapy if a patient has severe gout and requires a extremely low sUA target [32]. CPGs recommended starting at a low dose with subsequent dose titration (e.g. <100mg/day for patients without CKD and lower for patients with CKD [26], whilst the other suggested 80mg daily [31]. One CPG recommended increasing the dosage after 4 weeks to 120 mg daily, if necessary to achieve therapeutic target [31]. Febuxostat can be considered for patients with gout and CKD [32]. Patients with a high cardiovascular (CV) risk but no history of a CV event should consider the benefits/risks of this medication before potentially commencing [32]. If they have a history of cardiovascular disease (CVD) or have experienced a new CV event, consider switching to an alternative ULT agent if available and consistent with other recommendations in this guideline [26]. Consensus: Febuxostat can be considered for patients who have renal impairment and allopurinol is either contraindicated or hasn't allowed for therapeutic sUA target to be achieved.

	Clinicians can consider other ULT agents for patients who have a history of CVD or a new CV event.
Uricosuric agents	Two CPGs conditionally recommended and one CPG strongly recommended for the use of uricosuric agents either in combination with a XOI in patients who do not achieve a therapeutic serum urate target [29, 31, 32] with optimal doses of monotherapy XOI [31, 32] (in appropriate doses or maximum tolerated doses [32]) or in replacement of XOI's in patients who are resistant to, or intolerant of, XOIs [31] and have severe gout [29]. The preferred uricosuric agents are: ● Sulfinpyrazone (200-800 mg/day) [31]. ● Probenecid (500-2000 mg/ day) in patients with normal or mildly impaired renal function [31]. ● Benzbromarone (50-200 mg/ day) in patients with mild to moderate renal insufficiency [31]. o Benzbromarone can be considered as monotherapy if a patient has a poor response to treatment, are intolerant or has an adverse reaction to XOIs. Similarly, monotherapy can be considered if they have CVD or a history of CV event [32]. o If a patient has CKD, benzbromarone should only be prescribed after a poor response or adverse effects related to an XOI [32]. ● Lesinurad only in combination with XOIs and should be considered before benzbromarone [32]. Taking into • account the warnings and precautions for its use [32]. Lesinurad or benzbromarone should not be prescribed for patients with severe kidney disease [32]. Avoid Lesinurad if a patient has experienced a vascular event in the last 12 months [32]. One CPG recommended against checking urinary uric acid and alkalinizing urine for people taking uricosuric treatment [26]. Consensus: Uricosuric agents can be considered either in combination with XOI or as monotherapy in patients who have a poor response, are intolerant or have an adverse reaction to XOI's. Lesinurad or benzbromarone should not be prescribed for patients with severe kidney disease. Checking of urinary uric acid and alkalinizing urine for people taking uricosuric treatment is recommended against.
Pegloticase	One CPG conditionally recommended for the use of pegloticase for people with gout in particular cases [25]. Whilst two CPG reports conflicting recommendations, they strongly recommended for in some cases and against in other cases [26] or reported a combination of strongly and conditionally recommended for pegloticase [32]. Pegloticase is not recommended as a first-line therapy or for patients currently continuing ULT for patients who have failed to achieve sUA target with other treatment interventions such as XOIs, uricosurics, but who have infrequent gout flares (<2 flares/year) and no tophi [26]. Conversely, for patients who have failed to achieve sUA target [25, 26, 32] with other treatment interventions [26] and who have crystal-proven, sever debilitating chronic tophaceous gout and poor quality of life [25], or frequent gout flares (≥2 flares/year), or who have non-resolving subcutaneous tophi [26], pegloticase could [25] or should [26] be used. Pegloticase should be considered for patients with severe kidney disease, who haven't reached sUA target and who haven't tolerated other treatment options or as an alternative option to lesinurad + XOI, or benzbromarone as monotherapy in those who have a history of a CV event [32]. Consensus: No consensus.

Fenofibrate +/- Losartan	One CPG recommended against adding or switching to fenofibrate for people with gout [26]. One CPG recommended against the use of losartan and fenofibrate as primary ULT, however conditionally recommended for their combined use in treating hypertension or dyslipidaemia as they can have a weak uricosuric effect [31]. Consensus: No consensus.
IL-1 inhibitors	Four CPGs conditionally recommended for the use of interleukin 1 (IL-1) inhibitors [25, 26, 31] for people with acute gout [31] or who have frequent flares [25] and contraindications [25, 26, 29] or haven't responded adequately to standard treatment [26, 29, 31] such as: colchicine, NSAIDs and corticosteroid (oral and injectable)[25]. IL-1 inhibitors should not be considered if the patient has a current infection. ULT should be adjusted to achieve the sUA target following an IL-1 blocker treatment for flare [25]. Consensus: IL-1 inhibitors could be considered for people with acute gout, and/or frequent flares who have contraindications or haven't responded adequately to standard treatment. Do not use IL-1 inhibitors if the patient has a current infection.
Antihypertensive medications	Three CPGs conditionally recommended anti-hypertensive medications in certain circumstances [25, 26, 31]. Two CPGs conditionally recommend switching from hydrochlorothiazide to an alternate antihypertensive [26], preferably losartan [25, 26] or calcium channel blockers [25] to treat hypertension, when blood pressure is controlled [31] regardless of disease activity [26]. If a patient has gout and hyperlipidaemia and is receiving loop or thiazide diuretics, consider replacing the diuretics for a statin or fenofibrate [25]. Consensus: People with gout and hypertension could consider switching from diuretic drugs to an alternate antihypertensive medication preferably losartan or calcium channel blockers. People with gout and hyperlipidaemia could consider switching from diuretic drugs to an alternate antihypertensive medication statin or fenofibrate.
Screening/Monitoring	
Cardiovascular risk factors and co-morbid conditions	Three CPGs strongly recommended screening for cardiovascular risk factors, renal function and co-morbid conditions in all patients with gout [25, 29, 31] at the time of diagnosis [29], reviewed annually and managed appropriately [29, 31]. Cardiovascular risk factors, include: renal impairment [25, 29, 31], coronary heart disease [25], heart failure [25], stroke, [25], peripheral arterial disease [25], obesity, hyperlipidaemia, hypertension, diabetes mellitus, and smoking [25, 29, 31]. Consensus: All patients should be screened for cardiovascular risk factors and co-morbid conditions initially and reviewed annually.
Testing HLA–B*5801	Two CPGs conditionally recommended for testing HLA–5801 prior to starting allopurinol for patients of Southeast Asian descent (e.g., Han Chinese, Korean, Thai) [26, 32] and African American patients, who have a higher prevalence of HLA–B*580 [26]. Both CPGs recommended against testing in all other population groups [26, 32]. Consensus: Southeast Asian descent and African American patients can be tested for HLA–5801 prior to starting allopurinol. Testing in other populations groups is recommended against.

CKD – chronic kidney disease; COXIB – cyclooxygenase-2 inhibitors; CPGs – Clinical Practice Guidelines; CV – cardiovascular; CVD – cardiovascular disease; IL-1 – Interleukin-1; NSAID – non-steroidal anti-inflammatories; sUA – serum uric acid; ULT – urate lowering therapy; XOI – xanthine oxidase inhibitor.

Single CPG recommendations on interventions

Non-pharmacological
Adequate water intake One CPG strongly recommended >2 litres of water daily and avoid dehydration for people with gout and a history of urolithiasis. Alkalinization of the urine with potassium citrate (60 milliequivalent/day) should be considered in recurrent stone formers [31]. **Nurses involvement** One CPG strongly recommended for the support and regular follow-up of a specially-trained nurse for patients with gout [32].
Prevention
Probenecid One CPG conditionally recommended for the use of probenecid, starting at a low dose (500 mg once or twice daily) with dose titration over starting at a higher dose [26]. **Stopping aspirin** One CPG recommended against stopping low-dose aspirin in those with gout who are taking this medication for appropriate indications [26]. **Two medications with the same mechanism of action** One CPG recommended against two medications with the same mechanism of action (e.g. two XOI's) due to a lack of evidence.
Management options
Medical vs Surgical One CPG strongly recommended medical management to achieve a sustained reduction in sUA, only considering surgical management for selected cases such as: nerve compression, mechanical impingement, or infection [29].
Screening/Monitoring
Radiography One CPG recommended that plain radiography is used to assess the extent of joint damage and monitor bone erosions [32]. **Ultrasound** One CPG recommended that ultrasound is used to assess the effect of ULT, checking for urate deposits, double-contour sign and size of tophi [32]. **Frequency of monitoring** One CPG was unable to determine a optimal time interval for examinations [32]. **Dual energy computed tomography** One CPG was unable to recommend either for or against the use of dual energy computed tomography for follow-up [32].
Special populations
Solid organ transplant One CPG was unable to determine the most effective and safest treatment option for people with gout who have received a solid organ transplant [32]. These patients can have specialist input from nephrology, hepatology, and rheumatology units with experience in these cases [32].

CPG – clinical practice guideline; sUA – serum uric acid; ULT – urate lowering therapy; XOI – xanthine oxidase inhibitor.

Appendix I. What Are the Core Recommendations for Rheumatoid Arthritis Care? Systematic Review of Clinical Practice Guidelines: Supplementary Materials

I.1 Search Strategy

Medline

1. guideline*.ti,pt,kw.
2. Practice Guideline/ or Guideline/
3. 1 or 2
4. (arthriti* or osteoarthriti* or lupus or gout).mp.
5. exp arthritis/ or exp Lupus Erythematosus, Systemic/ or Gout/
6. 4 or 5
7. 3 and 6
8. limit 7 to (english language and yr="2015 - 2020")

CINAHL

1. MH Practice Guidelines OR TI guideline* OR PT Practice Guidelines
2. MH arthritis+
3. MH Lupus Erythematosus, Systemic+
4. MH Gout
5. (arthriti* or osteoarhriti* or lupus or gout)
6. S2 OR S3 OR S4 OR S5
7. S1 AND S6
8. S1 AND S6 limit to 2015-2020 and english

EMBASE

1. Guideline*.ti,kw.
2. *practice guideline/
3. 1 or 2
4. (arthriti* or osteoarthriti* or lupus or gout).ti,ab,kw.
5. exp *arthritis/
6. exp *systemic lupus erythematosus/
7. *gout/
8. 4 or 5 or 6 or 7
9. 3 and 8
10. limit 9 to conference abstracts
11. 9 not 10
12. limit 11 to (english language and yr="2015 - 2020")

PEDRO

1. Abstract and title: Osteoarthritis
2. Abstract and title: Rheumatoid arthritis
3. Abstract and title: Lupus / SLE
4. Gout

Method	Practice guideline
When searching	Match all terms with and
Published since	2015

I.2 Description of Clinical Practice guidelines

Title	Year	Type of developer	Country/ Region of Origin	Format	Informed by CPG quality tool	Accompanying documents accessed	Guideline topic	Target users
ACR [48]	2021	Medical Society	USA	Journal article	Yes	Appendix 1-6	Pharmacological treatment of patients with RA	Health care providers and patients with RA.
APLAR [45]	2015	Medical Society	International - Australia, Indian, Japan and New Zealand	Journal Article	Yes	Nil	RA management practices in the AP region.	Rheumatologists and all practitioners who manage RA.
BSR [42]	2018	Medical Society	Brazil	Journal Article	No	Additional file 1	Drug treatment of adults with RA in Brazil.	Brazilian rheumatologists, physicians.
CRA [51]	2022	Medical Society	Canada	Journal article	Yes	Supplementary Material	Pharmacological management of RA with disease-modifying anti-rheumatic drugs for adult patients. This includes patients whose RA began in childhood or adolescence as juvenile idiopathic arthritis and has persisted into adulthood.	Rheumatologists or other primary prescribers of RA medications, patients, in community and academic practice settings. May also be of interest to other provincial and federal RA stakeholders and decision makers.
EULAR [50]	2023	Medical Society	Europe	Journal article	Yes	N/A	Management with synthetic and biological disease-modifying antirheumatic drugs.	Rheumatologists, health professionals, patients, regulators, payers.

ISR [4]	2019	Medical Society	Europe - Italy	Journal Article	Yes	Nil	Management and safety of adult patients with RA in Italy.	Attending physicians (general practitioners, rheumatologists) and health professionals who manage patients with RA in primary care, and hospital and community practice settings. Patients, policy makers and those responsible for commissioning care for patients with RA in the Italian National Health Service (NHS).
Malaysia Health Technology Assessment Section [43]	2019	Medical society	Malaysia	Report	Yes	N/a	Diagnosis, investigations, treatment (non-pharmacological and pharmacological), special considerations and referral/follow-up for patients with RA.	Those who are involved in primary, secondary or tertiary care management of RA: Doctors, allied health professionals, trainees and medical students, policy makers, patients and their advocates and professional societies.
NICE [44]	2018	Government	UK	Report	Yes	Appendices Methods document Online development materials (e.g. implementation support, resource impact, summaries etc)	Diagnosing and managing RA in adults (people who are aged 18 or older).	Healthcare professionals, commissioners and providers, people with RA and their families and carers.
Peter et al. [49]	2021	Medical Society	USA	Journal article	Yes	Appendix document Supplementary figure	Physical therapy management for patients with RA	Physical therapists.
Santos et al. [47]	2021	Medical Society	Europe - Portugal	Journal article	Yes	Umbrella review	Management of patients with RA	Health professionals.
SER [41]	2019	Medical Society	Europe - Spain	Report	Yes	Nil	Management of adults with RA	Rheumatologists and other health professionals who may be involved in the care of patients with RA working in primary and specialist care, namely, those from the specialities of cardiology, pulmonology, traumatology, rehabilitation, family medicine, and nursing, as well as

								other specialists involved in the care for these patients. Patients and family members seen by these health professionals.
Tenten-Diepenmaat et al. [46]	2018	Expert panel	Europe – The Netherlands	Journal article	Yes	Additional files 1-3 Research questions Diagnosis framework Treatment framework	Multidisciplinary recommendations and frameworks for the diagnosis and treatment of foot problems in people with RA.	Health professionals who provide footcare for patients with RA e.g. rheumatologists, rehabilitation physicians, orthopaedic surgeons, specialised nurses, podiatrists, orthopaedic shoe technicians and pedicurists.
TLAR [8]	2018	Expert Panel	Europe - Turkey	Journal Article	No	Nil	Management of RA in Turkey.	Turkish rheumatologists and physical medicine and rehabilitation specialists.

*First author given where there is no stated organisation; ACR – American College of Rheumatology; APLAR – Asia Pacific League of Associations for Rheumatology; BSR – Brazilian Society of Rheumatology; CRA – Canadian Rheumatology Association; EULAR - European League Against Rheumatism; ISR – Italian Society of Rheumatology; NICE - National Institute for Health and Care Excellence; RA – Rheumatoid arthritis; SER – Spanish Society of Rheumatology; TLAR – Turkish League Against Rheumatism; USA – United States of America; UK – United Kingdom.
Adults are defined as: ≥18 years of age.

I.3 Clinical Practice Guideline AGREE II Domain Scores and Quality Assessment (%) Excluded Studies

	Domain 1 Scope and Purpose	Domain 2 Stakeholder involvement	Domain 3 Rigour of development	Domain 4 Clarity of presentation	Domain 5 Applicability	Domain 6 Editorial independence	Overall assessment score	Domain 2,3,6 combined value
Removed based on newer versions have been published and included (3)								
ACR (2016) [38]	81	83	81	83	52	58	75	74
EULAR (2017) [39]	78	56	73	86	19	67	75	65
EULAR (2019) [40]	75	69	81	92	27	58	67	70
Removed based on low-quality (11)								
APLAR (2019) [28]	56	36	51	72	8	21	33	36
BSR [34]	64	36	32	67	15	17	25	28
FSR [29]	42	56	40	75	48	13	33	36
*García-Vicuna R, et al. [32]	67	31	52	67	8	38	42	40
JCR [37]	33	19	9	64	17	58	33	29
KAR [30]	69	64	46	86	40	50	42	53
*Lin et al. [36]	33	31	51	22	2	25	25	36
MCR [31]	50	22	42	78	46	67	42	44
SER (2015) [33]	53	42	33	78	33	17	42	31
TRA (2017) [27]	72	44	57	72	23	46	50	49
TRA (2017) bDMARDs/tsDMARDs [35]	50	31	35	69	17	29	42	32

*First author given where there is no stated organisation; ACR – American College of Rheumatology; APLAR – Asia Pacific League of Associations for Rheumatology; bDMARDs – biologic disease-modifying anti-rheumatic drugs; BSR – Brazilian Society of Rheumatology; EULAR – European League Against Rheumatism; JCR – Japan College of Rheumatology; ISR – Italian Society of Rheumatology; MaHTAS – Malaysia Health Technology Assessment Section; NICE - National Institute for Health and Care Excellence; SER – Spanish Society of Rheumatology; TLAR – Turkish League Against Rheumatism; TRA - Thai Rheumatism Association; tsDMARDs – targeted synthetic disease-modifying anti-rheumatic drugs; FSR – French Society for rheumatology; KAR - Kuwait association of rheumatology; MCR - Mexican College of Rheumatology; SER – Spanish Society of Rheumatology.

I.4 Classification of Rheumatoid Arthritis Recommendations

Non-pharmacological recommendations

	ACR (2021) [48]	APLAR [45]	BSR [42]	CRA [51]	EULAR (2023) [50]	ISR [4]	MaHTAS [43]	NICE [44]	Peter et al. [49]	Santos et al. [47]	SER [41]	Tenten-Diepenmaat et al. [46]	TLAR [8]
Non-Pharmacological interventions										✓✓			
Patient education			✓✓				✓✓	✓✓	✓	✓✓	✓✓	✓✓	
Patient centered care/ Shared decision making	✓✓	✓✓	✓✓		✓✓			✓✓		✓✓		✓✓	✓✓
Exercise							✓✓	✓	✓✓	✓✓		✓✓ (General) ✓ (Foot & Ankle)	
Diet and complementary therapies								✓ Mediterranean diet O Replace evidence-based therapies O Impact clinicians' attitudes					
Other non-pharmacological management strategies (e.g. manual therapy, psychological and social interventions)									O ✓ Short term mobilisation O Cervical problems	✓			
Over-the counter shoes												✓✓ Sufficient room toe box and stiff sole ✓ Additional features	
Ready-made therapeutic shoes								✓✓				✓	
Custom-made therapeutic shoes												✓✓ Worn all day after a	

												habituation period ✓ Shoes	
Foot orthoses								✓✓		✓✓		✓✓	
Rigid foot orthoses												✓✓	
Total contact foot orthoses												✓✓	
Silicone toe orthosis												✓	
Toenail brace												✓	
Multi-disciplinary team			✓✓				✓	✓✓		✓✓		✓✓	✓✓
Nursing							✓✓	✓✓			✓✓	✓✓	
Physiotherapy								✓✓	✓✓				
Occupational therapy								✓✓					
Podiatry								✓✓					
Psychological								✓✓		✓✓			
Rheumatologist			✓✓		✓✓		✓✓	✓✓				✓✓	✓✓
Supervised program											✓		

✓✓Should do; ✓ Could do; O Do not do.

ACR – American College of Rheumatology; APLAR – Asia Pacific League of Associations for Rheumatology; BSR – Brazilian Society of Rheumatology; CRA – Canadian Rheumatology Association; EULAR – The European League Against Rheumatism; Example; ISR – Italian Society of Rheumatology; MaHTAS – Malaysia Health Technology Assessment Section; NICE – National Institute for Health and Care Excellence; SER – Spanish Rheumatology Society; TLAR – Turkish League Against Rheumatism.

Pharmacological recommendations interventions

	ACR (2021) [48]	APLAR [45]	BSR [42]	CRA [51]	EULAR (2023) [50]	ISR [4]	MaHTAS [43]	NICE [44]	Peter et al. [49]	Santos et al. [47]	SER [41]	Ten ten-Diepenmaat et al. [46]	TLAR [8]
Pharmacological interventions										✓			
Early initiation of DMARDs					✓✓								✓✓
Initial treatment with conventional synthetic disease modifying antirheumatic drugs (csDMARDs)													
csDMARDS (first-line)	✓ Initiation of a csDMARD without short-term GCs(<3 months) OR ✓✓ without longer-term (≥3 months) GCs	✓✓ Monotherapy	✓✓ Monotherapy		✓✓ Monotherapy	✓✓	✓✓ Monotherapy	✓✓ Monotherapy			✓✓ one or several (with GCs)		✓✓ Mono-therapy
Selection of csDMARDs													
Methotrexate (MTX)	✓✓ and ✓ MTX vs other pharmacological options ✓ MTX oral ✓ Switching to subcutaneous	✓✓ First line	✓✓ First line		✓✓ First line	✓✓ First line	✓✓ First line	✓✓ First line			✓✓ First line		✓✓ First line

	✓ MTX 15 mg per week ✓ A split dose of oral methotrexate												
Leflunomide (LEF), sulfasalazine (SSZ) and hydroxychloroquine (HCQ)	✓ HCQ ✓ SSZ	✓ LEF, SSZ or HCQ	✓✓ MTX with LEF or HCQ and SSZ OR switching MTX for another csDMARD (LLF or SSZ) alone		✓✓ LEF and SSZ	✓✓ LEF and SSZ		✓✓ LEF and SSZ ✓ HCQ alternative if mild or palindromic disease			✓✓ LEF + Biologic		✓✓ LEF SSZ
csDMARDs (second-line)		✓✓ Combination therapy MTX and other csDMARD or bDMARDs ✓✓ Triple therapy with cDMARDs	✓ Combination therapy		✓✓ Combination therapy	✓✓ other csDMARDs		✓✓ Combination therapy			✓ Combination csDMARDs or bDMARD O Triple therapy initially ✓ Triple therapy if GCs are contraindicated		✓✓ Combination therapy
Treatment if csDMARD fails													

Biologic disease-modifying anti-rheumatic drug (bDMARD) Targeted synthetic disease-modifying antirheumatic drug (tsDMARD)	✓ Switch to bDMARD or tsDMARD different class ✓ addition of these over triple therapy	✓ bDMARD (inadequate response or intolerance csDMARD) ✓ Early consideration for active disease with poor prognostic factors ✓✓ bDMARDs + MTX ✓✓ switch bDMARD at 6 months if failed to achieve treatment target	✓ bDMARD or tsDMARD + csDMARD (preferably bDMARD +MTX) ✓ Failure of an initial treatment scheme with bDMARD, swap to another bDMARD ✓✓ consider safety and cost of each bDMARD		✓✓ bDMARD ✓✓ bDMARD or tsDMARD + csDMARD ✓✓ bDMARD or tsDMARD failure, swap to another bDMARD or tsDMARD	✓✓ bDMARD or tsDMARD ✓✓ bDMARD or tsDMARD failure, swap to another bDMARD or tsDMARD	✓✓ bDMARD and tsDMARD ✓ bDMARD effective alternative to csDMARD				✓✓ bDMARD or tsDMARD ✓✓ bDMARD + LEF ? Specific biological agent ✓ biologic has failed bDMARD or tsDMARD		✓✓ bDMARD or tsDMARD + csDMARD ✓✓ bDMARD first line ✓✓ if failure, swap to another bDMARD or tsDMARD
Janus kinase inhibitor		✓ Tofacitinib	✓ Tofacitinib		✓	✓					✓		
TNF-inhibitor			✓		✓	✓							✓
non-TNF biologic						✓					✓		
Interleukin (IL)-6 inhibitors					✓ IL-6 inhibitors or tsDMARDs over other bDMARDs						✓✓		✓ IL-6 inhibitors or tsDMARDs over other bDMARDs
Anakinra								O					

								✓ Controlled long term clinical study					
Treatment Targets													
Treatment goal	✓✓ Treat-to-target approach who have not been previously treated with bDMARDs or tsDMARDs ✓ Treat-to-target approach who have had an inadequate response to bDMARDs or tsDMARDs ✓ Low disease activity goal	✓✓ Remission or low disease activity ✓✓ Quality of life and maintaining physical functioning	✓✓ Remission or low disease activity		✓✓ Remission or low disease activity		✓✓ Treat-to-target strategy ✓✓ Remission or low disease activity	✓✓ Treat-to-target strategy ✓✓ Remission or low disease activity ✓ Target remission for people with presence of anti-CCP antibodies or erosions on X-ray at baseline assessment		✓✓ Maximising their overall quality and enjoyment of life, through optimized control of the impact of disease			✓✓ Remission or low disease activity
Monitoring													
Monitoring	✓✓ Re-evaluate treatment decisions within 3 months based on efficacy and	✓✓ 1-3 months (recently diagnosis or active disease) ✓ 3-6 months (remission or low disease activity) ✓✓ A suitable and practical standardized			✓✓ 1-3 months			✓✓ Ongoing medication monitoring ✓ Review appointment at 6 months after achieving		✓✓ Validated instrument for monitoring			

	tolerability of the DMARD(s) chosen.	measure of disease activity ✓✓ Safety monitoring on bDMARD therapy						treatment target ✓✓ Annual review O Ultrasound routinely					
Tapering													
Tapering	✓ Continuing DMARDs at current dose rather than tapering ✓ Dose reduction>gradual discontinuation ✓ Gradual discontinuation> abrupt discontinuation ✓ Gradual discontinuation of SSZ >HCQ (if triple therapy) ✓ Gradual discontinuation of MTX > bDMARD or tsDMARD	✓✓ In patients who have achieved remission, a reduction in treatment should be considered ✓ 6 months remission - corticosteroids and NSAIDs tapered ✓ 6 to 12 months after discontinuation of NSAIDs, corticosteroids and bDMARDs, gradual reduction in cDMARDs	✓ Taper bDMARD	✓ In patients who have sustained low disease activity or remission for 6 months Tapering bsDMARDs and tsDMARDs O If rapid access to care or re-establishing access to medications is challenging	✓ Taper GCs Then dose reduction of DMARDs (bDMARDs/tsDMARDs* and/or csDMARDs)	✓✓ Sustained remission reduce treatment ✓ bDMARDs or tsDMARDs tapering then ✓ cDMARD tapering		✓ Reducing drug doses or stopping drugs in a step-down strategy at 12 months w/o glucocorticoids			✓✓ 6 months remission progressively taper biologic dose		✓ Tapering GC's (if using csDMARDs) ✓ Tapering bDMARDs ✓ Tapering cDMARDs if persistent remission
Adjunctive therapy													
Non-steroidal anti-		✓✓ Lowest dose, short-term					✓	✓					

inflammatories (NSAIDs)													
Glucocorticoids (GCs)	✓ Addition of or switching to DMARD > continuation of GCs or over the use of intraarticular GCs alone	✓✓ Prednisolone ✓✓ Lowest possible dose and tapered as rapidly as clinically feasible ✓ Oral corticosteroids Active RA in combination with cDMARDs O Oral corticosteroid monotherapy	✓✓ Short-term ✓✓ Consider risk-benefit ratio		✓✓ Short-term	✓ Short-term ✓✓ Intra-articular glucocorticoid injections	✓ Short-term	✓ Short-term ✓ Long-term if complications have been discussed and other treatment options have been offered			✓✓ Prednisolone (+ one or several csDMARDs)	✓	✓✓ Short-term use if csDMARD initiation or change
Pre-treatment investigations													
Pre-treatment investigations		✓✓					✓✓						

Vaccinations		✓✓ All vaccines ideally, especially live vaccines 4 weeks prior to bDMARD O Live vaccines whilst being treated with bDMARD	✓✓ Update of record			✓✓ All vaccines ideally 4 weeks prior to starting tsDMARD or bDMARD therapy ✓✓ Killed and recombinant vaccines before initating or during therapy with csDMARDs, tsDMARDs, bDMARDs O Live vaccines whilst being treated with bDMARD or tsDMARD							

✓✓Should do; ✓ Could do; ? Uncertain; O Do not do; > rather than.

ACR – American College of Rheumatology; Anti-CCP – Anti-cyclic citrinullated peptide; APLAR – Asia Pacific League of Associations for Rheumatology; BDMARDs – biologic disease-modifying anti-rheumatic drug; BSR – Brazilian Society of Rheumatology; csDMARDs – conventional synthetic disease-modifying anti-rheumatic drug; DMARD – disease-modifying anti-rheumatic drug; EULAR – The European League Against Rheumatism; GCs – glucocorticoids; HCQ – hydroxychloroquine; IL – Interleukin (IL); ISR – Italian Society of Rheumatology; LEF – leflunomide; MaHTAS – Malaysia Health Technology Assessment Section; MTX – methotrexate; NICE – National Institute for Health and Care Excellence; NSAIDs – non-steroidal anti-inflammatories; SER – Spanish Rheumatology Society; SSZ – sulfasalazine; TLAR – Turkish League Against Rheumatism; tsDMARDs – targeted synthetic disease-modifying antirheumatic drugs.

Special populations recommendations

	ACR (2021) [48]	APLAR [45]	BSR [42]	CRA [51]	EULAR (2023) [50]	ISR [4]	MaHTAS [43]	NICE [44]	Peter et al. [49]	Santos et al. [47]	SER [41]	Tenten-Diepenmaat et al. [46]	TLAR [8]
Interstitial lung disease											✓✓Abatacept ✓ Rituximab ? Interstitial pneumonia medications		
Infections	✓ Addition of csDMARDs ✓ Addition of/switching to DMARDs	O bDMARD									✓✓ Abatacept or Etanercept		
Foot conditions												✓✓ Fungal nail or mycosis - treatment prevent ulcers and secondary bacterial infections ✓✓ Hyperkeratotic lesions - Normalisation of pressure and shearing forces ✓✓ Excessive hyperkeratotic lesions treated ✓✓ Pre-ulcer or infection is detected, consult the treating physician ✓ Applying a provisional therapy (e.g., felt padding) in wound care	

Cancer						✓ csDMARDs rather than tsDMARDs or bDMARDs Previously treated Lymphoproliferative disorders ✓ Rituximab ✓ Combination of csDMARDs or Abatacept or Tocilizumab ✓ Previously treated solid organ malignancy, same response as those without this condition					✓✓ Biological therapy on a case-by-case basis ? No evidence for a specific biologic		
Tuberculosis		✓✓ Screening ✓✓ Latent TB - prophylactic anti-TB therapy ✓✓ Active TB - adequate treatment before bDMARD				✓✓ Screening ✓✓ If positive TST or IGRA - further investigations ✓ If negative, no further workup ✓✓ Annual testing for at risk areas ✓✓ Active or latent TB, appropriate anti-tubercular treatment ✓ Referral to specialist ✓ tsDMARDs or bDMARDs following treatment and 1 month of latent TB							
Hepatitis	✓✓ Prophylactic antiviral therapy vs frequent monitoring ✓ Frequent monitoring alone of viral load and liver enzymes	✓✓ Screened for TB, and HBV and HCV infections before initiating bDMARD therapy O Avoid bDMARDs if pt active or untreated chronic HBV infection and active HCV infection				✓✓ Screened before bDMARD and tDMARD ✓✓ AntiHBcAb positive or HBsAg negative should undergo further evaluations ✓✓ HBsAg positive should undergo further evaluations ✓✓ Active HBV treated entecavir or tenofovir ✓✓ Acute HB receive antiviral ✓✓ Inactive HBV carriers prophylaxis 4 weeks before immunosuppressive ✓✓ Patients stopping prophylaxis should be closely monitored							

Pregnancy and lactation		✓✓ only consider bDMARDs after assessing benefits/risks											
Nontuberculous mycobacterial lung disease	✓ Lowest possible dose of GCs (discontinuation if possible) ✓ Addition of csDMARDs ✓ Abatacept												
Pulmonary disease	✓ MTX												
Congestive heart failure (CHF)	✓ Non–TNF inhibitor bDMARD or tsDMARD ✓ Switching to a non–TNF inhibitor bDMARD or tsDMARD vs TNF inhibitor					✓ Use combinations of csDMARDs or non TNF biologic or tsDMARDs over TNFi ✓ CHF worsening on current TNFi therapy: Use combination DMARDs on non-TNF or tsDMARDs over another TNFi							
Cardiovascular disease (CVD)						✓✓ Risk assessment every 5 years ✓✓ CVD risk prediction models should be adapted ✓ Screening for asymptomatic atherosclerotic plaques ✓✓ Lifestyle recommendations ✓ Antihypertensives and statins ✓✓ Use caution when prescribing NSAIDs							
Non-alcoholic fatty liver disease	✓ MTX vs alternative DMARDs												

Persistent hypogammaglobulinemia without infection	✓ Rituximab												
Subcutaneous nodules	✓ MTX vs alternative DMARDS ✓ Switching to a non-MTX DMARD over continuing MTX												
Lymphoproliferative disorder	✓ Rituximab												

✓✓Should do; ✓ Could do; ? Uncertain; O Do not do.

ACR – American College of Rheumatology; APLAR – Asia Pacific League of Associations for Rheumatology; BDMARDs – biologic disease-modifying anti-rheumatic drug; BSR – Brazilian Society of Rheumatology; CRA – Canadian Rheumatology Association; CVD – Cardiovascular disease; csDMARDs – conventional synthetic disease-modifying anti-rheumatic drug; DMARD – disease-modifying anti-rheumatic drug; EULAR – The European League Against Rheumatism; HBV – Hepatitis B virus; HCV – Hepatitis C virus; IGRA – Interferon gamma release assay test; ISR – Italian Society of Rheumatology; MaHTAS – Malaysia Health Technology Assessment Section; NICE – National Institute for Health and Care Excellence; SER – Spanish Rheumatology Society; TB – Tuberculosis; TLAR – Turkish League Against Rheumatism; TNF – Tumour necrosis factor; TNF-i – Tumour necrosis factor inhibitor; tsDMARDs – targeted synthetic disease-modifying antirheumatic drugs; TST – Tuberculin Skin Test.

Surgical recommendations

	ACR (2021) [48]	APLAR [45]	BSR [42]	CRA [51]	EULAR (2023) [50]	ISR [4]	MaHTAS [43]	NICE [44]	Peter et al. [49]	Santos et al. [47]	SER [41]	Tenten-Diepenmaat et al. [46]	TLAR [8]
Refer for surgical opinion								✓✓ Suspected persistent synovitis of undetermined cause, negative anti-cyclic citrullinated peptide antibodies or rheumatoid factor, the small joints of the hands or feet are affected, > more than one joint is affected, there has been a delay of 3 months or longer between onset of symptoms and seeking medical advice ✓✓ Do not respond to optimal non-surgical management: Persistent pain, worsening joint function, progressive deformity, persistent localised synovitis ✓ (Imminent or actual tendon rupture, nerve compression, stress fracture)				✓✓ Do not response to conservative treatment.	
Education on surgical benefits								✓✓					
Medical and surgical management								✓✓ (Suspected or proven septic arthritis)					
Magnetic resonance imaging and surgical referral								✓✓ (Cervical myelopathy)					
Joint replacement surgery for younger adults								✓					
Lower limb surgical interventions												✓ Resection arthroplasty of the MTP joints ✓ Arthrodesis of the MTP1 joint ✓✓ Arthrodesis of the subtalar joint and/or arthrodesis of the calcaneocuboid joint and talonavicular joint ✓ Arthrodesis of the tibiotalar joint or an ankle prosthesis	

✓✓Should do; ✓ Could do.

ACR – American College of Rheumatology; APLAR – Asia Pacific League of Associations for Rheumatology; BSR – Brazilian Society of Rheumatology; CRA – Canadian Rheumatology Association; EULAR – The European League Against Rheumatism; ISR – Italian Society of Rheumatology; MaHTAS – Malaysia Health Technology Assessment Section; MTP – Metatarsophalangeal; NICE – National Institute for Health and Care Excellence; SER – Spanish Rheumatology Society; TLAR – Turkish League Against Rheumatism.

I.5 Narrative Synthesis of CPG Recommendations

This table is a synthesis of Gout CPG recommendations. A common consensus statement was identified when two or more CPGs reported on an intervention. Consensus statements were either: ‘should do’, ‘could do’, ‘do not do’ or ‘no consensus’. Where one CPG reported on an intervention, no consensus statement was developed (Table 5).

Non-pharmacological management interventions narrative summary

Management interventions	Narrative Summary
Patient education	Six CPGs strongly recommended [41-44, 46, 47] and one CPG conditionally recommended [49] patient education for people with rheumatoid arthritis (RA). Educational programs [41, 44, 47] and supporting materials [47] should be offered as verbal and written information, that is written in a way that can be easily understood [44]. These programs should be based on a trusting therapeutic relationship between the patient and clinician, to improve patient adherence to treatment modalities [41]. Throughout the course of their disease, clinicians should offer patients the opportunity to talk about and agree all aspects of their care and respect the decisions they make [44]. Information and advice can be individualised for each patient, and include information to support self-management and optimising health and well-being [49]. Content should include: - General aspects of the disease [47, 49] to improve the patients understanding of RA [44]. - Possible consequences of RA [49]. - Management options [44, 47, 49] - Risks and benefits of treatment options [44]. - Patients’ role in the shared-care process [47]. - Common assessments and interventions [47]. - Countering any misconceptions they may have [44]. - Counselling on lifestyle habits [42]; mentioning the importance of exercise and a healthy lifestyle (including decreasing stress and fatigue) and how this lifestyle can be achieved and maintained [49]. - Information about how and when to access specialist care [44]. The following information should be included for those who experience hand or foot RA-related symptoms: - Joint protection advice with hand strengthening and mobilisation exercises [43]; - Individual shoe-advice e.g. information on fit, cosmetics, function, durability and correct use of the shoes [46]. - Preventive foot care [46]. - Cause and disease course of RA-related foot disease [46]. - How to recognise infection and increased disease activity (systemic and local) [46].

	- Footcare and hygiene [46]. - Recognition and use of adequate footwear [46]. - Encourage a timely consultation by a healthcare professional if sign/symptoms of a foot infection, increased disease activity, pain, problems finding adequate footwear, and skin and nail conditions; and who would be the appropriate healthcare professional [46]. - Treatment plan in relation to footcare [46]. - The importance of treatment adherence and compliance [46]. - The expected treatment outcomes in relation to pain, physical functioning, activities, and participation levels [46]. - Possible adverse events [46]. - Costs and reimbursement of the treatment [46]. Consensus: Patient education should be included as a standard practice of care. Information can be delivered either as verbally or written and content should include: information on RA, its management options (benefits and risks), common assessments and address patients beliefs about RA and its care.
Patient centered care (PCC)/ Shared decision making	Eight CPGs strongly recommended care should be patient centered and shared decision making [8, 42, 44-48, 50]. The clinician should provide information and/or clarification about the disease, including the short and long-term outlook of the disease [47] and the available therapeutic options [42, 47], then both patients and clinicians should follow a shared decision-making process [8, 42, 45-48]. Clinicians should respect patients decisions regarding RA care [44]. A treatment option should be started once the patient is diagnosed [45] and should be tailored to the individual patient [46] circumstances. These include: disease activity [8, 50] and/or poor prognosis [45], comorbidities [8, 45, 50], progression of structural damage [8, 50], clinical features, abilities, preferences and needs [47]. Interventions should be targeted to specific individualised goals, regularly monitored with validated instruments and adapted accordingly [47]. Safety of medications [42, 50], individual [8, 50], medical and societal costs should be taken into consideration [8, 42, 50], especially when medications report a similar efficacy [42]. Consensus: Patients and clinicians should adhere to a shared decision-making process and care should be tailored to the patient and their circumstances.
Exercise	Four CPGs strongly recommended [43, 46, 47, 49] and two CPGs conditionally recommended [44, 46] exercise therapy for people with RA. All patients should follow a regular physical exercise program to reduce pain, functional disability, fatigue and global impact of disease [47]. This included ‘general’ exercise therapy [46, 47], hydro-kinesiotherapy [47], and joint specific programs. **Hand and wrist programs** Two CPGs supported hand exercises programs [43, 44]. One CPG recommended a combination of joint protection advice with hand strengthening and mobilisation exercises [43]. Whilst the other CPG supported a tailored strengthening and stretching program, delivered by a practitioner with relevant skills and training [44]. Interestingly, the CPG recommended that an exercise program can be considered if people experience hand or wrist pain and dysfunction and they are not on a drug regimen for RA, or they have been on a stable drug regimen for RA for at least 3 months [44].

	Foot and ankle programs Exercise therapy specific to the foot and ankle can include: strengthening exercises for the intrinsic foot muscles and M. tibialis posterior, active stretching exercises for the plantar fascia, achilles-tendon, and peroneal muscles and active exercises to improve joint mobility [46]. One CPG recommended that physiotherapists (PTs), classify patients with RA into one of 3 treatment profiles based on the initial assessment [49]: 1. A short period of education, advice, and exercise/movement instruction. Exercises can be offered and are to be completed primarily independently [49]. 2. A short period of guidance and supervision in addition to 1, e.g., due to the complexity or severity of problems or limited self-management skills. Exercise therapy should be offered [49]. 3. Intensified guidance and supervision in addition to 1, e.g., due to the presence of serious comorbidity or complications of the disease or its treatment. Exercise therapy can be offered [49]. Regardless of the treatment profile, exercise therapy recommendations should be aligned with the patient's need for assistance, and adhere to the principles regarding the frequency, intensity, type, and duration of the exercise therapy [49]. Consensus: Exercise therapy should be offered to all patients with RA, and tailored to individual patient circumstances. Modalities can include general exercise therapy, hydro kinesiotherapy and joint specific programs; comprising of strengthening, stretching and joint mobility exercises.
Other non-pharmacological management strategies	One CPG conditionally recommended non-pharmacological interventions can be included as part of standard care, as an adjunctive or as an alternative to medication or surgery where appropriate [47]; they can only be considered if there is no evidence based supported alternative, if they have consensual approval by qualified health professionals and they are safe and accepted by a duly informed patient [47]. Examples include: pain relief, energy management, joint alignment and support, thermotherapy, psychological interventions, daily leisure and work activities, family involvement, social participation and social care, sleep hygiene and general management of comorbidities [47]. Whilst one CPG recommended against offering low-level laser therapy, electrostimulation (including transcutaneous electrical nerve stimulation), ultrasound, massage, thermotherapy, medical taping, dry needling and passive mobilisations of joints and muscles [49]. They conditionally recommended for short-term passive mobilisation of an affected joint only as an adjunct to exercise therapy for patients without active inflammation to increase joint mobility and recommended against for patients with cervical problems [49]. Consensus: No consensus.
Shoes	
Ready-made therapeutic shoes	One CPG strongly recommended and one CPG conditionally recommended therapeutic footwear for patients with RA if indicated [44, 46]. One CPG recommended ready-made therapeutic shoes in cases of abnormal foot function, foot joint damage/deformity, or malalignment of the feet, and their feet that do not fit in over-the-counter shoes, but for whom custom-made shoes are not indicated [46]. These shoes should have extra depth, support, incorporated inlays, and optional technical adaptation can reduce forefoot plantar pressure and foot pain and improve gait characteristics, physical functioning, and health-related quality of life [46]. Consensus: Ready-made therapeutic shoes can be considered for patients with RA.
Orthoses and Braces	

Orthoses	Three CPGs strongly recommended foot orthoses [46, 47]/functional insoles [44] for people with RA with abnormal foot function, when adequate over-the-counter shoes are insufficient in reducing foot symptoms such as: forefoot plantar pressure and pain. The function of foot orthoses should be assessed in relation to the patient's footwear [46]. Foot orthoses can reduce pain, functional disability and global impact of disease [47]. Consensus: Orthoses should be offered to patients with RA, and abnormal foot function, where over the counter shoes have been insufficient in symptom relief.
Health professionals	
Multi-disciplinary team	Five CPGs strongly recommended [8, 42, 44, 46, 47] and one conditionally recommended [43] patients should have a multi-disciplinary team [42, 44, 46, 47], with a named member who is responsible for coordinating their care [44]. The team should: - Conduct regular assessments of the patients pain levels, fatigue, impact on daily life activities, mobility, ability to work or take part in social or leisure activities, quality of life, mood and impact on sexual relationships [44]. - Provide relevant information for the patient to be involved in the shared decision-making process, including the disease prognosis and of the available scope of treatment interventions [47] (non-pharmacological and pharmacological); adopting a holistic bio-psycho-social view to health [47]. - Select interventions relevant to the patient and encourage adherence [47]. - Focus on prevention and management of comorbidities and adverse effects [47]. - Patients should be regularly inquired for unmet needs, using validated large-scope instruments, and referenced to the most appropriate health professional(s) in the team [47]. A multi-disciplinary team approach is needed to diagnose and manage RA-related foot problems, as this often requires the expertise of several disciplines [46]. One CPG recommended that rheumatologists, physical medicine and rehabilitation specialists are the main clinicians responsible for RA care [8]. Consensus: All patients should be offered a multi-disciplinary team approach to care.
Nursing	Four CPGs strongly recommended nurses [41, 43, 44, 46], who specialised in rheumatology are included in the care team [46]. Nursing staff can lead coordination of the care [43, 44], deliver ongoing, specific individual or group educational programmes [41] and/or perform regular feet check-ups [46]. Check-ups should include a patient history of foot disease, foot inspection, and palpation of foot joints for the detection of swelling and pain at a minimum [46]. Consensus: Nursing staff should be included in the multi-disciplinary team. Their role includes coordinating patient care, delivering education programs and performing regular feet check-ups if relevant.
Physiotherapy	Two CPGs strongly recommended PTs should be offered to all patients with RA [44, 49] with periodic review [44]. Their role is to encourage improving general fitness [44] and exercise therapy [44, 49] with joint flexibility and muscle strengthening exercises and managing other functional impairments [44]. Education of the short-term pain relief of passive treatment modalities such as transcutaneous electrical nerve stimulators should be provided to patients [44]. PTs should perform a comprehensive subjective assessment of the patient's health status, the course of the disease and its current impact on the patient's life and previous and current pharmacological treatment [49]. They should then perform an objective assessment exploring current disease activity (extent and severity of joint pain, swelling, and limited joint ROM), the presence of structural joint damage and deformities, general exercise tolerance, and muscle function during physical examination, including examination of the cervical spine and the jaw joints [49]. PT should

	use measurement tools to assist with diagnosis and evaluating treatment, it is recommended to combine a self-reported questionnaire and a performance based test to examine physical functioning [49]. The following are examples of outcome measures that should be used [49]: - Numeric Rating Scale for fatigue - Numeric Pain Rating Scale - Borg Rating of Perceived Exertion Scale (Borg RPE scale 6-20) - Dutch Consensus Health Assessment Questionnaire Disability Index - Patient-Specific Complaints - Six-Minute Walk Test Consensus: Physical therapy should be offered to all patients, PTs can assist with history taking, assessment and treatment of RA. The main treatment modality that should be encouraged is exercise therapy.
Psychological	Two CPGs strongly recommended offering psychological interventions to patients with RA [44, 47]. Intervention options include: relaxation, stress management and cognitive coping skills (such as managing negative thoughts) [44]. The aim of these is to assist with adjustment to living with their condition [44], help reduce pain, functional disability, fatigue and global impact of disease [47]. Consensus: Psychological interventions should be offered to patients with RA.
Rheumatologist	Six CPGs strongly recommended that a rheumatologist is involved [8, 42-44, 46, 50] in a multi-disciplinary team [42], either as the primary care provider [8, 42] or a co-management plan with healthcare providers [8, 43]. All patients with RA should have rapid access to specialist care [44]. Two CPGs discussed indications for referral to rheumatologists [43, 44], these included: - All patients suspected of having RA [43]. - Suspected persistent synovitis of undetermined cause [44]. - Refer urgently (even with a normal acute-phase response, negative anti-cyclic citrullinated peptide [CCP] antibodies or rheumatoid factor) if: o The small joints of the hands or feet are affected o More than one joint is affected o A delay of 3 months or longer between onset of symptoms and seeking medical advice [44]. Rheumatologists should perform regular feet check-ups [46]. Check-ups should include a patient history of foot disease, foot inspection, and palpation of foot joints for the detection of swelling and pain at a minimum [46]. Consensus: Rheumatologists should be considered in a multi-disciplinary team or as the primary care provider for patients with RA.

CPGs – Clinical practice guidelines; PCC – Patient centered care; PT – Physiotherapy/Physical therapy; RA – Rheumatoid arthritis; RPE – Rating of perceived exertion.

Pharmacological management interventions narrative summary

Management Principles	Narrative Summary
Pharmacological management	
Early initiation of DMARDs	Two CPGs strongly recommended Disease-Modifying Antirheumatic Drug **(**DMARD) therapy is initiated 'soon after' RA diagnosis is made [8, 50]. Consensus: DMARD therapy should begin once a patient is diagnosed with RA.
Initial treatment with csDMARDs	Eight CPGs strongly recommended Conventional Synthetic DMARDs (csDMARDs) [4, 8, 41-45, 50] and one CPG reported a combination of both strong and conditional recommendations [48]. csDMARDs should begin as soon as a person is diagnosed with RA [4, 42, 45], within 3 months of onset of persistent symptoms [44]. Majority of CPGs recommended that monotherapy should be offered in the first instance [41, 45]. Consensus: csDMARDs should be initiated when a patient is diagnosed with RA.
Selection of csDMARDs	**Methotrexate (MTX)** Eight CPGs strongly recommended MTX [4, 8, 41-45, 50], whilst one CPG report a combination of strong and conditional recommendations depending on the context for people with RA [48]. MTX should be used as a first-choice treatment strategy csDMARD [4, 42, 43, 45, 50], unless contraindicated [43-45]. Dosages varied amongst CPGs from at least 10 mg/week [41] (when in combination with anti-TNF agents) to at least 15 mg/week within 4 to 6 weeks [48]. Preferred method was in an oral form, before considering a split dose of oral MTX over 24 hours or subcutaneous injections and/or an increased dose of folic/folinic acid rather than switching to alternative DMARD(s) [48]. MTX monotherapy is recommended over other pharmacological options, for example: other csDMARDs (hydroxychloroquine (HCQ), Leflunomide (LEF), sulfasalazine (SSZ), bDMARD or tsDMARD monotherapy tumour necrosis factor inhibitors (TNFi), Tofacitinib [48] or combination therapies, such as: MTX, plus a TNFi, non–TNF inhibitor, biologic DMARDs (bDMARD) targeted synthetic (tsDMARD), or double or triple csDMARD therapy [48]. Combination therapy (csDMARDs or a bDMARD) can be considered when monotherapy fails [41], despite an escalated dose (as tolerated) [44]. Consensus: Methotrexate monotherapy should be used as a first-choice treatment strategy csDMARD. **LEF, SSZ or HCQ** Five CPGs strongly recommended [4, 8, 41, 42, 44, 50] and three CPGs conditionally recommended [44, 45, 48] LEF, SSZ or HCQ for patients with RA. LEF, SSZ or HCQ should be added in combination with MTX, for patients who haven't achieved treatment target [42, 44]. LEF [4, 8, 41, 42, 45, 50] (with a biologic [41]), SSZ [4, 8, 42, 45, 50] or HCQ [44, 45] should replace MTX, for patients who are contraindicated, exhibit an early intolerance to MTX. Consensus: LEF, SSZ or Hydroxychloroquine should be considered when a patient is contraindicated, demonstrates an early intolerance to or has failed to achieve treatment target with MTX.

Treatment if csDMARD fails	**Combination therapy** One CPG strongly recommended patients have access to several drugs with different modes of action to address the heterogeneity of RA; they may require multiple successive therapies throughout life [50]. Five CPGs strongly recommended [4, 8, 44, 45, 50] and two CPGs conditionally recommended [41, 42] combination therapy of csDMARDs (e.g. double or triple csDMARD [41, 42, 44, 45]) if treatment target is not reached with the first treatment regimen [4, 8, 44, 45], despite dose escalation [44] and in the absence of poor prognostic factors [4, 8, 44, 50] or as first-line therapy [42]. Interestingly, one CPG disagreed, and recommended for patients with poor prognostic factors [45]. MTX should be used an anchor drug, unless contraindicated [42, 45]. One CPG recommended against triple therapy initially, unless Glucocorticoids (GCs) are contraindicated [41]. Combination therapy of csDMARDs should be considered if treatment target is not achieved with csDMARD monotherapy. **bDMARD or tsDMARDs** Three CPGs strongly recommended [4, 8, 50], one CPG conditionally recommended [48] and four strongly and conditionally recommended bDMARDs and tsDMARDs [41-43, 45] depending on the context. A bDMARD and/or tsDMARD addition should be considered [4, 8, 41, 43, 50] if treatment goal cannot be reached with the first treatment regimen [8] or two schemes of csDMARDs [42] and in the presence of poor prognostic factors [4, 8, 50]. Majority of CPGs recommended this is in conjunction with a csDMARD [8, 41, 42, 45, 50], preferably MTX [42, 45]. Adding a bDMARD or tsDMARD can be recommended over triple therapy if maximum dose of MTX is currently being taken [48]. bDMARDs should be recommended in the first instance [8, 28, 42, 43, 50] with no specific bDMARD being preferred over another [41]; clinicians should consider drug cost and safety [42]. Early bDMARD use can be considered in patients who have active disease with poor prognostic factors [45]. If adding a bDMARD or tsDMARD fails to achieve treatment target this should be swapped to another bDMARD or tsDMARD [4, 8, 42, 45, 48, 50] of the same class [42] or with another mechanism of action is effective and safe [42, 48]. Consensus: bDMARD and tsDMARDs should be recommended if csDMARDs fail to achieve treatment target, with a bDMARD being added in the first instance. **Janus kinase inhibitor (JKI)** Five CPGs conditionally recommended for the use of JKI [4, 41, 42, 45, 50]. This can be added to a bsDMARD and tsDMARD if csDMARDs are contraindicated [4, 41] but pertinent risk factors* must be taken into account [50]. Tofacitinib can be used after failure of bDMARD [42, 45]. Consensus: JKI can be recommended in combination with bDMARDs and tsDMARDs if csDMARDs are contraindicated. Tofacitinib can be used after failure of bDMARD. **Tumor necrosis factor inhibitor (TNF-i)** Four CPGs conditionally recommended a TNF-i [4, 8, 42, 50]. A TNF-i can be added to a bDMARD or tsDMARD [4]. If a TNF-i fails, another TNF-i or medication can be added of the same class [42] or with a different mechanism [4, 8, 42, 50]. Consensus: TNF-i can be recommended in conjunction with DMARD therapy.

	Non-TNF Two CPGs conditionally recommended non-TNF [4, 41] in conjunction with MTX [41] or a bDMARD or tsDMARD [4]. If the first non-TNF fails, a second non-TNF agent or a biologic acting on a different therapeutic target, depending on the type of inefficacy and patient characteristics can be added [41]. Consensus: non-TNF can be recommended in conjunction with DMARD therapy. **IL-6 inhibitors** Two CPGs conditionally recommended [8, 50] and one CPG strongly recommended [41] for IL-6 inhibitors. If bDMARDs fail, addition of IL-6 inhibitors or tsDMARDs could be preferred over addition of other bDMARDs [8, 50]. One CPG recommended monotherapy of IL-6 inhibitors rather than an anti-TNF agent if csDMARDs are contraindicated [41]. Consensus: IL-6 inhibitors can be recommended if bDMARDs fail.
Treatment Targets	**Treatment goal and Treat-to-target (T2T) strategy** Treatment should include both non-pharmacological and pharmacological interventions [47] and focus on assisting patients in maximising their overall quality and enjoyment of life [45, 47], through optimized control of the impact of disease [47] and maintaining physical functioning [45]. A treat-to-target strategy is recommended rather than a non-targeted approach [43, 44, 48]. Six CPGs strongly recommended that the treatment goal should be sustained clinical remission or if that is not possible, low disease activity [8, 42-45, 50] within six months of using a treat-to-target strategy [43]. One CPG reported a combination of strong and conditional recommendations depending on the context [48]. Remission can be preferred over low disease activity if a patient has increased risk of radiological progression (presence of anti- cyclic citrullinated peptide antibodies or erosions on x-ray at baseline assessment) [44]. Whilst one CPG argues that low disease activity can be preferred over a goal of remission initially [48]. Consensus: Treatment should be initiated early and aim to improve the patient's quality of life and reduce the impact of disease. The treatment goal should be remission, or if that is not possible than low disease activity and treatment should follow a treat-to-target strategy.
Monitoring	**Frequency** Five CPGs reported on monitoring medications [44, 45, 47, 48, 50]. One CPG recommended treatment is monitored ongoing [44], whilst other CPGs provided time intervals for monitoring based on disease activity. Three CPGs recommended patients should be monitored for disease activity every 1–3 months [45, 50] or within 3 months [48] after initiating treatment or changing treatments until disease is stabilised and treatment target is achieved [45]. If treatment fails to improve the patient's condition in the first 3 months [50], or achieve treatment target by 6 months, therapy should be adjusted [44, 50]. If treatment is stabilised, and target is achieved patients can be monitored every 3-6months [45]. A review appointment should occur at the 6 months post-achieving treatment target to ensure this is maintained [44]. **Assessment/outcome measures**

	A suitable and practical standardised [45] validated measure [47] of disease activity should be routinely performed to assess patients' response to treatment [45]. The following parameters should be used: Safety monitoring for patients who are on bDMARD therapy [45] /ongoing drug monitoring [44]. Examples of validated instruments described within CPGs main text and included: - Disease Activity Score 28 joints (DAS28) [4, 8, 43-45] - Simplified Disease Activity Index (SDAI) [4, 8, 41, 43, 45] - Clinical Disease Activity Index (CDAI) [4, 8, 41, 43, 45] - Other criteria e,g, ACR-EULAR criteria [42, 43, 45, 50] - According to a composite measure with no swollen joints [51] - Several CPGs didn't describe preferred instrument/define remission/low disease activity [46-49]. One CPG recommended monthly monitoring of disease activity using a outcome measure, in addition to measuring C-reactive protein until the patient has achieved treatment target [44]. In those who have achieved a treatment target, offer an annual review to: - Check for the development of comorbidities, such as hypertension, ischaemic heart disease, osteoporosis and depression [44]. - Assess disease activity and damage, and measure functional ability (using, for example, the Health Assessment Questionnaire [HAQ]) [44]. - Assess symptoms that suggest complications, such as vasculitis and disease of the cervical spine, lung or eye [44]. - Refer to appropriate members of a multidisciplinary team [44]. - Assess the need for referral for surgery [44]. - Assess the effect the disease is having on a person's life [44]. Ultrasound should be avoided in routine monitoring [44]. Consensus: Disease activity should be monitored every 1-3 months if the patient is recently diagnosed or changing treatment strategies. Then monitoring can occur at every 3-6 months if disease is stable and the patient has achieved treatment target, with a review appointment at 6 months. This should include a practical, standardised and validated disease activity measure.
Tapering	One CPG strongly recommended [41] and five CPGs conditionally recommended [8, 42, 44, 48, 50] and two CPGs reported both strongly recommended and conditionally recommended [4, 45] taping medications when a patient is in remission. One CPG recommended against tapering if the patient doesn't have rapid access to care or will experience difficulty re-establishing access to medications [51]. CPGs vary on the amount of time a patient needs to be in remission or at low disease activity before tapering can occur. Several CPGs support 6 months [41, 45, 48, 51], whilst others supported 12 months [44, 45]; One CPG supported both time intervals depending on the treatment being tapered, e.g. corticosteriods at 6 months, bDMARDs at 12 months [45]. The remaining CPGs didn't provide a time frame [4, 8, 42, 50]. If a treatment target is not met, patients should return promptly to the previous DMARD [44]. Recommendations on medications that can be tapered include:

	GCs - GCs (e.g. Corticosteroids and non-steroidal anti-inflammatories (NSAIDs) [45]) should be tapered [8] in the first instance [50] with the aim of eventually stopping these treatments [45]. DMARD - Tapering of DMARDs can be considered [44, 45, 50] following glucocorticoid tapering and maintain the treatment target for 6-12months [44, 45]. Cautiously reducing drug doses or stopping drugs in a step-down strategy is recommended [44]. - Whilst on CPG reports continuing all DMARDs at their current dose can be recommended rather than reducing their dosages. A dose reduction can be recommended rather than gradual discontinuation and a gradual discontinuation can be recommended over an abrupt discontinuation for patients who are at target for at least 6 months [48] bDMARDs - Progressive taping of bDMARDs [4, 41, 45, 50, 51] can be considered especially if this this treatment is combined with a csDMARD [4, 8]. This may involve reducing [41, 42] or spacing out the doses [42] of the medication and should be recommended despite the risk of relapse [41]. Based on shared-decision making and provided patients are able to rapidly access rheumatology care and re-establish their medications in case of a flare [51]. - Based on shared-decision making and provided patients are able to rapidly access rheumatology care and re-establish their medications in case of a flare [51]. tsDMARDs - tsDMARDs tapering could be considered [4, 50, 51] especially when in conjunction with csDMARDs [4]. Based on shared-decision making and provided patients are able to rapidly access rheumatology care and re-establish their medications in case of a flare [51]. csDMARDs - If a patient is in persistent remission, tapering the csDMARD could be considered [4, 8, 45, 50] with caution and as a shared decision between the patient and clinician [45]. - Gradual discontinuation of SSZ can be recommended over HCQ for people taking triple therapy who wish to discontinue a DMARD [48]. - Gradual discontinuation of MTX can be recommended over bDMARD or tsDMARD for patients taking MTX + a bDMARD or tsDMARD [48]. Consensus: No consensus
Adjunctive therapy	**NSAIDs** One CPG strongly recommended [45] and two CPGs conditionally recommended NSAIDs [43, 44] including traditional NSAIDs (+/- a proton pump inhibitor or cox II selective inhibitors [44, 45]. This should be taken orally [8, 44], at the lowest effective dose for the shortest duration [44, 45] in combination with DMARDs [43] to reduce pain and inflammation [8, 43]. Clinicians should consider gastrointestinal, liver and cardio-renal toxicity, and the person's risk factors, including age and pregnancy and monitor these risk factors for adverse events on a regular basis [44]. If a person with RA needs to take low-dose aspirin, other treatments should be considered before adding an NSAID with a proton pump inhibitor [44].

	Consensus: NSAIDs can be used as adjunctive treatment at the lowest effective dose for the shortest duration. **GCs e.g. Prednisolone** Four CPGs strongly recommended [8, 41, 42], four CPGs conditionally recommended [43, 44, 46, 48, 50] GCs and two CPGs reported a either a combination of recommendations depending on context [4, 45]. Glucocorticoids can rapidly decrease inflammation [44] or reduce radiographic progression [45]. Short-term glucocorticoids can be considered: - In response to a patient experiencing a flare/to control active RA [4, 44]. - In combination when initiating or changing csDMARDs [4, 8, 41, 43-45, 50]. - and the risk-benefit ratio have been considered [42]. Monotherapy is not recommended [45]. GCs can include different dose regimens and routes of administration [8, 50] e.g. oral, intramuscular, or intra-articular injections [44]. Injections could be considered for the relief of local symptoms of inflammation [4, 46], pain, synovitis and/or tendinitis (in the foot) and could be guided by ultrasonography to improve accuracy [46]. The chosen GCs should be administered at the lowest dose [4, 42-45] and tapered as rapidly as clinically feasible [4, 8, 41, 42, 45, 50] to avoid side effects [4, 8]. Definitions of short-term varied amongst CPGs from <3 months [43] to <6 months [4]. Similarly, dosage of prednisone, a commonly selected GCs ranged from ≤ 7.5 [8, 45], ≤10 mg once daily [43] or 10-30 mg/day [41] and is recommended in combination with a csDMARDs [41]. Long-term treatment with GCs can be prescribed when patients are aware of the complications and have been offered other treatment options [44]. The adding or/switching of DMARDs is recommended over continuing GCs [48]. Consensus: Short-term GCs can be considered in combination with other interventions, at a low dose and tapered as soon as clinically feasible.
Pre-treatment investigations and vaccinations	
Pre-treatment investigations	Two CPGs strongly recommended that patients with RA should undergo investigations prior to starting medications [43, 45] e.g. bDMARDs, tsDMARDs [43] and csDMARDS [45]. Patients should complete a blood count [45] and be examined for active or current infections [45] and viruses including: Hepatitis B (HBV) and Hepatitis C (HCV) infection [43, 45], tuberculosis [43, 45] and human immunodeficiency virus [43]. Patients should also be assessed for comorbidities and possible contraindications to treatment modalities including: screening for tumours and malignancies, renal and liver function tests, chest radiography and pregnancy screening [45]. Consensus: Patients should undergo investigations before commencing treatment. These can include blood tests, renal and liver function tests.
Vaccinations	Three CPGs reported recommendations strongly for or against in relation to vaccinations [4, 42, 45].

	Patients vaccination status and special situations such as pregnancy and lactation should be recorded [45]. Vaccination records should be updated as needed [42]. - Ideally all vaccinations should be administered four weeks prior to initiating therapy (bDMARD [4, 45] or tsDMARDs [4]); especially live vaccines [45]. - Concurrent live, attenuated vaccines are contraindications for patients being treated with bDMARD [4, 45] or tsDMARDs [4]. - Killed vaccines (Pneumococcal, Influenza- yearly, HBV) or recombinant vaccines (Human Papilloma) should be given before initiating or during DMARD therapy [4]. Consensus: All patients should be assessed for infections and vaccinations should be provided prior to DMARD therapy and updated as needed. Do not administer live vaccines whilst patients being treated with bDMARDs or tsDMARDs.

bDMARD – biologic disease-modifying anti-rheumatic drug; CDAI – Clinical Disease Activity Index; CHF – congestive heart failure; CPG – clinical practice guideline; csDMARD – conventional synthetic disease-modifying anti-rheumatic drug; DAS28 – Disease Activity Score 28 joints; DMARD – disease-modifying anti-rheumatic drug; GC – Glucocorticoids; HAQ – Health Assessment Questionnaire; HBV – Hepatitis B virus; HCQ – hydroxychloroquine; HCV – Hepatitis C virus; LEF – Leflunomide; MTX – methotrexate; NSAID – Non-steroidal anti-inflammatories; RA – Rheumatoid arthritis; SDAI – Simplified Disease Activity Index; SSZ – sulfasalazine; TNFi – tumour necrosis factor inhibitors; tsDMARDs – targeted synthetic disease-modifying anti-rheumatic drug.

Special populations narrative summary

Special populations	
Serious Infections	Three clinical practice guidelines (CPGs) reported on infections with varying recommendations on the preferred treatment [41, 45, 48]. One CPG strongly recommended either with abatacept or if an anti-tumour necrosis factor (TNF) is preferred, etanercept if a patient is on biologic disease-modifying anti-rheumatic drug (bDMARD) therapy and has developed a serious infection [41]. Whilst another CPG disagrees and advises bDMARDs should be stopped and the patient be treated appropriately if experiencing an active infection of an infection is suspected [45]. One CPG conditionally recommended that if the patient has experienced a serious infection in the last 12 months adding a conventional synthetic disease-modifying anti-rheumatic drug (csDMARD) is preferred rather than a bDMARD or targeted synthetic disease-modifying anti-rheumatic drug (tsDMARD), although noted that disease-modifying anti-rheumatic drug (DMARDs) can be added or switched before considering initiation/dose escalation of glucocorticoids [48]. Consensus: No consensus.
Cancer	Two CPGs reported on interventions used for patients with cancer and rheumatoid arthritis (RA) [4, 41]. One CPG strongly recommended that patients who have a history of cancer are assessed on an individual basis before starting bDMARDs, with no specific treatment being preferred over another [41]. Treatment decisions should be made based on consensus between the patient, oncologist and other specialists involved [41]. One CPG reported specific recommendations for certain types of cancers: Previously been treated for low-grade melanoma or non-melanoma skin cancer: - csDMARDs should be recommended rather than tsDMARDs or bDMARDs, although bDMARDs and tsDMARDs can be recommended with close skin surveillance by a dermatologist [4]. Previously treated for lymphoproliferative disorder: - A combination of csDMARDs or abatacept or tocilizumab could be recommended over TNF-inhibitor - Rituximab should be recommended over TNF-inhibitor [4]. Previously treated solid organ malignancy - They should be treated consistent with recommendations for people with RA and no malignancy [4]. Consensus: No consensus.
Tuberculosis (TB)	Two CPGs strongly recommended that patients are screened for TB prior to commencing bDMARD [4, 45] or tsDMARD therapy [4], this should include The Mantoux tuberculin skin test (TST) or Interferon gamma release assay test (IGRA). IGRA being preferred if the patient has a history of Bacillus Calmette-Guerin vaccination [4]. Annual testing is recommended in RA patients who live, travel or work in situations where TB exposure is likely while they continue treatment with bDMARDs or tsDMARDs [4].

	If the patient returns a negative result for TST or IGRA, exhibits no risk factors and/or clinical suspicion for TB they may not require additional testing [4]. However, if the patient returns a positive result on either TST or IGRA initially, they should repeat the screening and complete a chest radiograph [4]. If the patient is positive for past TB exposure or active TB, then they should complete a sputum examination [4]. If the RA patient has active or latent TB based on the test results they should be prescribed appropriate anti-tubercular treatment [4, 45] and a referral to a specialist (pulmonologist or infectious disease specialist) can be considered [4]. Those with active TB need to be adequately treated [45] and experiencing one month of latent TB with anti-tubercular medications before initiating or resuming bDMARD or tsDMARDs therapy [4]. Consensus: All patients should be screened for TB infection before commencing DMARD therapy. If the patient has active or latent TB they should be prescribed anti-tubercular treatment and be adequately treated before resuming bDMARDs or tsDMARDs.
Hepatitis	Two CPGs strongly recommended that patients should be screened for Hepatitis B virus (HBV) infections [45] (e.g. HBsAg, antiHBcAb) and immunity (e.g. antiHBsAb) [4] and Hepatitis C virus (HCV) before commencing bDMARD [4, 45] or tsDMARD therapy [4]. Three CPGs reported a mix of strong, conditional and do not do recommendations for treatment options in HBV or HCV patients [4, 45, 48]. **HBV** - If a patient has an active or untreated chronic HBV infection, bDMARDs should not be recommended [45]. - AntiHBcAb positive, HBsAg negative o Further examination: HBV, DNA, liver function tests before starting immunosuppressive therapy [4]. o Viral load monitoring every 6-12months [4], frequent monitoring can be recommended over prophylactic antiviral therapy for patients initiating a bDMARD other than rituximab or a tsDMARD [48]. o Treatment consistent with recommendations for RA patients who are negative for HBV [4], whereas one CPG recommended prophylactic antiviral therapy should be recommended over frequent monitoring alone for patients initiating rituximab who are AntiHBcAb positive (regardless of hepatitis B surface antigen status) [48]. - HBsAg positive o Further examination: quantitative HBsAg, HBeAg, antiHBe, HBV DNA and anti HDV IgG and liver function tests, before starting immunosuppressive therapy [4]. o Prophylactic antiviral therapy should be recommended over frequent monitoring alone for patients initiating any bDMARD or tsDMARD who are Anti-HBcAb positive and HBsAg positive [48]. - Active HBV carriers o Entecavir or tenofovir should be recommended before starting immunosuppressive therapy [4]. - Acute HB occurring in patients with RA, such as asymptomatic infections occurring in patients previously negative for HBV serology o Antiviral treatment should be recommended consistent with international guidelines [4]. - In inactive HBV carriers o Prophylaxis should be started 4 weeks before the immunosuppressive therapy and continued for 12 months after its discontinuation (24 months in the case of rituximab-treated patients) [4]. o Patients stopping prophylaxis should be closely monitored [4].

	HCV - If a patient has an active HCV infection: o bDMARDs should not be recommended [45] o Further investigations: gastroenterological / infectious evaluation for any anti-viral eradicative therapy and should not be treated differently from patients with AR without HCV infection [4]. Consensus: Patients should be screened for HBV or HBC infections and receive further evaluations and treatment based on their results.
Congestive heart failure (CHF)	Two CPGs conditionally recommended interventions with patients who have CHF [4, 48]. Use combination of DMARDS (csDMARDs, bDMARDs or tsDMARDs), and a non-TNF-inhibitor e.g. tofacitinib over a TNF-inhibitor [4, 48]. Even in cases of heart failure, the addition of or switching to a non–TNF inhibitor, bDMARD or tsDMARD is still preferred over the addition of or continuing a TNF inhibitor for patients have an inadequate response to csDMARDs [48]. A TNF-inhibitor should only be used if there are no other reasonable options, and then, perhaps, only in compensated heart failure [4]. Consensus: Do not use a TNF inhibitor in persons with a history of CHF, unless there is no other reasonable option, and the CHF is compensated.

bDMARD – biologic disease-modifying anti-rheumatic drug; CHF – Congestive heart failure; CPG – clinical practice guideline; csDMARD – conventional synthetic disease-modifying anti-rheumatic drug; DMARD – disease-modifying anti-rheumatic drug; HBV – Hepatitis B virus (HBV); HCV – Hepatitis C virus (HCV); IGRA – Interferon gamma release assay test; RA – Rheumatoid arthritis; TB – Tuberculosis; TNF – tumour necrosis factor; tsDMARDs – targeted synthetic disease-modifying anti-rheumatic drug; TST – The Mantoux tuberculin skin test.

Surgical management interventions narrative summary

Management Principles	Narrative Summary
Referral for surgical opinion	Two CPGs strongly recommend early consultation with an orthopaedic surgeon [46] or specialist surgical opinion [44], in certain clinical situations. If any of the following do not respond to optimal non-surgical management: - Persistent pain [44, 46] due to joint damage or other identifiable soft tissue cause [44]. - Worsening joint function [44] or stiffness [46]. - Progressive deformity [44] malalignment of the foot (e.g., hammer toes) causing mobility limitations and pain or problems finding adequate shoes [46]. - Persistent localised synovitis [44] > 6 months of synovitis in foot and ankle joints [46]. - Tenosynovitis or tendon ruptures [46] imminent or actual tendon rupture [44]. - Returning callosity/clavus [46]. - Wounds/(pre)ulcers [46]. - Osteomyelitis/septic arthritis [46]. - Nerve compression [44]. - Stress fracture [44]. This aims to address joint damage or deformity before it becomes irreversible and provide pain relief [44]. Cosmetic improvements should not be priority [44]. Referral should be urgent if the patient the patient has suspected persistent synovitis of undetermined cause, (even with a normal acute-phase response, negative anti-cyclic citrullinated peptide antibodies or rheumatoid factor) and any of the following applies: - the small joints of the hands or feet are affected - more than one joint is affected - there has been a delay of 3 months or longer between onset of symptoms and seeking medical advice [44]. Consensus: Surgery should be considered when conservative management has not been successful, and the patient meets the above criteria.

CPG – Clinical practice guideline.

Single CPG recommendations on interventions

Non-pharmacological
One clinical practice guideline (CPG) strongly recommended that non-pharmacological interventions are an important aspect of standard care and should be considered throughout the course of the disease as an adjunctive or alternative to pharmacological or surgical interventions where appropriate [47]. Examples of interventions include: joint alignment and support, exercise, education, sleep and energy management [47]..
Dietary advice and complementary therapies
One CPG conditionally recommended Mediterranean diet principles e.g. more bread, fruit, vegetables, and fish; less meat; and replace butter and cheese with products based on vegetable and plant oils [44]. Clinicians should educate patients that there is no strong evidence to support experimental diets, and therefore should not be considered as an alternative to evidence-based therapies [44]. Diets may provide short-term symptomatic benefit however their long-term efficacy is yet to be determined [44].
One CPG recommended against patients replacing evidence based treatment for complementary therapies and that if patients decided to use these therapies it should not prejudice attitudes of clinicians[44].
Shoes
Over-the counter shoes
One CPG strongly recommended over-the counter shoes for people with rheumatoid arthritis (RA) should have sufficient room in the toe box and a stiff sole allowing a heel-to-toe gait [46].
The following features were conditionally recommended for certain foot conditions and depending on the patient's wishes: - Light weight, spacious, adjustable, and easy to close in-step/heel girth. - Strong, raised, and padded heel part. - Inflection points at the metatarsophalangeal (MTP) joints. - Adequate length and width, measured in standing position. - No seams on the inside. Technical adaptations to over-the-counter shoes can reduce pain and improve physical functioning. These adaptations can be prescribed in patients with abnormal foot function, foot joint damage/deformity, or malalignment of the feet, provided that the feet fit in over-the-counter shoes [46].
Custom-made therapeutic shoes
One CPG conditionally recommended custom-made therapeutic shoes for patients with abnormal foot function, foot joint damage/deformity, or malalignment of the feet, and feet that do not fit in over-the-counter shoes or ready-made therapeutic shoes [46].
These shoes should be worn all day after a habituation period and can reduce pain and improve physical functioning [46].
Orthoses and Braces
Rigid foot orthoses; Total contact foot orthoses
One CPG strongly recommended rigid foot orthoses for feet with correctable malalignment, to assist with foot positioning during weight-bearing. Whereas if the feet have malalignment that can't be corrected or fragile skin, total contact foot orthoses are strongly recommended. The material used for the production of total contact foot orthoses depends on the required characteristics of the foot orthoses [46].

Silicone toe orthosis; Toenail brace
One CPG conditionally recommended for a silicone toe orthosis in cases of malalignment of toes and secondary pain or high pressure. This can be prescribed if there is a sensibility disorder or peripheral artery disease; a skin defect on the foot of interest; and sufficient room in the shoe for wearing the toe orthosis. Whilst a toenail brace was conditionally recommended for treating ingrowing or an ingrown toenail if the patient has a sensibility disorder or peripheral artery disease; a skin defect, inflammation, or onycholysis on the toe of interest; and the use of biologicals [46].
Health professionals
Occupational therapy
One CPG strongly recommended specialist occupational therapy involvement in care, with regular review if they are experiencing difficulties with any of their everyday activities, or problems with hand function [44].
Podiatry
One CPG strongly recommended all patients with RA and foot problems should have podiatrist involvement in the care team for assessment and regular review of their foot health needs [44].
Supervised program
One CPG conditionally recommended a supervised treatment program to improve adherence, especially in women, elderly and comorbid patients [41].
Pharmacological
One CPG strongly recommended pharmacological interventions are considered as part of standard care [47].
Anti-IL-6
One CPG strongly recommended the use of an anti-IL6 agent rather than an anti- TNF agent as monotherapy [41].
Anakira
One CPG recommended against the use of anakinra except in the context of a controlled, long-term clinical study and against the use of Anakira in combination with tumour necrosis factor-α (TNF-α) inhibitor therapy [44].
Patients taking anakinra should continue therapy until they and their health professional recommends stopping to avoid impacting on the patients wellbeing [44].
Recommendations for specific populations
Interstitial lung disease
One CPG strongly recommended abatacept for patients with RA and interstitial lung disease who require treatment with a biologic, whilst conditionally recommended rituximab as an alternative [41].
Based on current available evidence, the CPG was unable to determine either for or against these medications for interstitial pneumonia.
Foot conditions
Fungal nail or mycosis
One CPG strongly recommended that treatment should be started to prevent ulcers and secondary bacterial infections for patients with a fungal nail or mycosis [46].
Hyperkeratotic lesions

One CPG strongly recommended that pressure and shearing forces should be normalised in feet with hyperkeratotic lesions. For normalisation of pressure and shearing forces:

- Advice on footwear and socks can be given [46].
- Foot orthoses, silicone toe orthosis, technical adaptations to over-the-counter shoes, ready- or custom-made therapeutic shoes, or a provisional therapy (e.g., felt padding or taping) can be prescribed [46].

Excessive hyperkeratotic lesions

One CPG strongly recommended that excessive hyperkeratotic lesions should be treated. During the treatment the following factors should be considered: i) a sensibility disorder or peripheral artery disease, and ii) fragile skin, plantar bursa, and prominent metatarsal heads on the foot of interest [46].

Preulcer or infection

One CPG strongly recommended that when a pre-ulcer or infection is detected, the treating physician should be consulted [46].

Wound-care

One CPG conditionally recommended that in wound-care, a provisional therapy (e.g., felt padding) can be applied to reduce pressure. When material with an adhesive layer is used, fragile skin should be taken into consideration [46].

Pregnancy and lactation

One CPG strongly recommended that biologic disease-modifying anti-rheumatic drug (bDMARDs) should only be considered after thorough assessment of benefits and risks for those who are pregnant or lactating [45].

Cardiovascular disease (CVD)

One CPG strongly recommended that all RA patients complete a CVD risk assessment at least once every 5 years and should be reconsidered following major changes in antirheumatic therapy. CVD risk estimation for patients with RA should be performed according to national guidelines and the SCORE CVD risk prediction model should be used if no national guideline is available. CVD risk prediction models should be adapted for patients with RA by a 1.5 multiplication factor, if this is not already included in the model [4].

One CPG conditionally recommended screening for asymptomatic atherosclerotic plaques by use of carotid ultrasound as part of the CVD risk evaluation in patients with RA [4].

Lifestyle recommendations should emphasize the benefits of a healthy diet, regular exercise and giving up smoking for all patients [4].

In CVD risk management, antihypertensives and statins may be used as in the general population. Prescription of non-steroidal anti-inflammatories should be given with caution, especially for patients with documented CVD or in the presence of CVD risk factors [4].

Nontuberculous mycobacterial (NTM) lung disease

One CPG conditionally recommended the following: [48]

- Use of the lowest possible dose of glucocorticoids (discontinuation if possible) over continuation of glucocorticoids without dose modification for patients with NTM lung disease.
- The addition of conventional synthetic disease-modifying anti-rheumatic drug (csDMARDs) over addition of a bDMARD or targeted synthetic disease-modifying anti-rheumatic drug (tsDMARD) for patients who have moderate-to- high disease activity despite csDMARD monotherapy.

- Abatacept over other bDMARDs and tsDMARDs for patients who have moderate-to- high disease activity despite csDMARDs

Pulmonary disease

One CPG conditionally recommended methotrexate (MTX) over alternative disease-modifying anti-rheumatic drugs (DMARDs) for the treatment of inflammatory arthritis for patients with clinically diagnosed mild and stable airway or parenchymal lung disease, or incidental disease detected on imaging, who have moderate-to- high disease activity [48].

Non-alcoholic fatty liver disease (NAFLD)

One CPG conditionally recommended MTX over alternative DMARDs for DMARD-naive patients with NAFLD, normal liver enzymes and liver function tests, and no evidence of advanced liver fibrosis who have moderate-to- high disease activity [48].

Persistent hypogammaglobulinemia without infection

One CPG conditionally recommended In the setting of persistent hypogammaglobulinemia without infection, continuation of rituximab therapy for patients at target over switching to a different bDMARD or tsDMARD [48].

Subcutaneous nodules

One CPG conditionally recommended MTX over alternative DMARDs for patients with subcutaneous nodules who have moderate-to-high disease activity [48].
Switching to a non-MTX DMARD is conditionally recommended over continuation of MTX for patients taking MTX with progressive subcutaneous nodules [48].

Lymphoproliferative disorder

One CPG conditionally recommended rituximab over other DMARDs for patients who have a previous lymphoproliferative disorder for which rituximab is an approved treatment and who have moderate-to- high disease activity [48].

Surgical

Education surgical benefits

One CPG strongly recommended explaining the expected benefits of surgery for patients with RA, this includes: pain relief, improvement, or prevention of further deterioration, of joint function, and prevention of deformity [44].They highlight cosmetic improvements should not be the dominant concern [44].

Medical and surgical management

One CPG strongly recommended offering a combination of medical and surgical management urgently, to adults with RA who have suspected or proven septic arthritis (especially in a prosthetic joint) [44].

MRI and surgical referral

One CPG strongly recommended that if an adult with RA develops any symptoms or signs that suggest cervical myelopathy (for example, paraesthesia, weakness, unsteadiness, reduced power, extensor plantars), clinicians should request an urgent MRI scan, and refer for a specialist surgical opinion [44].

Joint replacement surgery for younger adults

One CPG conditionally recommended clinicians do not let concerns about the long-term durability of prosthetic joints influence decisions to offer joint replacements to younger adults with RA [44].

Lower limb surgical interventions
Resection arthroplasty of the MTP joints
One CPG conditionally recommended resection arthroplasty of the MTP joints to improve joint mobility and to reduce pain, forefoot plantar pressure, and problems finding well-fitting shoes. In severe malalignments of the toes or damage to the MTP joints, resection arthroplasty is preferred. Without severe malalignments/damage, a MTP joint-preserving surgical technique can be considered [46].
Arthrodesis of the MTP1 joint
One CPG conditionally recommended arthrodesis of the MTP1 joint to reduce pain and improve the weight-bearing capacity of the forefoot [46].
Arthrodesis of the subtalar joint and/or arthrodesis of the calcaneocuboid joint and talonavicular joint
One CPG strongly recommended arthrodesis of the subtalar joint when performing surgical treatment of the hindfoot is indicated. For flat feet, an additional arthrodesis of the calcaneocuboid joint and talonavicular joint should be considered (triple arthrodesis) [46].
Arthrodesis of the tibiotalar joint or an ankle prosthesis
One CPG conditionally recommended arthrodesis of the tibiotalar joint or an ankle prosthesis when the patient is experiencing severe pain and damage of the tibiotalar joint. An arthrodesis is preferred, provided that the Chopart-joint-line is intact and the status of other joints does not form a contraindication. An ankle prosthesis can be considered when preservation of mobility in the tibiotalar joint is important (according to the patient) and the preoperative status of the patient does not form a contra-indication [46].

bDMARD – biologic disease-modifying anti-rheumatic drug; CPG – clinical practice guideline; csDMARD – conventional synthetic disease-modifying anti-rheumatic drug; CVD – cardiovascular disease; DMARD – disease-modifying anti-rheumatic drug; MTX – methotrexate; MTP – metatarsophalangeal; NAFLD – non-alcoholic fatty liver disease; NTM – nontuberculous mycobacterial; RA – rheumatoid arthritis.

I.6 PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title and abstract
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Manuscript Introduction Line 150-155
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Manuscript Introduction Line 159-161
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Table 1
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Manuscript Line 166-169
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Online Resource 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Manuscript Line 172-175
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Manuscript Line 198-205
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Online resource 2 Online resource 4 Online resource 5
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Online Resource 3 Table 3
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Manuscript Line 180-196
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/a
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Table 1 Manuscript

Section and Topic	Item #	Checklist item	Location where item is reported
			Line 190-196
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Manuscript Line 208-215
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Manuscript Line 198-205
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Manuscript Line 208-215
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Manuscript Line 180-196
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure B
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Online resource 3
Study characteristics	17	Cite each included study and present its characteristics.	Online resource 2 Table 3
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 3 Online Resource 3
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/a
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Table 3 Online resource 3
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Manuscript Results Line 218 Line 429-438

Section and Topic	Item #	Checklist item	Location where item is reported
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Manuscript Line 376 – AGREE 2 Line 493 – Management options
	23b	Discuss any limitations of the evidence included in the review.	Manuscript Line 454
	23c	Discuss any limitations of the review processes used.	Manuscript Line 454
	23d	Discuss implications of the results for practice, policy, and future research.	Main document Research: Line 367-374 Line 376-391 Line 406-422 Line 424-438 Line 440-452 Practice: Line 393-404
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Manuscript Line 76-77
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Manuscript Line 165-166
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Manuscript Line 175-177
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Manuscript

Section and Topic	Item #	Checklist item	Location where item is reported
			Line 89
Competing interests	26	Declare any competing interests of review authors.	Authorship/Disclosure Form Competing interests Main document Line 84
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Data extraction forms – Online resources 3,5 Data analysis forms – Online resource 4 Online resource 5 Online resource 6 Table 3 Analytic code – Figure A Table 2 Other materials – Online resource 1,2 Figure B

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix J. Developing Arthritis Education Resources: Integrating Evidence From Indigenous Peoples' Lived Experience and Clinical practice Guidelines: Supplementary Material

J.1 Yarning Guide – Information Needs and Preferences of Aboriginal Participants with OA, RA and Gout

General approach: use a research yarning approach[1]. A research yarning approach is informal, conversational, participant-led, and could include a social yarn, research yarn, and therapeutic yarn. In this guide to the research yarn, researchers can adapt their language and approach as is appropriate to facilitate a comfortable yarn that includes the areas outlined.

Preamble to the research yarn:

Thanks for agreeing to sit down with us and have a yarn today about your [condition]. We're doing this to find out what information and [condition] would be most helpful to you to help you look after it.

- (Understanding) Can you tell me what you understand about your condition?
    - What caused it?
    - Why did it start? What does it do? How does it work?
    - How severe is it?
    - What will happen over time?
    - What worries/fears do you have about it?
    - How was it diagnosed?

- (Management) What do you do to look after it?
    - Where did you learn this?
    - What affect does it have for you? How useful is it to you?
    - What do you think you need to do? (Why?)

- (Previous experience) What information have you been given previously about your condition? If you have:
    - What was it? (description)
    - Where did you receive it?
    - What did you take on board from it?
    - What did you think of it? (was is helpful/unhelpful, good/bad etc..). Why?

- (Preferences) What information about your condition would be most helpful to you?
    - What content?
    - What format? (e.g. written, pictorial, video, online)
    - Who is best to provide information? Where would it be best to receive it?

- (About them) Clarify their age, how long they've had pain, and pain location if not already discussed.

Finish the research yarn by thanking the person, summarising the main areas and checking if there is anything else the person would like to say. Ask they have any questions. Explain what will happen next in the project. Check if they are happy to be re-contacted if there are follow-up queries and the best way to return results to them.

Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in indigenous research. International Journal of Critical Indigenous Studies 2010;3(1):37-50

J.2 CPG Education Recommendations – Data Analysis

Category	Clinical practice guideline recommendations
Disease knowledge (Information about what condition is, what causes it, consequences, prognosis)	Gout Pathophysiology, associated co-morbidities, lifelong lowering of SUA below a target level to eliminate crystals [1], the causes and consequences of gout and hyperuricemia [2]. Discussing potential illness perceptions or barriers to care [2]. RA Information about RA [3-6]/diagnosis [7], nature of disease [7], possible consequences [6] or complications of RA [7] and common assessments [5]. Counter any misconceptions they have or barriers to care [4]. OA Information about OA [8, 9], nature and course of disease [10] and its prognosis [9].
Management options	Gout Effective treatments [1] Non-pharmacological: Diet and healthy lifestyle advice [1, 2]: Avoid sugar-sweetened drinks, heavy meals, excessive intake of meat and seafood [1, 11] and alcohol (especially beer and spirits) [1, 2, 11]. Low-fat dairy products should be encouraged [1]. Regular exercise [1, 2, 11], weight loss if appropriate [1, 2, 11, 12] and ceasing smoking [11] should be encouraged. Pharmacological: Managing acute attacks – early initiation of treatment (ideally within 24 hours) [1, 2]. Urate lowering therapy (ULT): Rationale [2], aims [2] - Use of ULT to target urate levels [2, 11] and when to commence ULT [11]. RA Management options [3-5]/Common interventions [5] and information to support self-management and optimising health and well-being [6]. Non-pharmacological Counselling on lifestyle habits [3], foot preventative and curative care [13] and discussing the importance of exercise and a healthy lifestyle (including decreasing stress and fatigue and how this lifestyle can be achieved and maintained) [6]. OA Optimal management [9] self-management and treatment options [10]. Non-pharmacological Maintaining healthy body weight [9, 14], and encouraging weight loss of overweight or obese [14].

	Exercise regimen: strengthening, low-impact aerobic exercises, and neuromuscular education [14] and joint protection measures, fitness, exercise, goals and approaches [8] Vocational rehabilitation, including counselling on modifiable work-related factors (if at risk of work disability) [14] and ergonomic principles: Pacing of activity and use of assistive devices [10].
Information about treatment risks and benefits.	Gout ULT benefits, harms and costs [15], emphasising the importance of continuing an established ULT during an attack [2] and its ongoing use to prevent return of gout attacks [2, 11]. RA Risks and benefits of treatment options [4, 7]. OA Medication efficacy and potential side effects [8].
Information about care pathways including how and when to access to care.	RA Information about how and when to access specialist care [4].
Providing education (verbal and written formats).	Gout Education should [1, 2, 11, 15] or could [12] be provided in both verbal and written formats [2]. RA Education should [3-5, 7, 13, 16] or could [6] be provided in written and verbal [4] supporting materials [5] and educational programmes [4, 5, 16]. OA Education should be provided [8, 10, 14, 17, 18] or reported no consensus [9] as a formal face to face program [8, 9].
Personalised/ individualised information.	Gout Individualised management options [2, 15]. RA Individualised information and advice [6] and joint specific education (ankle/foot, hand) [7, 13]. OA Information, education and an individually tailored program, including long-term and short-term goals, intervention or action plans to reduce the degenerative damage of the OA should be provided [14].

Shared decision-making.	Gout Shared decision making [11, 12] RA Patients' role in the shared-care process [5] and provide an ongoing opportunity to talk about and agree all aspects of their care, respecting the decisions they make [4]. OA Self-management principles [10].
Reassurance, strengths-based communication.	OA Techniques to promote hope, optimism, and a positive expectation of benefit from treatment [17].
Trust in information – including person providing it (MDT, key worker).	RA Trusting therapeutic relationship between the patient and clinician, to improve patient adherence to treatment modalities [16].

OA – Osteoarthritis; RA – Rheumatoid arthritis.

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J.3 Research Yarning – Participant Demographics

Location		Recruitment strategy	Gender	Age
Gout (n=4)				
Victoria	Metropolotian	Network investigators	Male	32
Victoria	Metropolotian	Network investigators	Male	66
Western Australia	Regional	Network investigators	Male	53
Western Australia	Regional	Network investigators	Male	60
Osteoarthritis (n=19)				
Victoria	Regional	ACCO	Female	42
Victoria	Regional	ACCO	Female	66
Victoria	Regional	ACCO	Male	52
Victoria	Metropolitan	Network investigators	Female	22
Western Australia	Regional	ACCO	Female	68
Western Australia	Regional	Network investigators	Female	63
Western Australia	Regional	Network investigators	Female	60
Western Australia	Regional	Network investigators	Female	49
Western Australia	Regional	ACCO	Female	71
Western Australia	Regional	ACCO	Male	75
Western Australia	Regional	Network investigators	Female	66
Western Australia	Regional	ACCO	Female	68
Western Australia	Regional	ACCO	Female	55
Western Australia	Regional	Network investigators	Female	64
Western Australia	Regional	ACCO	Female	59
Western Australia	Regional	ACCO	Female	62
Western Australia	Regional	Network investigators	Male	55
Western Australia	Regional	ACCO	Male	72
Western Australia	Remote	Network Investigators	Female	74
Rheumatoid arthritis (n=5)				
Victoria	Regional	ACCO	Female	33
Victoria	Regional	ACCO	Female	42
Western Australia	Remote	Network investigators	Female	60
Western Australia	Regional	ACCO	Female	34
Western Australia	Rural	ACCO	Female	48
Rheumatoid arthritis and osteoarthritis (n=2)				
Victoria	Regional	Network investigators	Female	68
Western Australia	Regional	ACCO	Male	63

ACCO – Aboriginal Community Controlled Organisation.

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