Public Submission Cover Sheet

Please complete this sheet and submit with any attachments to the Sustainable Health Review Secretariat

Your Personal Details ***This information will be used only for contacting you in relation to this submission***	
Title	Mr ☒ Miss ☐ Mrs ☐ Ms ☐ Dr ☐ Other ☐
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Publication of Submissions

Please note all Public Submissions will be published unless otherwise selected below

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Submission Guidance

You are encouraged to address the following question:

In the context of the Sustainable Health Review Terms of Reference listed below, what is needed to develop a more sustainable, patient centred health system in WA?

- Leveraging existing investment in Primary, Secondary and Tertiary healthcare, as well as new initiatives to improve patient centred service delivery, pathways and transition;
- The mix of services provided across the system, including gaps in service provision, sub-acute, step-down, community and other out-of-hospital services across WA to deliver care in the most appropriate setting and to maximise health outcomes and value to the public;
- Ways to encourage and drive digital innovation, the use of new technology, research and data to support patient centred care and improved performance;
- Opportunities to drive partnerships across sectors and all levels of government to reduce duplication and to deliver integrated and coordinated care;
- Ways to drive improvements in safety and quality for patients, value and financial sustainability, including cost drivers, allocative and technical efficiencies;
- The key enablers of new efficiencies and change, including, research, productivity, teaching and training, culture, leadership development, procurement and improved performance monitoring;
- Any further opportunities concerning patient centred service delivery and the sustainability of the WA health system.

Submission from Arthritis and Osteoporosis WA (AOWA) to the Sustainable Health Review

Arthritis is one of the most prevalent, disabling and costly chronic diseases in Australia, affecting more than 3.5 million Australians of all ages and ethnicities; costing the health system well over $4.3 billion annually[1]. In Western Australia the prevalence and costs for arthritis are in line with national data and show significant increases in total health care costs. WA. Costs are predicted to increase by 55% (2030).Osteoarthritis costs will increase by 57.7% from $65.87 million dollars per year to $261.64 million dollars (2030). Rheumatoid Arthritis costs will increase by 55.05% from $47.89 million dollars per year to $71.82 million (2030)[2]. In 2014-15, the ABS National health survey stated that 15.3% of Australians (3.5 million people) had arthritis, with prevalence higher amongst women than men (18.3% compared with 12.3%)[1]. Of persons with arthritis, more than half (58.9%) had osteoarthritis, 11.5% had rheumatoid arthritis and 34.8% had an unspecified type of arthritis.

Introduction & Overview

With finite health budgets, changing demographics and aging populations; innovative and alternative paradigms of health care must be explored, tested and if appropriate adopted to provide sustainable health care solutions. Non-Government Organisations (NGOs operating in the health domain, work at the interface of consumers and health professionals providing cost effective health services. In Western Australia, Arthritis and Osteoporosis WA is the only NGO working in this specialised health arena, adding value and expertise to existing health services.

AOWA offers education and self-management programs as well as specialist exercise and hydrotherapy classes to the arthritis and osteoporosis population in the metro and some regional areas. AOWA also coordinates an outreach clinical rheumatology service to rural and regional WA, and this economically worthwhile service must be sustained to enable this rural consumer group to receive comparable health care.

The need for sustainable health care for consumers with arthritis and osteoporosis is necessary as this population requires ongoing long term costly health care. AOWA provides specialist health professionals and trained volunteers delivering accessible health care programs in community settings to all socio-demographic and ethnic groups. Providing the right services in the right locality gives the consumer more health choices and improved health outcomes.

As life expectancy continues to increase so do chronic diseases, more people are now living in the community with long term health conditions than previously. Although the mortality rates for arthritis appear low this is probably a contradiction as arthritis increases and contributes to life threating co-morbidities, depression, cardio-vascular diseases (CAD, and stroke), and cancer. Recent research has shown adding arthritis to another chronic conditions increases disability and morbidity adding to the ever increasing diseases burden[3]. Over the next two decades as Australia's population ages, the prevalence of musculoskeletal conditions will rise substantially. By 2032 it is projected that the number of cases of arthritis and other musculoskeletal conditions will increase by 43% to 8.7 million (a rise of 2.6 million), affecting 30.2% of the population. While prevalence rates are higher in older Australians, more than half of those with musculoskeletal conditions (58.4%) are currently between the ages of 25 and 64 years – the prime working age population.

Taking steps now to reduce the impact and severity of arthritis is critical, according to Arthritis Australia 'Time to Move' (2014)[4] strategy document, which states –

- Improvements in longevity in recent decades mean that not only are more people developing arthritis, they are living longer with the condition and because arthritis is mostly progressive, the longer people live with the condition, the more severe it becomes.
- In addition, arthritis is a leading cause of disability and early retirement, costing $1.3 billion annually in Disability Support Pension payments and $9.4 billion in lost GDP due to early retirement[1].

Arthritis is an umbrella term for over 100 conditions affecting joints and connective tissues, the main condition are Osteoarthritis, Rheumatoid Arthritis, Gout, Ankylosing Spondylitis and JIA.

Snapshot of Main Conditions

Osteoporosis is a condition of the musculoskeletal system in which a person's bones become fragile and brittle, leading to an increased risk of fractures. Fractures can lead to chronic pain, disability and loss of independence. In 2014-15, 801,800 Australians (3.5%) had osteoporosis. Similar to arthritis, osteoporosis is considerably more common amongst women than men (5.5% of all females having osteoporosis in 2014-15 compared with 1.4% of all males), and is more common at older ages. Around one in five women (25.8%) aged 75 years and over had osteoporosis in 2014-15, compared with one in fourteen men (7.2%) of the same age. The estimated total number of fractures over the next 10 years is over 1.6 million[4]. **Osteoarthritis** (OA) is a disease of the whole joint not just the breakdown of articular cartilage, and it is the most common joint disease not only in Australia but worldwide, it is a major cause of pain and disability. Despite increased prevalence of this disease the aetiology is still unknown, and at present no treatment that cures OA is available. However evidence based strategies are available to help people manage their disease and slow down progression. AOWA's patient centred evidence based education program for 'OA of the Knee' (OAK) is available and sustainable. This program needs to be adopted more widely at all levels of health care.

Rheumatoid Arthritis (RA), Juvenile Idiopathic Arthritis (JIA), Ankylosing Spondylitis (AS) and other inflammatory arthritis conditions are serious immune modulated progressive conditions requiring medications to manage and prevent significant deformities. At present there are no cures available but disease modifying medications help to control the progression. RA is an auto immune disease causing synovitis and swelling in numerous joints it is accompanied by pain and fatigue and disability. It can occur at any age but usually commences between the 25-60 years (Arthritis Australia 2014d)[5]. The cost of RA is not just financial $550 million in 2015; Ackerman et al 2016)[6].The physical and psychosocial consequences are often of greater cost to the person, their family and carer. AOWA's patient centred evidence based education program for 'Rheumatoid Arthritis' (RA-P) is available and sustainable. This program needs to be adopted more widely at all levels of health care.

Ankylosing Spondylitis (AS) is an auto inflammatory disease affecting young adults in their twenty and thirties. Statistically affecting more men than women, AS affects the spine and sacroiliac joints causing severe back and hip pain inflammatory in nature it may be accompanied with systemic symptoms of fatigue depression and sometimes peripheral joint pain. AOWA's patient centred evidence based education program for 'Ankylosing Spondylitis' (AS-P) is available and sustainable. This program needs to be adopted more widely at all levels of health care.

Juvenile Idiopathic Arthritis (JIA) Around 6,000 Australian children under the age of 16 years are affected by juvenile idiopathic arthritis (JIA) (Ackerman et al. 2016), similar to the number of children affected by Type 1 diabetes. JIA is one of the most common and serious chronic conditions of childhood, causing disabling pain, fatigue, restrictions in physical activity, and potentially growth abnormalities, irreversible joint damage and other complications. There are psycho-social, educational and financial impacts for children and their families (Arthritis Australia 2014b).

Regardless of the pathology all arthritis conditions cause pain and this is one of the main problems of living with arthritis[7] Living with arthritis pain is challenging early intervention and good pain management strategies are essential to improve quality of life and to prevent the downward spiral into the triad of chronic pain anxiety and depression.

People with RA, JIA, AS and other inflammatory arthritis conditions require reliable access to specialist rheumatologists especially those living in rural areas. AOWA organises and co-ordinates an outreach clinical rheumatology service throughout rural WA. This service which commenced in 1974 has been the envy of all other states providing best practise rheumatology care until recently and now this service is under threat.
Ten rural rheumatology nurses were employed and worked though out the state now only one remains. These nurses have been eroded due to changes in WACHS community health now (population health) management priorities.
This management decision coincided with the introduction of the new expensive biologic (bDMARD) drugs which need frequent monitoring and without designated staff this treatment involves 4-6 monthly visits to Perth incurring costly PAT's fee's. It is axiomatic that removing these nurses for a management decision has caused immense distress to this vulnerable population. Best practice rheumatology requires a team approach and without support from WACHS this outreach service is not sustainable.

Consumer Centred Care and Sustainability

Arthritis and Osteoporosis WA believes in the concept of the well informed consumer and provides educational and health evidence based education/self-management to enable this. Empowering the arthritis consumer to make the right choices about their health care in partnership with their health care provider is promoted.

In Australia there are no guidelines for patient-centred care (PCC) in arthritis therefore AOWA adopted guideline from the UK on (RA).The guideline states using a (PCC) shows relevant impact on treatment outcomes and empowers patients to take personal responsibility for their treatment, and 'the patient' should be actively involved in the management of their disease. Five different PCC activities are suggested:- Patient education, Patient involvement/shared decision-making; Patient empowerment/self-management; Involvement of family and friends; Physical and emotional support.

Using these principles AOWA has developed and tested disease specific education/self-management evidence based programs:

- OAK for consumers with 'Osteoarthritis of the Knee'
- RA-P for people with inflammatory arthritis 'RA and PsA' (Psoriatic Arthritis)
- AS-P for people with 'Ankylosing Spondylitis'

Under the supervision of specialists and academics programs were developed using an action research model and tested. Consumer representatives were involved in all stages, focus groups, discussions and review. In study design and analysis the project team worked closely with Curtin University (Ethics) and the rheumatology department at SCGH and UWA. Initial funding for the first pilot project (OAK) was obtained through the federal governments AMQuiP grant. Subsequent funding was obtained to continue on with a RCT and comparative study.

To add value and capacity building to the projects an action research model was also used to develop a 'Train the Trainer' program to train health professionals to deliver the programs ensuring sustainability. This model uses a collaborative, multidisciplinary approach to patient care, reinforcing best practise rheumatology. Clinicians from a variety of health professions and clinical settings have been trained to deliver these programs. Outcome evaluations show increased knowledge, intra disciple collaboration and professional satisfaction adding extra dimensions to their primary role.

Quantitative evaluation of consumer programs have shown significant clinical improvements in pain, function and quality of life and have been presented at best rheumatology scientific meetings nationally (ARA) and internationally (EULAR) and (ACR), with peer review paper published in prestige rheumatology journals.

Qualitative evaluation has shown 98% of RA participants stated that this program should be offered to all people diagnosed with Rheumatoid Arthritis the OAK program 95% of participants concurred.

When asked would you recommend this program to other people 96% of RA-P attendees said Yes; alongside 93% of OAK attendees; Asked "do you Intend to make any change in your lifestyle as a result of the program" 95% of both cohorts said Yes

These evidence based 6 week consumer programs provide alternative service delivery they have very low drop-out rates and partners and carers are encouraged to attend. Programs have continued to gain momentum as service delivery and are offered at the Wyllie arthritis centre and at outreach venues in the metropolitan region and in limited rural areas. Program availability is limited only by lack of human resources', available affordable venues and health managers allowing staff time off for training. This program model is portable and transferable and can be delivered in hospitals and community settings.

Discharge planning and clinical pathways should include information about community programs relevant to the person's needs and people waiting for knee replacement surgery should be informed and offered the 'OAK' program. Counting the cost (Arthritis Australia 2016) Implementing conservative management strategies for people with severe knee OA could result in substantial cost savings for the Australian healthcare system, if implemented at a broader population level. The potential cost savings from avoiding or delaying knee replacements alone would be over $170

million in 2015, increasing to over $233 million in 2030.(*In a small survey during the OAK pilot study participants delayed TKR and reduced bed day stays)*

Arthritis is a costly disease to both consumer and society and these costs will rise exponentially unless something is done. Arthritis is not a glamorous disease. Rarely requiring hospitalisation until serious complications occur, consumers with arthritis are treated in the community attending GP's and private rheumatologists because hospital waiting lists are too long for the person with inflammatory disease. There is poor understanding of the arthritis conditions by both consumers and health professionals and although a health priority in WA; Arthritis does not receive the same funding or acknowledgment as other chronic diseases such as Diabetes or Asthma. Consequently there are huge gaps in service delivery at all level of care. The consumers with arthritis feel they are not validated often told by health practitioners that nothing can be done. They suffer from pain, fatigue, depression and are often isolation in the community because of immobility. This also applies to young adults with inflammatory arthritis anecdotally and reiterated in 'Painful Transitions' young people experiences of living with persistent pain[8].

Gaps and Recommendations

1. Gaps in Public Awareness
   - 'Arthritis' a misnomer for many conditions which are inadequately understood by both the consumer and health professional.
   - Recommendation: Develop public awareness campaign to better inform the public 'something can be done'. Seek cross sectional partnership and consumer input in the development of the right messages.
2. Gaps in Health Professional Knowledge
   - Recommendation: Increasing the knowledge base of health professionals at under graduate and post-graduate level. Use cross sectional buy-ins from specialist health professionals, rheumatologist and AOWA.
3. Gaps in Community Service Delivery
   - Recommendation: Referral to AOWA evidence based programs from primary care providers and hospital discharge pathways.
   - Recommendation: Buy-ins to AOWA to provide more education/self-management and specialist exercise programs.
4. Gaps in the provision of the Rural Clinic Service
   - Recommendation: Reinstatement of designated rheumatology nurses and allied health support providing a seamless and best practice care. Administrative/clerical support for the visiting rheumatologists in clinics where this is not provided.
5. Gaps at Tertiary Care
   - Recommendation: Cross sectional partnership and buy-ins to AOWA for the provision of in-service education to all level of carers in hospital and nursing homes.
6. Gaps in Consumer Education
   - Obesity is a risk factor in arthritis, in both osteoarthritis, increasing stress on joints, and inflammatory arthritis, increasing cytokine production.
   - Recommendation: Seed funding and intra organisational collaboration to develop a evidence based program to encourage weight loss in the consumer with arthritis

Barriers

- Enabling best practise rheumatology requires change in health department management culture and attitudes at all levels to NGOs (narrative heard at HDWA meeting, we call NGOs 'No Gos').

Concerns

- Lack of communication between regional management in WACHS and AOWA
- Two regions have cancelled rheumatology clinics and redeployed the rheumatology nurses

References

1. Time to Move, Arthritis Australia, Sydney, Australia 2014
2. Australian Bureau of Statistics 2009. *Disability, Ageing and Carers, Australia: Summary of Findings, 2009*
3. Impact of Arthritis and Multiple Chronic Conditions on Selected Life Domains — United States, 2013

4. Osteoporosis costing all Australians*: A New Burden of Disease Analysis – 2012 to 2022,* Osteoporosis Australia*,* Glebe, NSW, Australia
5. Arthritis Australia 2014d, Time to Move: Rheumatoid Arthritis. A national strategy to reduce a costly burden.
6. Ackerman IN, Bohensky M, Pratt C, Gorelik A, Liew D: Counting the cost - the current and future cost of arthritis, Health care costs Part1, Arthritis Australia 2016
7. Living with Rheumatoid Arthritis, Chapter Three, Arthritis & Osteoporosis WA, 2017, Perth, Australia
8. Slater H, Jordan JE, Chua J, Schütze R, Briggs AM (2016): Young people's experiences of living with persistent pain, their interactions with health services and their needs and preferences for pain management including digital technologies. Melbourne: Arthritis and Osteoporosis Victoria and Arthritis and Osteoporosis Western Australia.
9. Coleman et al. Arthritis Research & Therapy 2012, 14:R21, A randomised controlled trial of a self-management education program for osteoarthritis of the knee delivered by health care professionals.

The OAK and RA-P programs are endorsed by the Australian Rheumatology Association (ARA). Health professional training programs are endorsed by the Australian Rheumatology Association, Australian Physiotherapy Association (APA) and Australian College of Nursing (ACN).

Published Papers

Short and medium term effects of an education self-management program for individuals with OA of the knee, designed and delivered by health professionals: a quality assurance study. Coleman S, Briffa K, Conroy H, Prince R, Carroll G, McQuade J. BMC Musculoskeletal Disorders Sept 2008, **9**:117 http://www.biomedcentral.com/1471-2474/9/117

Effects of self-management, education and specific exercises, delivered by health professionals in patients with osteoarthritis of the knee. Coleman S, Briffa N K, Carroll G, Inderjeeth C, Cook N, McQuade J, BMC Musculoskeletal Disorders Oct 2008, **9:**133
http://www.biomedcentral.com/1471-2474/9/133

Self-management for osteoarthritis of the knee: Does mode of delivery influence outcome?
Coleman S, McQuade J, Rose J, Inderjeeth C, Carroll G, Briffa N K, BMC Musculoskeletal Disorders 2010, 11:56
http://www.biomedcentral.com/1471-2474/11/56

A randomised controlled trial of a self-management education program for osteoarthritis of the knee delivered by health care professionals. Coleman S, Briffa N K, Carroll G, Inderjeeth C, Cook N, McQuade J. Arthritis Research & Therapy Jan 2012, **14**:R21 -http://arthritis-research.com/content/14/1/R21

Evaluation of a disease specific rheumatoid arthritis self-management education program, a single group repeated measures study. Vermaak V, Briffa N K, Langlands B, Inderjeeth C, McQuade J, BMC Musculoskeletal Disorders (2015) 16:214 http://dx.doi.org/10.1186%2Fs12891-015-0663-6