



**ARTHRITIS
NEW ZEALAND**

KAIPONAPONA AOTEAROA

*Our Vision: Improving the life of
every person affected by arthritis*

*Ko tō mātou aronga: Kia whakapiki
i te oranga o te hūnga kua pāngia
e te mate kaiponapōna*

SUBMISSION TO THE HEALTH AND DISABILITY SYSTEM REVIEW FROM ARTHRITIS NEW ZEALAND

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Submission Summary

Arthritis New Zealand commissioned a study of the economic cost of arthritis in New Zealand in 2018. Deloitte established a total cost of health sector costs and indirect costs (including carer costs, loss of productivity, lost tax revenue, and government payments) of \$4.3 billion for 2018. Additionally, well-being costs are quantified using the standard measure of disability-adjusted life years. For arthritis in 2018 this was \$7.9 billion. The total cost is estimated at \$12.2 billion in 2018.

High costs to the Government related to hospital-based treatments for severe arthritis, loss of productivity related to early retirement and absenteeism, and welfare system and residential care costs can be significantly reduced by earlier intervention, as can suffering in communities. As the population ages this change becomes more urgent.

Arthritis New Zealand agrees with the Annual Report of the Ministry of Health in 2018 which identified the need for several system shifts. This submission pays special attention to two shifts the Ministry identified, that is, the need to reduce the cost of acute care through effective early interventions and lower prevalence of chronic conditions. and the need to focus more on those that do not have access to the services they need and have poor health outcomes.¹

The following equity issues are addressed in this submission:

- Cost barriers to accessing services including costs of transport and healthy food/drink
- Geographical barriers to accessing services
- Discriminatory attitudes to older people reflected in the limited availability of pain management services and other services for people with arthritis
- The invisibility of young people with arthritis – arthritis also affects children and teenagers but at present there are no estimates of the number of people under 15 affected
- Disproportionate impacts of gout arthritis on Māori or Pacific Peoples that are unacceptable in modern times and require urgent action to remedy.

Reducing the cost of acute care and increasing equity of health outcomes are mutually reinforcing and inter-dependent. A greater focus on prevention and early intervention that would be capable of significantly reducing expenditure on acute care and support services would require health, disability and welfare system changes that directly address inequities.

¹ Page 28, Annual Report of the Ministry of Health, 2018.

Introduction

The mission of Arthritis New Zealand is “improving the life of every person affected by arthritis”. We see ourselves as the “go to” organisation for information, advice and advocacy on all aspects of living with and managing arthritis. We have been in operation for over 50 years providing community-based services and support for people with arthritis. In the 2017-2018 financial year over 65,000 people used our education, information and support services. One in five of our clients are Māori or Pacific Peoples.

Over 80% of our annual income comes from grants, donations, and community fundraising throughout New Zealand. We receive approximately 19% of our income from the Government via contracts with Districts Health Boards (DHBs) and a contract for a national Disability Information Advisory Service from the Ministry of Health.

This submission responds to the questions proposed by the review.

1. What are the most important values for our future public health and disability system?

- Efficiency and effectiveness
- Evaluative processes and thinking built into the planning and delivery of all services
- Accountability and transparency
- Fair access for all New Zealanders to health promotion, early intervention and treatment services
- Whole of government policies that lead to a reduction of health inequalities
- Responsiveness to Treaty of Waitangi principles.

2. Think about how the best health and disability system for New Zealand might look in 2030. How would that be different from the system we use today?

2.1 Greater focus on prevention

By 2030 we would hope that the Government as a whole (NZ Inc) will have increased its focus on addressing the determinants of health. Brave leaders will have acted on the knowledge that change is needed to limit increasing costs arising from the ageing of the population, new technologies and increasing clarity regarding unmet needs. This will have led to fundamental change as follows:

- Additional funds will have been made available for more and better investment in early intervention and prevention of non-communicable diseases (NCDs) including arthritis, so these conditions do not worsen and require expensive hospital-based treatments.
- All participants in the health and disability sector will have worked hard to increase public understanding of any tradeoffs necessary to support an early intervention approach and delivery of high-quality health and disability services going forward.
- The Government will have prioritised implementation of the Healthy Ageing Strategy including its focus of prevention of NCDs including muscular-skeletal conditions such as arthritis.

2.2 Arthritis as an example of what is needed and what can be achieved

Arthritis demonstrates the scale of gains that can be made from early intervention. Currently there are 1:6 (670,000) people in New Zealand affected by arthritis. This number is projected to reach nearly one million by 2040.

Arthritis New Zealand commissioned a study of the economic cost of arthritis in New Zealand in 2018. Deloitte established a total cost of health sector costs and indirect costs (including carer costs, loss of productivity, lost tax revenue, and government payments) of \$4.3 billion for 2018. Additionally, well-being costs are quantified using the standard measure of disability-adjusted life years. This is expressed as the number of years lost due to ill-health, disability or early death with a cost attached to each year. For arthritis in 2018 this was \$7.9 billion.

High costs to the Government related to hospital-based treatments for severe arthritis, loss of productivity related to early retirement and absenteeism and welfare system and residential care costs can be significantly reduced, as can suffering in communities.

2.3 Supporting a dynamic non-government sector

New Zealand's ethnic makeup is changing overtime. This provides an impetus for increasing our collective knowledge about what works for different communities. Currently Europeans (including "New Zealanders") are the largest ethnic group at 72% although this group is expected to fall to 65.5% by 2038. At present the Asian group is 15%, Pacific is 8% and Māori is 16%. By 2038 these groups are predicted to increase to 22%, 10% and 18%, respectively.²

By 2030, community and voluntary sector, Māori and Pacifica organisations will have greater certainty regarding funding from the Government. Government funding will be provided for the duration of the period needed to deliver on agreed outcomes. Some activities can be appropriately funded on an annual basis while others require longer term multi-year funding, particularly those directly addressing health inequities. Multi-year funding is needed to enable service providers to plan their activities in a way that supports efficiency and effectiveness.

Non-government organisations actively working on high priority health issues including arthritis should be able to exert greater influence on health policy due to regular and formalised consultation processes with the Ministry of Health. By 2030 consultations will discuss progress against national strategies that exist for high priority health issues.

2.4 Collaboration between sectors

By 2030 we hope there will be a high level of collaboration and trust between all sectors working on health and disability related issues. The biomedical model whereby the system works most intensively to treat people once they are seriously ill would be rebalanced. The five action areas outlined under the Ottawa Charter for Health Promotion, would all be functioning effectively and be mutually supportive:

1. Building healthy public policy

² Data from Statistics New Zealand May 2019.

2. Creating supportive environments
3. Strengthening community action
4. Developing personal skills
5. Re-orienting health care services toward prevention of illness and promotion of health.

For example, health services would be more friendly for the first-time visitor in terms of cost, approachability and face-to-face time. GPs and other health professionals would be more skillful and knowledgeable regarding appropriate referrals to other services including non-medical services in their communities. Community based services would be sufficiently funded and advocacy for healthy public policy would raise public awareness of health issues and how communities and individuals can support each other to improve their health.

2.5 Long-term planning

By 2030 implementation of health and disability work-force development plans including for prevention and treatment of arthritic conditions, should be well underway. The current gap in data on the numbers of children and young people under 15 with arthritis will have been remedied.

The limited number of publicly funded rheumatologists is an on-going problem particularly for those in underserved geographical communities.

2.6 System changes

Some funding could be released for prevention and early intervention by ensuring that government bureaucracy is as light as possible whilst still providing high quality policy advice and services.

The current DHB system needs re-design to promote efficiency. In a country with a small population, the current system of 20 DHBs leads to unnecessary duplication and fragmentation of services and to a lack of consistent prioritisation of arthritis in all regions. We do not see a consistent approach to analysis of need for arthritis treatment and prevention services in each DHB population. Also attracting very experienced and skilled managers to leadership roles across 20 DHBs presents a challenge.

Services should be more joined up so that any first contact would lead to appropriate referral to other parts of the system. We need more rheumatologists, nurses, occupational therapists, pharmacies and physiotherapists able to participate in multidisciplinary management of arthritic conditions. Medical practitioners should consistently refer their clients to community-based organisations such as Arthritis New Zealand for support and information and screen patients with high risk factors for arthritic conditions.

By 2030 agreed integrated care protocols would be in place and working effectively at the interface between community based and hospital services. A holistic approach is needed to address psychological and social needs as well as physical needs to counteract the isolating impacts of chronic pain and immobility.

3. What changes could make our health and disability system fairer and more equal for everyone?

3.1 Some targets are useful

Whilst pursuit of targets provides risks of narrowed focus and working in silos, targets are useful to ensure that neglected issues and communities are prioritised. For example, for diagnosis and treatment of gout arthritis.

Approximately 185,000 people in New Zealand suffer from gout arthritis which during acute episodes leads to intense pain and the need for time off work. Long terms health impacts from untreated gout arthritis include joint and kidney damage.

Māori and Pacific Peoples have two to three times the gout arthritis prevalence of non-Māori and non-Pacific but they are less likely to receive the required treatment to manage their condition. As both the prevalence and severity of gout arthritis is higher in Māori and Pacific Peoples and they are younger when they are affected, greater targeting is required for these groups.

Both Māori and Pacific Peoples are susceptible to gout arthritis for genetic reasons. Effective treatment for gout arthritis is relatively cheap and failure to provide it can be viewed as discriminatory.³

Arthritis New Zealand has proposed a target to increase the percentage of people with gout arthritis on a managed gout arthritis programme from 42% to 55% by 2024.⁴ This would mean a further 23,123 people would be on a urate lowering programme.

Gout arthritis is caused by high levels of uric acid which can be resolved through medication. Achieving adherence to an on-going medication regime requires a substantial education and support effort. The major cost is not in the medicine itself but in the support that people need to fully accept an ongoing requirement to take preventative medicine. Integration of this gout arthritis target into existing health targets and programmes would be beneficial, e.g. diabetes and cardiovascular disease programmes.

3.2 National strategies are needed

Long-term conditions particularly those that will increase with the ageing of the population and therefore provide a substantial burden on the health system going forward, should have an agreed national strategy with reporting on outputs and outcomes and a defined model of care. These strategies should pay strong attention to prevention and early intervention to avoid unnecessary suffering and reduce an explosion of costs as the population ages.

Some NCDs have drivers of chronic pain and mobility problems in common. For example, the risk of developing hip and knee osteoarthritis increases by 11% and 35% respectively for each 5 unit increase in body mass index (BMI). The Ministry of Health report “Health Loss in New Zealand: A

³ See “Gout in Aotearoa New Zealand: the equity crisis continues in plain sight”, New Zealand Medical Journal 2018, Volume 131, Number 1435.

⁴ Prevalence data from the Health Quality and Safety Commission 2018 Update.

report from the New Zealand Burden of Diseases, Injury and Risk Factor Study 2006-2016” found that a high BMI accounts for approximately 60% of health loss.

Our closest neighbor Australia has a national strategic action plan for arthritis and agreed models of care in some states.⁵ The national strategy notes that its implementation will slow the demand for joint replacement surgery in the medium to long term as a result of better management of earlier stage disease, improve workforce participation, reduce arthritis related disability and reduce the considerable pain burden of the disease. It advises that up to 70% of the osteoarthritis of the knee is preventable by avoiding excess weight and joint injuries.

Arthritis New Zealand asks the Minister of Health to develop in collaboration with Arthritis New Zealand and other key stakeholders, a national strategy for the management of arthritis and that it reports back to the Health Select Committee on progress by 2021 and to the public in the Ministry of Health’s Annual Report. Further, we ask for development of a model of care that includes good practice guidance on:

- Arthritis prevention - early intervention, healthy lifestyles
- Early diagnosis - trained and resourced health professionals
- Early treatment - primary care or access to specialist services
- Ongoing treatment - coordinated care, information and advice to adopt healthy lifestyles and remain in the workforce
- Advanced care and surgery - multidisciplinary management, timely referral, and clear information.⁶

The lack of a model of care for arthritis is reflected in current delivery as follows:

- Limited resourcing for arthritis prevention and early intervention
- A shortage of rheumatologists and special interest GP’s
- Lack of a training pathway for rheumatology nurse specialists and practitioners
- General practice nurses and doctors untrained in managing musculoskeletal disorders
- Poor adherence to guidelines for care of people with osteoarthritis and gout arthritis
- Joint replacement is difficult to access except for the most disabled or those who can pay
- Postcode health care – some geographical areas are better off than others.

4. What changes could most improve health for Māori?

Poverty reduction would improve health and reduce stress related to poor housing and overcrowding. It would reduce cost barriers to health services and broaden transport options. Poverty reduction would contribute to increased enrollment with GPs services and improve access to healthy food.

Implementation of the NZ Māori Health Strategy, He Korowai Oranga, requires that Māori participation is supported at all levels in the health and disability sector. We would like to see improvement in the quality of partnerships between Māori providers, iwi, Māori communities and mainstream organisations through greater sharing of information at strategic and operational levels.

⁵ National Strategic Action Plan for Arthritis, Department of Health, Australian Government, 2019.

⁶ An osteoarthritis model of care should be a national priority for New Zealand, Baldwin, J., Briggs, A., Bagg, W., and Larmer, P. (2017) New Zealand Medical Journal, 130 (1467), 78-86.

Arthritis New Zealand supports implementation of a model of care for arthritis that is culturally sensitive and will lead to improve cultural capability in services including increasing numbers of Māori staff to improve service delivery to Māori.

Urgent efforts are needed to increase the number of Māori people receiving effective treatment for gout arthritis including development of a sufficiently funded and culturally appropriate social marketing campaign for gout arthritis.

Obesity and lack of exercise significantly worsen arthritic conditions therefore these issues need to be addressed more effectively via both mainstream services and Māori services. This requires increased focus within the health system on prevention and early intervention.

Investing in research on rongoā Māori would provide an evidence base in relation to traditional Māori medicines for pain management.

5. What changes could most improve health for Pacific peoples?

Pacific Peoples experience similar issues to Māori associated with relative poverty in New Zealand. Along with poverty reduction, Pacific Peoples would also benefit from urgent action on gout arthritis. Pacific Peoples may not label themselves as poor as they experience the strength of their family, community and church relationships as a source of wealth. Pacific Peoples want a stronger role in designing solutions for Pacific communities and recognition of the diversity of Pacific Peoples. This involves development of a culturally appropriate model of care.

Pacific Peoples seek greater flexibility in contracts with the Government to enable them to do things differently, that is, to do their work their way. Funding would be longer term and would provide opportunities for Pacific services to undertake staff training, research and evaluation and scale up knowledge and use of information technology.

6. What changes could make sure that disabled people have equal opportunities to achieve their goals and the life they want?

Greater appreciation of disability as a human rights issue would be useful. New Zealand played a leadership role in the development of the Convention of the Rights of People with Disabilities and maintains a strong voice on disability rights internationally. Matching this international leadership with domestic policy is an on-going challenge.

Research shows that long-term pain has a big impact on mental health, especially depression, and the causal relationship between pain and low mood most likely works in both directions.⁷ People with arthritis would benefit from improved access to adequately funded pain management services and recognition that arthritic pain is a cause of anxiety and depression. Depression is linked with many rheumatological conditions, particularly fibromyalgia. People need support to manage their psychological needs associated with a diagnosis of arthritis.

⁷ Studies have found a relationship between pain and depression, for example, Gureje et al 1998, 2007 & Demyttenaere et al, 2006.

People with poorly managed arthritis are more likely to be depressed than those with well controlled arthritis. The link between mental health and arthritis is more evidence of the need for early intervention on arthritis to avoid deteriorating health in other areas.

Mandatory standards at national level for accessible packaging would make life a lot easier for some people with disabilities. Accessible product packaging benefits people with arthritic conditions, diabetes, and sensory and muscle weakness problems.

In line with the Expert Advisory Group's Report on Welfare: Whakamana Tangata,⁸ Arthritis New Zealand would like to see early intervention via the welfare system to help people with arthritis remain in or return to work. Work opportunities help with mental health and well-being and assist with managing additional costs of disability. The welfare system should do more to support part-time work for people with arthritis in its many forms. This means addressing abatement rates for beneficiaries, for example, 70 cents in every dollar for the Supported Living Payment after a person earns more than \$200 a week and accepting that for some people part time work is the most that they can manage. One way to do this in respect of the Supported Living Payment is to raise the abatement threshold to \$250 as proposed in Whakamana Tangata.

7. What existing or previous actions have worked well in New Zealand or overseas? Why did they work and how might they make things even better in the future?

Arthritis has not been sufficiently prioritised as a health issue in New Zealand. Other countries, for example, Australia and Ireland, have developed national strategic plans. These high-level plans aim to address the mismatch between the burden and cost associated with arthritis and its prioritisation in policy and resourcing. This mismatch may reflect commonly held views that arthritis only affects old people and that it is an inevitable part of ageing about which little can be done.

An example of improved quality of care in Australia is the New South Wales Osteoarthritis Chronic Care Program (OACCP). This provides assessment and non-surgical management for people on the waiting list for joint replacement surgery. Evaluation of the model found that it improved clinical outcomes, facilitated earlier access to surgery where clinically indicated, and reduced demand for surgery, with 11% of participants waiting for knee replacements and 4% awaiting hip replacements deciding they no longer required surgery.⁹

Unfortunately, New Zealand does not have a nationally consistent approach at present. There are, however, pockets of innovation and good practice.

For example, the Mobility Action Programme (MAP) is an early intervention programme for people with musculoskeletal conditions including arthritis. A first phase of evaluation found that the programme has contributed to improvements in mobility, function and pain and people's ability to self-manage their conditions. A final evaluation will be completed in 2020. Arthritis New Zealand will be watching progress closely with a view to supporting the Ministry of Health to quickly scale up the programme should this be warranted.

⁸ 3 May 2019

⁹ National Strategic Action Plan for Arthritis, Department of Health, Australian Government, 2019.

The Gout Stop Programme run by Manaia PHO, Te Tai Tokerau PHO and Northland DHB (Arthritis NZ was involved in the early stages) is making progress. It is a collaborative project with GPs, pharmacists and health workers to improve gout arthritis management in Northland. It challenges the whakamā (embarrassment/shame) around gout arthritis throughout Northland by providing community-based education, help with easy medication management (blister pack medication, prescription protocols and point-of-care testing). It encourages re-admission into the programme if required.

The results from the Gout Stop Programme from June 2015 - October 2018 were:

- 63% of total patient numbers completed the treatment programme
- Of those, 41% successfully achieved the treatment target and 25% required further medication changes
- 65% of the total completed number of patients continue to be prescribed preventative medication. This is above the national rate of 42%.¹⁰

8. What are the most important changes that would make the biggest difference to New Zealanders?

For people with arthritis the most important change we seek is the development of a national model of care. New Zealand needs to take arthritis more seriously and move away from outdated attitudes including the view that debilitating arthritis is an inevitable condition of ageing. This change needs to be part of a health and disability system change towards provision of more funding and support for public health approaches.

Government funding for preventative approaches to health issues has been whittled away in recent years. The public health workforce is small and fragmented. Primary Health Organisations (PHOs) have found limited capacity to reach out with health promotion services and public health policy advice. Some large PHOs and Maori providers have health promotion units, but these are the exception rather than the rule. The Health Promotion Agency appears to be relatively well funded but works on a limited number of issues.

While the Health Promotion Forum has played a valued role in promoting professional development for the health promotion work force, it remains the case that health promoters have fewer opportunities for professional development than doctors and nurses.

The Ministry of Health needs to strengthen its expertise and resources in public health. Arthritis New Zealand supports establishment of an adequately staffed public health group within the Ministry of Health that is headed by a Director of Public Health who is part of the Ministry's senior management team. This Division should consider and advise on all preventative health approaches that can improve the lives of people with arthritis. A focus on prevention of arthritis, including through addressing obesity and lack of exercise, will have substantial benefits for other NCDs and mental health.

Recreation of a Public Health Commission would promote independent examination and public consultation on politically challenging public health issues.

¹⁰ Reported by the Gout Atlas of the Health Quality and Safety Commission of New Zealand: In 2016, on average, 42% of people identified with gout regularly received urate-lowering therapy.