Arthritis Foundation of Australia
Level 2, 255 Broadway, Glebe NSW 2037
PO Box 550, Broadway NSW 2007
p: +61 2 9518 4441
e: info@arthritisaustralia.com.au
w: www.arthritisaustralia.com.au

Submission to

National Medicines Policy Review

ABOUT US

Arthritis Australia is the peak arthritis organisation in Australia and is supported by affiliate offices in ACT, New South Wales, Northern Territory, Queensland, South Australia, Tasmania and Western Australia.

Arthritis Australia provides support and information to people with arthritis as well as their family and friends. It promotes awareness of the challenges facing people with arthritis across the community, and advocates on behalf of consumers to leaders in business, industry and government.

In addition, Arthritis Australia funds research into potential causes and possible cures as well as better ways to live with the disease.

For further information on this submission contact:

Louise Hardy, National Policy and Government Relations Manager

Introduction

Thank you for the opportunity to make a submission to the review of the National Medicines Policy (NMP). Few other jurisdictions worldwide have a national medicines policy, so this review represents an opportunity for Australia to lead and innovate, in reviewing the impacts of its 20 year old policy and ensuring that it is contemporary and fit for purpose moving forward in an environment of rapid technological development.

Medicines policy has a range of significant impacts on people living with arthritis, and we have attempted to highlight the key issues and address the consultation issues of most relevance to our consumers.

We note that this is a review of high level policy, as opposed to the various programs involved in delivery, but the NMP must enable the development, coordination and improvement of policies and programs to deliver better health outcomes for the Australian community.

Our key recommendations are summarised as follows:

- We recommend an additional principle along the lines of: Safe care across the patient journey by maximising the utilisation of information.
- Equity is not currently being achieved and the NMP must provide a framework to address the variations and inequities of access and governance by jurisdiction and at the hospital and specialist level
- In order to achieve consumer centricity, a diverse range of consumers must have input at every level and be supported to actively participate. Key information must be communicated in a way that can be readily accessed and understood, including for people without internet access.
- Increased transparency and accountability is needed, with overarching governance and performance measures, and greater transparency around the real cost of medicines and how cost factors into decision making are made.
- The NMP must include a consideration of potential unintended consequences of regulations and restrictions around high cost drugs at the individual patient level, including the stress and anxiety of navigating complex processes. It is essential that these complex processes and restrictions are communicated clearly and transparently, and patients are supported to navigate them.
- Continuity of medicines supply must be a core component of the NMP, given the serious adverse impacts on patients of medicines shortages such as the current tocilizumab shortage. The medicines shortage task force or an equivalent group should become a permanent feature.
- There continues to be an important role for an independent implementer, such as NPS Medicinewise, that has the capacity to bring diverse stakeholders together.
- The NMP must be responsive to new technologies in therapeutics.
- We recommend that researchers are included as key partners in the NMP.

The burden of arthritis

Arthritis is one of the most common, costly and disabling chronic conditions in Australia, affecting 3.9 million people, or one in six Australians. Musculoskeletal conditions cost the

Australian health system $14 billion in 2018/19, or 10.3% of total health expenditure that can be allocated by disease[1], the majority of which is related to arthritis.

There are over 100 types of arthritis, with the most common being osteoarthritis, which affects 2 million people. Inflammatory forms of arthritis, including rheumatoid and juvenile arthritis and related conditions affect 1.7 million Australians. Arthritis and musculoskeletal conditions account a similar total burden of disease and injury in Australia as mental health conditions.

Arthritis is a leading cause of chronic pain and disability in Australia, and is one of the most common comorbid conditions. Three out of four people with arthritis have at least one other chronic condition, and arthritis increases the risk of developing other chronic conditions, and complicates their management for reasons including its treatment[2].

Medicines in arthritis treatment and pain management

Patients with arthritis often require medicines for treatment and pain management, including (for inflammatory arthritis) immunosuppressive drugs and biologics which must be prescribed by a specialist and only if other medicines have failed. Medicines prescribed include:

- Analgesics, ranging from over-the-counter to prescription opioids
- Non-steroidal anti-inflammatory drugs
- Corticosteroids
- Disease-modifying anti-rheumatic drugs (DMARDS)
- Biologic disease-modifying anti-rheumatic drugs (bDMARDS)

Musculoskeletal conditions including arthritis are the leading cause of chronic non-cancer pain and are the leading health problems for which opioids are prescribed in primary care[3].

A recent Arthritis Australia consumer survey found that one in four respondents were dissatisfied with the medications and treatments available for their condition, most commonly people with osteoarthritis.

[1] Australian Institute of Health and Welfare 2021. Disease expenditure in Australia 2018-19. Cat. no. HWE 81. Canberra: AIHW. Viewed 22 October 2021, https://www.aihw.gov.au/reports/health-welfare-expenditure/spending-on-disease-in-australia

[2] Arthritis Australia 2019. Evidence to support the National Strategic Action Plan for Arthritis p 4. Viewed 22 October 2021, https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2019/06/190612-Final_Evidence-to-Support-the-NSAPA_Word-Refs.pdf

[3] Arthritis Australia 2018. Arthritis Australia submission to the TGA consultation on Prescription strong (Schedule 8) opioid use and misuse in Australia – options for a regulatory response p. 1. Viewed 22 October 2021, https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2020/01/Arthritis-Australia-submission-to-the-TGA-consultation-on-opioids-March2018.pdf

For people with inflammatory forms of arthritis, the most common concerns were finding and accessing the right treatments, fear of certain medications and medication side effects [4].

Arthritis patients face a range of challenges in relation to medicines including:

- Out of pocket costs, particularly for patients prescribed multiple medications who may need to fill well over 100 scripts per year, in addition to the costs of tests and specialist care. It is common for people with arthritis to be forced to reduce their work hours or retire early due to their condition, which compounds the financial impact.
- Polypharmacy and the risk of drug interactions and adverse health outcomes.
- Effective pain management, including use of opioids, in circumstances where non-pharmacological interventions such as physiotherapy can be difficult or costly to access.
- Use of complementary medicines or other unproven therapies, which may be ineffective or cause harm. People with arthritis and musculoskeletal conditions are major users of complementary medicines with around 60% of people trying a range of products[5].
- For patients with inflammatory forms of arthritis, accessing high cost drugs such as biologics requires navigating various restrictions which may contribute to stress and fear of missing out on treatment or running out of treatment options:
    - Early diagnosis and treatment can have a major impact on health outcomes
    - Patients are only able to try a limited number of biologics before becoming ineligible
    - Patients may respond well to a drug initially, but over time it may stop being effective
    - Requirements for prescriptions to be reapproved on a six monthly basis, which includes the need for a specialist appointment and submission of forms mostly via mail, can lead to delays and gaps in the patient's supply of the medicine
    - The potential health impacts of repeatedly switching between biologics and biosimilars are not known
    - Drug shortages have occurred, particularly in the covid context, and are likely to be a continuing issue. The current shortage of tocilizumab, which is being used to treat covid patients, has meant that many Australian patients, including children with severe arthritis, have had to change medications and risk adverse health outcomes. All possible efforts must be made to avoid this situation in future, and to this end the medicines shortage taskforce should become a permanent feature, in order to manage ongoing and future shortages.

[4] Arthritis Australia 2020. Consumer Research Activities 2018-2019 p. 7-8. Viewed 22 October 2021, https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2020/05/Arthritis-Australia-Consumer-Research-Report_May-2020.pdf

[5] Bishop FL, Yardley L, Lewith GT. A systematic review of beliefs involved in the use of complementary and alternative medicine. J Health Psychol 2007; 12:851-67

It is important that the refreshed NMP and its principles provide a comprehensive framework through which policies and programs can evolve to address issues faced by specific patient groups such as people with arthritis.

Feedback on the National Medicines Policy and the proposed principles

Arthritis Australia supports the articulation of underlying principles for the refresh of the NMP. Our comments in relation to the principles proposed and relevant considerations for policy are below, but we would also propose an additional principle as follows:

Safe care across the patient journey by maximising the utilisation of information

There are well documented fragmented systems and information transfer issues for patients transitioning between primary, secondary and tertiary care in Australia, including on their medicines. This can result both in unnecessary duplication and in potential adverse outcomes from polypharmacy, side effects and interaction of medications or clinical decisions based on incomplete information.

To provide safe care for the whole patient journey, we must integrate data and maximise the utilisation of data across the health system.

Equity

Equity is an essential principle for the NMP, and consumers need timely access to the right evidence based therapies to treat and manage their condition. However, this needs to go beyond the Pharmaceutical Benefits Scheme to consider what equity means in a federated health system and how to address the variations and inequities of access and governance by jurisdiction and at the hospital and specialist level. Reducing out of pocket costs for consumers must be a key focus.

Consumer centred approach

We strongly support this principle, and agree that the passive framing of the NMP needs to be reworked so that consumer input and codesign is central to the development and implementation of policy, recognising that current systems have often evolved around the needs of providers rather than consumers. Consumer representatives must be provided with support to take an active role.

More broadly, increasing the awareness and understanding of medicines policy in the community must be a key aim of the NMP. We support the recommendations contained in the Consumer Health Forum's submission, and particularly the need to move away from a deficit frame of consumer's lack of health literacy, instead putting the onus on health system stakeholders to communicate with consumers in a way that can be readily understood by them, including people who do not have internet access.

The NMP itself and supporting communications should be drafted in plain English, and visual tools such as maps should be used to show how key programs and policies connect.

Partnerships

There continues to be an important role for an independent implementer, such as NPS Medicinewise, that has the capacity to bring diverse partnerships together.

Accountability and transparency

Unfortunately, it is clear that at least some objectives of the NMP, such as equity of access, are not currently being met. We recommend that in order to meet the objectives of the NMP, particularly given the complexities of our federated system, active overarching governance is required to develop and monitor performance indicators and ensure accountability and a focus on outcomes. The role of patient reported experience measures and patient reported outcome measures should be considered. We therefore recommend that the wording of this principle be revised to include stronger reference to monitoring of performance and outcomes.

Consumers must play a key role in the implementation of this principle, and there should be mechanisms to ensure input from consumers with a diverse range of health conditions. We support the recommendation of the Consumers Health Forum for an annual National Medicines Policy Forum, which would be open to anyone who wishes to attend.

Increased transparency around the real cost of medicines and how cost factors into decision making are made is also recommended.

Stewardship

We strongly support this principle, however as noted above, access to high cost and early access to new drugs is vitally important to people suffering from severe forms of inflammatory arthritis. This principle must include an awareness of potential unintended consequences of regulations and restrictions at the individual patient level, including the stress and anxiety of navigating complex processes. It is essential that these complex processes and restrictions are communicated clearly and transparently, and patients are supported to navigate them.

Scope of the policy

The NMP must be responsive to new technologies in therapeutics. We recognise that there are compelling arguments on both sides of the proposal to include medical devices and vaccines, with devices, diagnostics and medicines becoming increasingly enmeshed and genomic technologies not fitting neatly into traditional categories, as described in the Discussion Paper.

A policy that is forward looking and designed in a consumer centric way will need to recognise these developments without detracting from the focus on issues relating to medicines, and ensure that there is overarching coordination with any other relevant policies and identification of overlaps.

We also support the call of the Australian Patient Advocacy Alliance to include equitable access to clinical trials and medicines access programs in the refreshed NMP.

Other consultation questions

We recommend that researchers are included as key partners in the NMP.