

1. Introduction

Musculoskeletal Australia (www.msk.org.au) is a consumer-driven organisation working to support people for better musculoskeletal health. We work on behalf of the nearly 7 million Australians living with conditions such as osteoarthritis, back pain, rheumatoid arthritis, gout, osteoporosis, fibromyalgia and more than 150 different musculoskeletal conditions. Musculoskeletal Australia has been supporting people with arthritis and musculoskeletal conditions for 50 years.

We are committed to empowering people with musculoskeletal conditions and those at risk of them. We do this with empathy and understanding through the provision of information, services, and products.

Musculoskeletal Australia works in partnership with other relevant groups, including health professionals, universities, research organisations and government to achieve its aims. Importantly, it has a very active Consumer Advisory Committee that supports the Musculoskeletal Australia Board and management on the strategic direction and future planning of our programs and services.

Further information regarding this submission, please contact Ms Genevieve Nolan, Policy and Programs Manager, Musculoskeletal Australia via email genevieve@msk.org.au or via phone 03 8531 8018.

2. Responses to the questions posed in the 'Review of the National Medicines Policy - Discussion Paper'

TERMS of REFERENCE No.1

- A. Are these proposed principles appropriate? With regards to the proposed principles, is anything missing or needing to change?
- In relation to the first proposed principle of 'equity', Musculoskeletal Australia suggests that the word 'timely' be added to the explanatory statement and that people's differing circumstances be more clearly spelt out and defined, i.e. 'all Australians receive effective, safe, high-quality, affordable and timely access to medicines when needed, irrespective of their geographic, financial, socio-economic circumstances and diverse backgrounds.'
- Depending on the 'appetite' of the Committee and in the interests of a more humane Australian society, the above amended statement could also be further re-worded to include refugees and asylum seekers as follows '... irrespective of their geographic, financial, socio-economic and legal circumstances and diverse backgrounds.'

Regarding the second principle of a 'consumer-centred approach', the explanatory statement should be reworded to reflect that a truly consumer-centred approach will, not be achieved 'by simply engaging, informing and empowering consumers to participate in medicines policy', but will also require a more receptive and permissive environment to be engendered within the broader health system. This more receptive and permissive environment should then enable, promote and respect the participation of individual consumers in shared decision-making with their healthcare professionals, as well as the input of consumer representative organisations in broader policy development and implementation. Without this broader, systemic approach to empowering consumers (and the concomitant change in health providers' attitudes and behaviours that is required), consumers will continue to 'hit brick walls' regardless of their levels of information and empowerment.

Musculoskeletal Australia suggests that a rewording of the explanatory statement for the 'consumer-centred approach' principle as follows: 'Consumers should be informed, engaged and empowered to participate in medicines policy, with relevant stakeholders in the healthcare industry also playing an important role by actively facilitating this engagement and empowerment on both an individual and broader levels.'

- Instead of the suggested principle of 'partnership based', Musculoskeletal Australia recommends that the principle of 'Collaboration' be used, as this better captures the sense of diverse interest groups and stakeholders agreeing to work together for a common purpose.
- Musculoskeletal Australia supports the inclusion of the principle 'accountability and transparency' however, the explanatory statement should provide some guidance as to who or what all stakeholders will be accountable. Without this clarification, the statement lacks strength and meaning. Even if the National Medicines Policy (NMP) simply provides the framework for many services and programs which are implemented, the 'flow through' of the Policy into these services and programs must be overseen.
- While the term 'stewardship' is a friendlier and gentler word than the term 'governance', it does convey the spirit with which the NMP and all related programs and services should be developed, managed, monitored and evaluated by all stakeholders. Musculoskeletal Australia therefore believes that, incumbent within the concept of stewardship, should be the notion of timely review and reflection and suggests this principle be re-worded to 'Stewardship and timely review'.
- B. Are these four objectives still relevant? Should any be modified, or any additional objectives be considered? If so, how and why?

Musculoskeletal Australia believes that the four current objectives are sufficiently broad and robust to remain relevant within a revised NMP. There are, however, components of the details of each of the objectives which need to be more clearly articulated and strengthened.

These include the following, based on the reported experiences of many consumers with musculoskeletal conditions:

- Timely access to medicines There can be time delays between some medications being prescribed by healthcare professionals and finally being obtained by consumers. An example involves biologics and biosimilars with the latter often having a PBAC-assigned streamlined authority (or approval for use), whereas some biologics have a 'written authority required' and less streamlined approval for use which takes longer.
- Medicines at a cost people can afford Musculoskeletal Australia's national consumer survey conducted in 2020 (www.msk.org.au/mskconsumersurvey2020/) clearly identified the financial strain experienced by many people with at least one or more chronic health conditions. Of the 65% of survey respondents that indicated they experienced financial stress as a result of their condition, 39% indicated that the main cause of their financial stress was the cost of their medications.
- Quality use of medicines Unfortunately, it appears to be a fairly common occurrence that
 medicines provided to patients in hospital settings are not always accompanied by clear
 information detailing their risks and benefits. If a patient/consumer's capacity and health status
 allows, they are still entitled to receive the relevant information about the medications they are
 receiving, particularly regarding potential side-effects.

TERMS of REFERENCE No.2

A. Should the current NMP definition of medicines be expanded to include medical devices and vaccines? Why or why not? How would a change in definition of medicines be reflected in the policy's high-level framework?

Musculoskeletal Australia does not have a specific view in relation to this issue, however, if it strengthens the access, quality, safety and efficacy of medical devices and vaccines to have them included within the one policy with medicines, then Musculoskeletal Australia would view this positively. On the contrary, if their inclusion weakens the overall policy and oversight, they are best dealt with separately.

B. Does the policy's current title. The 'National Medicines Policy' reflect the breadth of health technology developments within the policy's scope? If not, how best can these and future health technologies be better represented in the policy's title?

As per the Therapeutic Goods Administration's (TGA) website, and should medical devices, vaccines and other health technology developments be included within the scope of the revised policy, should the 'National Medicines Policy' be renamed to the 'National Therapeutic Goods Policy'?

The TGA website defines therapeutic goods as:

- **Medicines** including prescription, over-the-counter and complementary medicines, such as paracetamol and echinacea
- Biologicals something made from or containing human cells or tissues, such as human stem cells or skin
- Medical devices including instruments, implants and appliances, such as pacemakers and sterile bandages

TERMS of REFERENCE No.3

A. How has the NMP been able to maintain its relevance and respond to the changes in the health landscape?

Musculoskeletal Australia believes that it is timely (if not overdue) to review the NMP given it was formulated over 20 years ago. As per the comments of audience members in several 'NMP Review' information sessions recently attended by Musculoskeletal Australia staff, many people had never previously heard of the NMP.

Given the NMP is designed as a high-level framework, it cannot be expected to anticipate and cover in detail all recent and future developments in the areas of medicines and health technologies. If anything, the objectives of the current NMP have been sufficiently broad but robust to ensure the NMP has 'stood the test of time' and retained a level of relevance over the last two decades.

Keeping up with developments in the areas of medicines and health technologies might be one consideration in relation to the NMP moving forward, but it is even more important that the Policy remain relevant and up-to-date in line with the contemporary experiences of health consumers. This will be assisted by a having several consumer representatives involved in oversight and governance processes.

B. How could the NMP be refreshed so that the policy framework is able to better address current and future changes in the health landscape? What is missing and what needs to be added to the policy framework, and why?

If the next version of the NMP is to remain as a high-level framework and not get 'bogged down' in specifics, the challenge will be to create a policy that has key elements (i.e. objectives, principles, overarching key issues and considerations) that are sustainable; broad, but still suitably targeted and relevant; and not time-dependent.

The section of the 'Review of the NMP - Discussion Paper' relating to Terms of Reference 3 outlines various recent and emerging developments in the fields of medicines, health technologies and related research. While these are all highly relevant, Musculoskeletal Australia does not believe that the NMP would benefit from detailed coverage of current and emerging issues. Instead, it should be the task for

the NMP Review Committee to somehow acknowledge and cater for these and other relevant issues in the over-arching policy they develop.

One area that does deserve additional attention in the revised NMP is, what is meant by and how best to achieve, a truly consumer-centric NMP and related services and programs (see Musculoskeletal Australia's response to the next question).

TERMS of REFERENCE No.4

A. How can the NMP's focus on consumer centricity and engagement be strengthened? Is anything missing and what needs to be changed?

The need to strengthen the consumer-centricity of the next iteration of the NMP is required on two levels – at the decision-making level in relation to national policy development and approval of new medicines and health technology, as well as at the individual patient/consumer level.

The section of the 'Review of the NMP - Discussion Paper' relating to Terms of Reference 4 outlines the range of national committees and initiatives where consumer representatives are actively involved and this is to be commended. It is also pleasing that a consumer representative is involved as a member of the NMP Review Committee, although it was previously common practice for more than one consumer representative to be appointed to a committee to provide a more supportive experience. Consumer representatives and their organisations must be adequately resourced and supported to maintain this level of engagement. Consumer representatives should also be drawn from a range of consumer organisations to ensure a diversity of consumer perspectives and experiences.

While the involvement of consumer representatives in national committees and initiatives is commendable, the challenge for the committees (not just the consumer representative members) is to then communicate with the broader group of health consumers about the findings, outcomes, results of their deliberations and work. More effort, resources and contemporary communication 'know-how' must be committed to this cause, so that relevant health information is communicated to the general public in 'plain language' and translated or made accessible for its very diverse intended audience. Consumer organisations can play a role in this information dissemination but must be adequately resourced; the principal responsibility for this information dissemination and communication, however, must rest with the relevant level/s of Government.

In relation to the NMP's goal of achieving improved health outcomes, much work needs to be undertaken to promote a greater level of engagement and informed/shared decision-making at the individual patient/consumer level.

As revealed in Musculoskeletal Australia's 2020 national consumer survey (www.msk.org.au/mskconsumersurvey2020/), to be able to make informed decisions, people need information that is factual, up-to-date and based on solid research. It should also be available in a format that best suits their needs and is easy to understand. The respondents to our survey showed a

clear interest in understanding their musculoskeletal condition/s and how to manage them with 35% wanting a better understanding of their condition/s and how to manage them and 24% wanting information resources that are easy to access and understand.

Furthermore, our survey also showed that 54% of people sourced their information through online searches and 10% used social media. Although these are rich sources of information, the volume can be overwhelming. It can also be difficult to find and identify credible information as people are often time poor and may lack the skills to critically appraise the information they access online.

While consumer-focused organisations such as Musculoskeletal Australia are working hard to meet the information needs of consumers, true consumer engagement and informed/shared decision-making also requires a more receptive and permissive environment to be engendered within the broader health system. Without this broader, systemic approach to empowering consumers (and a concomitant change in health providers' attitudes and behaviours to facilitate this empowerment), consumers will continue to 'hit brick walls' regardless of their individual levels of information and empowerment.

Musculoskeletal Australia is a strong advocate of the concept of self-care' which focuses on empowering people with the knowledge and ability to be active participants in their own health and wellness.

The importance of engendering a more receptive and permissive environment within the broader health system is outlined comprehensively in the Mitchell Institute's report, 'Self-care for health: A national policy blueprint', which was launched by the Federal Minister for Health in October 2020. One of the nine 'building blocks' within the Blueprint covers the importance of health workforce competencies and skills being improved to effectively support self-care. A key component of consumer self-care is being informed and health literate, so this provides a very translatable and relevant exemplar for the revision of the NMP. Other building blocks within the Blueprint include a consumer engagement framework and national health literacy strategy.

TERMS of REFERENCE No.5

A. What opportunities are there to strengthen governance arrangements for the NMP? What would these be and why?

Musculoskeletal Australia believes that governance arrangements within the next iteration of the NMP must be determined and clearly outlined. The current version of the NMP promotes the notion of partnership and all relevant stakeholders working together, however, achievement of the NMP's objectives will be better ensured if there is a level of oversight and governance.

A specifically created governance or oversight group could involve representatives from the various partners mentioned in the current policy. In particular, there should be several consumer representatives on the oversight group to ensure a diversity of consumer perspectives and experiences.

B. How can communication about the NMP be enhanced or improved?

As mentioned earlier, there are many people (even people involved with health sector organisations) who have never heard of the NMP. Starting at such a low baseline, communication efforts around the NMP can only get better!

Sufficient resources and contemporary communication 'know-how' and a variety of methods and channels must be committed to informing relevant stakeholders and the broad audience of health consumers about the revised NMP. A communication plan around the NMP should be developed to ensure all communication is coordinated and integrated rather than occurring in an *ad hoc* and piecemeal fashion.

Any information should be communicated to the general public in 'plain language' and translated or made accessible for its very diverse intended audience. Again, consumer organisations can play a role in this information dissemination but must be adequately resourced.

Not that health consumers need to be made aware on a daily basis about the NMP, but they should be aware of its existence and the system it aims to establish and oversee. If health consumers are aware of the NMP, they can ensure that the NMP is meeting its goals of delivering healthcare of a high standard and which is responsive to their needs.

C. What would be effective mechanisms to support communication about the policy?

Consumer organisations, such as Musculoskeletal Australia, could be resourced to play an important role in the dissemination of information about the revised NMP to health consumers.

These consumer organisations could facilitate the input of their consumer audiences to ensure that the information developed is in relevant, accessible language and provided in diverse formats. Much current health information intended for a consumer audience is developed by health bureaucrats, who exist in a 'world away' from the reality of health consumers' lives and experiences.

TERMS of REFERENCE No.6

A. How should the NMP's 'partnership based approach' be defined?

As previously stated, Musculoskeletal Australia recommends that the principle of 'Collaboration' be used instead of 'partnership based' as this better captures the sense of diverse interest groups and stakeholders actively agreeing to work together for a common purpose.

The notion of partnership is not well defined in the current NMP and would benefit from greater clarity and specific direction. The literature around partner relationships indicates that there is a continuum of different partnership arrangements and styles, such as:

- Networking exchanging and disseminating information between partners;
- Coordination working alongside each other to reach common goals and align advocacy efforts;
- Cooperation sharing resources and expertise;
- Collaboration working together with a shared purpose and to reach common goals with shared goals, resources, and mutual responsibilities.

Thought needs to be given as to what levels and types of partnership are being required or recommended within the NMP to achieve its objectives.

Furthermore, a specifically created governance or oversight group, involving representatives from the various stakeholder groups, would play a key role in monitoring all partner relationships, their progress and outcomes.

B. What is missing from the policy's reference to the NMP partners? Are there other partners that should be included in the policy? Who would they be and why?

Musculoskeletal Australia suggests that the current review process governing the NMP will reveal all interested and relevant stakeholders, should there be other groups beyond those identified in the current policy.

C. How could the NMP be refreshed to support greater accountability amongst the NMP partners? How could the partnership approach be improved?

Musculoskeletal Australia believes that many of its previous responses sufficiently indicates its views in relation to this question.

D. How are conflicts of interest currently managed and should more be done to address this amongst the NMP partners? What approaches could be taken?

Musculoskeletal Australia believes that a specifically created governance or oversight group, involving representatives from the various partners, should have a key role in monitoring potential conflicts of interest and have relevant policies and processes to deal with them, should they arise.