



Arthritis NZ

Matepona
Aotearoa

**Submission from Arthritis NZ to Pharmac on
Exceptional Circumstances Framework
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1. About Arthritis NZ

Arthritis NZ welcomes the opportunity to comment on Pharmac's Exceptional Circumstances Framework

We do so on behalf of more than 860,000¹ New Zealanders living with arthritis, a diverse group spanning over 100 different conditions, from osteoarthritis and gout to complex inflammatory diseases such as ankylosing spondylitis, psoriatic arthritis, lupus, and scleroderma. For many of these conditions, access to medicines is not a *nice to have*- it is imperative for them to manage their condition so they can continue to work.

Our organisation exists to ensure that people affected by arthritis have equitable access to the information, education, and support they need to live well. We provide frontline services through Arthritis Assist, national and online peer groups, community-based programmes, and advocacy that ensures consumer voices are heard in health policy discussions, including those involving Pharmac.

These voices consistently emphasise that certainty, equity, and fairness in medicine funding are key concerns, and these values are reflected in this submission.

2. Background to this submission

Applications for arthritis medications to the Exceptional Circumstances Framework are usually made through the NPPA process and that is the process that this submission will focus on. These applications are usually for medications to manage inflammatory arthritis. We have read the New Zealand Rheumatology Association (NZRA) answers to the questions posed in the Questions for Consultation and agree strongly with their responses.

This submission is based on consultation with consumers and Arthritis NZ staff and is focused on consumer experience and perspectives. We have chosen to respond with this format as the Questions for Consultation do not provide enough opportunity for us to communicate consumer perspectives. It will focus on the NPPA process of the Exceptional Circumstances Framework as that was the focus of consumer feedback.

3. Named Patient Pharmaceutical Process

The following issues have been identified in the feedback we have received

¹ NZ Health Survey, 2024/25

Equity

Some specific examples of when Pharmac decisions appear to be arbitrary and inequitable are

- The decision several years to decline funding for a patient with Vexas. Other NPPA applications for patients with this condition had been approved as the condition was considered rare. An increasing number of applications led to a decision that the condition was no longer rare, so this NPPA application was therefore declined. We wish to know what exactly the cutoff point is numerically for making a condition exceptional.
- No consideration being given to societal impact- factors such as loss of employment, caregiving burden, disability support costs and avoidable hospitalisation are not considered
- Some medicines are being funded for one condition but not another. This has been the subject of some real distress to consumers. A specific example is a biologic that is funded as a first line biologic for psoriatic arthritis, but it is a second line biologic for ankylosing spondylitis. Another is the availability of biologics for rheumatoid arthritis at an earlier and broader stage than other forms of inflammatory arthritis.
- The current process of staircasing is not responding to an individual's situation- using the process of staircasing to access biologics- -X months on methotrexate, followed by methotrexate plus another treatment for 3 months- all the time with their condition deteriorating
- Consumers often do not understand the NPPA principles and must rely on specialists to prepare applications. Specialists who are more familiar with Pharmac's processes are more likely to succeed, while less experienced clinicians may give up, as the NZRA has noted. This creates inequity by making access to treatment depend on whether consumers can see a specialist in their region with experience making application to Pharmac

Language and Communication

- For a consumer with severe inflammatory arthritis, a lack of definitions can be confusing and discouraging. For example, in the Pharmac questionnaire the term exceptional is used to describe a required feature of an application for NPPA funding.

This term is used without definition. For a consumer with severe inflammatory arthritis, this lack of clarity can be confusing and discouraging. They regard their condition as

exceptional as they had never heard of it before diagnosis, and do not know of anybody else who has this condition.

Hearing that Pharmac does not consider their condition exceptional and therefore will not fund a treatment that the consumer believes could be life-changing, can be devastating for consumers.

- We suggest that consumers and clinicians need more detail as to why an application does not meet the guiding principles of NPPA applications. We suggest that both consumers and clinicians need more detail why an application does not meet the guiding principles of NPPA. This will also improve clarity around decision making if definitions are provided for key terms such as “exceptional clinical circumstance”
- All decisions made should be based on New Zealand evidence if possible and be congruent with other definitions- for example the definition of Rare Disorders in New Zealand
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- The requirement that application is made by a clinician can also lead to very patchy communication from Pharmac to the patient. Some clinicians are excellent at copying in patients to all communications with Pharmac- others not as good. This can lead to the patient not being updated on what is happening to the application leading to consumer stress and disillusionment. This issue was the main problem highlighted by consumers.
- Similarly, consumers do not always understand Pharmac processes. The website assumes a uniform level of knowledge by all using it. We suggest a consumer section of the website that uses plain English and consumer friendly infographics to illustrate the pathway of applications This is common on many health websites.
- In the questionnaire the statement is made that during the application Pharmac **may also seek additional advice from the NPPA advisory panel**. We suggest that it needs to be made clear what will prompt the application to be referred to the NPPA panel. Use of the term **may** needs further explanation and is a good example of Pharmac being seen to use unclear language.
- Some feedback received has asked if there are condition specific panels for the NPPA application process or is the same panel used across all conditions.

4. Other Questions in the Pharmac questions for consultation

- More detailed reporting (such as outlining what exceptional means) would be of assistance and would improve understanding of exactly what information is required before application is made

5. Recommendations

- Information provided should be accurate and user-accessible in plain language that addresses issues of trust and clarity and provides definition of key terms such as **exceptional**
- Where conditional terms are used, such as **may be referred to**, include the circumstances which trigger such a referral and ensure that patients receive notification of this.
- A consumer section of the website is developed to provide consumer information.
- Consumers receive regular and ongoing updates on the progress of the application once submitted by their clinician
- Equity issues as outlined in this submission are addressed in any new pathway for NPPA applications.

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