Submission to Health and Disability Commission

Arthritis NZ Mateponapona Aotearoa

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1. About Arthritis NZ Mateponapona Aotearoa

Arthritis NZ Mateponapona Aotearoa (Arthritis NZ) is the sole organisation in Aotearoa New Zealand dedicated to addressing all types of arthritis, impacting over 700,000 New Zealanders of all ages with varying levels of pain and symptoms, making it a leading cause of disability in this country. The most common forms of arthritis are osteoarthritis, gout arthritis, and rheumatoid arthritis.

While arthritis is popularly associated with old age, half the people with arthritis are of working age. Arthritis can also affect children and teenagers.

Those diagnosed face numerous barriers, from accessing medical care to undertaking daily tasks to issues with employment and financial security. Our mission is to enhance the life of every person with arthritis through various support services, including awareness campaigns, advocacy support, collaboration with healthcare professionals, and direct support initiatives like Arthritis Assist, evidence-based information resources, webinars, and support groups.

Arthritis has no cure, so we provide support to people who are diagnosed, their caregivers and loved ones through education, support, and fostering resilient communities.

Over the past year our organisation has focussed on interaction with consumers and consumer advocacy (see Section 3*)*.

2. Acknowledgement of current constraints on the Health and Disability Commission

Arthritis NZ recognises the constraints the Health and Disability Commission (HDC) outlined in its 2022/23 Annual Review to the Health Select Committee (Health and Disability Commissioner, 2024), that it is under considerable pressure from a significant increase in demand in recent years. This includes:

- Since 2020/21 the volume of complaints has increased by 40%, and currently receives approximately 300 complaints a month.
- HDC is not resourced to close as many complaints as it receives.
- Rising costs have also resulted in a reduction of the Advocacy Service for it to work within its contracted funding baseline which, owing to HDC's funding pressure, has not been adjusted for several years.
- Service levels have reduced, with the number of advocates declining from 48 in 2013/14 to 24 in 2022/23. We understand this has had a significant impact on the geographical coverage of the Advocacy Service.

3. What we have learned from advocacy work with consumers

Our work with consumers is increasing. In addition to establishing a Consumer Reference Group, we regularly seek opinions and experiences from consumers who comprise our large social media community and receive regular enquiries about access to health services. These queries cover such topics as taking a support person to an appointment with a health professional, how to work effectively with health professionals, employment concerns and access to services such as home support.

We also represent consumer interests on a Health NZ | Te Whatu Ora Pathway group working to improve management of osteoarthritis and have initiated a project intended to improve access to allopurinol for those affected by gout arthritis.

We have in the past run training sessions for consumers through utilising regional advocates from the HDC.

In the past year we have also made a complaint to the Medical Council, acting on a complaint lodged with HDC and related online consumer feedback (see Appendix A for general details).

From our engagement with consumers who are considering making complaints about their treatment, or who have made a complaint with the HDC, we have observed the following:

- If a consumer requests support from a patient organisation with a complaint to the HDC, the pathway for supporting that person is unclear.
- If a patient organisation is made aware of several complaints about a health provider, they have no stated standing to make the complaint on behalf of these consumers, if the consumer asks for this support.
- Social media enables patient organisations to monitor issues that consumers have with health providers. There is however no clear path on how this information may be used. We do not know how to use social media information to help our consumers and inform providers that there may be a problem with the service they provide, especially when social media users want to maintain anonymity.
- There appears to be no functional link enabling identification and shared investigation of connected complaints made to the HDC and Medical Council (see Appendix A).
- Notifications of complaint outcomes are not readily available for patient organisations who have an interest in the outcome of a complaint.
- Consumers who have contacted the HDC have identified long time frames for complaints to be considered and this has eroded their confidence in making a complaint.

4. What steps could be taken to improve the Health and Disability Commission process?

> *What do medically harmed New Zealanders wish for the most? The most common answer is they want acknowledgement, and for no one else to experience the same trauma, the same harm, and the loss that they have experienced. Their biggest hope is for meaningful change; and to not feel like a lost statistic" (Korte, Astill, Gibbons, & Claridge, 2023).*

Arthritis NZ believes HDC processes are reactive, inflexible, and work better to resolve isolated individual complaints than those that suggest multiple failures in good practice. A proactive process and systems that can identify systemic, or multiple instances of harm would better serve consumers of Aotearoa New Zealand's health services. Some options to assist this could include:

- Accredited patient organisations having an official advocacy role in the complaints process where they have information regarding more than one complaint about a health practitioner. This can allow for consumer anonymity when named disclosures would deter a consumer from making any complaint. We acknowledge that training and accreditation would need to be addressed.

- We see value in HDC considering the English Patient Safety Commissioner's role in embedding the patient voice through 'Partnership Working' and the Patient Voice Network. This "ensures that those organisations leading the engagement with patients are working together effectively to further their aims" and "embed patient safety and patient voice throughout the healthcare system" (Office of the Patient Safety Commissioner for England, 2024).

- Reporting, even anonymously (e.g. surveys, comment box, patient organisation disclosure), can provide an early warning that there are problems within a particular hospital service). This information can be utilised by an on-site advocate to resolve service problems before they escalate.

- An accredited patient organisation may also enable issues with health practitioners to be raised with the health service provider (e.g. public or private hospital management) when a consumer issue has been raised.

- Social media comments should be treated as potentially relevant information about health practitioners as part of an investigation. This could be extremely useful when concerns involve multiple patient experiences that are concerning and similar.

- A patient advocate within public and private hospitals and aged care facilities to liaise between patients and/or consumer organisations and management. This is especially important when patients want to retain anonymity due to fears of reduced access for patients and their families if they complain. Such a system could be useful in mapping patterns of behaviour that are concerning. The current requirement that organisations have a designated Privacy Officer could be used as a potential model.

- Arthritis NZ would like to see resourcing of the HDC revisited to increase the likelihood that the HDC could meet its strategic objectives to promote and protect the rights of health and disability services consumers through:

- The resolution of complaints: that complaints are resolved in a fair, simple, speedy, and efficient way,

- Improved understanding of rights: that participants in the health and disability system understand their rights and obligations under the Code of Rights,

- Better, safer, more equitable care: systems, organisations, and individuals learn from complaints and improve practices, and

- Provider accountability: systems, organisations, and individuals are held to account for upholding the Code of Rights.

Given financial and staff constraints, lengthy times to resolutions and patient reluctance to complain, we ask that the Health and Disability Commission review considers how the organisation could reduce patient reluctance to make complaints to improve patient experience and safety.

5. Our recommendations:

1. That there is clarity within healthcare organisations about the process, and who patients can approach with a complaint. We understand and support the preference of HDC to have complaints advocate involvement at the earliest possible stage of the complaints process to enable a triaging of complaints before they are escalated. That more consideration is given to the reasons patients are reluctant to make a complaint (especially fear of future treatment for them and/or their families being denied), and that there are options for reporting breaches of good practice that include patient anonymity.

2. That the HDC better considers the patient voice in all areas of HDC work, including the incorporation of accredited patient organisations within the process of identification, investigation, and resolution of patient complaints, and considers the appointment of patient advocates within health services.

3. That greater transparency and dissemination to parties with a legitimate interest is progressed.

4. Consideration is given to HDC staff having portfolios that allow regular engagement with consumers with the intention of resolving issues before a complaints process is triggered. A portfolio for example covering aged care could be the first port of call rather than a way down the track of a complaints process.

5. Utilisation of NGOs (non-governmental organisations) to assist in triaging of complaints and supporting consumers to use the HDC well.

6. Proactive use of social media to communicate information about the role of HDC and using consumer friendly language to outline how to best utilise the HDC processes. Consideration needs to be given to how resources are best and appropriately used in an age of digital communication.

Appendix A: Case History from client files

In mid-2022 Arthritis NZ was approached by a person who had a traumatic experience with a private health practitioner. They had contacted the HDC advocacy services to make a complaint about their treatment a year earlier and were looking for support and advice about the complaint because the process seemed stalled.

While we cannot go into detail of our conversations, the first complainant eventually went to the press due to the slow resolution of the claim, and concern that more people would suffer similar experiences.

Coincidentally, in our regular scanning of social media a conversation was seen about a public hospital health practitioner who treated patients in a remarkably similar way. The complaints included:

1. Alternative Diagnosis
2. Failure to Treat
3. Inappropriate Physical Examinations (i.e. Failure to ask for Consent, Failure to provide a support person during intimate examinations)
4. Incorrect Patient Notes
5. Attitude towards patients

At least three of the social media commenters were willing to support the complainant with their comments, however they wished to remain anonymous. Arthritis NZ contacted the HDC advocacy team and found there was no pathway to add this supporting information to the original complaint because of the request for anonymity.

The complainant and the social media commenters were, and remain, unknown to each other. Arthritis NZ, with the permission of the original complainant, and the social media commenters, lodged a request for review with the Medical Council (MC). While the HDC case number was referenced in the MC complaint, we did not get any feedback from either organisation to determine whether these organisations worked together to resolve a complaint.

In response, the private health practitioner countered the patient's claims about examinations that were quite forceful. The social media commenters' experience add weight to the first complaint's experience but to our knowledge were never considered by the HDC in their investigations.

A recent call from a health professional concerned about a patient's welfare means we know at least one patient has been left without specialist care for three years after being discharged without treatment or a follow-up plan from the public hospital by the health professional in question. At the time of writing, no publication of the outcome of the HDC investigation has been published, meanwhile the health professional has continued to practice under supervision[1]. Because Arthritis NZ has no standing with the HDC, and the MC have not published an outcome report, this has affected the advice and information we can provide our consumers (and our patient support staff) of the potential for patient harm.

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[1] Supervision was ordered by the Medical Council.

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