



Arthritis NZ

Mateponapona
Aotearoa

**Submission from Arthritis NZ on the Advocacy
Guidelines Draft Content
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Contact Philip Kearney

Philip.Kearney@arthritis.org.nz

027 419 8946

P.O. Box 100 020 Wellington 6143

1. About Arthritis NZ

Arthritis NZ welcomes the opportunity to make a submission on the Health and Disability Commission Advocacy Guidelines as we have a strong ongoing interest in the work of the Advocacy Service.

The 2024/25 NZ Health Survey estimates approximately 860,000 people are living with one or more forms of arthritis (including osteoarthritis, gout arthritis and autoimmune inflammatory arthritis), and more than one in three people who report an arthritis diagnosis also report living with a disability.

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.

It is not well understood that arthritis does not just affect the elderly- all ages groups can be affected by arthritis including children and young people.

Last year we conducted research on the health and care of people with arthritis, and 1,563 people completed our Arthritis Confidence Index survey. Some key findings of this survey were:

- More than half of our respondents (53%) reported poor (22%) or fair health (31%).
- Mental health and wellbeing continue to be adversely impacted by arthritis (58% agreed with our statement relating to mental health).
- Financial anxiety was a concern with issues such as loss of income from being unable to work and using up sick leave being cited as major factors.
- 70% of respondents were either dissatisfied (40%) or very dissatisfied (30%) with the government's management of the health sector.

A full link to the survey results can be found here [2025-Arthritis-Confidence-Index-Report-1.pdf](#)

The Health and Disability Commission's Advocacy Service is an important source of support and information for our clients. We have therefore provided more detailed commentary than the survey format allows.

2. Background to this submission

We made a submission to the Review of the Commission in 2024 and in that submission made a recommendation for a role for accredited patient advocacy groups in the advocacy process. This would enable them to be able to engage with clients and the Advocacy Service in a clearer role than they presently have.

We repeat this recommendation in this submission. As the case history in Appendix 1 shows consumer advocacy organisations simply do not have the standing to engage meaningfully in working with both clients and the Health and Disability Advocacy service.

We note that the Guidelines state HDC advocates cannot determine whether there has been a breach of the Code of Health and Disability Services. However, proactive engagement with consumer organisations such as Arthritis NZ could support the Advocacy Service and help resolve issues before they escalate into complaints under the Code. Advocacy organisations may also be aware of the scope of provider issues that a single complainant, who may feel very alone in making their experience heard. We see significant merit in this proposal, particularly in relation to the Consumer and Whānau Engagement Guidelines.

3. Comment on the principles that apply- Matapono

- **Empowerment**-this content assumes significant knowledge and skill on the part of consumers when in our experience many do need significant support. The assumption that consumers have the skill and experience necessary reads as idealistic and not anchored in the experience of consumer advocacy organisations.

We suggest rewording to read *The Advocacy Service is committed to the belief of empowering consumers to be able to learn what is needed to help resolve their concerns.*

- **Efficiency**- a definition of the term *timely* used in this section is required so consumers understand just how long it may take to resolve their issue. Consumers who have contacted the Advocacy Service have identified long time frames for their issues to be considered, and this has eroded their confidence in raising issues.
- **Accessibility** –while cultural accessibility is important, other forms of accessibility need to be taken into account. This includes geographic and digital accessibility, client satisfaction, services that are appropriate for gender and age, and accessibility for deaf and blind clients. Are clients surveyed about the accessibility of all aspects of the Advocacy Service?

4. Comment on the updated guidelines

- **Prioritise engagement with consumers and whanau**

We recommend developing a formal role for accredited consumer advocacy organisations, as this could improve the timeliness of support and strengthen trust by involving an organisation already known and trusted by the person seeking assistance.

A case study of a complaint received by our advocacy team is one such example of the need for closer connection with the Advocacy Service. This is outlined in Appendix 1. We learned through working on this case that a consumer organisation has the ability to gather social media posts to demonstrate a pattern of behaviour that enables us to see a wider picture and make reference to that wider picture.

Issues raised in this 2024 submission which is based on our experience as a consumer advocacy organisation were:

- Making the pathway clearer for a person who requests support from a consumer advocacy organisation to make a complaint to be raised with the Advocacy Service.
- If a consumer organisation is made aware of several concerns about a health provider, they have no stated standing to make the complaint on behalf of these consumers.
- Social media enables consumer organisations to monitor issues that consumers have with health providers. There is no clear path on how this information can be used with the Advocacy Service.

We also suggest that in addition to outlining what advocates can do there should also be an inclusion outlining what they *cannot* do. We often have queries about ACC and Work and Income and in the past, it has been explicitly stated by Advocates that the Advocacy Service does not cover these agencies, even though they both require client assessment by health professionals. It would therefore be useful to know *exactly* what Advocates can and cannot do.

- **Compliance and Practice**

There is no mention of timeliness and given its inclusion in the principle of efficiency we think there should be a general timeframe for the response to a query, the time taken to deal with it and any resolution ultimately reached. Feedback from consumers is very much concerned at the time taken to respond to queries. We acknowledge resource constraints around this service.

The Guidelines do not define “priority populations”. It is unclear whether this includes older people, people without digital access, people receiving benefits or low wages, or people with disabilities. Because the Guidelines refer to a pathway for priority populations, this term should be clearly defined. For example, would an elderly person whose disability is caused by arthritis be considered part of a priority population?

5. Recommendations

- Rewording of the empowerment section to read: *The Advocacy Service is committed to the belief of empowering consumers to be able to learn what is needed to help resolve their concerns.*
- Development of a pathway to accreditation for consumer advocacy groups to have a clear role in the advocacy process, the use of social media and resolutions reached.
- Expand the recommendations on accessibility to include other forms of accessibility such as digital access.
- Define some timeliness targets to give clients a guide to approximately how long the complaint will take to resolve.
- Clarify which groups are included under the terms “priority populations” and “diverse communities”.

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 supervision¹. 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.