New Zealand House of Representatives
Te Whare Māngai o Aotearoa

Health Committee
Komiti Whiriwhiri Take Hauora

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Petition of Health Consumer Advocacy Alliance: Establish an independent Patient Safety Commissioner accountable to Parliament

Presented to the House of Representatives
by Sam Uffindell, Chairperson

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Petition of Health Consumer Advocacy Alliance

Recommendation

The Health Committee has considered the petition of Health Consumer Advocacy Alliance—Establish an independent Patient Safety Commissioner accountable to Parliament—and recommends that the House take note of its report.

Request for a Patient Safety Commissioner to be established

This petition was signed by 230 people. It was presented to the House by Ricardo Menéndez March on 27 June 2024 and transferred to us on 21 November 2024. It requests:

> That the House of Representatives establish a fully resourced, independent Patient Safety Commissioner (PSC) accountable to Parliament to take a proactive approach to preventing patient harm, with powers to take or require action.

Background

The Health Consumer Advocacy Alliance (HCAA) is a group of health care advocates with "a common passion for creating positive, effective, and lasting change". The HCAA believes that too many people have been harmed because of health system failures that were not identified. It sees no ability within the system to assess and prevent harm, only to respond after harm has occurred.

The HCAA considers that the Health and Disability Commissioner, Health Quality and Safety Commission, ACC (Accident Compensation Corporation), and Medical Council lack independence. The HCAA therefore advocates establishing the new role of Patient Safety Commissioner, modelled on existing roles in the United Kingdom.[1]

Comments from the petitioner

The HCAA told us that urgent action is needed to address preventable medical harm in the health system. It believes that the situation cannot continue because New Zealanders' health and safety is too important. The HCAA told us that the health system must ensure safety, and harmed consumers should not have to prove that there is a problem.

Lived experience

One of the founders of the HCAA, Denise Astill, told us that the health system failed her. She described having:

> the best life, with a great job, about to start your family and bang, your whole life disintegrates. You can't have a career anymore; instead, you are

[1] The United Kingdom's first Patient Safety Commissioner was appointed in 2022. The person nominated to be the first Patient Safety Commissioner for Scotland is expected to start the role in September 2025.

> going to have to care for your children for the rest of your life and must plan for someone to look after them when you are gone.

While pregnant with her children, Ms Astill took daily medication to control her epilepsy.[2] She told us that there were no warnings on the medication packaging about how it could affect a baby *in utero*. Ms Astill said that she was ill-advised by two specialists whom she consulted, despite having asked the right questions. Thus, she considers she could not give informed consent or make an informed choice.

Ms Astill showed us a diagram of the health effects that her daughter has suffered because she was exposed to the medication *in utero*. Ms Astill told us that as her daughter grows, they discover more health issues. She told us that taking the medication while pregnant has had a catastrophic effect upon her children, her husband, her family, her whānau, and herself.

According to Ms Astill, archived documents show that the Government knew that the medication could harm a baby exposed during pregnancy before it came onto the New Zealand market in 1975. She said that there are still no legislative safeguards on the use of medication during pregnancy. With her knowledge of medicines taken by pregnant women affecting babies *in utero*, including thalidomide, and her own experience with anti-seizure medicine, Ms Astill wonders what the next medicine will be that will cause harm in this way.[3]

Ms Astill explained that people who have been harmed by systemic failure have little trust in the health system. Engaging with the system causes them anxiety and they feel unsafe and vulnerable.

Voices not being heard

The HCAA told us that consumers, whānau, and medical staff are gravely concerned about medical harm but that neither consumers nor staff are being heard. It feels that their concerns are dismissed, and action is delayed. When issues that cause harm are known, the HCAA believes that health entities take too long to react and often only do so after serious harm has occurred.

We heard that medical harm affects health professionals as well as consumers. The group is concerned that health professionals are not being looked after. The HCAA members have spoken to many people who work in health and heard that they continue to witness harm, including severe harm, and feel powerless.

Opportunities for improvement

The HCAA has investigated some promising initiatives in the health system. It described two initiatives to us; in both cases it considers that there is more work to be done.

It told us that it fully supports the development of a formal safety strategy, which the Health Quality and Safety Commission is working on. The HCAA said that the strategy should

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2 The medication was sodium valproate, known as Epilim in New Zealand. Medsafe data sheet about Epilim.

3 Thalidomide was widely prescribed globally in the 1950s and early 1960s to pregnant women. As a result, many children were born without arms and legs and suffered health conditions. NZ Herald article, 24 October 2012.

represent best practice and what is expected for safety standards. However, it believes that without an independent body to monitor its implementation the strategy is at risk of failure.

The group is interested in Kōrero Mai, a programme that supports patients, families, and whānau to escalate their concerns about a patient's health deteriorating.[4] It believes the programme could improve patient safety, but the group has struggled to find information about its implementation in hospitals. Without data about where it has been implemented, how visible it is, and how well it is working, the HCAA sees the programme as a missed opportunity. It urged us to investigate the programme's progress to ensure its success.

Data capture and analysis

The HCAA says it has been told repeatedly that preventable medical harm is not a problem because there is no data to suggest that it is. The group finds this claim absurd because it considers that the health system is not measuring and analysing data about harm effectively. The group described the public health data capture system as "siloed and ineffective".

ACC codes

We heard that the HCAA believes that ACC is not reporting all severe adverse events to the Health Quality and Safety Commission. It told us that ACC is required to report two levels of such events and that it is not reporting one of the levels.

Benefits of a Patient Safety Commissioner

The HCAA told us that an independent Patient Safety Commissioner should put health first to rebuild trust and ensure the health system is safer. It considers that the New Zealand health system faces similar barriers to those faced by the United Kingdom. The HCAA told us that the commissioner role was set up in the UK after a review of medicines and medical devices, including several that have caused harm to New Zealanders.[5]

The HCAA met with Dr Henrietta Hughes, England's Patient Safety Commissioner, who told the alliance that all parts of the system work with her to achieve a safer health system. We were told by the HCAA that she works with the sector to:

- drive systemic change
- improve the culture to promote safety
- reduce preventable harm
- promote transparency
- break down barriers between health entities so they can work together effectively.

The HCAA believes that having an independent Patient Safety Commissioner would save money. Proactive intervention and harm prevention cost less than treating the effects of harm, including downstream health and ACC costs, it told us. It also considers that the work

[4] More information about Kōrero Mai is available on the Health Quality and Safety Commission website.

[5] Independent Medicines and Medical Devices Safety Review report | published 8 July, 2020. The Chair of the review was asked to look at the cases of vaginal mesh, sodium valproate, and hormone pregnancy tests, in this case Primodos.

done by the Commissioner would enable more New Zealanders to lead healthier and more productive lives.

We asked the HCAA whether it sees the role of Commissioner as comparable to that of the Ombudsman, who points out issues and recommends changes rather than making policies. The group believes that for the role to be effective it needs to have a legislative mandate, rather than just an ability to point out issues. We heard that when the Director-General of Health paused the use of surgical mesh for stress urinary incontinence there was no legislation to support the ban.[6]

During our discussion we also asked whether England's Commissioner risks its independence by working with the system to improve safety. The HCAA referred to its meeting with Dr Henrietta Hughes, who said that independence is a positive part of her role and that everyone wants to meet her. The group said it has seen the barriers between health entities in New Zealand and it believes that an independent Commissioner will enable those entities to have difficult conversations.

Comments from the Ministry of Health

We sought and received written information from the Ministry of Health. We were particularly interested in the scope of the Health and Disability Commissioner's role, and whether the petitioner's recommendation to establish a Patient Safety Commissioner would not simply replicate the Health and Disability Commissioner's role.[7]

The role of the Health and Disability Commissioner

The Ministry of Health explained that the role of the Health and Disability Commissioner (HDC) is to promote and protect people's rights under the Code of Health and Disability Services Consumers' Rights,[8] and investigate any apparent breach of the Code. The HDC is an independent Crown entity, so it is generally independent of government policy. It is also independent of providers and consumers.

Broadly, the HDC assesses, investigates, and resolves complaints about the quality of care. It makes recommendations to health organisations and monitors their implementation. It also educates consumers about their rights and providers about their obligations.

Outcomes

The aim of the HDC is to use insights gained from complaints to improve quality and safety and influence policies and practices throughout the health and disability system. This aim includes escalating and resolving emerging systemic issues. We note that the HDC can initiate inquiries into systemic issues based on complaints it receives from consumers.

6 Surgical mesh statement from Director-General of Health | Ministry of Health NZ.

7 The ministry's written submission also includes information about other entities with quality and safety roles in the health system, and their legislative basis.

8 The Code of Health and Disability Services Consumers' Rights.

Possible overlap with the role of Patient Safety Commissioner

The Ministry of Health considers that the role of the HDC already covers matters that the petitioner has suggested the Commissioner would be responsible for:

- **Independence**—the HDC is an independent Crown entity with an independent role regarding patient safety. It is not affiliated with providers, and legislation requires that its management of complaints be judicial.
- **Proactive approach to issues**—the HDC can proactively manage systemic issues whether or not a complaint has been made. Concerns raised can be escalated immediately by the HDC if required.
- **Voice for consumers**—the HDC's legal role is to promote and protect consumers' rights by investigating complaints and providing a consumer advocacy service.

The ministry emphasised that the legislative powers of the HDC allow it to investigate any issue across the health and disability system. Recent examples include an investigation into cancer care delays in the Southern district,[9] and an investigation into informed consent practices for the involvement of students and other trainees in clinical care.[10]

National Quality Forum

The National Quality Forum is an inter-agency group that aims to provide "national collaborative leadership and oversight of quality and safety across the Aotearoa New Zealand public health and disability system".[11] The ministry considers that the National Quality Forum has some similar aims to the proposed Patient Safety Commissioner. The petitioner said that one of the PSC's goals would be to improve identification of systemic safety issues and work with health entities to improve the system's coordinated response to such issues.

The Forum updated its terms of reference in 2024 to enable members to lead or support its work. The updates have given the Forum a process for escalating critical risks and issues—it can now report them, and report on progress, to the Health Leadership Forum, which is chaired by the Director-General of Health.

Work programme

The Ministry of Health detailed work under way or planned to address issues raised by the petitioner.

Government Policy Statement on Health

One of the Government's five priorities for the health system is about quality: "ensuring that New Zealand's health care and services are safe, easy to navigate, understandable and welcoming to users, and are continuously improving".[12] The ministry says that the

[9] Commissioner-initiated investigation into delays in provision of non-surgical cancer services, HDC website.

[10] Consent for the involvement of students and other trainees in clinical care, HDC website.

[11] The Ministry of Health, Health Quality and Safety Commission, Health New Zealand, ACC, consumers, Cancer Control Agency, Whaikaha | Ministry of Disabled People, NZ Blood and Organ Service, Royal New Zealand College of General Practitioners, and Pharmac are all represented at the National Quality Forum.

[12] Government Policy Statement on Health 2024–2027.

Government Policy Statement on Health acknowledges that ongoing, unintentional harm remains a challenge in the health system.

The statement outlines changes planned for the next three years to improve coordination across the health system, and strengthen the ways that entities gather and respond to the voices of those with lived experience, and their whānau. The statement sets out specific expectations for the next three years, which include:

- better information and data-sharing about patient outcomes or health service quality
- a safety strategy with expectations that can be compared to other countries
- improved data collection, reporting, monitoring, and sharing for providers and Treaty partners, enabling outcomes to be monitored by ethnicity, gender, age, rurality, and disability
- an improved national approach to gathering feedback and responding to and learning from complaints and harm incidents; developing culturally appropriate and accessible feedback channels, and restorative practice
- extended development of patient-centred measures.

Patient Safety Commissioners in the United Kingdom

As mentioned above, England and Scotland are the first countries to have established PSCs. However, neither commissioner have an entity that is comparable to the HDC. The ministry indicated that in England the role is restricted to dealing with medicines and medical devices. With the roles having been established so recently, no evidence is available about their effectiveness.

The PSC for England received 226 pieces of correspondence in 2023/24. Its performance has been shown through the three sets of recommendations relating to:

- redress for those harmed by valproate (an anti-seizure medicine) and pelvic mesh
- setting up a rule for families to raise concerns on behalf of patients
- safe use of the most potent teratogens.

Looking at the roles of staff employed by the PSC in England, the ministry commented that roles involving the same functions appear to exist already in New Zealand. Those roles are in the ministry, Health Quality and Safety Commission, HDC, and Health New Zealand.

Cost estimate

We sought information on the potential cost of establishing a Patient Safety Commissioner in New Zealand. The ministry said that, while insights can be drawn from the UK model, New Zealand's health system operates differently. As the role was only recently established, its long-term effects remain unknown. We were informed that England's Patient Safety Commissioner cost NZD 1.4 million in 2023/24.

Cost–benefit analysis of establishing a Patient Safety Commissioner

The Ministry of Health provided us with an appraisal of the potential merits and limitations of appointing a Patient Safety Commissioner in New Zealand.

Benefits	Challenges
Potential to provide further advocacy for patients and whānau	Could cause confusion to patients and whānau about who to contact to raise complaints and concerns
Further capacity for systematic issues relating to concerns for consumers to be fully investigated when required	Further recommendations are made to providers that cannot be implemented in a timely way
There would be another independent Patient Safety Commissioner reportable to Parliament	Legislative change would be required to establish a Patient Safety Commissioner accountable to Parliament
Further capacity for more timely investigation of consumer concerns with appropriate resolution	Additional resource and funding would be required to establish an office that responds to concerns in a timely way
There would be an additional voice for consumers	Duplication of functions of the HDC and HQSC who promote consumer voice as part of their functions

Comments from the Health and Disability Commissioner

We heard from the Health and Disability Commissioner, Morag McDowell. The HDC also provided us with written information.

The Commissioner commended the HCAA for its strong advocacy to improve patient safety. She told us that she agrees completely with the group that the patient's voice should be central to quality and safety. The Commissioner acknowledged the barriers that some consumers and consumer groups have faced to making their voices heard and seeing changes made to the system.

The Commissioner told us that the HDC has a broad and flexible range of powers to make changes at both an individual and systemic level. She described its work as advocating a consumer-centred health and disability system, in which people's rights are understood, upheld, and protected.

Proposed Patient Safety Commissioner

The Commissioner said she is not persuaded by the HCAA's argument that adding another agency would address the quality and safety issues the group has raised. She considers that another agency could add complexity to the system, resulting in fragmentation and confusion. We heard that the Commissioner believes that any new agency should add value to, and strengthen, the existing quality and safety framework, rather than duplicate existing functions.

The Commissioner said that supporting the current agencies to better work together to amplify the consumer voice may be a better way to improve quality and safety. She also suggested that agencies could help Health New Zealand and other providers to involve consumers in the design and delivery of the health system and to address some of the longstanding structural barriers to sustained quality improvement.

We brought up the petitioner's belief that a Patient Safety Commissioner who is an officer of Parliament could raise consumers' issues directly with MPs. We asked the Commissioner whether she has experienced any barriers to improving the system and, if she has, whether she thinks that having a direct link to Parliament would help. The Commissioner said that 90 percent of the HDC's recommendations are complied with, and that the HDC follows up on any recommendations that have not been implemented.

Tracking recommendations and implementation

The HDC makes over 400 recommendations a year; the Commissioner said that many aim to improve the system. We asked the Commissioner where the public can see her recommendations for improving the health system and how they can track progress on their implementation. She told us that her recommendations are published with her opinions but are not collected in one place. The HDC's annual reports include information about the rate of compliance with recommendations and examples of recommendations.

The HDC acknowledges that there is no central and public list of its recommendations, or of progress on implementing recommendations. It told us that it understands how valuable it would be for the public to be able to access the information in this way. However, the HDC told us that publishing such information is complex. It might entail a lot of resources to extract the information from the current system and avoid identifying individuals and exposing private information. As the HDC has significant constraints on its resources and increasing demand for its services, creating a central and public list of recommendations and corresponding implementation progress is not a priority for it.

The HDC told us that it plans to reconsider this in early 2026, when its new digital complaints system is in place. The HDC considers that the new system may make publishing the information less resource intensive.

Implementation rate in 2024

The HDC monitors the implementation of its recommendations, and the Commissioner said that her office engages with agencies if it is not satisfied with the work that is being done. In 2024, the HDC made 757 recommendations; of those, 91 percent were complied with. There were 66 not complied with, which related to 37 complaints and involved 34 providers.

We asked the HDC how much success it has following up with the agencies that have not complied with recommendations. Around half of these did not receive a response from providers. Where appropriate, the HDC referred these providers to their professional body or another relevant authority. In a small number of cases, the HDC publicly named the provider for failing to comply.

Systemic issues

We asked the Commissioner whether she can reach conclusions about systemic issues, such as understaffing. The Commissioner referred to an inquiry that identified a lack of systems to identify patient harm and respond adequately. Although we consider that the inquiry report was helpful, we noted that it was conducted some time ago and that its findings related to one department in one part of the country, rather than the whole system.

The Commissioner said that every complaint she looks at involves considering the context in which health professionals work. For example, she said that she recently raised concerns with Health New Zealand about the lack of resources for stem cell transplants in Auckland. Her concerns included how Health New Zealand was addressing the potential harm that the situation was causing for patients.

Medicines and medical devices

The Commissioner considers that there is a lack of regulation and monitoring of medical devices. We heard that she hopes future legislation will address the gap.

The Commissioner said she considers that the HDC can be a watchdog in relation to medicines and medical devices. Following a medicine brand change, for example, the HDC had recommended that agencies work together. As a result of that recommendation, a safer dispensing and prescribing hui was held, which then became a steering committee.

Our response to the petition

We thank the Health Consumer Advocacy Alliance for its work on this petition, and its members for sharing their work and experiences with us. We are grateful for the group's advocacy on behalf of all New Zealanders, and particularly those who have suffered medical harm. While we examined this petition, we also considered the petition of Gareth Lowndes: Increase resources for the Health and Disability Commissioner. We report these two petitions in two separate reports, but concurrently, to reflect our systemic approach to the issues raised in both petitions.

We are aware of the systemic issues that the health sector is facing, including on the resourcing and staffing fronts. These tensions contribute to the poor, and sometimes tragic, consumer experiences with the health system that we have heard from the petitioner and others. Although we understand that the HDC can investigate systemic issues, we remain concerned that the HDC is not resourced to deal with an increasing number of complaints. As noted in our report on the petition of Gareth Lowndes, we are not convinced that every measure to improve processing times has been taken by the HDC. We consider that prominent leadership and initiative to address systemic issues is lacking. Future resourcing may be required to address some of these concerns. We also note that there is no system accountability for organisations which choose not to respond to the recommendations.

We acknowledge the petitioner's concerns and advocacy to give consumers and whānau a stronger voice. However, having considered the current functions of the Health and Disability Commissioner, we are not satisfied that a new Patient Safety Commissioner would provide additional benefits to users of the health system. We consider that the role of the HDC should be strengthened to help break down barriers and improve patient safety and protect consumers' rights.

We hope that the work of the Health and Disability Commissioner and other health sector entities—such as the Health Quality and Safety Commission, the Mental Health and Wellbeing Commission, and the Aged Care Commissioner—will help address systemic issues in the health sector. We hope to see strengthened advocacy and improved healthcare services for patients, whānau, and staff.

Appendix

Committee procedure

The petition was signed by 230 people on the Parliament website. It was presented to the House by Ricardo Menéndez March on 27 June 2024. The Petitions Committee transferred the petition to us on 21 November 2024. We met between 18 December 2024 and 17 December 2025 to consider it. We received written submissions from the petitioner, the Ministry of Health, and the Health and Disability Commissioner. We met with the petitioner and the Health and Disability Commissioner.

Committee members

Sam Uffindell (Chairperson)
Dr Hamish Campbell
Dr Carlos Cheung
Ingrid Leary
Cameron Luxton
Hūhana Lyndon
Jenny Marcroft
Debbie Ngarewa-Packer
Hon Dr Ayesha Verrall

Related resources

The documents we received as evidence in relation to this petition are available on the Parliament website. Recordings of our hearings can be accessed online on the Parliament website at the following links:

- Hearing with the petitioner on 19 February 2025.
- Hearing with the Health and Disability Commissioner on 21 May 2025.