The Health Consumer Advocacy Alliance

Experts by Experience

Health Consumer Advocacy Alliance

Supplementary Submission E

11th June 2025

Response to Ministry of Health (MOH) |Manatū Hauora Written Submission

Response to Health and Disability Commissioner (HDC) |Te Toihau Hauora Written Submission

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

The Health Consumer Advocacy Alliance (HCAA) welcomes the opportunity to respond to the Ministry of Health's (Manatū Hauora) written submission dated 4 April 2025 and the HDC |Te Toihau Hauora submission dated 21 May 2025.

Acknowledgement

We acknowledge and support the ongoing work of the Health and Disability Commissioner (HDC) and it is absolutely vital that HDC continues the work they are doing. The HCAA feel strongly that HDC must be funded properly and better resourced. The positive shift toward valuing consumer voices is clear, particularly under Commissioner Morag McDowell's leadership. This change is meaningful, and necessary, but it is not sufficient. Patient safety failures continue to occur, and for many whānau, the harm is lifelong and irreparable. Recognition without action is not justice.

We also acknowledge the collaboration and ongoing work of the National Quality Forum which promotes and supports continuous improvement in the quality and safety of health and disability services across Aotearoa.

HCAA Response to Ministry of Health (MOH) |Manatū Hauora Written Submission

Our petition **does not** seek to replace either the HDC or the Health Quality & Safety Commission, but to establish an independent, complementary role focused specifically on system-level safety oversight and accountability. The HCAA query why the HQSC has not yet been asked by the Health Committee to provide input into our petition, considering they are one of Aotearoa's leading patient safety organisations.

While the HDC and HQSC each serve important functions, neither has the clear, system-wide mandate or independence needed to prevent harm across the national health system. This petition does not propose to replace them, it proposes to do what they cannot. It calls for an independent Patient Safety Commissioner who reports directly to Parliament, with the authority to hold the health system to account when no one else will. The lives and wellbeing of New Zealanders deserve more than reactive apologies after avoidable medical harm occurs, they deserve proactive protection.

This gap in accountability highlights the need for a dedicated body with the sole mandate of advocating for consumers and addressing system-wide safety concerns, without conflict or institutional alignment.

There is no mechanism for consumers to complain about our Health Entities or oversight bodies including the Ministry of Health, Health New Zealand, the Health and Disability Commissioner, Accident Compensation Corporation and associated agencies, other than the Ombudsman which should be the last resort. These agencies enforce accountability in the health system but are not themselves meaningfully accountable to the public.

If consumers are mistreated or dismissed by these entities, their only option is the Ombudsman, which is not designed for routine or systemic complaints. This lack of oversight undermines trust and leaves

consumers with nowhere to turn when the watchdogs fail. This lack of accountability entrenches power imbalances, prevents system learning, and erodes public trust. A truly fair and safe health system must include independent oversight of its own watchdogs—anything less leaves consumers vulnerable and silenced.

The PSC would act as an impartial advocate for patients, ensuring that no part of the system is above scrutiny, and that consumer voices lead to genuine accountability and meaningful change across all levels of the health sector.

Independence – Lack of Clarity

In the Ministry of Health's (MoH) submission (Point 2) refers to the Health and Disability Commissioner (HDC) as "generally independent of government policy." Yet, in its own submission dated 19 May 2025, the HDC clearly states it is "independent **from** Government policy." These are not semantic differences they are contradictions. If two of the most central agencies in health oversight cannot even agree on the extent of their independence, then how can the public, or Parliament trust the robustness of current accountability structures? Confidence, in Point 8, which suggests the system's independence is working as intended, is fundamentally undermined by this lack of clarity.

Proactive vs. Reactive System Response

MoH offers the Southern cancer services as a case study of "proactive" system intervention (Point 8). Yet, that intervention came only after media attention and consumer pressure forced the issue into the spotlight. That is not proactivity. That is a system reacting under duress.

We do acknowledge the Ministry's concession that "there is room to improve the health quality system," as outlined in the Government Policy Statement (GPS). But we must ask: if that room for improvement is acknowledged, where is the mechanism to ensure it happens and happens with urgency.

The Role of Independent Oversight - Enhancing the Effectiveness of the Government Policy Statement (GPS)

Ensuring continuity of health system improvements regardless of political cycles is a massive issue. There is not enough public assurance that progress is being made or even tracked effectively. A Patient Safety Commissioner could independently monitor GPS implementation and publicly report on whether progress is real, or merely aspirational.

Framed as oversight in government policy, often what is presented in annual reports does not reflect the reality of what is happening behind the scenes. A good example is critical infrastructure for system learning, such as health data and digital teams within Te Whatu Ora being severely culled. Regarding Point 12c, gains in system capability are not on track for recovery within three years.

Point 12d commits to "improving the national approach to gathering feedback and responding to and learning from complaints and health care harm, including the development of culturally appropriate and accessible feedback channels, as well as restorative practice" Yet the lived experience of harmed consumers tells a very different story. There is an assumption in Point 12 that something is already happening, although there is no national restorative framework for groups harmed by systemic failure, such as those affected by Fetal Anti-Convulsant Syndrome (FACS). In fact, Te Whatu Ora's National Consumer Engagement Team will be gutted, an indefensible weakening of the system's ability to listen, learn, and respond.

This is not system strengthening. It is regression, back to fragmented, localised, and inequitable responses. Likewise, in Point 12e, claims to expand patient-centred outcome measures are vague.

Who is leading this work? **How** are the measures being defined? **What role** do those with lived experience play? How can consumers provide input?

Without transparency, these are empty assurances.

Medical Products Bill - A Missed Opportunity with Real Consequences

The Ministry's claim that a future Medical Products Bill will strengthen regulatory oversight lacks credibility. The Ministry's confidence in future regulation through a new Medical Products Bill rings hollow following the repeal of the previous Bill a reversal that severely erodes public trust, especially as previous reforms have failed to deliver change.

New Zealand continues to rely on outdated, grandfathered medications and unregulated devices that pose serious harm without effective monitoring or safety checks. This includes old grandfathered medications e.g. teratogenic medicines which are harmful to babies during pregnancy and unregulated medical devices that remain in circulation which are still causing harm. These should have been addressed decades ago.

Even the HDC concedes: "Progress to close this gap has been slow over many decades." This is precisely where an independent Patient Safety Commissioner with legislative authority could act to address these persistent regulatory gaps and encourage long-overdue systemic change.

National Quality Forum (NQF) - Opaque and Unaccountable

The HCAA concur the NQF is an essential working group, it is presented by the Ministry as a key mechanism for identifying systemic safety risks (Point 19). Yet the public and many in the health sector have never heard of it because there is no transparency around its work. The HCAA note the NQF is starting to become more publicly visible, which is positive, yet without transparency, or being independently scrutinised; serious questions remain:
- Who audits the NQF?
- Who holds it to account?
- Where is the evidence of meaningful consumer engagement, other than two consumer representatives who attend NQF meetings?

Further, the omission of HDC from the list of involved entities suggests inaccurate reporting. As the average consumer is not aware of who are members of the NQF a reasonable question would be; who else is missing off the list?

Point 20 describes past barriers to progress however, there is no evidence that these challenges have been resolved. Where is the evidence that those barriers have now been removed? Fetal Anti-Convulsant Syndrome is one of those "hard to progress" system wide issues and there has been little achieved in this space. The progress that has happened is primarily because of FACSNZ's perseverance. Fetal Anti-Convulsant Syndrome remains a system-level issue with little demonstrable progress, despite being identified as a system-level concern. What exactly has changed?

Dr Shane Reti in his speech to the National Quality Forum in 2024 stated that the forum's aim is to "to provide national collaborative leadership and oversight of quality and safety across the Aotearoa New Zealand public health and disability system". He described it as "the peak body for quality and

safety for the public health and disability system in New Zealand." The HCAA agree with Dr Reti, "the importance of collaboration and coordination of quality and safety initiatives across the health agencies' cannot be underestimated. But if you look at Point 22, the NQF is described as escalating risks to the Director-General of Health. In other words, the system is reporting to itself.

How do we know that NQF is effective now? What happened to those system wide issues identified? There is no independent scrutiny. No transparency. No assurance for consumers that meaningful action follows identification of risk.

Legislative Change - Not a Barrier, But an Obligation

MoH states that legislative change would be required to establish a PSC. That is not a reason to resist reform. Proactive change is both necessary and justified. The costs of inaction both human and financial are significant. The return on investment from establishing an independent PSC, with powers to investigate and enforce systemic change, would be substantial.

Final Comments

MoH's submission assumes the system is already operating proactively. However, the evidence just simply isn't there to support this view.

We appreciate the Ministry acknowledging:
- A lack of coordination across health entities;
- That improvements are needed in how entities work together;
- That current entities may not be fulfilling their roles effectively.

We respectfully submit that only a truly independent Patient Safety Commissioner accountable to Parliament can provide the necessary oversight to reduce harm, proactively drive improvement, and rebuild public trust. This position is supported by the Cartwright Collective, Patient Voice Aotearoa, Terry Taylor, and many harmed consumers and whānau.

Everybody shares the same goal of wanting less consumers being harmed, but we also need someone in the corner of health staff who feel unheard and completely overwhelmed. We would like to bring to the attention of the Health Committee, that many health professionals privately support our petition but feel unable to do so publicly due to fear of repercussions or being identified by their employer, employers who, in many cases, are the very health entities under scrutiny. This highlights a concerning culture of silence, where speaking up about patient safety or systemic accountability is seen as a risk rather than a professional responsibility.

The fear of blame, silences voices, and silence can be dangerous and, in some cases, deadly.

HCAA Response to Health and Disability Commissioner (HDC) |Te Toihau Hauora Written Submission

Refer to Supplementary F for further context in HCAA's response to Miss Mc Dowell's oral presentation to the Health Committee on our petition.

Too many New Zealanders are being harmed by system failures that no one is truly accountable for. The current health oversight landscape is fragmented, reactive, and lacking the independence needed to protect patients before harm occurs.

It is no longer acceptable for preventable harm to be met with silence, delay, or fragmented response. The absence of clear, independent system-level oversight continues to put patients at risk. While the HDC plays an important role, it was never designed to lead systemic safety reform and it is not equipped to address these persistent, system-level risks. Miss McDowell states, they have legislative powers to contribute to systemic change however, HDC's core function is the resolution of individual complaints after harm has occurred. Its powers to initiate systemic investigations are rarely used and are not oriented toward proactive system-level surveillance or real-time risk mitigation.

The HDC submission implies the creation of a Patient Safety Commissioner would duplicate HDC's role. In fact, the proposal clearly calls for a complementary and specialised agency to focus on system-level safety, accountability gaps, and the independent escalation of emerging risks beyond individual complaint pathways. It would in fact allow HDC to focus more on what their primary role is, with the limited resources they have. In the long term, the PSC would support the HDC by reducing complaints with its primary focus of improving patient safety, preventing avoidable harm and addressing systemic deficiencies.

Acknowledging that the system is under pressure and has failed consumers, is not enough. HDC's own admission that improvement is hampered by fragmentation, poor data integration, and structural barriers underscores the very need for an agency empowered to cut across silos and hold agencies to account collectively.

A growing body of media coverage reflects a groundswell of public concern and a deepening lack of trust in current accountability mechanisms to independently safeguard patients from harm. While HDC states it "amplifies the consumer voice," thousands of consumers and frontline professionals feel that existing agencies, including HDC, are not adequately hearing, empowering, or protecting them.

The HDC use a flawed comparison with the UK Model; the UK Patient Safety Commissioner was created in response to institutional failures, exactly the kind of persistent risk the petition seeks to address in Aotearoa. The UK's Patient Safety Commissioner does not solely focus on medicines and devices; it was created in response to system-level failures and patient harm not adequately addressed through existing regulators. The model embodies independent, proactive system advocacy, precisely the gap the petition seeks to address. (Refer to Supplementary F -Scotland's appointed PSC with broader powers)

By design, HDC responds to individual complaints after harm has occurred. It is not resourced, empowered, or structured to identify and escalate systemic risks before they manifest in harm. Even the HDC acknowledges structural barriers, poor coordination, and inequities within the current system. These are not issues that can be resolved by better collaboration alone; they require clear, empowered, and independent leadership.

One example of systemic issues that should be proactively addressed is the impact of staff fatigue on patient safety. In the UK the Health Services Safety Investigations Body has just completed an investigation about staff fatigue and the impact on patient safety. HDC would not have the resources to investigate such significant system wide issues, neither would the HQSC. Another example of a

missed opportunity for effective patient safety harm mitigations is Korero Mai, dedicated funding to properly implement this program nationally must be urgently secured to ensure patients and whānau are genuinely heard, respected, and safe within the health system. (Refer to Supplementary G).

HDC monitors provider compliance with its recommendations, but the public has little visibility into how frequently recommendations lead to measurable system change, and what follow-up occurs when they are ignored. A Patient Safety Commissioner would provide public-facing transparency on whether system-level risks are truly mitigated. The submission highlights coordination efforts with groups like the National Quality Forum but such efforts lack statutory power, transparency, auditing, and independence. Coordination alone cannot substitute for a formal, legislated mandate to compel change.

There have been numerous public safety failures (e.g., Middlemore ED crisis, cancer treatment delays, anti-seizure medicines in pregnancy and pathology sector crisis) where early warnings were missed, ignored, or failed to trigger system-wide accountability. Consumers and families harmed by these failures consistently report difficulty navigating the current system and no clear, independent avenue for raising concerns about system-level risks. Well-intended measures in health too often result in a tick-box approach, mistaken for meaningful action. This practice overlooks the real needs of patients and frontline staff. The surgical mesh issue is an excellent example; decades on, mesh injured are **still** struggling to access much needed wrap around services, yet the push behind the scenes to lift the mesh suspension is visceral, not ideal when the two available mesh clinics are barely coping with the amount of people needing their services.

"We are still not learning in healthcare and the same incidents are happening time and time again with devastating impacts on patients and families."

Dr Rosie Benneyworth, HSSIB

The HDC plays an important statutory role in complaints resolution and rights protection. However, it is not- and cannot be- a stand-in for a truly independent, system-level watchdog focused on preventing harm before it occurs. We urge the Committee to recognise that no single agency currently holds the mandate, independence, and authority to ensure national safety accountability.

Establishing a Patient Safety Commissioner is a necessary and overdue reform to restore public trust, drive systemic change, and elevate the patient voice at the highest level. A dedicated, legislated, and independent Patient Safety Commissioner is urgently needed to protect the public, prevent harm, and ensure system-wide learning and accountability.

Recommendation to the Committee

That the Health Select Committee recommends legislative change to establish an independent Patient Safety Commissioner, reporting to Parliament, with powers to investigate, audit, and enforce system-level safety improvements.

Whakawhetai koe | Thank you