The Health Consumer Advocacy Alliance
Experts by Experience

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16th August 2024

Submission for Review of the Health and Disability Commissioner Act 1994 and Code of Health and Disability Services Consumers' Rights

Tēnā koutou Morag, Rose, Catherine and the Review team,

We are grateful for the opportunity to provide feedback[1] on proposed changes to the Health and Disability Commissioner Act 1994 and Code of Health and Disability Services Consumers' Rights. We would like to acknowledge Commissioner Morag McDowell and team for ensuring there has been inclusivity of all views for this review process; wider consultation was needed, and all attempts were made to ensure different voices were taken into consideration for this review.

The Health Consumer Advocacy Alliance provided input as stakeholders into the earlier scoping stage of the review and were thankful for being given the opportunity to provide a written submission, which is included as Appendix Two. We would like this to be included as part of our overall feedback.

General Comments

The HDC play a pivotal role in our health sector, not only for consumers harmed in our health system, but as a 'watch dog' working constructively with other health entities to help protect, prevent further harm to consumers, and ensure the rights of consumers are both valued and upheld by all. Collaboration and connection between our health entities is essential. We know the HDC work constructively with multiple health entities to ensure improvements are made to our health system; yet there is little transparency regarding what actions are being taken 'behind the scenes' to improve safety and the wellbeing of New Zealanders.

The HDC are a member of the National Quality Forum who meet regularly. We understand that as part of these discussions' patterns of harm and potential 'red flags' are identified, yet these discussions are held behind closed doors and the actions taken, or discussions held, are not visible to the public. The HCAA encourages the HDC to be the driving force to help foster a culture of honesty, openness and transparency.

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[1] ***Please note*** *that one of the contributors to this submission, Sue Claridge, is also a Member of the Auckland Women's Health Council and she wrote the AWHC submission. As many of the concerns and interests relating to the HDC and the review of the Act and Code are the same for both organisations, there are portions of both submissions that are very alike or identical.*

In the short time that Morag McDowell has been at the helm we have seen a proactive approach to making improvements and changes to processes that are both meaningful and consumer centric.

We would like to acknowledge the impact of the recent overhaul of our health sector, the current strain on our health system, which includes the restructuring of health entities, loss of funding and disestablishment of roles. The HDC were already under strain with huge increases in complaints, under resourcing and further budget cuts of $2.9 million, which the HCAA certainly do not support.

We are concerned that this will further restrict the HDC's ability to undertake thematic investigations which renders them unable to meet their strategic objectives and remit of being our 'watch dog'.

Topic 1: Supporting better and equitable complaint resolution

Did we cover the main issues about supporting better and equitable complaints resolution?

While HCAA absolutely agree implementing a hui ā-whānau and hohou te rongo option for complaint management for Māori is crucial, HCAA believe that non-Māori should also have equal access to the same resolution pathways. The hohou te rongo relational approach to dispute resolution using principles and values from Te Ao Māori has already proven successful, and alongside the more traditional complaint resolution pathways, this approach could be of huge benefit to all New Zealanders, including health professionals and consumers.

Legislative amendment to the HDC Purpose Statement & Strategic Objectives

We understand that the Purpose Statement and Strategic Objectives are high-level goals outlining what the HDC want to achieve. The HCAA recommend more specificity in the wording and would like the wording of both statements to include a greater emphasis on patient safety and patient outcomes.

We recommend that the World Health Organisation Patient Safety Rights Charter 10 be incorporated into the wording of both the Purpose Statement and Strategic Objectives, or at be least referenced. Although many of the Patient Safety Rights[2] (see below) are similar to the HDC Code of Rights, the specific wording regarding the competency of health professionals, safe procedures, safe medical products and their use is much more explicit. Particularly the ones highlighted below:

1. Timely, effective and appropriate care;
2. Safe health care processes and practices;
3. Qualified and competent health workers;
4. Safe medical products and their safe and rational use;
5. Safe and secure health care facilities;
6. Dignity, respect, non-discrimination, privacy and confidentiality;
7. Information, education and supported decision making
8. Access medical records;
9. To be heard and fair resolution;
10. Patient and family engagement.

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[2] Patient safety rights charter (who.int)

Negative implications of early, speedy efficient resolution of complaints

We feel the words ‘prompt and clear response’ plus a ‘comprehensive analysis’ is important to include in the rewording of the Purpose Statement, Strategic Objectives and Code. Please refer to our earlier written submission in Appendix Two regarding concerns on the current emphasis of efficient, speedy resolution.

Clarify cultural responsiveness

HCAA suggest re-writing this statement to include more inclusive language and recommend the wording “Cultural responsiveness recognises culture, language, needs, values, and beliefs of all groups such as tāngata whaikaha | disabled people, people from LGBTQI+ communities, and diverse ethnic groups.”

Ensure gender inclusive language

We support changes being made to the Code of Rights to ensure inclusivity of all New Zealanders. It is important that the updated Code of Rights clearly stipulates the importance of valuing and validating diversity. It is essential that any amendments made, dignify and take into account members of the LGBTQI+ communities and those who identify as non-binary or having multiple pronouns.

Protect against retaliation

The HCAA fully support including a non-retaliation statement in the Code. We feel the need for this to be stipulated in the Code is applicable to both consumers and for health professionals who are put in a position of having to report wrongdoing of colleagues, their own organisation and/or an external organisation.

Reticence of consumers and health professionals to report harm/wrongdoing stems from a lack of trust, which is increased when there is a belief that afterwards it will result in retaliation. As noted in HDC’s ACT/Code review document health, professionals facing negative repercussions and/or vilification for speaking out often prevents them from reporting. HDC rely heavily on both consumers and health professionals reporting, yet early identification of critical indicators of harm, ‘red flags’ without a safe pathway to report, means this is not always possible, this restricts their ‘watch dog’ capability.

The Protected Disclosures (Protection of Whistleblowers) Act 2022 was passed with the aim of providing more protection for health professionals when speaking out about harmful practice, or reporting unjust/unlawful behaviour yet there is “no obligation on employers to provide risk assessments to reporters for any allegation that moves forward, as well as ongoing support for their wellbeing.”[3] Strengthening and extending the HDC Advocacy Service to ensure ongoing support and wellbeing of reporters is something the HCAA believe is required.

Receiving ongoing treatment is definitely a contributing factor to consumers not wanting to report to HDC, losing ACC entitlements is also a key concern.

Becoming a signatory to the Code of Expectations

(refer to our previous submission in Appendix Two)

While the Pae Ora (Healthy Futures) Act 2022 does not require HDC to act in accordance with the Code of Expectations as outlined in the 2024/2025 Statement of Performance Expectations report, it is clear the HDC do ensure the principles and intent of the Code is built into their work. While we commend this approach and fully support the ongoing work and continued adherence to the Code of Expectations, the HCAA do not believe the current reasoning for HDC acting in accordance with to the Code of Expectations, which is that the current legislation permits them from doing so, is justified.

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[3] TINZ website 11.8.24 Whistleblower protections watered down yet again in new Bill (transparency.org.nz)

The HDC's role is to promote consumer rights. With the review of HDC Act and Code this is the perfect time for the HDC Act to be amended to require the HDC to act in accordance with the Code of Expectations, and the HCCA strongly support this.

Clarify provider complaints processes

The lack of complaints to hospitals and providers is significant and we support clarification of the provider complaints processes in the Code. Our biggest concern is an ingrained hierarchical power imbalance that exists between providers, consumers, and also hospital managerial staff. This power imbalance is a significant barrier for consumers, who are either too afraid to complain, or who may think there is no point due to the inherent bias of a 'skewed' process with the expectation that it will go in favour of the provider.

We are very concerned about the inconsistency in current dispute resolution processes between different health organisations and between public and private entities. If this type of dispute resolution is to be encouraged, competent, consistent facilitation and culturally safe resolution approaches must be provided.

Both restorative practice Hui ā-whānau and ho ho te rongoa resolution pathways must be accessible to all. We recommend that a focus on facilitator competence be included in the wording of any amendments made to the Code.

Strengthen the Advocacy Service

The Advocacy Service plays a crucial role, yet are restricted because as soon as there is a response from a provider the advocacy role ends. Strengthening and extending their role to support the consumer throughout the entire HDC complaint process would be beneficial, if this course of action is desired, or a restorative/ho ho terongo resolution pathway. Understanding the subsequent process and being supported with navigation through this is just as important.

Perceived lack of independence of Nationwide Health and Disability Advocacy Service

Regarding the perceived lack of independence of HDC Advocacy Service and need for a separate annual report, which HCAA recommend, refer to Appendix Two.

The perspective of many complainants and the general public is that the Nationwide Health and Disability Advocacy Service is not independent of the HDC. This perception, whether accurate or not, is a barrier for many and they choose not to access the Advocacy Service for this reason. Although the HDC does externally contract these Advocacy Services, the HCAA believes there is not enough distance between these organisations and we feel it is necessary to clarify this distinction further. One solution would be for the Director of Advocacy, and also the new Quality Manager of the Advocacy Service, to become more visible in the public domain. We encourage the Nationwide Health and Disability Advocacy Service to undertake formal and much wider consultation with consumers regarding improvements made to policy, their services and systems.

Improve the language of complaint pathways in the Act

We wholeheartedly agree with the Auckland Women's Health Council submission that a No Further Action decision would "have to be one of the most depressing and demoralising outcomes that is possible for a complainant. Irrespective of what has gone on in the preliminary assessment, those three words tell many complainants that whatever happened to them – sometimes serious harm and life-long disability – didn't warrant an investigation and that the provider about whom they complained is not required to take responsibility, make amends, apologise or change their practice." We also concur that in the majority of cases there is no real closure for the hundreds of complaints that receive this verdict, especially when serious harm has occurred. When recommendations are made that are usually educational comment, or telling someone to write better notes, or undertake proper informed consent training, this is just not acceptable to those who have suffered such harm.

The Health Consumer Advocacy Alliance do not agree with just changing the name of a ‘No Further Action’ decision, there must be a change of policy and process because the current process is unjust and we believe it breaches the Human Rights Act. We would like to see increasing transparency of the decision-making process, a much clearer rationale for why the HDC reaches a decision, and regardless of the outcome a new process developed to ensure that, as much as possible, complainants feel as if they have had proper resolution to their complaint. We would also like to see a clear indication that follow up of complainants has been undertaken to ensure compliance with any recommendations made.

As noted in several HDC annual reports there is an extremely low number of investigations being undertaken (between 4.5 and 6% of closed cases), without an appeal right we just do not believe that HDC can fulfil their stated purpose of protecting the rights of consumers.

What other changes, both legislative and non-legislative, should we consider for supporting better and equitable complaints resolution?

We commend the lowering of the threshold of investigations but would like to see more detail around what changes have occurred.

We strongly recommend that all relevant information pertaining to the complaint must be released to both the provider and complainant. Before a Provisional Opinion is finalised by the Commissioner, only the provider(s) are given a “reasonable opportunity to respond” (under section 67 of the ACT). The principles of natural justice, open disclosure of providers, and transparency of review/investigation process should supersede the current justification for not releasing this information. Releasing information to providers only, gives them (and their lawyers) a tactical advantage. An unbalanced advantage.

The HDC have stated that the statutory obligation under section 67 makes it difficult for the HDC to “give consumers the opportunity to respond to provisional opinions at the same time as the provider.”4 Currently a consumer and/or their whānau will only be given the opportunity to comment on the information ‘gathered’ during an investigation, which includes only the factual background or summary of events section of the report, before it is finalised. In the majority of cases, the HDC waits until they receive a response from the provider(s) to the provisional decision, then they make changes to the provisional opinion before sharing the provisional decision with the consumer/their whānau.

From time to time, HDC do share the amended provisional investigation opinions with the consumer/complainant (following the Provider response) but the decision by the HDC is on a case-by-case basis. This undoubtably results in a cherry-picking scenario. The 2020 Health Information Privacy Code clearly states in Rule 6 Access to Health Information 1a, b the consumer is entitled to see a provider response. (Refer to Appendix One)

HDC publishing NFA and Closed File/internal 2nd look decisions?

HDC occasionally will publish NFA decisions in their annual report or where they believe a decision has an educative value.[4] Although we fully understand and appreciate the difficulties the HDC as an organisation are facing, especially with recent cutbacks and under resourcing prior to the cutbacks, finding a way to do this is important in order to fulfil obligations of transparency. The HCAA fully support further funding be provided to the HDC TO meet the obligations of transparency and with the substantial increase in complaints.

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[4] Email correspondence between HDC and Charlotte Korte on behalf of HCAA.

Treating complainants and providers with dignity and respect

When a consumer submits a complaint, the decision to take this action is not taken lightly, especially knowing how difficult this process will be and that it often results in further trauma. When a provisional opinion is released to the complainant – who has already been through a lengthy, stressful HDC complaint experience – to receive a phone call to say the decision has been made is the minimum that the complainant (especially) deserves. If not in person, a Zoom meeting should take place as this would 'lesson the blow' when the outcome is not favourable. Providers also find an HDC complaint distressing, and for this reason the same response should absolutely be applicable to the provider.

In their oral submission on Renate Schütte's petition requesting a right of appeal be implemented,[5] Health and Disability Commissioner, Morag McDowell confirmed they had already lowered the threshold for decisions to be investigated. The HCAA thinks this is extremely positive, but recommends the HDC is more transparent regarding exactly what changes have been made, and what is distinctly different now relative to before lowering this threshold.

Lower the threshold for access to the HRRT

The HCAA support lowering the threshold for access to the HRRT and to ensure that not only complaints that relate to sexual harm or drug/alcohol related complaints are included. Currently leaving the decision up to the complainant to undertake after an investigation has been completed is not appropriate, or fair on the complainant after already going through the HDC process.

Topic 3: Making the Act and the Code work better for tāngata whaikaha | disabled people

It is important that the current definition of 'disability' used by our health entities is amended in the Act and Code because many New Zealanders do not meet current 'criteria' of disability but are disabled. The language used to describe disability and current policy/legislation needs to change, so it is inclusive of all.

The HCAA fully supports strengthening disability functions in the Act and updating definitions relating to disability. Aoteroa New Zealand needs to have a consistent disability definition and we believe the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which New Zealand has signed up to and which the HDC are currently using, needs to be used by all health entities. This definition comes from a social aspect and is more inclusive, rather than just being from a diagnostic point of view. Currently in the health system it is extremely difficult to get a diagnosis for many disabilities.

Access to quality disability care services

There are huge issues with accessing quality care services and uncertainty around which agency is responsible: ACC, Ministry of Health or MSD. This can make a huge difference in the quality of care. The gap in care between those covered by ACC and the Ministry of Health, or who receive disability allowance to cover health costs, is well known.

Recently, 12 'grey area' organisations, who are extremely concerned about this lack of inclusivity and inability to access much needed disability support services, wrote a formal submission titled, "Critical Issues and Challenges in Current Disability Support Services: A Consumer Perspective"[6] All 12 organisations and their members should be receiving Disability Support Services, but are receiving only limited support or none at

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[5] Petition of Renate Schütte: A right to appeal decisions made by the Health and Disability Commissioner, Oral submission from HDC, Morag McDowell. Oral submission starts at 34 seconds.

[6] Critical Issues and Challenges in Current Disability Support Services: A Consumer Perspective.

all. In the submission it states “New Zealand should apply the United Nations definition (to which we are a signatory under the UNCRPD) of disability when considering eligibility for DSS.

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (Article 1).[7]

We would also like to emphasise that the New Zealand Government’s own definition does fit all conditions and disabilities represented in (that) submission, yet the eligibility criteria does not. A disability is an impairment — physical, intellectual or sensory — that lasts for more than six months and limits your ability to carry out day-to-day activities. This can include psychiatric illness.[8]

Recommendation:

The HCAA recommend the HDC provide a directive to all health entities and health stakeholders to adopt the same definition of disability and through collaboration with these agencies try to obtain consistency and inclusivity for all.

Strengthen and clarify the right to support to make decisions

Determining competence

The HCAA has received (on several occasions) anecdotal feedback that has shown that some Providers have made assumptions about a person’s ‘competence’ or ‘incompetence’ in making decisions about their healthcare in a 5-minute consultation. One example of this is when a young virgin woman presented at the doctor to talk about birth control. Her doctor went on to explain that a person who hasn’t birthed a child shouldn’t have an IUD, but didn’t explain why. Her advocate intervened when she could see there was confusion and explained in a way that this young woman could understand. If this had been a different situation, where this young woman wasn’t supported, she could have ended up being put through trauma for no reason.

Additionally, there needs to be education of providers about the Protection of Personal and Property Rights Act 1988[9] because the situation can arise where the Welfare guardian is not advised of services and procedures, etc. that are provided to/carried out on the person for whom they are the guardian.

Topic 4: Considering options for a right of appeal of HDC decisions

Introduce a statutory requirement for review of HDC decisions

Two HCAA co-founders and trustees, Charlotte Korte and Sue Claridge, supported Renate Schütte’s petition to Parliament requesting the right to appeal decisions made by the Health and Disability Commissioner. Sue Claridge wrote a substantial submission on behalf of the Auckland Women’s Health Council[10] and Charlotte Korte co-wrote Renate Schütte’s submission.[11] Both Charlotte Korte and Sue Claridge made oral submissions to the Health Select Committee.[12] Please refer to those submissions for further information.

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[7] United Nations Convention on the Rights of Persons with Disabilities: Article 1.

[8] Human Rights Act 1993: Part 2: 21 (1) (h)

[9] Protection of Personal and Property Rights Act 1988

[10] Submission of the Auckland Women’s Health Council on the petition of Renate Schütte on the right to appeal decisions made by the Health and Disability Commissioner.

[11] Written submission of Renate Schutte.

[12] Oral submissions on Renate Schütte’s petition from Sue Claridge for AWHC (starts at 28 minutes), and Charlotte Korte (starts at 34:18).

All members of the HCAA strongly support introducing a statutory requirement for the review of HDC decisions. As identified by the Health and Disability Commissioner, one of their four strategic objectives is to "protect the rights of health consumers and disability services consumers under the Health and Disability Commissioner Act and Code."[13] The HCAA does not believe this key objective can be met because current HDC policy, and the complaints process, prioritises resolving complaints quickly and efficiently, rather than emphasising, validating and protecting the rights of those who complain and who feel they need a comprehensive review. We believe that the HDC are working hard to provide fair and just resolution. Yet, equity of access and the right to justice is just not possible for the majority of complainants because the legislative limitations of the HDC Act 1994 not only enhances disparity, but it actually promotes it. Without an appeal right fair and just resolution is not attainable.

The HDC recognises the imbalance of knowledge and power that exists between consumers and providers[14] but it does not address the issue of the power hierarchy that exists between consumers and health authorities, such as the HDC. The only way to create a fair and just complaints system is to ensure the current power imbalance between the Commissioner and complainants is finally addressed and resolved. An appeal right will provide an assurance that the Commissioner is not exercising unaccountable power. The HCAA concur with Professor Jo Manning's statement that the "barriers to achieving greater justice in complaint processes and outcome are embedded in the HDC's design."[15]

After an HDC investigation when providers have been found guilty of serious breaches of the code, once referred to the Deputy of Proceedings, then to the Human Rights Review Tribunal (HRRT), not only can providers appeal an HRRT decision, they then have the right to appeal decisions in the High Court. The clear advantage providers have over consumers cannot be overstated. Having Professional Indemnity insurance enables providers the financial means of redress; in contrast financial constraints impede consumers who are unable to take advantage of this same privilege, and often those who have been severely harmed are unable to cope with another 'new' investigation when they may be already traumatised, extremely unwell. If death has occurred, whānau are left fighting for recognition and accountability. This stark inequality is unjust.

For the HDC to allow a mechanism that enables providers to have legal redress and the ability to appeal breach findings, while the same redress is not possible for consumers, goes against the right to justice, including the right to the observance of the principals of natural justice, which is an affirmed right in section 27 of the New Zealand Bill of Rights Act 1990. The right of appeal ensures when a decision is inaccurate, or unjust, there is avenue for redress to make sure this is rectified.[16]

Protecting vulnerable New Zealanders is the HDC's role; having your voice heard is a basic human right. If the right of appeal is not implemented now, it will be a missed opportunity to promote and protect consumers' rights.

Barrister Gaeline Phipps in a recent *New Zealand Doctor* article stated that she wants more timely resolution of Health and Disability Commissioner complaints but feels an appeals process would "just add another layer of delay and more costs to the health sector."[17]

The HCAA recognise that the HDC is underfunded and resources are scarce, especially with the $2.9 million funding cut bestowed on them in June (that HCAA feels was unjustified), and we realise this places more pressure on the HDC as an agency. However, we refute the notion that concern around further delays should displace natural justice, and believe this argument is both unethical and morally wrong.

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[13] The purpose and vision of the Health and Disability Commissioner.

[14] Office of the Health and Disability Commissioner Te Toihau Hauora, Hauātanga Statement of Intent 2023–2027.

[15] Manning, J. Access to justice and accountability: The quest for a right of appeal in New Zealand's Health and Disability complaints scheme. Journal of Law and Medicine; 30, 822-838 (2023).

[16] Oral submissions on Renate Schütte's petition from Charlotte Korte (starts at 34:18).

[17] Forbes S: HDC review to consider right of appeal, New Zealand Doctor, 8 May 2024.

The resources that would be required to implement an appeals process, and the negative impact of a right to appeal HDC decisions, are unconscionable reasons to deny New Zealanders justice when their rights as consumers of health and disability services have been breached. Without the right to appeal, many complainants are denied justice and closure, and our no-fault ACC system prevents consumers from seeking remedies through the court when they have been harmed by medical care and other services obtained from health and disability services providers.

We do not agree with the suggestion that complainants could take their complaint to the Human Rights Review Tribunal (HRRT) if not happy with a decision after an investigation. The HRRT are already resource constrained and this option is only applicable for the 4.5 to 6% of complainants who have actually had their complaint investigated.

Suggested Model for an independent Appeals Process

HCAA recommend a completely independent panel be created to hear appeals after HDC decisions have been handed down. We do not believe that this process should be part of existing HDC processes and feel independent review is essential. We are in complete agreement with Alison Douglass, Auckland Women's Health Council and Professor Joanna Manning that this panel could be partially modelled on the Health and Disability Ethics Committees.

First, applications to have a decision go to appeal would have to be independently assessed, or triaged, before being passed on to an independent appeal body. There would need to be criteria for appeals applications. There should be a set of weighted criteria; for example, higher weighting would be given to complaints where serious injury, disability/disfunction or death was an outcome in the original complaint. Such weighted criteria would enable screening or scoring of complaints lodged for appeal.

The process must be transparent, and the criteria should be publicised; some sort of 'calculator' or flow chart for applicants may reduce the number of appeals that would not pass the initial screening. Those applicants that are rejected for appeal should be given an opportunity to discuss why their appeal application was rejected; this may prevent repeat or vexatious applications.

The Independent Appeal Body

The AWHC envisages an appeals body – a panel or committee – of approximately six to eight people, including at least two consumer representatives with relevant knowledge of the health and disability sector, and lived experience. The panel would also include at least one member with a background in health/medical ethics, two or three health and disability services professionals with broad knowledge, and perhaps people from the Advocacy Service with a thorough understanding of the Code of Rights, but who are not involved in HDC decisions.

The membership of the panel/committee may need to change on a regular basis depending on the complaints to be considered. There may need to be a pool of potential members that could be called upon.

The appeals body would meet on a regular basis, say every two months, but this would be dependent in part on the number of appeals. The evidence and paperwork for each "case" to be considered would be provided in advance to the members of the appeals body and each member would need to familiarise themselves with each case before an in-person or virtual meeting to discuss. The appellant would have the opportunity to speak with the appeals body to discuss their complaint and the reasons why they have appealed, why they believe the incorrect decision on their complaint was made.

Many complainants feel unheard in the current complaints process, and to have an opportunity to face the decision makers and plead their case is an important part of resolution for many complainants.

The appeals body would need to have powers to overturn the HDC decision and send the case back to the HDC for a full investigation, or to modify the decision or to instruct the HDC to engage in some other process with the appellant (e.g. mediation and perhaps a restorative justice style approach with both the HDC and the provider in the case of consumer appellants).

Alternatively, of course, the appeals body may determine that the HDC decision was fair and just and the correct decision, and reject the appeal.

Topic 5: Minor and technical improvements

Revise the requirements for reviews of the Act and the Code

We believe that this review by our current HDC Commissioner (and team) has been done extremely well, we commend the huge effort put into the early scoping of the review, with wider public consultation. The HCAA would recommend reviews to be undertaken every five years but only if review recommendations are taken seriously by the government of the day (which has not happened previously) and tokenistic reviews are avoided.

We agree that there needs to be greater deterrent for those who refuse to comply with the HDC Act and code and there should be an increase the maximum fine for an offence under the Act from $3,000 to $10,000.

In principle, HCAA agrees that the Director of Proceedings should be given the power to require information as long as this information does not result in removal of supports, such as ACC no longer covering injury.

We support the proposal to substitute the phrase ‘aggrieved person’ for the phrase ‘the complainant (if any) or the aggrieved person(s) if not the complainant’.

In principle we support changes that would “level the playing field” for complainants and agree that providers, with all their resources and the legal advice available to them, should not be able to use the Privacy Act and the Official Information Act 1982 to gain an advantage over complainants.

We believe there should be an expanded requirement for written consent in the case of other forms of sedation that are not currently covered in Right 7(6)(c), where any form of sedation has an impact on a person’s ability to make or remember decisions. We would like to expand this further with the addition of when there is a public health risk. One example HCAA can use to illustrate the need for this inclusion, is that currently people are not being provided with proper informed consent or informed choice around the use of anti-seizure medicine used in pregnancy. This should be a notifiable public health risk because there is a clear risk of serious adverse effects on the baby. Many people of childbearing potential are not aware of the risk to an unborn baby if exposed during pregnancy, and may not even know they are on an anti-seizure medicine if used for other reasons such as depression or anxiety. Additionally, if there are unplanned pregnancies consumers have the right to know about potential risks of harm.

We look forward to further hui and collaboration with the HDC and welcome further involvement in this review process as it proceeds.

Consumer Advocacy Alliance Co-founders:

Charlotte Korte | Health Advocate
Denise Astill | Foetal Anti-Convulsant Syndrome New Zealand
Kat Gibbons | Pelvic Floor Dysfunction Support NZ |
Sue Claridge | Auckland Women’s Health Council

Appendix One

Rule 6 Access to personal health information[18]

1) An individual is entitled to receive from a health agency upon request—
   (a) confirmation of whether the health agency holds any health information about them; and
   (b) access to their health information.
2) If an individual concerned is given access to health information, the individual must be advised that, under rule 7, the individual may request the correction of that information.
3) The application of this rule is subject to—
   (a) Part 4 of the Act (which sets out reasons for refusing access to information and procedural provisions relating to access to information); and
   (b) clause 6 (which concerns charges).
4) This rule applies to health information obtained before or after the commencement of this code.

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[18] Health Information Privacy Code 2020

Appendix Two

Health Consumer Advocacy Alliance early input into the HDC Act and Code of Rights Review

The Health
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13 March 2023

Regarding the early input into the HDC Act and Code of Rights Review

Tēnā kōrua Morag and Rose,

The Health Consumer Advocacy Alliance appreciates the opportunity to provide early input into your review of the HDC Act and Code of Rights.

Thank you so much for the opportunity to meet with Rose, Catherine and Michael on the 13th of March. We felt it was a productive meeting and helped to clarify for us what we include and how we present our views to you in this letter.

We have structured our submission starting with our recommended amendments to the HDC Act 1994 (Comments 1-13), including two comments on the role and functions of the Commissioner (14 and 15), followed by our concerns with the Code of Rights (comments 16-18). Comments 19 to 30 are important submissions on a range of issues within the HDC and the complaints process that are not issues that can or should be addressed through changes in the legislation. The order of our comments should not be taken to indicate priority or importance, and some issues we believe to be of utmost importance appear later in our submission (for example, our comments on the notification, reporting and analysis of harm and treatment injury; 19-21).

Amendments to the HDC Act

1. **Right to appeal HDC decisions.** We believe that the Act should be amended to allow both complainants and providers to appeal HDC decisions. Both Charlotte Korte and Sue Claridge made submissions in support of Renate Schütte's petition to Parliament seeking the right to appeal decisions made by the Health and Disability Commissioner, and refer you to those submissions and others in support of Ms Schütte's petition.

2. **Signatory to the Code of Expectations.** We believe that that the HDC Act must be amended to require the HDC to be a signatory to, and act in accordance with, the Code of Expectations for health entities' engagement with consumers and whānau, as required of other health entities under sections 59 and 60 of the Pae Ora (Healthy Futures) Act 2022, and report annually on how it has given effect to the code.

3. **Tiriti Te Tiriti o Waitangi**. The Act needs to be amended to reflect a greater acknowledgement of te ao Māori and Te Tiriti o Waitangi, as is the case in much recent legislation and health agency and Government documents.

4. **Independent review of investigations.** The Commissioner has said that the rise in complaints to HDC is unprecedented and complaints are increasing in complexity. The final decision on what 'acceptable'

practice is, relies heavily on ensuring the Commissioner 'gets it right' after receiving advice from HDC 'expert' advisors and assessors, both internal and external. In future, to mitigate any inconsistencies between decisions made by different Commissioners, we feel that independent review of investigations is warranted. Independent panels could be appointed to provide independent reviews of complaints and decisions. The structure and make-up of panels could be modelled on the HDECs in that: the panel would comprise medical experts, consumer representatives and medical ethicists; the panel would meet regularly (e.g. monthly) to review and discuss complaints and decisions, having been provided with all the (anonymised) paperwork pertaining to each complaint. An independent review panel should reduce the number of decisions appealed (see point 1).

5. **The creation of mandatory enforcement powers.** Where there are persistent breaches or infringements of the Code of Rights, particularly by institutions, the Commissioner needs the ability to ensure compliance. For example, ongoing breaches of informed consent rights in teaching hospitals and in the face of the 2015 Consensus Statement on medical students and informed consent rights. There should be provision for the Commissioner to have the power to mandate compliance with the Code of Rights.

6. **Negative implications of early, speedy efficient resolution of complaints.** The focus of the HDC and wording in the Act and Code needs to change from 'speedy efficient, early resolution', to 'a prompt and clear response, and comprehensive analysis'. Comprehensive analysis should not sacrifice timely resolution of a complaint. Investigations have taken as long as three years, during which time the complainant and their family/whānau have experienced greater distress waiting for resolution. Investigations, even for complex complaints, must be undertaken in less time.

7. **Delays in making preliminary assessments.** Delays in a preliminary assessment of a complaint, as well as being distressing and frustrating for the complainant, can also delay awareness of the HDC of potentially serious issues with providers, or unsafe therapeutic products (medicines, devices) or procedures. There should be a clear threshold detailed in the Act which prioritises serious/severe harm events so, if needed, the Commissioner can intervene earlier, and action can be taken to ensure further harm does not eventuate.

8. **Independence of the Advocacy Service**. We believe that if the Advocacy Service is to be truly independent, it should compile an independent, separate annual report to be submitted to Parliament, or to the Minister of Health. We fail to see how the Advocacy Service can be a truly independent body if it is included in the HDC's annual report. The Advocacy Service annual report, like the current HDC Annual report needs to be made publicly available.

9. **Patient choice in the resolution pathway.** Complainants have very little choice in the resolution pathway chosen for their complaint. The Advocacy Service works well for minor complaints, but not for complex ones or where serious harm is involved. We agree with the Commissioner, who has spoken about the need to include a Restorative Justice approach to complaints resolution; however, this should be as a separate optional service independent of the HDC.

10. **Visibility of follow up.** We recommend that the legislation is amended to ensure greater transparency from HDC regarding who is responsible/accountable for ensuring that improvements/ changes have occurred after recommendations have been made by the HDC, as part of the complaints resolution process. This is especially important for breach findings. The provider does have a responsibility to ensure they have complied with HDC recommendations. However, if recommendations are made, it must be mandatory for the HDC to ensure compliance, there should be audits of compliance with recommendations and results of audits should be published. These audits should be unscheduled so there is no possibility that providers can suddenly implement recommendations or alter notes or other documents. When there has been a breach of informed consent or informed choice a consumer should be included in this audit.

11. **Greater transparency regarding the communication between the HDC and other health related entities**. The HDC and other entities involved with collecting information on patient safety and treat-ment injury should be formally required to share information, including notifications/ complaints of harm and PROMs, including but not limited to ACC, HQSC, MoH/Medsafe/Pharmac (or, in time, the new Therapeutic Products Regulator). While we are aware that there will be privacy issues regarding both the complainant and providers, it must be possible to share data so that there is a clear understanding across all Government health entities and agencies regarding the level of harm caused. To ensure proper surveillance and monitoring of the safety of therapeutic products, procedures and providers of health care services, amendments must be made within the Act, so such obligations are mandatory. It is vital that data and other information collected is not just collated into anonymised themes, but also on an individual practitioner level so repeat offenders can be identified, monitored, and if needed, contacted by the relevant agency to prevent further harm.

12. **Transparency of complaints process/inequitable access to relevant information.** There is a lack of transparency over how decisions are made, and what evidence is used to support a decision (process). Consumers need access to the same information that is shared with providers. The investigation process does not currently comply with the Code of Rights, because of inequity of access to information. The complainant is not given a full copy of the provisional opinion, nor all relevant documentation considered as part of their complaint. Providers should not have access to more comprehensive information than that which the complaint has access to. Not only is this unethical, but consumers are also unable to identify if all relevant information they deem is important has been included and considered as part of the inquiry/investigation.

13. Ethics Committees. There should be a clear overarching legal framework for research ethics committees; their role and function to be clearly set out in primary legislation and their accountabilities to support the National Standard for Ethics Committees and to maintain their independence. As a consumer group, we consider it is an essential role of ethics committees to protect consumers from harm and to benefit them and population groups previously disadvantaged by being excluded or harmed from research in the wide range of health and disability research, to be set out in legislation or through the HDC Code. This is a gap in our legal framework which has never been filled following the Cartwright Inquiry in 1988.

Alison Douglass would be a suitable person to work with HDC to put together a suitable policy, legal and ethical framework. Alison is a Deputy Chair of the Health Practitioners Disciplinary Tribunal; former Chair of the Wellington Ethics Committee; former Chair of ACART for the Minister of Health; established and was co-Chair of the ACC research ethics committee for 10 years (Alison Douglass: ADLS). The Health Consumer Advocacy Alliance would be happy to put you in touch with her if needed.

Functions and Role of The Commissioner

14. **The role of Commissioner in publicly promoting and protecting consumer rights.** The Commissioner has a statutory obligation to publicly promote and protect consumer rights, and we believe the Commissioner needs to be more visible in the public domain, especially when serious issues become apparent and ongoing harm is occurring. It is important for the public to hear the voice of the Commissioner, to see that the Commissioner is visibly stepping up in public and making comment on serious issues, particularly systemic issues/breaches, repeat offenders (particularly institutions such as hospitals) and on devices, medicines and procedures that repeatedly cause harm. This also gives validation to those who are harmed, and misinformation can be reduced.

15. **Accountability/performance reviews of Commissioner.** Often a given Commissioner may have a long tenure, and the public have a right to be assured of competence in the decisions made. The public need more information on who the Commissioner is accountable too, how the position and performance is reviewed, and the KPIs for the Commissioner and how these are measured.

Concerns Regarding the Code of Rights

16. **Inclusivity and gender diversity**. Where appropriate, the Rights set out in the code need to include gender diversity in rights of dignity and respect; services that consider the needs, values, and beliefs of gender diverse people, and freedom from discrimination, coercion and harassment, exploitation.

17. **The right to fully informed consent**.

    (a) There is ongoing inadequate provision of information to consumers about surgical mesh risks, and risks of medicines in pregnancy. These sorts of situations emphasise the need for all health agencies and individual health practitioners to be accountable for ensuring that all information shared or published is accurate. Before any information is endorsed there must be stricter scrutiny of who is disseminating this information, whether their level of expertise enables them to provide this information, and if this information/training corresponds to best practice and international guidelines. Information must not be misleading as it would be interpreted by a consumer. Specifically, it must not mislead or minimise the amount and severity of harm that has happened or may occur. To obtain informed consent a patient must be provided with all treatment options. The BRAN[19, 20] method should be endorsed by HDC:

    Benefits – all the benefits of proceeding with the health care professional's suggestion

    Risks – all the risks explained to the consumer

    Alternatives – advise the consumer if there are any alternatives available

    Nothing – explain the likely outcomes to the consumer if they choose to do nothing

    (b) Currently there are significant issues with cognitive bias in current consenting practices, and not just with surgical mesh. The nature of cognitive bias is such that health professionals are unlikely to present comprehensive information about alternatives to the treatments they offer. There is also no requirement for practitioners to disclose if they are unable to provide specific treatment options themselves. We support amendments to make this a legal requirement.

18. The right to be fully informed about breach findings.

    (a) For the HDC to have the power to recommend or direct providers in certain decisions with breach findings, to advise future patients that they have previously been found to have breached the Code of Rights.

    (b) Consumers should be able to request information about the competency and expertise of health care providers, including details about any previous complaints before commencing treatment.

Notification, Reporting and Analysis of Harm and Treatment Injury

19. **The importance of a Red Flag alert.** The current harm reporting and identification system is not working, or in some cases not available. We suggest a 'Red Flag alert' to be developed and implemented within the HDC internal system, so HDC can use this early indicator to identify, track, and monitor repeated harm from individuals and more widespread harm from particular health disciplines, devices or medicines.

20. **HDC definition of serious harm**. The only recourse for patients to obtain 'justice' is the HDC complaints process as they do not have the ability to sue in New Zealand. Judicial hearings are traumatic and too expensive for the average consumer, and Ombudsman investigations are of limited benefit. HDC send few complaints to the Director of Proceedings for disciplinary action, and predominantly practitioners are

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[19] BRAN Analysis at https://qilothian.scot.nhs.uk/pc-resource-bran-analysis

[20] Choosing Wisely: Shared decision making resources at https://choosingwisely.co.uk/wp-content/uploads/2020/11/CWUK_patient_leaflet_100120-1.pdf

likely to face prosecution in only cases of sexual misconduct, misuse of drugs or fraud. Therefore, we feel that HDC should closely consider what constitutes serious harm, and which type of complaints meet the threshold for disciplinary proceedings.

21. **Annual analysis of harm data.** A formal function of the HDC is to protect patients from harm. We believe that regular 'deep dives' into complaint data, and the release of subsequent formal, publicly available, reports are necessary. This includes looking at disparities in data between relevant health entities, and collating and analysing patterns of complaints, breaches of rights and physical harm. It is essential that the HDC be able to identify individual repeat offenders and vocational sectors of health care that are over-represented. If this is currently not possible, new systems and policy needs to be created to ensure repeat harm on an individual basis can be monitored.

Other Issues, Concerns and Recommended Changes

22. **Published guidelines on threshold of HDC investigations.** More transparency is needed regarding what the threshold is for deciding whether a complaint goes to investigation. HDC should rewrite the existing guidelines so they contain more comprehensive, clear information that all consumers will understand. We also strongly encourage HDC to publish 'No Further Action' decisions, so the public have a greater of an understanding of the reasons why cases are not being fully investigated.

23. **Internal HDC reviews to be published.** We strongly recommend that HDC formalises and publishes internal HDC reviews. Such internal reviews need to be overseen by an independent body that can provide a 'fresh look' at the complaint from someone who has not seen or been involved previously in this process.

24. **Criteria for standards and expertise of HDC advisors/complaint assessors.** Outcomes of complaints are largely dependent on 'expert' opinions from advisors engaged by HDC. In our experience, and from the consumers we are hearing from, there are concerns about whether HDC internal and external advisors have the requisite knowledge to be able to provide a comprehensive expert opinion on some complaints. We suggest the HDC look at how these advisors are chosen and examine the current criteria for advisor knowledge and expertise prior to engagement. In the case of surgical mesh, many specialists (some of whom are currently engaged by HDC and deemed 'experts' in such procedures) may not be competent enough to offer expert opinion, especially if they have not met credentialing standards. This issue does not just pertain to surgical mesh but may be found in all vocational disciplines.

    In the example of Foetal Anti-convulsant Syndrome (FACS) and individual syndromes, there are currently 'experts' who are relying on research that is more than ten years old, instead of the much more current information available. As well as criteria for standards, we also recommend that, in specialised cases such as FACS and surgical mesh, as well as assessors/advisors (that meet the criteria), expert consumers are involved in assessing the complaint. Additionally, it would be wise to ask 'experts by experience' which medical/clinical experts they would recommend to be advisors on specific issues. It is often the 'expert by experience' consumer who has significant knowledge of the medical condition at the heart of complaints, and know who are the most experienced and skilled or knowledgeable health practitioners or clinicians in that discipline.

25. **Imbalance of power between complainants and providers.** There is an imbalance in the weighting given to consumers/complainants and the information they provide compared to that submitted by the provider; essentially more trust or belief is placed in what healthcare professionals say compared with what complainants say. A healthcare professional who has caused harm might have seen a consumer years ago and have seen hundreds of patients since, yet they are believed ahead of the consumers. This imbalance of power has a flow-on effect, causing more harm, and leading to consumers having even less faith in a system they already mistrust. The Code of Consumer Expectations places consumers on a level footing with their health practitioner; consumers are experts by experience.

26. **Consumer fear of lodging a complaint with the HDC.** Some consumers are afraid of lodging a complaint with the HDC if they are receiving supports through ACC, as they believe they will have their ACC revoked. This fear is exacerbated if this has occurred in the past. We know of a situation in which a family/whānau had their child's ACC entitlement revoked as a result of going to HDC, and the whānau then had to fight through the court to get ACC back. The family won, but at what cost? There needs to be a guarantee that, irrespective of the HDC decision, there will be no revocation of their ACC entitlements. For example, an HDC decision may find that a treatment injury complaint does not meet the threshold of a breach of rights, but this does not mean that a treatment injury has not occurred, and meets the criteria for ACC entitlement.

27. **Broaden the HDC definition of disability.** The current definition of disability and criteria for who fits this category must be changed to ensure it is inclusive of all people living with a disability. The HDC must adopt the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD); New Zealand is a signatory to the UNCRPD and the HDC must comply with this convention.

28. **Post decision feedback and communication with the complainant.** It would be advantageous, after receiving the provisional decision letter from HDC, that a video call between the complainant and HDC is undertaken. This would make the complainant feel more human, valued, and respected and would be particularly beneficial when it is a complex complaint that has taken some time to properly investigate.

29. **Customer satisfaction:** To ensure the HDC is fulfilling its obligations to protect and promote consumer rights, and that the complaints process meets the needs of consumers, engagement with consumers in a variety of ways on a more regular basis is needed. We don't believe that only surveys and "exit interview" style assessments of consumer satisfaction are adequate. While they may provide some limited understanding of the consumer experience, we recommend a more focussed "listening circle" style of forum to review consumer experience of the complaints process, perhaps facilitated by a neutral party to ensure that consumers feel able to speak freely about their experience.

30. **That the HDC is adequately resourced** (financially and in terms of staffing and expertise) to ensure that the volume of complaints can be dealt with in a timely manner for the benefit of both complainants and providers, to enable other critical work (such as research into patterns of complaints) can be undertaken, and to enable the monitoring/auditing of past breaches.

We believe that the Office of the Health and Disability Commissioner, the Code of Rights and the complaints process are a vital and integral part of our health system. They have a critical role in not only upholding consumer rights in the provision of health and disability services, but ensuring improved patient safety, and contributing to positive changes in culture within our health system, and health institutions and provider organisations.

We hope that any apparent criticisms we may have of the HDC, the Act and the Code of Rights, are taken as our genuine desire to work with the HDC as consumer advocates; to participate in ensuring that the complaints system, and all its parts, offer New Zealanders the very best opportunities to address breaches of their rights and help create a better, safer health system.

Ngā mihi nui

Health Consumer Advocacy Alliance
Co-founders:
Charlotte Korte | Patient Advocate
Denise Astill | Foetal Anti-Convulsant Syndrome New Zealand
Kat Gibbons | Pelvic Floor Dysfunction Support NZ
Sue Claridge | Auckland Women's Health Council