The Health Consumer Advocacy Alliance
Experts by Experience

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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 treatment 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[1, 2] 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 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.

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

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

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

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