

15 July 2024

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

Thank you for the opportunity to provide comment on proposed changes to the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights (Consultation document April 1994), in particular the right to appeal HDC decisions. My comments are founded on my personal experience as a health consumer. I am not in a position to provide comment on legal technicalities regarding options for incorporating the right of appeal. In this regard I make reference the work of Professor Jo Manning¹.

The circumstances which motivated the *Petition of Renate Schütte: A right to appeal decisions made by the health and disability commissioner* included issues of informed consent, specifically the rights to be fully informed (Right 6) and to make an informed choice and give informed consent (Right 7). This is covered in the evidence presented with the petition ([15926f70f943af858c28d4fab32caa7e28e8b33c \(www.parliament.nz\)](https://www.parliament.nz/bills/52-1/15926f70f943af858c28d4fab32caa7e28e8b33c)) and I request that this be considered part of this submission. I maintain that informed consent is fundamental to ensuring patient rights, and fundamental to the purpose of the HDC.

Decisions on informed consent, more so than other possible breaches of rights, are subjective and also often a case of 'he said, she said'. The decision-maker is put in the position of having to make a call on conflicting views and facts. The decision on these complaints is often No Further Action (NFA), with NFA decisions the most common decisions on complaints overall. There is no option to appeal these NFA decisions.

Lodging a complaint often comes with significant emotional, mental and physical demands on the complainant. I suggest that if a patient (or their family) goes to the trouble of lodging a complaint on the basis of a lack of informed consent, it is highly likely that the mere lodgement of the complaint in itself strongly suggests that they have **not** been provided with the level of informed consent that meets **their** needs - as per Right 6 (2) "*Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent*" and Right 7(1) "*Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise*".

It is entirely possible that the patient who has received an NFA decision may have further evidence and witnesses that can corroborate their complaint if they were given the opportunity to be heard through an appeal process (this was certainly so for my own personal complaint). In the interests of natural justice they deserve to be given this opportunity. In the interests of broader improved patient safety and possible identification of patterns of harm they must be given this opportunity.

The importance of this can be illustrated by the informed consent process for the covid-19 vaccination programme. I note the Rory Nairn decision in which the Commissioner found a breach of the right to informed consent (Right 6(1)) due to not being informed on the risks of myocarditis. It is likely that the vast majority of vaccination recipients were not advised of this risk, and possibly other risks, even though information was available to the relevant authorities regarding this risk at least 5 months prior.

If a right of appeal had been available, possible NFA decisions on complaints concerning inadequate informed consent for the covid-19 injection could have been challenged. This could have had the potential to highlight a systemic issue and prevent unnecessary harm.

I do not support internal reviews as an alternative to a right of appeal. The process needs to be external to provide independency and transparency.

I understand and appreciate that over recent years HDC have been keen to make improvements to the complaints process. I strongly encourage inclusion of a legislative appeal right in the Act to ensure robust HDC decisions that are above all “fair”.

A handwritten signature in black ink that reads "Renate Schütte". The script is cursive and fluid.

Renate Schütte

ⁱ 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)