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Tēnā koe Morag

## **NEAC's feedback on the Review of the HDC Act and the Code**

Thank you for your invitation to provide feedback on the Commission's review of the HDC Act and Code. The National Ethics Advisory Committee – Kāhui Matatika o te Motu (NEAC) is an independent advisor to the Minister of Health on ethical issues related to health and disability research and services and we are pleased to provide the following submission to the review.

NEAC supports the development of the HDC Act and Code and agrees with the general approach taken to the topics that have been identified. The three issues within these topics that are of particular interest to NEAC are the proposed changes to the complaints process (and drawing upon tikanga), research with those who have affected capacity and public reporting requirements.

### ***Supporting better and more equitable complaint resolution***

NEAC supports adopting the Hohou te rongo proposed hui process, acknowledging that a deep understanding of the matauranga and long history contained in the use of the phrase should accompany its adoption. While we understand that this is primarily about equity for Māori, we wonder whether this might be a process that could be of value to tangata tiriti. Exploring approaches to complaint resolution that are also instances of restorative justice sounds very promising, but perhaps resource intensive.

NEAC is strongly supportive of the HDC being funded so that it can develop and sustain this approach to complaint resolution.

NEAC supports the explicit incorporation of tikanga into the Code and agree that "mana" has been successfully introduced into the Substance Addiction (Compulsory Assessment and Treatment) Act 2017, which demonstrates that it can play an important role in New Zealand Legislation. We note that "mana" has also been introduced as an ethical principle into the *National Ethical Standards for Health and Disability Research and Quality Improvement* and this draws upon the articulation of that idea in the *Te Ara Tika Guidelines for Māori research ethics: A framework for researchers and ethics committee members*.

We also note the work of the Law Commission on how law can best engage with tikanga to maintain the integrity of both the law and tikanga ([NZLC SP24](#)) and understanding the full meaning of concepts like mana and what must be considered when they are used.

NEAC supports the HDC being able to take a proportionate approach to complaints, including the introduction of processes to fast-track complaints and work more pro-actively with complainants to achieve earlier resolution of more complex complaints. We are also supportive of the recognition of the risk of retaliation in Right 10 (the right to complain). We hope that the fast-tracking processes prioritise complaint resolution when complainants have no feasible option but to continue to receive health and/or residential care from, or supervised by, people and organisations that they have made a complaint against.

We support the HDC seeking to understand the experience of complainants and service providers during the complaint processes. It will be important that feedback is collected from both HDC and health service provider complaint processes. We recommend that a range of quantitative and qualitative methods are used in the evaluation process, rather than limited to surveys and that it would be useful to explore why people who are dissatisfied with a health or disability service do not make a complaint. We would also support the HDC reporting on this annually.

### ***Research with those who have affected capacity***

NEAC thanks the HDC for its commitment to further consideration of research involving those with affected capacity. The HDC's earlier report on this issue is a high quality and careful analysis of the issues and its recommendations should be considered by policy makers.

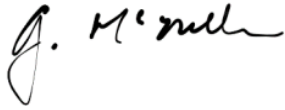
NEAC agrees with the view that the current necessity and best interests' justification of Right 7(4) is unworkable for research. The NEAC plans on discussing the importance of a statutory change so as to accommodate minimal risk research with the Minister and would welcome the opportunity to communicate further with the HDC about this.

### ***Public Reporting Requirements***

The HDC Act 1994 is currently silent on public reporting requirements. NEAC values the current reporting of trends in complaints provided by the HDC, providing as it does an indication of parts of the health and disability sector that may not be operating well and therefore helping to inform our work. We therefore encourage consideration of a clear definition of the public reporting responsibilities of the HDC in the Act, in order to help ensure that such work is done and is appropriately funded. We encourage the provision of further detail in periodic public reporting by the HDC regarding its complaints processes and those of health and disability services.

We would be pleased to meet with the HDC to discuss these matters and consider how the Code and the National Research Standards might be better integrated and optimise outcomes.

Nāku noa, nā

A handwritten signature in black ink, appearing to read 'J. McMillan'. The signature is fluid and cursive, with a large initial 'J' and a long, sweeping underline.

Professor John McMillan  
**Chair, National Ethics Advisory Committee**