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Submission: Health Information Privacy Code 2020 Amendment No 1

The Federation of Women's Health Councils Aotearoa – New Zealand (FWHC) is a national umbrella organisation of women's health councils, women's health groups, and individual women throughout New Zealand. The Federation has a commitment to providing a powerful voice for women consumers of health and disability services, and to act as a public good advocate in matters that affect their well-being interests and those of their family/whanau. We have made submissions on previous amendments to the Health Information Privacy Code including Schedule 3 Use and Disclosure of Information Derived from Newborn Babies' Blood Spot Samples.

1. FWHC supports the minor technical word changes that align the HIPC with other relevant legislation.
2. We understand Health New Zealand (HNZ) will assume primary responsibility for the National Health Index (NHI) and HPI/CPN (Common Provider Number). Contrary to the proposed amendment to Rule 13 (b), it is essential, to avoid any doubt, that the HIPC clearly states HNZ is responsible for both of these national collections if our understanding is correct.
3. We have ongoing concerns around the general public understanding of matters relating to the NHI, and the potential to consider its use for increasingly wider purposes/uses, -just because it is technically possible from an IT perspective and the NHI presents as a convenient repository for information and/or data. The NHI and NHI number are not the same, although this amendment is largely focused on the identity purpose. We understand the NHI is the index of information held about respective individuals. It includes the NHI number assigned to each individual along with their identifying and administrative information. The NHI number is used to identify a person and link their health records.
4. FWHC contends the use of the word 'assign' needs to be clarified. It is disappointing the use of 'assign' was continued in Privacy Act 2020 as it is confusing, particularly so for the public. There needs to be a lay interpretation and/or clarification of 'assign' so that people understand what it means in practice. Currently it is more than the allocation of a unique NHI number to an individual. With respect to Schedule 2 of

HIPC we understand it allows approved agencies to access and use the NHI and NHI numbers. But have we got that right?

5. FWHC has noted the addition of 'State services' to the Interpretation and that new para (15) in Schedule 2 provides for '*Any health agency that is funded (whether wholly or partly and whether directly or indirectly) by a State service to provide health or disability support services*'. This is confusing and without further information and explanation it is difficult to assess all the implications of such a broad provision that has no restrictions or limitations attached to it. Indirect funding by a State service of a health agency is also questionable from a number of perspectives. FWHC believes para (15) as drafted, goes too far and we cannot support it. There must be some restrictions and in this regard we strongly urge that the use of the NHI number be restricted to the health and disability support sector only; that it must not be recorded outside of the health and disability support system; and this needs to be made explicit in the HIPC.
6. Allotment of a unique NHI number to each living individual is an assignment of that number. In our view anything further is a 'use' of that number. We strongly urge that use of the NHI number must be restricted to use within the health and disability support system only and this needs to be made explicit. There must be some restrictions and in this regard we strongly urge that the use of the NHI number be restricted to the health and disability support sector only; that it must not be recorded outside of the health and disability support system; and this needs to be made explicit in the HIPC.
7. Without restrictions and protections FWHC is concerned about increasing risks of identity theft, fraud and misuse/ malicious use of NHI numbers and the associated information held in the NHI. This has become more apparent with the Covid-19 pandemic. We are also concerned that authorised or thoughtless inadvertent wider use of the NHI number risks becoming expected practice and evolving into the de facto universal identifier number in Aotearoa New Zealand. We would strongly oppose any moves that enable this potential shift to arise.

Thankyou for this opportunity to provide our consumer-focused views.