Hauora Health Privacy Working Group

3rd May 2022

Submission:

Privacy Act 2020
Health Information Privacy Code 2020 Amendment No 1

1.Introduction

Thank you for this opportunity to comment on the proposed amendments to the Health Information Privacy Code (HIPC) 2020 which will align the Code to the Pae Ora (Healthy Futures) Bill. We agree with the minor updates and correction of drafting errors etc. However we have substantive comments relating to the proposed amendments to Rule 13(4)(b) and Schedule 2 (15). Our comments necessarily cover:

- the assignment of NHI numbers
- the implications of the addition of 'State services' to the Interpretation
- the current use and potential further use of NHI numbers outside of the health and disability support sector
- the National Health Index (NHI)

2.Rule 13 Unique Identifiers
The use of the NHI number as the unique health identifier

Clarification of 'assign' and its application in Schedule 2

The Group believes it is important for the Privacy Commissioner to provide clarification of 'assign' with respect to its application in Schedule 2 of the HIPC. Our understanding is that 'assign' is more than the initial assigning/allocating of an NHI number to an individual; that it includes access to and use of NHI numbers. Furthermore we understand only those agencies listed in Schedule 2 are permitted to 'assign'/use NHI numbers. Clarification and/or a lay interpretation could be provided by way of a footnote or Explanatory Note to the HIPC.

Implications of 'State services' added to Interpretation and Schedule 2 (15)

'State services' as defined is very broad.

As drafted, paragraph (15) in Schedule 2 has no limitations on which state services may be involved with funding health and disability support services. Without more information, it is extremely difficult to understand and/or fully assess the implications and future risks with respect to the use or recording of NHI numbers (and personal health information) by state service funders from outside of the health and disability support sector. Further, without clear limitation or clear scope of use, there

may be a lack of transparency and misaligned expectations on state services which may impact public trust.
An additional concern is the reference to "indirect" funding. It does not reflect our expectations of best practice funding by state services and risks compromising transparency and accountability obligations. It is unclear in what circumstances this could/would arise and we consider there must be clear limitations should services receiving indirect funding be included.
Specifics of funding/contractual arrangements are unknown currently under the structural reforms. Whilst it is acknowledged that there will be more state sector agencies likely to contract with health and disability support agencies, a cautious approach to approved agencies should be taken until more, and much clearer details are available.

Schedule 2 reads as a defined, exhaustive list of agencies and we are of the view that the current wording of para (15) widens this scope too far.

Use or recording of NHI numbers outside the health and disability support sector
We are aware of NHI numbers being used or recorded by some electricity retailers and telecommunication companies with respect to Medically Dependent Consumers and/or Vulnerable Consumers. We are still trying to establish by what process this was authorised or enabled when this arrangement was put in place, presumably in the mid-2000s, given these companies are not, and should never be, listed in Schedule 2.

Our first concern is around who has access to the NHI number (and the associated personal health information) in these utility companies and the potential for identity theft, misuse, fraud etc. There is also the potential for a variety of future risks arising from unforeseen uses of all this data.
Our second concern is that such use may be the beginning of the 'slippery slope' to the NHI number becoming the unique National Identifier by default, 'because everyone has one, so why not'.

The introduction and use of National Identifiers poses unique risks and challenges to consider. Within the US and Canada, they are difficult to change or protect in the event of a data breach. This was evidenced in the Equifax data breach causing life-long privacy and fraud risk. The use and spread of NHI numbers within NZ by industries and agencies raises concerns of similar risks.

Uses of the National Health Index (NHI)
We are aware that data on the NHI is used to assist with the planning, coordination and provision of health and disability support services, research, preparation of statistics, as well as its initial purpose as an identity tool. In recent years upgrades to the NHI have seen new data elements proposed, some of which have related to enhancing the identity tool, some have been for administrative purposes and some have been opportunistic, special interests and an inappropriate use of the NHI. There was an increased focus on using the NHI for the planning and provision of health and disability support services in the most recent upgrade. Not all new uses have been accepted and not all proposed new data elements to support either existing or new uses have been accepted. To date, any proposals to record clinical information on the NHI have not been accepted as this has been deemed inappropriate. Notably, the Ministry of Health website gives the assurance that 'Clinical information is not recorded on the NHI.'

We acknowledge this discussion is out of scope with respect to this amendment to the Code. However we are sufficiently concerned with the potential for function creep and future risks if the

amount and types of data elements /personal information held on the NHI are permitted to 'grow like topsy'. We are concerned the NHI is seen to be an easy /convenient place to add data elements of special interest to the various stakeholders, but it is not necessarily the most appropriate place from a privacy perspective.

As Privacy Commissioners have pointed out in the past, the more personal health information that is collected on the NHI the more tempting it is to be subject to misuse, malicious use and fraud.

3.Amendments

Health Provider Index/Common Provider Number - Amendment to Rule 13(4)(b)
Assuming that responsibility for maintaining the HPI and CPN transfers to Health New Zealand we do not agree with the proposed amendment *whereby the reference to the Ministry of Health would be removed* – the justification being that *this would be consistent with the reference to the National Health Index (NHI) number which does not specify which agency has primary responsibility for the national collection.* This justification is weak and is no longer applicable in the restructured environment where there is now more than one agency which could be primarily responsible.

Recommendation: the agency that is to have primary responsibility for both the HPI/CPN and the NHI must be specified in the Code for transparency and accountability purposes. The public must not be left to guess which agency is primarily responsible for these two indexes.

Amendment Schedule 2 Agencies Approved to Assign NHI number

(14) Ministry for Disabled People – while it sits outside the health sector /Pae Ora legislation it continues the disability support services function that was part of the sector under the NZ PH&D Act. We consider that the establishment of the Ministry and its purpose is transparent and its inclusion on Schedule 2 is appropriate

(**15) 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** – Aligned to our comments above, we are concerned that this drafting is too wide. It risks relinquishing control over who can assign NHI numbers, inappropriate use and/or scope/function creep.

It would appear inappropriate for an agency whose funding is unclear to the public because it is received "indirectly", to be permitted to assign NHI number.

It is unclear if state service funders outside of the health and disability support sector will be permitted to record NHI numbers (and personal health information) e.g. as part of reporting and accountability requirements from contracted health and disability support agencies.

Given the health sector principles include addressing the wider determinants of health, we are concerned that there is the potential for "creep" with respect to the use of NHI numbers. The special protection afforded to NHI numbers must be preserved and focus kept to being assigned by health agencies only where it is necessary to carry out their functions effectively.

Therefore the Group does not support para 15 as drafted. Restrictions or limitations must be put in place.

Recommendation: A narrow, limited approach must be taken to the approved agencies listed in the Schedule until there is greater clarity on what agency and organisation collaboration in the health and disability support sector looks like.

Schedule 1 Specified Health Agencies
We query whether NZ Health Partnerships Ltd should be retained on the Schedule. It is a wholly owned subsidiary company of all the DHBs and its functions may be absorbed into HNZ. Its status needs to be clarified.

4.Summary

As a Working Party of the Privacy Foundation, our primary interest is in the impact of this Amendment as it relates to the fostering of trust in the preservation of health information and data privacy. We believe that there are aspects of the Amendment that need to be clarified or amended.

Specifically, the meaning and limitations on the concept of "assign" need to be included in the HIPC as this is the point at which the personal meets the organisational. There is a risk that organisational convenience will compromise privacy rights and interests.

Further clarity and transparency around which agency has primary responsibility for the NHI and for the HPI/CPN is essential to maintain trust in their ongoing operation and use.

We recommend the explicit restriction of the use and/or recording of NHI numbers to health agencies in the health and disability support sector to prevent "function creep" and potential future risks.

Schedule 2 (15) is a specific concern as it goes too far in widening the assignment and use of the NHI number. Our recommendation is that this section of the Amendment be substantially reviewed and further amended. 'Indirectly' must be deleted and restrictions must be put in place as outlined above.

This submission has been prepared by the Privacy Foundation's Hauora Health Privacy Working Group.

Barbara Robson MNZM
Patricia Cunniffe MNZM, MA
Rebecca Hawkins LL.B, IAPP, CIPT
Natasha Mazey PhD, CIPM
Andelka M. Phillips BA/LLB, LLM (1st Class Hons) (Auckland), DPhil (Oxon)