

**From:** Sebastian Morgan-Lynch  
**Sent:** Thursday, 13 August 2020 10:52 AM  
**To:** privacy.code@privacy.org.nz  
**Subject:** Comments on HIPC amendment

Thank you for seeking our views on the replacement Health Information Privacy Code 2020.

As noted, the code is not intended to enact any policy changes, and is directed at ensuring the code is harmonised with the provisions of the Privacy Act 2020. However, given the Commissioner's ability to use his code-making power to alter the application of the provisions in the Act, we have made some additional suggestions for consideration either at this amendment or as part of a later one.

Where no comment is made about a change, ACC has no concerns or suggestions for change.

#### **Definition of health agency**

It is unclear why the definition of health agency is not inclusive of rule 13 for the purposes of agencies that no longer provide health services. It seems appropriate and reasonable for rule 13 to continue to regulate historical data held by agencies that no longer provide health services or the personal representative of a deceased individual. As written the law creates an incongruous hole.

## **Definition of representative**

While this definition is unchanged, we note that the Privacy Act 2020 does not define representative in its interpretation section, although the term is used throughout that Act. We suggest the Office consider this in any guidance it offers, and whether this could be remedied in any future Act amendments. Representative is an important legal concept and carries significant legal powers and abilities, but it is not completely intuitive. See also the comment on rule 4, below.

We also invite the Commissioner to consider whether the definition of representative is still fit for purpose where it relates to deceased individuals. Currently only the personal representative of a deceased person can exercise any rights over their health information. In effect this is the administrator or executor of a deceased estate. The parents or guardians of a child under 16 do not have any rights to access their child's health information, and nor does the spouse of an individual who has died intestate. We consider this problematic and arguably unjust. We suggest, e.g., amending this definition to allow the parent or guardian of a deceased individual under 16 years to be considered that individual's representative, and to allow a similar role for someone acting in a similar role to a personal representative (e.g. surviving spouse).

**This issue has frequently arisen for ACC when a surviving spouse requests their deceased partner's information. We consider that they should be entitled to it, especially in situations where the deceased client has granted the spouse 'authority to act' on their behalf and has therefore expressed a clear intention. However, if the spouse is not listed as the executor or administrator, presently we are declining these requests as we consider that we have no legal basis to disclose the deceased client's information. This is a harsh approach which we consider is distressing for grieving families, who often need the information for practical purposes (such as resolving compensation issues)**

In our view this change would be proportionate. In the context of health information privacy the main change would be to allow that representative to make an access request under section 22F and rule 11(5) (with any appropriate changes) for information about the deceased, by a process which already allows for withholding, refusal, and review of decisions by your office.

### **Subrule 1(2)**

We support the insertion of subrule 1(2) to reflect the new obligation to collect anonymous health information where that is consistent with the purpose of collection. We note that, per section 22H of the Health Act 1956 this anonymous information can be freely used and disclosed for any purpose and it may be worth making this clear in any guidance issued by the office on this change.

### **Rule 2(2)(c)(iii)**

We support retaining the existing formulation for this rule, rather than importing the new Privacy Act formulation.

### **Section 54 authorisations (various)**

We think retaining all the references to section 54 is a useful and user friendly approach, given that the code is likely to be read independently of the Act and should therefore be as self contained as reasonably practicable.

### **Rule 4**

We support the change to rule 4, but suggest that the Office may wish to consider issuing guidance on the meaning of the change to information about children or young people, perhaps in consultation with relevant stakeholders such as the Children's Commissioner and Oranga Tamariki. It is not immediately obvious what 'particular care' means in this context.

We also note that the phrase "children or young persons" is defined neither in the code or in the new Privacy Act. This may create confusion and uncertainty around the definition of representative, which effectively uses 'person under 16' as a proxy for a child.

## Rule 12

Allowing representatives to authorise offshore disclosure, having been informed of the details, is a sensible and appropriate addition to this rule that is in line with the overall health information privacy regime and we support it.

## Rule 13

We support the changes updating this rule to match the new Act's provisions.

We note that the changed subrule 13(9) does not refer to justice sector agencies, but the explanatory comment does – this may be an oversight.

## Clause 6(2)(b) Charges

We note that the provision allowing charging for providing a copy of a document produced by medical scanning technology is somewhat obsolete – any copy provided now would likely be electronic and therefore incur no meaningful expense. We suggest changing “copy” to “physical copy” for this reason.

## Schedule 1

We support this change to Schedule 1 removing the Regulator, as no longer reflecting the current environment.

Regards,

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