

Information Paper 4 of 5

Adding rule 3A to the Health Information Privacy Code 2020 (HIPC)

We propose a new rule 3A in the Health Information Privacy Code, as set out in the documents published with this paper.

- [Amendment No 2 to the Health Information Privacy Code 2020](#) (opens to PDF).
- [Health Information Privacy Code 2020 with changes marked up](#) (opens to PDF).

Other information papers available:

- [General Information Paper](#) (opens to PDF).
- [BPPC Information Paper](#) (opens to PDF).
- [CRPC Information Paper](#) (opens to PDF).
- [TIPC Information Paper](#) (opens to PDF).

The HIPC sets rules for health information and agencies

- 1.1. The HIPC sets specific rules for health information and health agencies. This is the largest individual sector currently covered by any code, and given the sensitive nature of health information, strong privacy safeguards are expected for health agencies. However, rules for the health sector also need to support timely and effective care for individuals who require health services.



We think health agencies can comply with rules on IPP3A

- 1.2. During informal engagement, one of the main concerns we heard about including IPP3A rules in the HIPC was the potential for high administrative burdens and costs, as indirect collection is common when people seek and receive healthcare. For example, a general practitioner may refer an individual to a specialist for follow up care or may receive discharge notes from a hospital that one of their enrolled patients attended. When the general practitioner refers an individual to the specialist, the specialist will be indirectly collecting information about the individual. If the specialist then shares any further information the general practitioner after seeing that individual, the general practitioner is also indirectly collecting information.
- 1.3. We understand concerns about the potential for administrative burdens. However, we think that agencies meeting existing rule 3 obligations will likely be able to comply, and on balance adding a new HIPC rule 3A will make it easier for health agencies to comply by allowing us to consider specific exceptions or requirements in the health context. We also consider that disapplying IPP 3A from the HIPC would not meet health consumer or community expectations. Our draft amendment includes the IPP3A(3) exception which means notification will not be needed where an individual has already been made aware of an indirect collection. Finally, our [full guidance on IPP3A](#) will clarify many of the issues initially raised to us. We also think the health sector would benefit from specific guidance and we will prioritise this in our programme of guidance work.

We are proposing to include exceptions drawn from IPP3A and aligned to the existing rules 2 and 3 under the HIPC

- 1.4. As set out in [Table 1 in the general information paper](#), we are proposing that new HIPC rule 3A would include all of the general IPP3A exceptions except those relating to public interest archiving, defence and international relations, and trade secrets or commercial position. We think these three exceptions are unlikely to be relevant in the HIPC.



- 1.5. We are also proposing to draw on existing health-specific exceptions found in rules 2 and 3 of the HIPC. We think this will make the rules for health agencies more consistent and easier to comply with.
- 1.6. The table below provides our proposed approach to how we intend to incorporate IPP3A into the HIPC, the exceptions we propose to include in the HIPC, and consultation questions to test our approach with stakeholders. We refer to the IPP3A exceptions with the numbering as set out in the Privacy Amendment Act, but the numbering of relevant provisions in the draft HIPC amendment will be different from that under IPP3A. For clarity, we have tried to align the numbering for rule 3A exceptions to the numbering for relevant exceptions in rule 3.
- 1.7. We are also proposing changes to update the language in the HIPC and align rule 12 to IPP12 as amended by the Statutes Amendment Act.

Proposed approach to IPP3A exceptions

Issue	Proposed approach in HIPC rule 3A
Treatment of IPP3A(1)(d)(i): requirement to make the individual aware of the name of the agency that has collected the information	<p>Some health agencies raised concerns that if other health agencies who are collecting information directly are going to make people aware of IPP3A matters on their behalf, the direct collecting health agency will not be able to name every single agency they intend on sharing the information with, and so the indirect collecting agency will not be able to rely on this exception.</p> <p>Our finalised guidance on IPP3A(1)(d)(i) provides more detail about how this requirement applies. We believe the guidance addresses this concern and are proposing to align rule 3A(1)(d)(i) to the existing wording of rule 3 in the HIPC.</p>



Issue	Proposed approach in HIPC rule 3A
No notification required where an individual has already been made aware of the indirect collection – IPP3A(3)	We are proposing rule 3A would bring in the general exception under IPP3A(3) which applies where an individual has already been made aware of the specific indirect collection. We think this is consistent and is likely to be a useful exception for the health sector to rely upon, so excluding it would likely have significant impacts for the sector.
No prejudice to the individual – IPP3A(4)(a)	The IPP3A exception applies where non-compliance would not prejudice the interests of the individual. We propose to include the IPP3A exception but raise the threshold to “compliance would prejudice the interests of the individual” to align with the existing exception in HIPC rule 3. This reflects the increased sensitivity of health information and the importance of transparency. We think it would be unusual to have the exception apply with different thresholds within the same code on the basis of some information being collected directly and some indirectly.
Information is publicly available – IPP3A(4)(b)	We are proposing to include this exception into the HIPC as it aligns with an allowed source of indirect collection under rule 2.



Issue	Proposed approach in HIPC rule 3A
Non-compliance is necessary – IPP3A(4)(c)	<p>We propose to include the IPP3A exception but narrowed to align to HIPC rule 3, which only provides an exception to notification on the basis of the prevention, detection, prosecution and punishment of offences.</p> <p>We are not proposing to include the rule 2 exceptions where the information was collected indirectly for the purposes of enforcing a law that imposes a financial penalty, protection of public revenue, and conduct of court/tribunal proceedings. We think that it is clearer and more consistent to align this provision to the narrower grounds in rule 3. The exceptions in IPP2 provide for collecting information from a source other than the individual, and we could see the other exceptions may be relevant in that context. We consider that it is unlikely that the public revenue and court proceedings exceptions would be relevant or justify not notifying an individual of the indirect collection of health information by a health agency. We are interested in hearing from stakeholders on this approach.</p>
Compliance would prejudice the purposes of collection – IPP3A(4)(d)	<p>We are proposing to include this exception in the HIPC as it is included in both rule 3 and IPP3A.</p>
Compliance is not reasonably practicable in the circumstances – IPP3A(4)(e)	<p>We are proposing to include this exception in the HIPC as it is included in both rule 3 and IPP3A.</p>



Issue	Proposed approach in HIPC rule 3A
Serious threat to health or safety – IPP3A(4)(f)	We propose to include this IPP3A exception. In the health context, this may be important to allow for agencies to respond to situations, for example, another individual's mental health crisis or risk of infectious disease. The Privacy Amendment Act includes a health-related example as an illustration of how this exception could apply. We are proposing to include this example in the HIPC for consistency.
De-identified or statistical and research purposes – IPP3A(4)(g)	We are proposing to include this exception, but with changes to align it with the equivalent exception in rule 3 so that where ethics approval is required for research, it must have been granted.
Public interest archiving – IPP3A(5)	We do not see a need for this exception in the health agency and health information context as we do not think it is likely to be relevant. We would like to hear if you disagree.
Security and defence – IPP3A(6)	We do not see a need for this exception in the health agency and health information context as we do not think it is likely to be relevant. We would like to hear if you disagree.
Disclosure of trade secret or prejudice commercial position – IPP3A(7)	We do not see a need for this exception in the health agency and health information context as we do not think it is likely to be relevant. We would like to hear if you disagree.



Proposed approach to specific issues under the HIPC

Issue	Proposed approach in HIPC rule 3A
Handling of notifications to representatives under rule 3A	<p>The HIPC recognises representatives of individuals may exercise some rights on behalf of an individual in respect of the individual's health information where the individual cannot give their authority or exercise their own rights.¹ If an agency collects information from a representative for an individual (such as an attorney acting under an enduring power of attorney or a welfare guardian), the collection is a direct collection under rule 3 and would not be covered by rule 3A.</p> <p>We propose to align rule 3A with rule 3, requiring a health agency to take reasonably practicable steps to notify the individual or the individual's representative, if there is one, when the agency has indirectly collected information about the individual from someone other than the individual themselves or their HIPC representative.</p>

¹ Under the HIPC a **representative** is an individual's personal representative (if the individual is dead), an individual's parent or guardian (if the individual is under 16) or for any other individual otherwise unable to give their consent or authority, or exercise their rights, a person appearing to be lawfully acting on the individual's behalf in the individual's interests. This definition differs from the Privacy Act, which does not define who an individual's representative may be.



Issue	Proposed approach in HIPC rule 3A
Treatment of health information privacy statements for rule 3A purposes	<p>In early engagement, we heard that some agencies wanted an additional exception to treat health information privacy statements given by agencies under rule 3 as automatically satisfying any rule 3A requirements. This would be a broadening of the current IPP3A(3).</p> <p>We do not agree with this proposal. We are not proposing a broader exception allowing agencies to rely on a general health information privacy statement to avoid notification requirements under proposed rule 3A. We think such an exception would not be consistent with other requirements under the HIPC, which generally require a higher level of authorisation than the IPPs. We think this would risk undermining the policy intent of IPP3A to make indirect collections more transparent and would ultimately create compliance risks for health agencies if they rely on very generally stated and potentially out of date statements for compliance with HIPC requirements.</p> <p><u>OPC has created guidance about compliance with IPP3A through privacy statements that will be relevant and useful in the HIPC context too.</u></p>



Issue	Proposed approach in HIPC rule 3A
Authorised collection – rule 2(2)(a)	<p>HIPC rule 2(2)(a) currently does not require direct collection if the individual or their representative has been made aware of the matters under rule 3(1) and authorises the collection.</p> <p>We propose to amend this to refer to rule 3A(1), as we consider that the original rule 2(2)(a) was a method of adding additional transparency obligations to indirect collections. The difference is that rule 3A(1) will not require notification of whether the supply of information is voluntary or mandatory and any consequences for non-compliance. We think this makes more sense. Indirect collection does not require steps to notify the individual about compliance as they are not supplying the information.</p>



Issue	Proposed approach in HIPC rule 3A
<p>Collecting information for family or genetic history – rule 2(2)(e)</p>	<p>HIPC rule 2 allows for an indirect collection of information for the purpose of assembling a family or genetic history. This means that a health agency can collect information about family members from the individual providing their family or genetic history, rather than requiring it to be collected from those family members directly. Because this is an indirect collection of those family members' personal information, rule 3 requirements do not apply. We are proposing to include this exception in rule 3A, so that family members of individuals who provide their family history to health agencies do not get notified that the information has been collected.</p> <p>We are proposing to include this exception for consistency with rule 2, which permits collection other than from the individual, and for practical reasons. Individuals routinely share information about their genetic and family history in order to inform treatment decisions about themselves. We believe it would be unexpected and unnecessary for every family member to be told by a health agency that their information was provided to them by the patient, when the family members may not have any relationship with the health agency and the health agency has only collected the information because of its relevance to the patient.</p> <p>We recognise that there may be tikanga concerns and other potential cultural concerns which we are keen to hear about in consultation. There may be cultural considerations which oppose the inclusion of this exception, as it means the other people who this information relates to would not be informed by a health agency about the collection of family history or genetic information from their family member.</p>



Questions on the proposed rule 3A for the HIPC

H1. Do you agree with our proposed approach to exceptions as set out above?

We are keen to hear from stakeholders to understand if what we have proposed meets the intent of IPP3A, is workable for the health sector, and is consistent with existing exceptions in the HIPC. You can comment on one, a few, or all points we have identified, as well as points you think we may have missed. If you disagree with a proposed approach, it would be useful if you can provide detail or evidence, such as describing a specific situation, about why you disagree. This will help us to consider whether we need to make changes to what we are proposing to incorporate into the HIPC.

H2. Are there tikanga Māori perspectives that we should consider?

Section 21(c) of the Privacy Act requires the Privacy Commissioner to take account of cultural perspectives on privacy. We are aware of the sensitive nature of health information. We are particularly interested in hearing about potential interactions with what we are suggesting and tikanga Māori perspectives.

H3. Are there other cultural perspectives that we should consider?

We are also interested in hearing other cultural perspectives on what we are proposing and how these may be considered when incorporating IPP3A into the HIPC.

H4. Do you agree with the proposed approach to drafting, including technical and language changes?

While we are proposing amendments to implement IPP3A, we also have the opportunity to make technical changes to update the language of the code including references to terms which have changed due to changes in legislation.

