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Office of the Privacy Commissioner |Te Mana Mātāpono Matatapu 11/215 Lambton Quay, Wellington Central WELLINGTON 6011

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Tēnā koe

## Privacy Commissioner Draft Guidance on the Information Privacy Principle (IPP)3A notification requirements for the indirect collection of personal information

The Royal New Zealand College of General Practitioners (the College) is the largest medical college in Aotearoa New Zealand with a membership of 6,018 specialist General Practitioners (GPs). Our General Practice Education Programme (GPEP) and Rural Hospital Medicine Training Programme (RHMTP) trains the specialist General Practitioner and Rural Hospital Doctor workforce. The Medical Council of New Zealand accredits the College to deliver a Vocationally Registered workforce through its Continuing Professional Development Programme, making up 40 percent of the specialist medical workforce. The College is committed to prioritising the reduction of health inequities experienced by Māori, honouring Te Tiriti o Waitangi, and the rights of Māori. To do this we prioritise initiatives that support our members to develop cultural safety capability throughout our Training, Member Professional Development and Quality¹ programmes.

Our members provide first point of contact medical care to patients and their whānau to manage 90 percent of all patient healthcare concerns in the community. Each year approximately 24 million<sup>1</sup> patient contacts are recorded by 1,085 general practice teams working across Aotearoa.

#### Information privacy

The College recognises that the <u>Privacy Act 2020</u> and <u>Health Information Privacy Code 2020 (HIPC)</u> are critical components of New Zealand's broader health data governance framework. As key mechanisms for balancing the effective use of health data with the protection of individual rights, we support the need to regulate and comply with legal standards to enhance the integrity and responsiveness of the health system.

#### In answer to your questions:

#### 1. Is the guidance fit for purpose? If not, how could it be improved?

### **Enhancing Transparency and Trust in Health Data Sharing**

- Improving transparency and alignment in how health data is collected and shared is essential for building patient trust and helping them to understand how their personal health information is managed.
- General practices registered in the College Quality Programme must meet requirements of the HIPC for
  collection, use, storage, and disclosure of health information. Replacing the general information privacy
  principles with tailored guidelines for the health sector provides patients with greater reassurance that
  their sensitive health information is confidential, safe, clinically relevant, and there is transparency
  about use of information to ensure it:
  - Remains confidential: collected within a trusted and professional healthcare environment.

- Treats personal details (body, lifestyle, emotions, and behaviour) sensitively.
- Is routinely collected to support continuity of care, clinical clinical care used for agreed purposes.
   Is used for clearly defined purposes, with patients being informed at the time of collection about how their information is used.

#### 2. Are there any parts of the guidance that need more clarity, or are hard to understand?

#### Third party information in the health and AI environment

- Experience shows that patients need more information about third-party providers in relation to security and use of information. Privacy breaches highlight vulnerabilities in handling of health data by third-party service providers, and recent investigations found that key health organisations lacked sufficient back-end protections for sensitive information shared with third parties did not demonstrate compliance with their data-sharing agreements.<sup>2</sup>
- Safeguarding personally identifiable health information is essential to ensure patient concerns are
  addressed, specifically about the collection, use, disclosure, storage and access to their personal
  information stored in a Practice Management System (PMS). Breaches of privacy and confidentiality can
  undermine a person's dignity and lead to harm, stigma, embarrassment, or discrimination.<sup>3</sup>
- We also raise awareness of the need to recognise that Māori as tangata whenua, have a right to data sovereignty and protection in alignment with obligations and rights under Te Tiriti o Waitangi. 4 5 6

#### 3. Are there more key terms we need to define or concepts that need more clarity?

#### Include a general practice example of indirect collection of personal health information.

• Managing patient information to protect private details is essential to keep trust between clinicians and patients. In New Zealand, 95 to 98 percent of the population are enrolled in 1,083 general practices and the details of 24 million patient consultations are recorded in Practice Management Systems (PMS) each year. Specified information is collected from PMS by various agencies, e.g. health, primary health organisations, justice, insurance, ACC, for purposes as agreed to by patients when they enrol with a practice, or patient requests to share information. Patients must be given information to support their agreement to information being shared.

### 4. Are the examples provided meaningful to you? If not, what kinds of examples would you want to see instead?

# The collection of patient health data plays a crucial role in addressing health disparities that are avoidable, unfair, and unjust. $^7$

- Guidance on third-party providers could be strengthened to help people better understand the risks associated with accessing health services through these channels: 8
- While the Privacy Commission document provides valuable direction, its section on transparency needs clearer guidance to understand what information can be trusted.

Patients need affirmation of their right to expect that their health information:

- Is kept confidential and collected in a context of trust and respect.
- Is treated as sensitive, as it may include personal details about the body, lifestyle, emotions, and behaviour.
- May be used in the future if it becomes clinically relevant.
- Is used for purposes for which it was originally collected.
- May be shared appropriately with providers to support equitable care.

#### In summary

Thank you for the opportunity to contribute to the Draft guidance on the IPP3A.

The College appreciates the Privacy Commissioner's continued leadership in upholding the privacy rights of New Zealanders and notes that the Draft Guidance on IPP3A offer valuable guidance to specialist GPs and general practice teams.

If you require further information or clarification, please contact Maureen Gillon, Manager Policy, Advocacy, Insights – <a href="Maureen.Gillon@rnzcgp.org.nz">Maureen.Gillon@rnzcgp.org.nz</a>.

Nāku noa, nā

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