

**Privacy
Foundation NZ**



INFO by Design

It's about them - putting your customers at the centre of how you manage their information

Patient Privacy & Information Sharing

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INFO by Design

Patient Privacy in New Zealand in 2021

- Privacy is not confidentiality
- Personal information is taonga
- You collect and use it to improve patient and community wellbeing
- If you hold patient information, you are the kaitiaki (guardian)
- Consumer expectations around consent, control and ownership are evolving
- Management of patient information needs to evolve too



Our Legislative Framework

- The NZ Privacy Act 2020 and Health Information Privacy Code 2020 govern the management of personal health information
- Health Act 1956, Official Information Act 1982, Oranga Tamariki Act 1989 and other laws and regulations impact on the application of these
- Typically viewed as a compliance hurdle, but is actually an enabling framework
- The Principles and Rules guide how to do it right, not all the things you can't do



Key Points re 2020 Reforms

- The Act didn't fundamentally change
- Mandatory data breach notification
- Only require someone to provide Personally Identifiable Information if it is necessary for the purpose
- Required to take care when collecting info from children or young people
- Powers for the Commissioner
- Criminal offences
- Review of HIPC



Missed Opportunities?

- More fulsome review of the HIPC
- Better clarity around Rule 3 collection practices
- Requirements for anonymisation and de-identification of health information
- Obligations to take steps to avoid re-identification
- Clarifying the requirements for managing third party agents
- Data portability

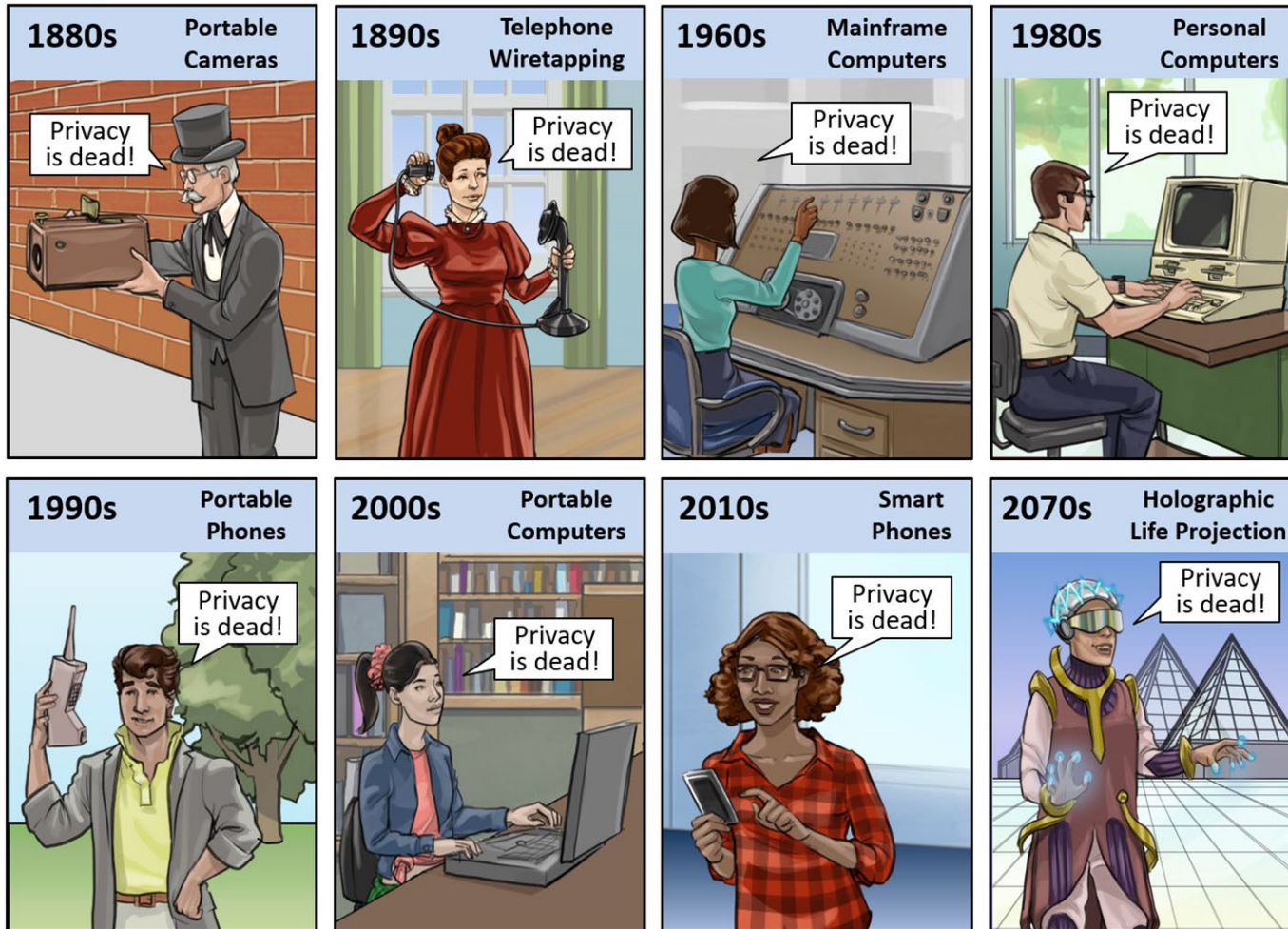


The 13 Health Information Privacy Rules (in plain English)

1. Only collect the information you need
2. Get it from the person concerned
3. Tell them what you're doing
4. Be ethical when you're doing it
5. Take care of the information once you've got it
6. They can see it if they want to
7. They can correct it if it's wrong
8. Make sure it's accurate before you use it
9. Get rid of it when you're done with it
10. Only use it for the purpose you got it for
11. Only disclose it if that's why you got it
12. Take care when sending it overseas
13. Be careful with unique identifiers



Law vs Technology – Fit for Purpose?



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Illustrated by Ryan Beckwith



Information Governance - Consent

- Not a requirement of the Privacy Act or HIPC
- Authorisation is required if you need an exception to the Privacy Principles / Rules
- Consent forms or privacy policies are often used as a mask for poor collection practices
- Click to consent is also not enough
- Transparency and engagement are what is required and doing this right can enable effective sharing



Information Governance - Control

- The Privacy Act gives control and agency to individuals over their information
- Across many dimensions of society, people are seeking to take back control from institutions
- This is growing in the privacy space too, both societally and legislatively
- They will cede control where they feel willing to trust
- The Principles and Rules provide a framework to build and maintain trust
- Privacy breaches erode trust



Information Governance - Ownership

- Ownership of personal information is a contentious subject
- Historically agencies' view was they owned the information in their files and systems
- People see it as theirs as it is about them
- Data sovereignty adds a further layer of complexity
- One model is to see health information as a resource and move away from concept of ownership



Information Sharing

- Poorly done at the moment
- High cost of entry and low levels of risk tolerance
- Poor technology infrastructure
- Often objectives, not outcomes, focused
- Opportunities get lost in the bureaucracy
- Requirements for success
 - Good collection practices
 - Shared benefit
 - Outcomes focused
 - Clearly communicated
 - Safe and secure methods of sharing



What Does Good Privacy Practice Look Like?

- Privacy treated as a design principle
- Effective and genuine complaints process
- Breach management and reporting process in place
- Privacy Impact Assessments completed and published
- Customers understand how their information is being protected
- Privacy is a decision criterion at Board and Executive level
- Mistakes are owned and apologies freely given
- Privacy is part of the procurement process



Privacy Foundation

Independent, informed
and fair public comment
on privacy

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A hand is shown holding a large, white, 3D question mark. The hand is positioned in the center of the frame, with the thumb and index finger gripping the top of the question mark. The background is a blurred blue and white, suggesting a studio setting.Several white question mark icons of varying sizes are scattered across the right side of the image. Some are simple outlines, while others have a 3D effect with a textured, shaded interior. They are set against a background of blurred blue and white light.

Questions?
