

Privacy Commissioner's submission on the Health (National Cervical Screening Programme) Amendment Bill

Introduction

1. As New Zealand's Privacy Commissioner, one of my functions under the Privacy Act 1993 is to examine legislation before Parliament and to consider any matters affecting individuals' privacy. The Privacy Act is New Zealand's main privacy law. It governs the collection, use, storage and disclosure of personal information and provides me with a mandate to consider wider developments or actions that affect personal privacy.
2. The Health (National Cervical Screening Programme) Amendment Bill (the Bill) amends Part 4A of the Health Act 1956 to enable broader access to the National Cervical Screening Programme ('NCSP') register by register staff, health professionals and screening support services staff.
3. I have no outstanding privacy concerns with the Bill as introduced. Expanding access to the register to people who need register information to provide care and services will support the register's objectives. In particular, the amendments will support the promotion of high quality screening, assessment and treatment, and regular recall of enrolled women.
4. Providing more people with access to the register comes with some increased privacy risk. I am satisfied the Bill provides for this risk to be mitigated through appropriate operational controls – access to the register will be controlled by the NCSP manager, and the Ministry of Health ('the Ministry') has advised the activity will be auditable.

Government should consider reviewing the law governing health information

5. Aside from the scope of this Bill, I encourage the Ministry to consider a first principles review of the law governing the collection, use and disclosure of health information.
6. When the Law Commission reported on its review of the Privacy Act in 2011, it recommended that the government "conduct a review of the handling of health information, with a view to enacting separate comprehensive legislation"¹. Acknowledging the complexity of the area and the importance of information to healthcare, the Commission considered the current legal framework for health information was not coherent and could benefit from a separate statute.

¹ Law Commission *Review of the Privacy Act 1993* (NZLC R123, 2011) at 12.91

7. Currently, health information is generally governed by the Health Information Privacy Code 1994 (which sets specific privacy rules for the health sector) and sections 22B to 22H of the Health Act. Various instances of health information are also specifically catered for by their own bespoke legislation, including cervical screening.
8. I agree with the Commission's recommendation and consider that the law governing cervical screening information is an excellent example of incoherent treatment. Cervical screening is an outlier that is subject to greater restriction than other screening programmes and most health information.
9. Even as amended by this Bill, Part 4A of the Health Act is complex, highly prescriptive and provides for various regulations to further restrict use and disclosure. These regulations establish the National Kaitiaki Group to approve disclosure, use and publication of cervical screening information that identifies a woman or women as being Māori. To my knowledge there is no other piece of legislation that treats Māori health information in this manner.
10. Part 4A reflects the particular historical context and sensitivity attached to cervical screening. Its foundations followed the recommendations of the Cartwright Inquiry into allegations concerning the treatment of cervical cancer at the National Women's Hospital. By contrast, breast and bowel screening programmes rely on general information provisions including the privacy protections in the Health Information Privacy Code.
11. More restrictive rules for certain health information may well be justified for reasons beyond protecting personal privacy. A more coherent approach would apply consistent principles across health information, as opposed to allowing special restrictions to develop out of particular history or societal significance.

Conclusion

12. I **recommend** that the Committee encourages the Ministry to conduct a review of the law governing the handling of health information, with a view to enacting separate comprehensive legislation.
13. I trust my comments will assist the Committee. I do not wish to appear in person but would be happy to, should the Committee find that helpful in its consideration of this Bill.



John Edwards
Privacy Commissioner