



## Review of the private sector provisions of the Commonwealth Privacy Act 1988

### 1. Introduction

- 1.1 The ANF is the national union for nurses in Australia with branches in each state and territory. The ANF is also the largest professional nursing organisation in Australia. The ANF's core business is the industrial and professional representation of nurses and nursing in Australia.
- 1.2 The ANF's 145,000 members are employed in a wide range of enterprises in urban, rural and remote locations in the public, private and aged care sectors, including hospitals, health services, schools, universities, the armed forces, statutory authorities, local government, offshore territories and industries.
- 1.3 The ANF participates in the development of policy in nursing, nursing regulation, health, community services, veterans affairs, education, training, occupational health and safety, industrial relations, immigration and law reform.
- 1.4 The ANF represents Australian nursing internationally through links with other national and international nursing organisations, professional associations and the international labour organisations. The ANF is a member of the Commonwealth Nurses Federation and the South Pacific Nurses Forum and is affiliated to the Australian Council of Social Services, the Public Health Association of Australia, and APHEDA, which is the overseas aid agency of the trade union movement.

1.5 The ANF's submission on the Review of the Private Sector Provisions of the Commonwealth Privacy Act 1988 is limited to those issues that affect or apply to the health sectors, nursing and nurses.

## 2. Summary of recommendations

2.1 That a process be initiated by the Office of the Federal Privacy Commissioner (OFPC) to consult with all stakeholders to develop a single piece of national health privacy legislation.

2.2 That national standards be developed for electronic health records and information management that complement national privacy principles.

2.3 That the Office of the Privacy Commissioner be included in any forums dealing with electronic health records and information management.

2.4 That the exemption from the Act of employee records be removed to allow for adequate privacy provisions of the information contained in them.

2.5 That the exemptions from the Act of small business and the media be removed.

2.6 That information contained in data registries be deemed relevant to public health and safety and that the OFPC make provision for the maintenance of such registries.

2.7 That a legal framework be developed to allow the OFPC to enact enforceable interventions and ultimately penalties on organisations that have breached the Privacy Act and that adequate resources be allocated to the OFPC to develop this framework and act on it.

3. The issue of national consistency in regulation of privacy
  - 3.1 It is the opinion of the ANF that overarching health privacy legislation is vital for the protection of people's health information and their rights as consumers of health services and products. The journey of an individual through his or her spectrum of health and ill health experiences will undoubtedly take them across many facets of the health system. The individual may of course, encounter episodes of care from a myriad of health professionals, although it is very likely to be a nurse who is responsible for providing that care, be it long term sustained care over a 24 hour period, or episodic care in a health centre, a rural clinic, in the home, school, maternal and child health centre, GP clinic or wherever care is provided. There are 250,000 licensed nurses in the Australian workforce, all of whom will, at some stage, collect, record and be entrusted with personal information related to health or otherwise. Nurses are often, as a result of their assessment of patients, the point of referral to other professionals, such as GPs, social workers, occupational therapists, dentists and so on. They are often the confidants of their patients and recipients of confidences that, with careful management, will require further intervention. This naturally necessitates the communication of personal information to service providers and individuals in either or both the private and public sectors.
  - 3.2 The trail of health information that is threaded across the health sectors, in and out of various points of health service delivery and often wound through multiple jurisdictions is established with copious amounts of personal information stored both on record and in the patient's and treating professionals' memories.
  - 3.3 This matrix of information presents complex and challenging issues for the protection of privacy, issues that are often cited as reasons against overarching privacy legislation. The ANF however contends that it is the very reason such legislation is necessary.

The OFPC has as one of its aims national consistency in privacy regulation. It was hoped that the NPPs would encourage the development of Codes of Practice in privacy protection by individual organisations. This has not been the case for various reasons outlined in the discussion paper. The reasons cited are bona fide but it may also be the case that the mish mash of legislation surrounding privacy, across jurisdictions and health sectors and general confusion surrounding different legislation present barriers to what is an onerous task.

- 3.4 Health may well be a more complex area than others when addressing privacy and the ANF acknowledges that in response to this AHMAC is currently working on producing a National Health Privacy Code (NHPC). The ANF made a submission to the National Health Privacy Working Group and we would be happy to make this paper available to this inquiry. And whilst it is noted that this inquiry will take the NHPC into account we find it equally important that any review of the Privacy Act and consequent changes, be incorporated into the final draft of the NHPC. This will ensure that NHPC can incorporate the concerns presented to this inquiry if necessary, and that confusion is minimised.
- 3.5 The current cross-jurisdictional differences present real issues where the collection of useful data is concerned, particularly with respect to complaints and breaches of legislation requirements. General confusion exists regarding complaints processes and it is difficult to gain a true understanding of the extent of complaints and their nature when several bodies are collecting their own data; when complainants contact more than one office with the same complaint; and when collected information varies in nature and content across jurisdictions and departments. It is suggested that nationally consistent legislation could ultimately include a national process for complaints and breaches.

*Recommendation:*

*That a process be initiated by the Office of the Federal Privacy Commissioner to consult with all stakeholders to develop a single national health privacy legislation.*

4. Technological developments

- 4.1 Generally speaking, nurses have welcomed the advent of technology with respect to record keeping, and telehealth. Computerised medication charts for example have lessened confusion caused by poor handwriting and transcribing errors. Nurses in remote locations can utilise computer and audiovisual technology for assistance with diagnoses and treatment advice. And the advent of electronic health records has enhanced the timeliness of the recall of data and patient histories. These advancements however have presented issues related to the transmission of that information, its consequent storage and the potential for security breaches across the 'ether'.
- 4.2 The ANF considers the development of national standards for the management of health information in an electronic environment to be of vital importance. Keeping any national privacy principles or legislation technologically neutral without complementary standards could leave health consumers at risk. One example of an issue that would require clarity is the de-identification of electronic data, and the current debate around the point at which it is de-identified and the very definition of de-identification. Standards for electronic health records and information dissemination could be derived to complement any principles and could be part of the NHPC, incorporated with the advice of the OFPC.

- 4.3 Concerns of consumers and nurses about privacy issues would be considerably allayed if the OFPC was included in any initiative, forum, committee or consultative process that involves the issues of electronic health management. We note that this is not the case for example in the development of the HealthConnect project. The involvement of the OFPC would ensure privacy issues are considered and offer the community and health professionals some confidence in the outcomes.

*Recommendations:*

*That national standards be developed for electronic health records and information management that can complement privacy principles.*

*That the Office of the Privacy Commissioner be included in any forums dealing with electronic health records and information management.*

5. Awareness and exercise of individual rights

- 5.1 The general confusion surrounding the 'patchwork' of privacy legislation is driven by many factors such as divisions between public and private sectors, state and federal governments divide, and the issues around emerging technologies, to name a few. But of major concern to the ANF are the gaps embodied in the federal legislation itself: particularly the small business exemption, the media exemption, and the employee record exemption.
- 5.2 The research results presented in the discussion paper indicate that there is now an awareness of privacy legislation, but that complaints or contacts with the OFPC are critically low. We recognise that the confusion caused by the patchwork mentioned above is most likely to be a major reason for this statistic. But the ANF contends that the exemptions too, are of such a vital nature as to cause major confusion about one's rights and others' responsibilities.

- 5.3 Media reportings of people's personal health issues, filming of patients in health service facilities, and presentation of information that contravenes privacy principles give the community the wrong messages about what is acceptable and what is not. This can be particularly disturbing in relation to people with mental health issues.
- 5.4 The reasons offered for small businesses being exempt give no comfort to those whose privacy has been breached. And the information contained in an employee record deserves the same respect as any other file or document.
- 5.5 We note that the treatment of employee records is not part of this review, however the enormous concern arising from the exemption of employee records from the private sector provisions necessitates a brief comment in relation to this matter.
- 5.6 The ANF in its submission to the Attorney General's Department discussion paper "Employee Records Privacy", argued that employee records should not be exempted from the operation of the Privacy Act.
- 5.7 While we acknowledge that the legislation seeks to balance the individual's right to privacy with a range of other community and business interests that balance is clearly compromised through the exemption of employee records.
- 5.8 Employee records can contain extensive information of a personal and sensitive nature. Potentially employers hold more information about an individual than anyone else. This information may include personal and family details, financial and banking details, health information, possibly medical records relating to specific health problems, pre-employment health assessments and a wide range of work related information such as absences, performance and disciplinary matters.

- 5.9 In the context of the employment relationship employees have little choice but to provide information to their employer or prospective employer as the case may be unlike others such as consumers, clients or suppliers to business. This lack of choice on the part of the employee/job applicant and the extensive nature of the information required makes privacy protection more imperative in respect to employee records.
- 5.10 It is widely accepted that personal health information is among the most sensitive and intimate of personal information, yet when it forms part of an employee record the individual cannot rely on the same protections afforded to other members of the community.
- 5.11 The recent experience of a Queensland nurse illustrates this point. The employer, a large acute hospital, required the nurse to undergo a health assessment. The report that followed was provided to the employer who acted on its recommendations to the detriment of the nurse. The nurse was refused a copy of the report. The employer also sent a copy of the report to the Queensland Nursing Council who again used it to the detriment of the nurse. The employer argued that the nurse is not entitled to a copy of the report because it forms part of the employee record and is therefore exempt from any requirement to do so.
- 5.12 The nature and extent of the information collected by employers gives rise to further concerns over the motives for collection and how it will be used by employers, particularly in the current industrial environment.
- 5.13 While so far not a common practice in the health industry, employees can be subject to various forms of testing ranging from breath testing; urine testing; blood testing; cognitive tests; psychological assessments; psychometric tests; performance appraisal with "attitudinal" tests imbedded; to various physical assessments and questions relating to personal behaviours.

- 5.14 The operation of the employees' records exemption leaves employee's potentially exposed to the collection of information without their knowledge; information can be provided to others including third parties or prospective employers; and incorrect information can be held without the employee having access and the opportunity to correct it.

*Recommendations:*

*That the exemption from the Act of employee records be removed to allow for adequate privacy provisions of the information contained there-in.*

*That the exemptions from the Act of small business and the media be removed.*

## 6. Consent

- 6.1 The issues of consent are far reaching. On this matter the ANF supports the recommendations to this inquiry made by the NHMRC but we would like to comment in particular on data registries. Health registries supply vital information for the health and well being of communities. The national asbestosis registry for example assisted in the establishment of the link between asbestos and the incidence of the diseases asbestosis and mesothelioma. Collection of data was, however, severely hampered in recent times by individual organisations' interpretation of the Privacy Act.

The dissemination of disease incidence and asbestosis related deaths was withheld in some cases, but equally disturbing was the withholding of demographic data such as postcodes of those diagnosed with the disease. Linking the place of work or residence was vital in establishing the link between the disease and the cause.

Certainly in the case of asbestos exposure, the link was vital to the gaining of compensation for those afflicted with the fatal condition. This was despite the fact that the data registry all but folded because of the interpretation of the privacy act.

- 6.2 The ANF strongly supports the development of complementary guidelines or standards to allow for the maintenance of disease registries in the interests of occupational health and safety and for the public interest generally.

*Recommendation:*

*That information contained in data registries be deemed relevant to public health and safety and that the OFPC make provision for the maintenance of such registries.*

## 7 Compliance

- 7.1 The ANF has concerns that the OFPC is not adequately resourced to handle the broad ranging and numerous issues presented by privacy requirements. Nor is the OFPC given enough power to ensure compliance. We note that many situations of breaches of the Act are settled in a conciliatory manner, but the OFPC cannot enforce compliance nor can it act upon breaches of the Act it uncovers through its own investigative initiatives.
- 7.2 The OFPC should be enabled to enact penalties on those organisations that are found in breach of the Act through a well developed legal framework of enforcement that encompasses both the light touch approach, but allows stricter follow up for further breaches or non-compliance.

*Recommendation:*

*That a legal framework be developed to allow the OFPC to enact enforceable interventions and ultimately penalties on an organisation that has breached the Privacy Act and that adequate resources be allocated to the OFPC to develop this framework and act on it.*

## 8. Conclusion

- 8.1 At some time or another everyone, their families, friends and acquaintances are likely to be in need of some form of health care, be it for an acute condition, a chronic condition, an accident or injury, vaccination, illness prevention through public health and health promotion strategies, school and other programs, or aged care. Wherever care is provided it is almost certain that nurses will be part of it.
- 8.2 Nurses have earned the respect of the Australian community. In December 2004 they were once again (for the 11<sup>th</sup> year running) ranked first as the profession most often mentioned by Australians as having very high standards of ethics and honesty (Roy Morgan Research, 2004). Nurses have a vested interest in gaining the confidence and trust of their patients as it enhances the therapeutic relationship. Privacy of information entrusted to them is a vital part of maintaining this trust and respect. Adequate privacy legislation therefore is an essential part of being able to continue to serve the community in the ethical manner they have come to expect.