



# australian nursing federation

## Review of the Medicare and Pharmaceutical Benefits Programs Privacy Guidelines

### 1.0 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 advocates for the protection of individuals' privacy particularly in relation to health information. Health professionals have long been entrusted with delicate and personal information of those they care for and have built solid reputations around the ethical and professional boundaries of recording and communicating any such information.
- 1.6 The ANF strongly supports the need for consent to the use of personal information for the purposes of primary research and particularly secondary uses and does not condone practices that amount to breaches of confidentiality, diminishing the trust relationship between a clinician and individual in their care. We do however recognise the need for access to data rich resources in the search for better health outcomes. But we have some grave concerns about linking the MBS and PBS data for research purposes, particularly in this environment of information technological advancements. Our concerns relate primarily to three issues:
  - The potential risks to privacy through data linkage and improved technological access,
  - The "cleanliness" of the data collected, and
  - Community attitudes to the trustworthiness of those who collect and keep their personal health data.

## 2.0 Risks to privacy

- 2.1 The advancements in technology have had and continue to have profound effects on the health sector. The ANF acknowledges that in most instances these developments contribute to overall improvements in health outcomes and assist clinicians in the delivery of care. Ultimately the development of an electronic health record will give health professionals access to a streamlined and potentially more accurate health care history that can be carried across health sectors and jurisdictions. Whilst this could be an invaluable advancement to health care, the complex systems that allow it, will also allow for much easier, and potentially unauthorised, access to an individual's data. It is in such an environment that protection of data should be stringent. There is a case for strengthening the MBS and PBS privacy guidelines, and for maintaining the functional separation of the databases.
- 2.2 Keeping the databases separate does not necessarily impede on the capacity to utilise the data and the guidelines do allow for the linking of de-identified data. The ANF is of the view that the linked data should be destroyed but that 3 months may be a short timeframe and 6 months would be more appropriate. The ANF also contends that de-identified linked data should be aggregated where possible in large sample 'bundles' making re-identification difficult.

## 3.0 The "cleanliness" of the data

- 3.1 The MBS and PBS are essentially funding tools and the clinicians, who contribute to that data view them as such and make data coding decisions based on a range of factors that include the social and emotional impact of a clinical diagnosis on an individual. Data entry is also usually carried out by clinicians in an environment of excessive workloads and multiple demands on their time and attention. Whether or not the data is true and accurate is questionable especially when considering some of the proposed uses of the data and decisions that may be made based on the outcomes of that use. There is concern, albeit anecdotal, that the data may in some instances be quite inaccurate as a reflection of care given or diagnosis treated. Further data cleansing was one of the six recommendations made to HIC by the Australian National Audit Office's recent report on the integrity of Medicare data.
- 3.2 It is difficult to see how the MBS data would contribute meaningfully (even with linkage to the PBS data) to the secondary uses suggested in the discussion paper. In addition to the concerns above, the MBS data is not qualitative, contains no diagnostic information, and has limited clinical value. In some instances eg adverse drug reactions and drug effectiveness, other, more accurate means are available to collect the data in a more timely manner. It is also apparent that the guidelines in their current form do allow for the use of linked data for specific purposes. It could be reasonable to review this section of the guidelines but still maintain the separation of the databases and the fundamental principles of protecting privacy.

## 4.0 Community attitudes

- 4.1 The community has a healthy skepticism when it comes to use of personal data. The nursing profession is the most trusted of professions, and we would not like to be involved in any processes that diminished that trust. We know that the community has high expectations of stringency with regard to the use of their health information and generally want to be informed about how their information is being used and by whom. But we also acknowledge the limitations and problems associated with gaining consent. The guidelines currently allow for use of the data with reasonable limitations and any loosening of the guidelines would be of concern to the ANF and to those people our members care for.

## 5.0 Conclusion

- 5.1 The ANF appreciates the opportunity to comment on the review of the guidelines and would like to reinforce the importance of maintaining the trust entailed upon our members by the community when care is provided to them and when confidential information is exchanged. We hope the OFPC considers this when the review is finalised.