



ANZDATA REGISTRY

Australia and New Zealand Dialysis and Transplant Registry

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Notice to contributing Units and Physicians

Privacy aspects of ANZDATA collection

You will be aware of recent changes to collection and management of health information in Australia. The Commonwealth Government has enacted amendments to the Privacy Act, which have extended the coverage of that Act to the non-government sector. In addition, State and Territory governments are in the process of implementing similar reforms.

The situation of ANZDATA is somewhat unclear. We are funded under a formal agreement with the Commonwealth Department of Health and Ageing which mandates collection of the data. A literal reading of the Privacy Act suggests that we may be exempt from the Act and do not need to gain consent for information which we are required under Commonwealth contract to collect. However, the contribution of other non-government bodies such as the AKF to the income of the Registry, and the private status of many of our contributors raise questions as to our status under the Act. Many contributors are subject to the new, non-government National Privacy Principles (NPP's) as outlined in the Act or the State / Territory equivalents. In view of this situation, and to ensure we meet and exceed expectations, we have chosen to meet the new private sector requirements.

The thrust of these requirements is threefold

- make all patients aware that personal data is being collected
- obtain consent to collect the data
- allow patients to view (and request alteration) to their data records.

The Privacy Commission specifically addresses the issue of consent as it applies to disease registries in their "Guidelines on Privacy in the Private Health Sector" (Office of the Federal Privacy Commissions, Canberra, 2001, available from http://www.privacy.gov.au/publications/hg_01.html#a53):

"Where consent is required from individuals for the collection and use of data for public health purposes, such as in relation to the establishment and maintenance of a disease register, it may sometimes be appropriate to take the approach of giving individuals the opportunity to opt out of being included on the register." (Section A.5.3)

Thus, from the point of view of obtaining consent to collect information regarding their treatment with dialysis and transplantation, we would advise that this section of the guidelines be followed for your patients. We have sought advice from the Office of the Privacy Commissioner regarding the acceptability of this approach, but are yet to receive a reply. We have also asked for a comment from the Human Research Ethics Committee of The Queen Elizabeth Hospital regarding the privacy information document. However, the urgency of obtaining information for this census period dictates that we proceed along these lines. It is clear that we are fulfilling the requirements of the Act by this approach.

The enclosed information sheet has been developed to facilitate this process. We ask that you provide this to all dialysis and transplant patients for whom you will be providing information to the Registry. Where questions arise, we are very happy to speak with you or patients directly to clarify issues. This step is important; it has been our experience that, once the purposes of ANZDATA are explained and the data safeguards are indicated, very few people object to the data collection. Nevertheless, the provision of the enclosed information is an important step in meeting current community standards.

If there are any concerns or questions, which arise from this, please contact us at the earliest opportunity.

Graeme Russ

Stephen McDonald

Monday, 22 July 2002