Appendix B1: Privacy/consent statement



CONSENT TO PROVIDE INFORMATION FOR THE PILOT COMMUNITY-BASED PALLIATIVE CARE CLIENT DATA COLLECTION 2006

This palliative care agency is taking part in a small survey of palliative care agencies that provide services to clients in community settings. The survey is being run by the Australian Institute of Health and Welfare (AIHW) for the Australian Government Department of Health and Ageing. During the two-week period, some agencies throughout Australia will be filling in survey forms about people who receive palliative care from them and about the services they receive.

This information is needed to find out what information is available, and can be collected, about palliative care being provided to clients in community settings.

All information sent to the AIHW is non-identifying, i.e. your name and address will not be recorded on the survey forms.

Part of the information that will be reported in this survey will come from your file in this centre. You have the right to see that file.

The completed forms will be collated by state and territory health departments and forwarded to the AIHW for processing. By law, all the forms must be kept confidential at the health department and at the AIHW. None of your information can be given to anyone outside of these organisations. It will only be used to produce statistics about palliative care provided by palliative care agencies in community settings. Once the statistics are produced, all forms will be destroyed. The statistics will be used to produce a report on palliative care.

Consistent with privacy legislation, the AIHW goes to great lengths to ensure that a person's identity cannot be established in any published material. For example, data are not published according to small geographic areas (e.g. postcodes) where it may be possible that only a small number of people with certain characteristics live.

Participation in this survey is voluntary. You are not required to participate if you do not wish to. If you choose to not participate, let one of your attending agency staff members know of your decision. You are not required to provide any refusal statements in writing.