
ALFRED ETHICS COMMITTEE POLICY: PROCEDURE REGISTRIES

ESTABLISHING OR CONTRIBUTING TO PROCEDURE REGISTRIES

A large number of registries currently exist to hold medical information. National guidelines would be welcome to ensure that such activities operate at an adequate ethical and scientific level, but in the meantime The Alfred has established a set of guidelines for those who wish to contribute to or establish registries.

The guidelines are as follows:

- Registries to which this hospital supplies data should generally be established under the auspices of a professional association, a learned college or a university;
- Data emanating from such a registry should be made widely available for quality improvement and audit purposes;
- Explicit arrangements should be in place to ensure the security and confidentiality of information concerning individual patients;
- Explicit arrangements should be in place to monitor the accuracy and completeness of data gathered;
- Investigators associated with registries should have sufficient expertise to ensure that analyses are conducted and presented in a scientifically sound fashion;

If the above criteria are fulfilled the Committee believes that it would be appropriate to provide identifiable patient data provided that

1. patients are informed on admission that their data will be used for quality improvement purposes and this may involve information about them being sent to registries maintained at other institutions or interstate;
2. patients should have access to an individual who can explain the purpose of the registry and issues concerning their participation;
3. an option should exist for patients to 'opt-out' by vetoing supply of their own information.

FURTHER INFORMATION

Any enquires regarding applications, Ethics Committee processes, documentation, or variations to the principles outlined above should be directed to the Ethics Manager.

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