**Appendix B**

**Explanation for the Fee required to use PATH data**

Although the PATH Project is funded by an NHMRC grant, this grant is for data collection for a specific wave of data only and does not provide funds for ongoing administrative costs associated with maintaining the full database, collaborative research agreements and governance. The Centre for Mental Health Research is an externally funded research centre at the ANU and all CMHR investigators on PATH hold NHMRC Fellowships. There is no institutional or government funding for the PATH study apart from the current project grant that funds interviewer salaries and equipment for the current wave of data collection.

The PATH database now comprises approximately 30 million data points, and is strictly managed to ensure compliance with the NHMRC Guidelines for Ethical Research practice and the Privacy legislation.

The PATH subject contact information needs to be kept up to date and death records are obtained for the sample at regular interval with subsequent updates to the datafiles.

With almost 100 collaborators, there is a substantial workload in maintaining the register of research proposals and approvals, and manuscripts that have been submitted for publication.

More specific tasks that are not funded by the NHMRC project grant and for which fees are required to cover include:

1. Managing the data collection and quality

a. Prepare raw data for analysis, including cleaning of data and development of syntax for

computing a range of secondary variables from the data.

b. Organising data linkage with other organisations (Medicare Australia, AIHW)

c. Assisting researchers with any questions they may have regarding the data, providing documentation on use of the data, providing new variables that are developed and may be of use to others researchers. Also, (although not often) errors are found in the data and all researchers have to be informed of this and corrections made.

2. Managing the distribution and monitoring the use of data. The size of the dataset and the number of researchers now accessing it, require careful monitoring of the use of the data. Specific tasks include:

a. co-ordinating the process of approval of proposals   
b. Organising a data sharing contract between ANU and any external users.  
c. Monitoring progress and use of projects approved. A database of all projects is

maintained and they are reviewed regularly.   
d. Monitoring the submission and publication of papers using PATH data.

e. Support for the PATH Governance Committee – the secretarial support to this committee is

substantial given the number of proposals and manuscripts that need to be approved.