Human Prion Disease Research and Resource Centre

Terms of Reference

1. Maintain an archive of blood and tissue samples from individuals with human prion disease, persons with an increased risk of prion disease and relevant healthy and disease controls.

2. Maintain an archive of animal samples that may represent animal models for all types of and stages of human prion disease.

3. Develop protocols whereby wet ante mortem biomarker tests for human prion disease may be evaluated, and to propose processes for the evaluation of such tests.

4. Perform evaluations of ante mortem tests referred to the Centre by the Oversight Committee.

5. Manage the distribution of samples from the archive

6. Ensure that all activities undertaken are compliant with ethical and legal requirements.

7. Ensure coordination and liaison between the Research and Resource Centre and the Oversight Committee with other advisory committees with overlapping interests.

8. Carry out relevant research to support the work of the Research and Resource Centre.

9. Provide secretariat to Oversight Committee.

10. Pursue international collaboration to facilitate these activities.

Human Prion Disease Resource Oversight Committee

Terms of Reference

1. Provide developers of wet ante mortem biomarker tests for human prion disease with an opportunity for independent evaluation of the tests suitability for purpose.

2. Agree the processes proposed by the Research and Resource Centre for the evaluation of ante mortem tests for human prion disease.

3. Refer wet ante mortem biomarker tests for human prion disease to CJD Research and Resource Centre for evaluation.

4. Review, and provide advice on, the application by the Centre of the evaluation processes.

5. Review the outputs of the evaluation processes, and report these to the test developer and appropriate advisory committees. Encourage publication of evaluation outcomes.

6. Review and agree proposals for the distribution of samples.