CPL Human Research Ethics Committee - Terms of Reference

1. PREAMBLE

The CPL Human Research Ethics Committee (HREC) composition, terms of reference, functions, responsibilities and method of operation must conform to the requirements of the current Statement on Experimentation and its Supplementary Notes (the NHMRC Statement) and other guidelines published from time to time by the National Health and Medical Research Council (NHMRC).

The CPL HREC is responsible for ensuring the ethical acceptability of research and practice conducted at CPL or by staff of CPL that involves human participants, human tissue, personally identifiable records, and for the provision of advice to CPL on related matters. All research undertaken at CPL must have approval from the CPL HREC. Researchers not affiliated with CPL, but who propose to conduct research at CPL are required to obtain ethical clearance from the CPL HREC prior to commencing the research.

2. VISION

To promote and safeguard the dignity, rights and wellbeing of CPL and its clients by providing ethical guidelines, education in ethical principles, and the necessary resources to monitor and implement ethical decisions.

3. MISSION

The resolution of ethical problems requires an Ethics Committee that is multidisciplinary and multisectoral in composition, includes relevant scientific and legal expertise, with balanced age, gender and ethnic distribution, as well as laypersons representing the concerns of the wider community. The committee will lay down appropriate guidelines based on established ethical principles, and in accordance with the values of CPL.

4. OBJECTIVES

1. Operate in line with ethical guidelines set out by the National Health and Medical Research Council
2. Ensure that guidelines are understood and accepted by CPL staff, and the wider community
3. Provide a mechanism for arranging consultation on ethical problems
4. Periodic review of ethical decisions taken to ensure they fall within the guidelines provided
5. Review research protocols and the conduct of research within CPL.

5. MEMBERSHIP

The CPL Board of Directors will appoint The Chair and via their delegate, members of the CPL HREC. At least eight members will be appointed in accordance with the requirements of the NHMRC Statement.

5.1 These members will be:

1. Chair
2. Laywoman not associated with the institution
3. Layman not associated with the institution
4. At least one person with knowledge of and current experience in areas of research regularly considered by the committee
5. At least one person with knowledge of and experience in professional care, counselling or treatment of people
6. At least one person with cerebral palsy
7. At least one minister of religion

8. At least one lawyer
9. Up to two persons co-opted from time to time and for particular purposes and specified periods.

6. TERMS OF REFERENCE

6.1 In accordance with the requirements of the NHMRC Statement the Committee is required on behalf of CPL to provide general oversight of all matters pertaining to research ethics. This will include:

a) Input and advice to policy, procedures and guidelines for research involving humans as subjects; and
b) Monitoring and review of research ethics at CPL;
c) To receive complaints, on a confidential basis, from participants, research workers or others on the conduct of research, and to deal with these in accordance with CPL's policies and procedures. Once the ethics complaint component - relevant to the ethical clearance - is assessed, the complaint will be passed onto the formal established CPL Complaints Process for reporting and complete resolution.

7. METHOD OF OPERATION

7.1 The Committee meets as required but not less than once a year.

7.2 The Committee will be appointed by the Board of Directors or their delegate.

7.3 Records of all decisions and ethics tracking must be maintained.

7.4 In exercising its functions, the Committee must take account of the following generally accepted statements of ethical principles to govern research and experimentation:

a. The research must conform to generally accepted moral and scientific principles and therapeutic standards.

b. The objectives of the project need to generally assist CPL in meeting their strategic directions and aim to improve client quality of life and/or outcomes.

c. The investigator, after careful consideration and consultation, must be satisfied that the possible advantage to be gained from the work justifies any discomfort or risks involved.

d. The investigator must be mindful at all times of his or her duty towards the individual subject of the research respecting the subject's personality, rights, wishes, consent and freedom.

e. Only suitably qualified persons having available facilities for the proper conduct of the work and for dealing with any emergency, which may arise, should conduct the research.

f. New therapeutic or experimental procedures which are at the stage of early evaluation and which may have long-term effects should not be undertaken unless full provision has been made for long-term observation.

g. The subject or his or her legal guardian should have given free consent, after comprehending the nature of the study, before research is undertaken. To this end the investigator is responsible for providing the subject or his or her guardian with sufficient information in language that he or she can understand about the purpose, methods, demands, risks, inconvenience and discomforts of the study.

h. The informed consent of the subject is mandatory in all research and experimentation projects. Evidence of consent should be obtained in writing in the case of research and experiments classified

as involving risk above the everyday norm and more generally where there is reason to believe or reason to suspect that subjects are in a dependent relationship.

i. Participation in research and experimentation must be voluntary but recompense may be made for inconvenience and time spent by volunteers.

j. Volunteers for research and experiments should ordinarily be called for by open advertisement, within or outside the CPL.

k. The subject or the subject's guardian must be free at any time to withdraw consent for further participation, and to withdraw any unprocessed data previously provided.

l. The investigator should discontinue or modify the research if it becomes apparent that continuation may be harmful.

7.5 In evaluation of situations where experimentation involving human subjects is being considered for purposes other than research, the same general principles will be applied.

7.6 In discharging its responsibilities, the Committee may seek the assistance of such experts as it chooses.

8.0 METHOD OF REPORTING

The CPL HREC will report to the CPL Board of Directors. The Chair of the HREC provides a service activity statement at least yearly or as required by the Board from time to time.

9. Research at Other Institutions

9.1 It is recognised that ethical responsibility for registered patients of hospitals and/or care facilities rests with the duly constituted authorities of these hospitals and/or institutions. Staff at CPL may undertake human research and experimentation at an institution affiliated with CPL, or other appropriate institution as determined by the Committee, provided written approval has been obtained for such research and experimentation from a duly authorised officer or committee of that institution.

9.2 Notwithstanding the above, where such research and experimentation involves studies with clients and staff of the CPL that is to be conducted by universities the CPL does not take responsibility and approval must first be obtained from (1) the University's Human Research Ethics Committee, and (2) CPL's HREC, as appropriate, before studies are undertaken.