PURPOSE

The Board has established the Ethics Committee to assist the Board in ensuring that research using data held by The Cancer Council NSW (Cancer Council) or undertaken by Cancer Council staff is ethically sound and meets the National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research, 2007 (National Statement).

GUIDING PRINCIPLES

A properly constituted Ethics Committee (Committee) must assess all research activity undertaken at Cancer Council involving humans and/or requiring access to data held by Cancer Council.

There will be a transparent and systematic process for ensuring that research proposals meet appropriate ethical standards.

The Committee will in all aspects operate consistent with the National Statement.

OBJECTIVES

The Board has established the Committee in accordance with clause 12.11 of Cancer Council’s Constitution.

The Committee’s objectives are to:

- ensure that all human research activity conducted by Cancer Council staff or requiring access to data held by Cancer Council complies with guidelines for Human Research Ethics Committees as stated in the National Statement and with Cancer Council’s Privacy Policy.
- protect the rights and welfare, including privacy and confidentiality, of participants involved either directly or indirectly, in the proposals referred to it
- promote ethical standards of human research and information privacy in proposals referred to it, by provision of guidance to investigators
- facilitate ethical research, through efficient and effective review processes, and
- ensure that all releases of health data held at Cancer Council occur in accordance with the National Statement and with relevant privacy legislation.

PROCESSES

- The Committee will assess applications for ethical approval of proposals in accordance with the National Statement (and any other legal requirements) in order to determine their ethical acceptability.
- The Committee will: consider proposals involving use of personal information owned or held by Cancer Council for research or other purposes; will determine the ethical acceptability of these proposals; and will advise the Board and the Chief Executive Officer (CEO) of Cancer Council accordingly.
- Proposals may involve either: the access of personal information, i.e. identifying or potentially identifying data; the linkage of data obtained from Cancer Council; or the linkage of a Cancer Council dataset with an external dataset.
- Proposals may emanate either internally (i.e. from within Cancer Council) or externally.
The Committee will, in its assessment of proposals, examine the extent of their compliance with Cancer Council policies on confidentiality and privacy, and standards for research ethics set down by the NHMRC and relevant legislation.

The Committee will advise the CEO and the Cancer Council Board of all research proposals considered and the decision of the Committee.

Under the National Certification Scheme accreditation awarded to the Committee by the governing body, NHMRC, the Committee will assess national multi-centre research projects of a population health and/or public health, qualitative health research, or market research nature.

Where Cancer Council staff participate in research approved by a ‘Lead Committee’ as designated by the NSW Ministry of Health, a site specific assessment (SSA) form will be submitted to the CEO of Cancer Council NSW (or their delegate) for approval and noted by the Committee.

The Committee will function as a properly constituted human research ethics committee in accordance with the National Statement.

**COMMITTEE COMPOSITION**

The Committee will have a minimum of eight members. The core membership of the Committee will be in accordance with the National Statement as amended from time-to-time by NHMRC.

The core membership comprises:
- a chairperson
- two laypeople (one man and one woman) not affiliated with Cancer Council, and not currently involved in medical, scientific, legal or academic work
- two people with knowledge of, and current experience in, the areas of research regularly considered by the Committee
- a person with knowledge of, and current experience in, the professional care, counselling or treatment of people
- a person who performs a pastoral care role in a community, and
- a lawyer.

The Cancer Council Board may appoint additional members to ensure the Committee has the expertise required to assess the applications regularly submitted for its consideration.

At least two-thirds of Committee members must be external to Cancer Council.

Where required, review of proposals by individuals external to the Committee who hold relevant scientific and/or ethical expertise may be sought.

**APPOINTMENT AND TENURE**

The Board of Cancer Council appoints Members of the Committee in accordance with Clause 12.12 of the Cancer Council Constitution.

Members are appointed for a term of three years and may serve three consecutive terms as a representative of any particular membership category.

The Cancer Council Board may approve the Chairperson, Deputy Chairperson and Chairperson of any sub-committee serving longer terms.

Membership of the Committee will lapse if a member fails to attend three consecutive meetings of the Committee, unless exceptional circumstances exist. The Chairperson will notify both the member and the Board in writing of such lapse of membership.
• The Board may terminate the appointment of a member at any time.
• Members are appointed as individuals for their expertise rather than in a representative capacity.
• Members may be asked to participate in relevant specialised working groups as required.

PROCEDURES
The Committee will perform its functions according to written Terms of Reference and Standard Operating Procedures. These Procedures will be reviewed on a biennial basis, and amended and updated as necessary. All Committee members will have access to, and be provided with, copies of the Standard Operating Procedures plus other relevant materials specified in the Procedures. The procedure for calling and conducting Committee meetings is set out in the Terms of Reference.

REPORTING
The Committee will submit to the Board a report on its activity at the Board meeting subsequent to the Ethics Committee meeting.

REFERENCES
• Cancer Council Ethics Committee Terms of Reference
• Cancer Council Ethics Committee Standard Operating Procedures

Created:  April 2004
Approved by Board:  April 2013, August 2016
To be next reviewed:  April 2015, June 2018