

# **Terms of Reference**

## **Advisory Committee on Assisted Reproductive Procedures and Human Reproductive Research**

The Advisory Committee on Assisted Reproductive Procedures and Human Reproductive Research (‘the Advisory Committee on Assisted Reproductive Technology’ or ACART) is established under section 32 of the Human Assisted Reproductive Technology (HART) Act 2004. These Terms of Reference outline the role and functions of ACART.

### **Functions of ACART**

ACART has the following functions:

- to issue guidelines and advice to the Ethics Committee on Assisted Reproductive Technology (ECART) on any matter relating to any kind of assisted reproductive procedure or human reproductive research and to keep such guidelines and advice under review
- to provide the Minister of Health with advice on aspects of, or issues arising out of, kinds of assisted reproductive procedure or human reproductive research and, without limitation, advice as to whether:
  - the HART Act should be amended to prohibit or provide for any kind of assisted reproductive procedure or human reproductive research
  - any kind of procedure or treatment should be declared an established procedure, on the basis of the information, assessment, advice, and ethical analysis required to declare a procedure to be an established procedure under section 6 of the HART Act
  - any established procedure should be modified or should cease to be an established procedure
  - a moratorium should be imposed on any kind of assisted reproductive procedure or human reproductive research
  - regulations should be made under section 76 of the HART Act to regulate the performance of any kind of assisted reproductive procedure or the conduct of any kind of human reproductive research.
- to liaise with ECART on general and specific matters relating to assisted reproductive procedures or human reproductive research
- to consult with any persons who, in the opinion of ACART, are able to assist it to perform its functions
- any other function that the Minister of Health assigns to ACART by written notice.

For the purposes of performing the above functions, ACART must monitor:

- the application, and health outcomes, of assisted reproductive procedures and established procedures
- developments in human reproductive research.

ACART should also monitor the decisions of ECART to ensure that they fall within the guidelines as intended by ACART. If, after consideration of one of ECART's decisions, ACART considers that the decision falls outside of its guidelines, ACART should inform ECART of this.

### **Guiding principles**

ACART shall be guided by the following principles:

- the health and well-being of children born as a result of the performance of an assisted reproductive procedure or an established procedure should be an important consideration in all decisions about that procedure
- the human health, safety, and dignity of present and future generations should be preserved and promoted
- while all persons are affected by assisted reproductive procedures and established procedures, women, more than men, are directly and significantly affected by their application and the health and well-being of women must be protected in the use of these procedures
- no assisted reproductive procedure should be performed on an individual and no human reproductive research should be conducted on an individual unless the individual has made an informed choice and given informed consent
- donor offspring should be made aware of their genetic origins and be able to access information about those origins
- the needs, values, and beliefs of Māori should be considered and treated with respect
- the different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect.

### **Guidelines**

ACART may issue guidelines to ECART only after it has:

- consulted on the proposed guidelines with the Minister of Health

- on the basis of a discussion paper or an outline of the proposed guidelines, given interested parties and members of the public a reasonable opportunity to make submissions; and
- taken any such submissions into account.

When ACART issues guidelines to ECART, it must:

- give copies of the guidelines to the Minister, the Director-General of Health, to ECART, and to providers; and
- publish the guidelines on the internet and in any other publications (if any) that the Committee thinks appropriate; and
- give public notice of the issue of the guidelines by publishing in any publication that it considers appropriate for the purpose a notice that states:
  - the date and subject matter of the guidelines
  - the internet website on which they are published.

### **Specific advice**

ACART must, within time frames agreed with the Minister, provide the Minister with information, advice, and if it thinks fit, recommendations on the following matters in relation to the use of gametes and human embryos in human reproductive research:

- cloned embryos
- donations of human embryos
- genetic modification of human gametes and human embryos
- human gametes derived from foetuses or deceased persons
- hybrid embryos
- requirements for informed consent
- the import into, or export from, New Zealand of *in vitro* human gametes or *in vitro* human embryos.

ACART must, within the time frames agreed with the Minister, provide the Minister with information, advice, and if it thinks fit, recommendations on the following matters in relation to human assisted reproductive technology:

- donations of human embryos
- embryo splitting
- gametes derived from deceased persons
- requirements for informed consent
- selection of embryos using preimplantation genetic diagnosis
- the import into, or export from, New Zealand of *in vitro* donated cells or *in vitro* donated gametes.

ACART may give advice on the above areas only after it has:

- on the basis of a discussion paper or an outline of the proposed advice, given interested parties and members of the public a reasonable opportunity to make submissions; and
- taken any such submissions into account.

### **Public meetings on proposed significant advice**

If, in the opinion of ACART, a significant number of persons wish to make oral submissions on a proposal to give specific advice on any of the above human reproductive research or human assisted reproductive technologies, ACART must hold as many meetings as are required to enable those submissions to be made.

ACART must:

- notify the persons who wish to make oral submissions of the time and place of any meeting to be held; and
- publish a notice on the internet and in any other publication the committee thinks appropriate that states the time, place, and purpose of any such meeting and that will be held in public.

### **Consultation**

Before ACART gives advice to the Minister or issues guidelines to ECART, it must consult on the proposed advice or guidelines with:

- any members of the public that the committee considers appropriate
- appropriate government departments and agencies
- any other person or group that the committee considers appropriate.

### **Composition and membership**

The Minister may appoint any person to be a member of ACART and must, before doing so, consult any persons who, in the Minister's opinion, are able to provide advice on prospective appointees who have the required expertise and the ability to reflect relevant perspectives and concerns, including, without limitation, the perspectives and concerns of women.

#### *Guiding principle*

The primary guiding principle for appointing members to ACART is to ensure that ACART has the appropriate expertise, skills, knowledge and perspectives to provide advice and guidelines of the highest quality.

#### *Member numbers*

ACART must consist of not fewer than 8 and not more than 12 members appointed by the Minister of Health.

### *Lay/Non-lay membership*

At least half of the members of ACART must be lay members.

For the purposes of these Terms of Reference, a layperson is a person who, at no time during the person's membership of ACART or in the 3 years before becoming a member of ACART:

- is a health practitioner within the meaning of the Health Practitioners Competence Assurance Act 2003; or
- is involved in health research; or
- is employed by or associated with, or has a pecuniary interest in, a fertility service provider.

### *Ex-officio attendance*

The chairperson of ACART, or a member of ACART nominated by the chairperson of ACART for the meeting may attend each meeting of the National Ethics Committee on Assisted Reproductive Technologies (ECART). The ACART member or Chair attending the Advisory Group meeting is not a member of the committee.

The chairperson of ECART, or a member of ECART nominated by the chairperson of ECART for the meeting may attend each meeting of ACART. ECART member or Chair attending the ACART meeting is not a member of the committee.

### *Member categories*

ACART's membership must include:

- one or more members with expertise in assisted reproductive procedures
- one or more members with expertise in human reproductive research
- one or more members with expertise in ethics
- one or more Māori members with expertise in Māori customary values and practice and the ability to articulate issues from a Māori perspective
- one or more members with the ability to articulate issues from a consumer perspective
- one or more members with the ability to articulate issues from a disability perspective
- one or more members with the ability to articulate the interests of children who, at the time of his or her appointment, holds the office of Children's Commissioner or is a representative or employee of the person who holds that office
- one or more members with expertise in relevant areas of the law.

### *Whole committee requirements*

Members should possess an attitude that is accepting of the values of different professions and community perspectives, and it is important that ACART be comprised of people from a range of backgrounds and ethnicities. All members of ACART are expected to have an understanding of how the health sector responds to Māori issues and their application to ethical review.

Despite being drawn from groups identified with particular interests or responsibilities in connection with health and community issues, Advisory Committee members are not in any way the representatives of those groups. They are appointed in their own right, to participate in the work of ACART as equal individuals of sound judgement and relevant experience.

### **Terms and conditions of appointment**

Members of ACART are appointed by the Minister of Health for a term of office of up to three years. The terms of office of members of ACART will be staggered to ensure continuity of membership. Members may be reappointed from time to time. No member may hold office for more than six consecutive years.

Persons who have served six consecutive years as members of the previous National Ethics Committee on Assisted Human Reproduction (NECAHR) shall not be immediately eligible for appointment to ACART.

A person may not be a member of ACART and ECART simultaneously.

Unless a person sooner vacates their office, every appointed member of ACART shall continue in office until their successor comes into office. Any member of ACART may at any time resign as a member by advising the Minister of Health in writing.

The Minister may, by written notice, terminate the appointment of a member or chairperson of the advisory committee.

The Minister may from time to time alter or reconstitute ACART, or discharge any member of ACART, or appoint new members to ACART for the purpose of decreasing or increasing the membership or filling any vacancies.

### **Chairperson and Deputy Chairperson**

The Minister may appoint any person to be a chairperson of ACART and must, before doing so, consult any persons who, in the Minister's opinion, are able to provide advice on prospective appointees who have the required expertise and the ability to reflect relevant perspectives and concerns, including, without limitation, the perspectives and concerns of women.

ACART may appoint one of its members to be Deputy Chairperson.

The Chairperson will preside at every meeting of ACART at which they are present.

## **Duties and responsibilities of a member**

This section sets out the Minister of Health's expectations regarding the duties and responsibilities of a person appointed as a member of ACART. This is intended to aid members of ACART by providing them with a common set of principles for appropriate conduct and behaviour and serves to protect ACART and its members.

As an independent statutory body, ACART has an obligation to conduct its activities in an open and ethical manner. ACART has a duty to operate in an effective manner within the parameters of its functions as set out in its Terms of Reference and in accordance with the HART Act.

### *General*

ACART members should have a commitment to work for the greater good of the Committee.

There is an expectation that members will make every effort to attend all ACART meetings and devote sufficient time to become familiar with the affairs of ACART and the wider environment within which it operates.

Members have a duty to act responsibly with regard to the effective and efficient administration of ACART and the use of ACART funds.

### *Conflicts of interest*

ACART members must perform their functions in good faith, honestly and impartially and avoid situations that might compromise their integrity or otherwise lead to conflicts of interest. Proper observation of these principles will protect ACART and its members and will ensure that it retains public confidence.

Members attend meetings and undertake committee activities as independent persons responsible to ACART as a whole. Members are not appointed as representatives of professional organisations and or particular community bodies. ACART should not, therefore, assume that a particular group's interests have been taken into account because a member is associated with a particular group.

Members should declare, and the committee regularly review their actual and potential conflicts of interest. ACART must exhibit transparency in avoiding or managing any real or perceived conflict of interest.

### *Confidentiality and information sharing*

The public has a right to be informed about the issues being considered by ACART. The chairperson of ACART must ensure that the agenda and minutes are published on the internet as soon as possible after they are confirmed by the members of the committee. ACART should have procedures in place regarding the release of information and processing requests for information.

Individual members must observe the following duties in relation to ACART information. These provisions ensure that ACART as a whole maintains control over the appropriate release of information concerning issues before it.

- Meetings of ACART, including agenda papers and draft minutes, are confidential. Members must ensure that the confidentiality of ACART business is maintained.
- Members are free to express their own view within the context of committee meetings or the general business of ACART.
- Members must publicly support a course of action decided by ACART. If unable to do so, members must not publicly comment on decisions.
- At no time should members individually divulge details of ACART matters or decisions of ACART to persons who are not ACART members. Disclosure of ACART business to anyone outside ACART must be on the decision of ACART, or at the discretion of the Chairperson of ACART between meetings. In choosing to release or withhold information, the Committee must comply with the Official Information Act 1982 and the Privacy Act 1993.
- ACART members must ensure that ACART documents are kept secure to ensure that the confidentiality of committee work is maintained. Release of committee correspondence or papers can only be made with the approval of ACART.

### **Meetings of the Committee**

Meetings shall be held at such times and places as ACART or the Chairperson of ACART decides.

When ACART has 12 members, at least seven members must be present to constitute a majority. When the number of appointed members is less than 12, a quorum is the minimum number constituting a majority. The quorum must include a reasonable representation of members with health practitioner, research, ethical and community/consumer expertise, knowledge and perspectives.

Every question before any meeting shall generally be determined by consensus decision-making. Where a consensus cannot be reached a simple majority vote will apply. In such circumstances, the Chairperson shall have the casting vote.

Subject to the provisions set out above, ACART may regulate its own procedures.

### **Reporting requirements**

ACART must, as soon as practicable after each 12-month period ending on 30 June, give the Minister of Health a report:

- on its progress in carrying out its functions; and
- on the number and kinds of decisions given by ECART in that period.

### **Fees and allowances**

Members of ACART are entitled to be paid fees for attendance at meetings. The level of attendance fees are set in accordance with the State Services Commission's framework for fees for statutory bodies.

The Chairperson will receive \$430 per day (plus half a day's preparation fee) and an allowance of two extra days per month to cover additional work undertaken by the Chairperson. The attendance fee for members is set at \$320 per day (plus half a day's preparation fee). The Ministry of Health pays actual and reasonable travel and accommodation expenses of ACART members.

### **Servicing of ACART**

ACART will agree a work programme with the Minister of Health. ACART will be serviced by permanent staff, sufficient to meet the Committee's statutory requirements, who will be based in the Ministry.