

Operating guidelines and procedures governing the conduct of research in the Disability Services Commission

This document forms the conditions for researchers applying to conduct research within the Disability Services Commission in relation to:

- Commission staff
- service providers
- clients who receive Commission-provided services or
- any instance where the Commission provides the data/information for research purposes.

For the purposes of this policy, research is defined as defined as the creation of new knowledge and/or the use of existing knowledge in a new and creative way so as to generate new concepts, methodologies and understandings. This could include synthesis and analysis of previous research to the extent that it leads to new and creative outcomes.

Modes of research

The Commission may be involved with research in any of the following ways:

- **Collaborative research:** Research projects jointly conducted with another party or parties, eg research grants.
- **Commissioned Research:** Research projects initiated and fully funded by the Commission.
- Commissioned research involves investigations conducted by consultants or external organisations and institutions (universities) that are under direct contract to the Commission.
- **Independent Research:** Research conducted by independent researchers in areas of relevance to the Commission and which may require access to Commission resources.
- **Graduate / Post-graduate Supported Research:** Research projects being undertaken as a component of an Honours, Masters or Doctoral program.

The requirements apply to research undertaken by:

- Commission staff where the research is not part of their normal duties
- students where the research involves Commission clients, staff or operated services and/or identifiable data
- external researchers where the research involves Commission clients, staff or provided services and/or identifiable data
- external researchers accessing de-identified Commission data.

These guidelines do not apply directly to research that has been contracted by the Commission as the requirements will be outlined in the contract.

The Commission has a responsibility to ensure that research participants are not exposed to undue risk, unnecessary or unwarranted intrusion and that issues of privacy, confidentiality and consent are adequately covered.

To this end, no research can commence until agreement attached to this document has been signed. A breach of the terms may, at the discretion of the Commission, result in the research project being terminated.

The Commission, recognising its responsibility to its clients, reserves the right to withdraw access, or vary the conditions applying, to an applicant's research involving departmental information.

Policy objectives

The Director General will be responsible for the evaluation of research projects and proposals to ensure projects and proposals involving the Commission are of a high standard and contribute positively in the development of knowledge, attitudes and services for people with disability. Research proposals should demonstrate how the research will inform these objectives.

The Director General will forward the proposal to the Research Approvals Committee for final endorsement.

These are the questions the reviewers must consider:

- Is the research technically adequate?
- Is the research consistent with the Disability Services Standards, in particular confidentiality and privacy?
- Is the research based on values in keeping with the Commission's philosophy?
- Will the knowledge generated from the research be useful in terms of informing practice or increasing understanding of the particular issues researched?
- Does the research have sufficient credibility to be undertaken, ie is it likely to contribute positively to the field? Will the research be appropriately supervised?

Responsibility

The Director General has responsibility to see that any proposal submitted to the Commission complies with the guidelines for acceptance outlined below. The rationale, research design and methodology will have been approved by the relevant university, training institution or agency before the proposal is submitted to the Director General. The research project must be conducted in an ethical manner and pose no risk or harm to service users. All projects must seek service user/parent /guardian consent and meet confidentiality requirements where individuals or groups are identified.

The Director General will give a brief statement on whether the guidelines are met including brief comments on suggested changes, if any are required, to the person submitting a proposal.

Guidelines for Acceptance of Research Project Proposals

1. Informed consent

Research participants must be fully informed regarding the intent, nature, purpose and scope of the research when deciding if they will participate. This includes advice to participants on whether personal or identifying information will be provided to any third parties who must be identified. Participation in the research project must be voluntary and participants should be fully aware that they are free to withdraw at any time.

Researchers must pay particular attention to the issue of informed consent and demonstrate that every attempt has been made to use an accessible medium and to appropriately attend to levels of comprehension in the presentation of all relevant information pertaining to the research project. Where individual participants are unable to comprehend sufficiently to give consent, this must be sought from the person or body who has the legal authority to make decisions on behalf of the person.

2. Privacy and confidentiality

The privacy and confidentiality of participants' personal details/information must be ensured at all times, including in the publication of any data, papers or reports.

The anonymity of participants, including Commission staff, must be ensured throughout the research process. For example, if the research project uses surveys, information should be stored in such a manner to ensure individuals participating in the project are not linked to the data provided. The identity of Commission sites that are participating in research projects should also remain confidential and not be disclosed in any published research material.

3. Data management

All projects must ensure that participant confidentiality is protected at all times regardless of the type of data collection instruments used (eg questionnaires, audio or video recordings). This condition also applies to research projects that involve longitudinal studies. Persons other than the researcher must not be able to link the information collected to individual participants. Researchers must provide details of the procedures they will use to ensure this protection in their research application (eg strategies for information storage, access and disposal of data).

The amount of personal data available to any researcher, including access to participants will be dependent upon the type and extent of the research and the potential benefits of the research. This will be mutually agreed on at the outset of the project.

The Commission follows the Australian Code for the Responsible Conduct of Research (2007) and has an obligation to ensure that data pertaining to individuals is not communicated to unauthorised person(s). As a result, information about specific individuals will not be communicated to third parties or published without the consent of the individual concerned or the appointed legal authority for that person.

The Commission's data that does not identify or pertain to individuals must not be provided to third parties without prior written approval from the Commission.

Researchers must comply with the principles and standards on collection, storage and security of personal information outlined in the Australian Code for Responsible Conduct of Research (2007) and the *Freedom of Information Act 1992 (WA)*.

4. Ethics clearance and ethical standards

The Commission acknowledges the vulnerability of its client group and for this reason, only research granted ethics clearance from a Human Research Ethics Committee will be considered.

Research applications must be consistent with the National Statement on Ethical Conduct in Human Research (2007) and the Australian Code for the Responsible Conduct of Research (2007) as published by the National Health and Medical Research Council. These documents are intended for use by any researcher conducting research with human participants.

The National Statement was developed jointly by the National Health and Medical Research Council, the Australian Research Council and Universities Australia. It replaces the 1999 National Statement on Ethical Conduct in Research Involving Humans. For more information, visit www.nhmrc.gov.au > Guidelines and Publications search > National Statement on Ethical Conduct in Human Research (2007) – Updated December 2013.

Research proposals must reflect contemporary knowledge of, and commitment to, proper ethical standards and measures, with due regard to issues of privacy, consent, power relations, accountability and transparency. The specific issues associated with research in the disability sector are outlined in 'Q & A: Ethical review of research in the disability services sector' (Association for the Study of Intellectual Disability, October 2013).

5. Protection for research participants

In order to protect the safety and wellbeing of people in vulnerable situations, it is important that all researchers wishing to conduct research with human subjects or who have access to identifying information about human subjects, submit to and are granted a criminal history clearance.

Researchers should approach their local police department to conduct the check. These are to be obtained at researchers' own expense. A criminal history clearance should be provided with the research application.

6. At risk

If during the research project a participant discloses confidential information to the researcher regarding their safety and wellbeing or issues that place a participant at risk, the researcher is required to inform the relevant Commission manager and notify or refer to any relevant external authority(s) as appropriate.

Researchers are required to inform the participant of the disclosure protocol and the action taken.

7. Intellectual property

In approving proposals to conduct research, the Commission places no claim on the researcher regarding new intellectual property created by the researcher.

8. Publication of research findings

The State of Western Australia retains the copyright in the records, data etc that may be made available to researchers. Unauthorised copying or publication of these records, data, film etc is in breach of the State's copyright laws.

Permission must be granted to the researcher from the Commission prior to publication or making publicly known, all or part of research that makes use of Commission data or information. An advance copy of that material must be provided to the Commission.

The Commission will review and comment on proposed publications. Consent to publish would only be withheld where the publication was seen to be detrimental to the interests of people living with disability, their families and carers or the Commission.

In the event of publication, the researcher will acknowledge the assistance of the Commission and supply a copy of the published material.

9. Monitoring and/or supervision of research projects

The nominated Research Review Coordinator within the Commission will monitor the progress of research projects and may call for specific and additional reports if necessary.

Appropriate supervision arrangements must be in place for students conducting research within Commission sites. Supervision (unless otherwise stipulated) remains the primary responsibility of the research institution affiliated with the researchers. The Commission must be fully informed of all supervision mechanisms and arrangements.

Researchers should note that even when there is approval of research proposals, in principle full approval to proceed can only be granted when informed consent is gained from all participants.

Research applications must include:

- a completed Application for Approval to Conduct Research in the Commission
- a copy of the Ethics Clearance for the proposed research
- all relevant documentation (police clearance(s), copies of all research instruments and documents for obtaining informed consent).

Applicants will be informed in writing of a decision regarding the research proposal within four weeks of lodging the application.

Guiding documents and legislation:

National Disability Services Standards

Visit www.dss.gov.au > Our Responsibilities > Disability and Carers > Standards and Quality

Assurance > Disability Services Standards (Advocacy Standards) 2012.

National Statement on Ethical Conduct in Human Research (2007)

Visit www.nhmrc.gov.au > [Guidelines and Publications](#) search > National Statement on Ethical Conduct in Human Research (2007) – Updated December 2013.

Australian Code for the Responsible Conduct of Research (2007)

Visit www.nhmrc.gov.au > [Guidelines and Publications](#) search > Australian Code for the Responsible Conduct of Research.

Western Australia legislation:

Refer to www.slp.wa.gov.au > Online Legislation Databases

- Carers (Recognition) Act 2004
- Commission for Children and Young People Act 2006
- Disability Services Act 2003
- Guardianship and Administration Act 1990
- Health and Disability Services (Complaints) Act 1995
- Freedom of Information Act 1992.

Commonwealth legislation:

Visit www.austlii.edu.au > Databases > Commonwealth of Australia > Consolidated Acts)

- Disability Discrimination Act 1992
- Disability Discrimination and Other Human Rights Legislation Amendment Act 2009
- Privacy Amendment Act 2004
- Racial Discrimination Act 1975.