



R E S E A R C H D E P A R T M E N T

A Policy Document
for
Conducting Research
in
COPE Foundation





This document provides a discussion of issues related to conducting research with people with intellectual disabilities. It has been drafted with a rights based approach in mind. The core principles for conducting research with people with intellectual disability are outlined in keeping with the policy documents which were reviewed for drafting this document (National Disability Authority (NDA), European Science Foundation (ESF), International Association for the Scientific Study of Intellectual Disabilities (IASSID) The World Medical Association (WMA)).

The document reviews research related issues under the following headings.

- o Research Definitions and Outcomes
- o Research Practice (with emphasis on codes of good practice)
 - Researchers
 - Training and recruitment of Researchers
 - Participants
 - Role of the Research Committee
 - Scientific Misconduct
- o Relevant References
- o Appendices
 - Appendix A: Research Proposal Form
 - Appendix B: Standards and Consent Form
 - Appendix C: Informed Consent Form
 - Appendix D: Research Resume Form:
 - Appendix E: Research Regulations:



Introduction

Good scientific practice in research is essential for the integrity of the practice of research. It safeguards against scientific fraud and nurtures trust between researchers and society. (ESF, 2000). In agreement with international standards as set out by the European Science Foundation COPE Foundation commits itself to

- Support and promote vigorously the concepts and principles of good scientific practice in research
- The principles of transparent research based on high quality practice and creativity
- An inclusive and participatory approach to research
- The harmony of policies and procedures with regard to research practice
- Clear, fair and robust guidelines for good research practice
- Equality and diversity in research design and planning issues



Moreover, as recommended by IASSID (2003) COPE Foundation adheres to the three ethical principles identified by the Council for International Organisations of Medical Science (2002) (CIOMS)

1. Respect for persons, including their autonomy and right to self-determination;
2. Beneficence for participants and the community i.e., maximizing benefits and minimizing risk; and
3. Justice, both legally and morally, in the treatment of those involved in research and in the treatment of the communities to which participants belong

COPE Foundation also endorses the principle that for research involving human participants, '...the well-being of the human subject should take precedence over the interests of science and society' (World Medical Association, Declaration of Helsinki, 2000; Article5). Furthermore, in line with the principles for conducting research with people with disabilities as set out by the NDA (2004) COPE Foundation advocates the core values of facilitation of participation in so far as possible, maintenance of the highest professional standards in research practice and recognition and fulfillment of relevant legal responsibilities.

For people undertaking research involving clients of COPE Foundation, researchers need to justify to both their peers, clients and their families and the organization that what they propose to undertake is in the best interests of people with intellectual disabilities and the methods by which this is done is according to the highest international standards.



What is Research?

Research is the systematic design, collection, interpretation, reporting and/or publishing of any such information relating directly or indirectly to any activity of COPE Foundation from time to time (COPE Foundation Research Department Objectives, Policies and Procedures).

- Research is a diverse and multifaceted set of activities which embrace a wide range of intellectual and practical endeavours
- These include theoretical studies, experimental work and surveys, evaluation of a service or programme, verification, further analysis, and extension of earlier work
- The objective is to extend human knowledge and understanding of the nature of Intellectual Disability (ID) and the lives of people with Intellectual Disability and to share this knowledge with others working in the ID field.
- Outputs of research include the publication of a report, presentations at COPE Foundation staff research seminars, presentations at other relevant national and international conferences and seminars and publication in the COPE Foundation Research Newsletter *Research News*. Outcomes should never take priority over critical and ethical research procedures.

Research Practice

Best practice in the design, conducting, and interpretation and reporting of research is a must. This practice builds on the trust between researchers, the clients, their families and the general public. Ethical issues and standards are of paramount importance in conducting research.

Inclusive methodologies must be used where appropriate (see NDA 2002; Guidelines for Including People with Disabilities In Research).

Best practices facilitate the external processes of peer review, verification of data and repeatability. This enables objective parties to judge the validity of new contributions to knowledge and understanding.

Legislation

All researchers undertaking research in COPE Foundation shall adhere to the guidelines for protection of data and information under the following legislation.

- The Data Protection Act (1988; 2003)
- The Freedom of Information Act (1997; 2003)
- The Equal Status Act (2000)



Researchers:

- Self-regulation of practices by researchers must be maintained at all times to ensure the highest professional standards
- This self-regulation must be built-in to the research process. Researchers must keep their own notes as proof of this regulation. Researchers will be asked regularly to submit an update of their research project to the Research Committee who will monitor the progress of all projects in this manner.
- Researchers must draw attention to the ethical issues of the use of data, reporting of data and feedback to participants in their proposal (Appendix A; Research Proposal Form)
- Researchers must demonstrate an openness with regard to research misconduct and demonstrate a critical open minded approach at all times when conducting research and analyzing data.
- Researchers must demonstrate absolute honesty at all times. i.e., they must observe the rules of plagiarism, breach of confidence, falsification of data etc. and they must acknowledge the assistance of others in conducting their research project.
- Researchers must provide for the dissemination of findings in a way that maximizes access to participants, their families and advocates and the rest of the organization.
- Researchers also hold responsibility for securing records and data.
- Authors must be open and frank about their work with clear accounts of procedures, materials, statistical techniques etc. They must also be clear and frank about the contribution of other researchers
- Publication in books or journals is an important part of the research process. Right to authorship is directly related to work output. In the case of joint authors each should have made a significant contribution to the creative or analytical process and each has to accept responsibility for the content.
- Researchers have an obligation to ensure that their work should be developed for the benefit of the community, in this case for the benefit of people with intellectual disabilities.
- Researchers must adhere to the ethical principles of conducting research with human subjects:
 - o They must inform individuals about all aspects of the proposed research
 - o They must secure voluntary agreement
 - o They must handle and store personal information under conditions of the highest possible confidentiality
 - o They must use this information exclusively for the purposes of the research project



Consent and Informed Consent

- Issues of consent and informed consent must be addressed before proposals are considered. The letter of explanation and the letter of informed consent must accompany all proposals put forward to the research committee (See Appendices B & C).
- Consent to participate must be informed, voluntary and free from any deception
- Informed consent to participate should in so far as possible be obtained from the participants themselves.
- In projects involving children (persons under 18 years of age) consent should also always be sought and agreed by parents/guardians
- In projects involving adults (persons over 18 years) consent should be sought from the individual, giving due concern to level of understanding, awareness and capacity to give consent. Where the person is deemed incapable of the latter, consent must be also sought from parent/guardian.
- In addition, parents/guardians must always be informed about research relating to their adult child/ward.
- The views of the person with ID must be respected whatever the view of others in the consent process
- Consent must be obtained in a format suitable for the individual involved (e.g., use of pictures, sign language or other suitable format)
- No inducements should be offered to participants to persuade them to participate in the research project

Participants

Participants will mean those who are directly involved in a research study. Where that person requires a parent/guardian to represent them in the research process the following guidelines will also apply.

- Participants must be assured of complete confidentiality and anonymity of data
- Participants must be informed that they have the right to refuse to participate in a study or that they can withdraw from the study at any time without fear of reprisal
- All participants must be treated equally in the research process. Results of research projects must be made available to any participants of that study after the research project has finished.
- At the request of participants all data relevant to themselves, must be made available to them at completion of a project to assist in on-going support or treatment



- Researchers must be aware of the tendency for some people or groups of people to be an over-researched group, particularly those with good communication skills and a willingness to participate. Researchers shall not be granted approval for a project to be conducted if the intended participant group have been 'researched' twice in the past five years. The frequency with which groups of individuals have been researched will be monitored by the Research Department and the Research Committee.

Training and recruitment of researchers

- Training and development of researchers employed by COPE Foundation is an important responsibility for those involved in research
- Training must involve technical skills, ethical standards and principles of best practice
- All researchers must receive supervision and support whilst conducting research at COPE Foundation.
- Where possible it is advisable that students (i.e., students on placement with COPE Foundation) have two appointed supervisors, one from within COPE Foundation and one from their academic institution. This would mediate any conflict situations or biased practices which may arise.
- When recruiting for research posts COPE Foundation recruits persons with competencies which include initiative, creativity and scientific excellence. Appointments are made in adherence with COPE Foundation recruitment procedures, which are in line with best practice.

Role of the Research Committee

The role of the Research Committee has been set out in the Terms of Reference for the Research Committee. (Ref: COPE Foundation Research Department Objectives, Policies and Procedures)

Terms of Reference of the Research Committee

1. To oversee, encourage and initiate where appropriate the research within COPE Foundation
2. To promote good practice in the commissioning and conducting of research
3. To ensure there are appropriate systems in place to monitor and manage research activities



4. To monitor adherence to the research guidelines as set out from time to time by the Research Committee
5. To facilitate where appropriate the dissemination of research findings internally, nationally and internationally.
6. To contribute to and encourage the developing of a research culture within COPE Foundation

The Research Committee acts as a resource to provide ideas and direction in the planning stage and feedback at intervals throughout the research process. At Research Committee meetings the members are informed of progress on the research projects through the updates on current research projects.

The Research Committee takes cognizance at all times of the codes of ethics and application forms and consent forms that have been approved by COPE Foundation. The research committee will ensure that any allegation of scientific misconduct will be processed through COPE Foundation's complaint procedure for clients and their families.

Codes of best scientific practice

- Data is an important resource; it may also be the starting point for further studies. All primary and secondary data must be stored in a secure and accessible form. Raw data (Questionnaires, interview transcripts etc) must be kept on file for a period of one year after completion of the research study. Following this period all files must be destroyed in an appropriate manner.
- Proposals and plans should be written in clear and unambiguous terms. They should have specific details on the aim, materials, methods and time scales involved.
- In making a decision whether to pass a research proposal the Research Committee will consider the issues already mentioned, how the research is to be explained to participants, how their consent is to be obtained, how they are to be treated during the research, how their personal information and results pertaining to them are to be stored and kept confidential, what safeguards are in place to minimize potential harm, what mechanisms are in place to respond to any adverse effects, what mechanisms are in place to maximize the benefits of the study to participants and report findings to them and what follow-up if any will be undertaken following the research study.
- The Research Committee will endeavour to ensure that policies and good research practices are followed at all times
- Where breaches of best practice have occurred the research project will be suspended while an investigation is conducted.



Grant-Aided/Funded Research or Multi-Agency Research

- The codes of ethics and principles are equally applicable to grant-aided research funded by commercial sponsored government bodies etc.
- These codes of ethics and principles are also equally applicable to multi-agency/interagency research.
- Careful thought needs to be given to whether each individual research project can be justified and most importantly whether it can contribute in a positive way to the lives of people with intellectual disabilities. There may be times when a collaborative approach (multi-agency/inter-agency) to research projects would be beneficial and assist in research design and planning. Where collaborative research is appropriate or warranted, careful consideration should be given to amalgamating research projects to enlarge the research sample and improve the validity and reliability of research findings. Such a collaborative method may also be used for improving cost effectiveness and allocation of research resources.
- Certain tensions may arise when there is a conflict of interest over ownership and exploitation of intellectual property and to publication arrangements. These issues should be clearly addressed and agreed before a contract is finalized.
- All research projects must be conducted in a manner consistent with the mission of COPE Foundation; **'to fulfill the potential of persons with intellectual disability'; the vision 'to enrich the community through the realisation of the full potential of all persons'** and the goals of COPE Foundation **'to strive to provide and develop the best models of service and care for persons with intellectual disability, to lead and manage the business of COPE Foundation in the most effective and efficient manner in order to maximize the use of resources for the benefit of persons with intellectual disability and their families and to influence policy and best practice and to advocate for persons with intellectual disabilities and their families.**
- Research proposals which are not consistent with the vision mission and goals of COPE Foundation will not be granted approval by the Research Committee.

Investigating Allegations of Scientific Misconduct

Incidents of scientific misconduct are rare or uncommon but are of such a serious nature they cause concern when they do occur. Any complaints regarding scientific/research procedure should be processed through the COPE Foundation's Complaints Procedure for clients and their families.



References:

Locke, L.F., Spirduso, W.W & Silverman, S.J. (1993) *Proposals that Work (3rd ed.)*. A Guide for Planning Dissertations and Grant Proposals. London; SAGE Publications.

European Science Foundation (2000) Good scientific practice in research and practice. European Science Foundation Policy Briefing.

World Medical Association Declaration of Helsinki (2000) *Ethical Principles for Medical Research Involving Human Subjects*. Initiated 1964 and adopted by the 52nd WMA General Assembly, Edinburgh, Scotland, October 2000.

NDA (2002) Ask Me Guidelines for Effective Consultation with People with Disabilities. Dublin, NDA.

NDA (2002) Guidelines for Including People with Disabilities in Research. Dublin NDA.

NDA (2004) Ethics in Disability Research. Dublin; NDA

Arcsott, K., Dagnan, D., Kroese, B.S. (1998) Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77-83.

Evans, D. & Evans, M. (1996) *A Decent Proposal: Ethical Review of Clinical Research*. New York; John Wiley and Sons.

Government of Ireland (1997) Freedom of Information Act. Number 13 of 1997.

Government of Ireland (2003) Freedom of Information (Amendment) Act. Number of 2003

Government of Ireland (1988) Data Protection Act. Number 25 of 1988

Government of Ireland (2003) Data Protection (Amendment) Act. Number 6 of 2003

Government of Ireland (2000) Equal Status Act

IASSID (2003) *Ethics Guidelines for International, Multi-Centre Research Involving People with Intellectual Disabilities*. (Draft Material for Discussion and Comment January, 2003). Prepared by the International Association for the Scientific Study of Intellectual Disability (IASSID) Ad Hoc Committee on International, Multi-Centre Research Ethics.



APPENDIX A: RESEARCH PROPOSAL FORM

Title of Project:

Name of Researcher(s):

Position:

Department:

Address:

Tel. No:

E-mail Address:

Date of Proposal:

Proposed starting date:

Proposed finishing date:

Abstract:

(In less than 250 words please state the objectives of the study, the methodology which will be employed and the relevance of the study to COPE Foundation)



Literature background:

Objectives/ hypotheses:

Participants:

1. **Recruitment of Participants** (*including inclusion/exclusion criteria*)
2. **Process for Obtaining Consent:** (*attach consent form and letter explaining the study to participants and/or advocate*)

Procedure/ Methodology:

1. **Research Materials/Assessment Instruments:** (*including obtaining additional information from database or files etc. with justification for doing so*)
2. **Monitoring of Project** (*including what procedures are in place to monitor project include procedures on storing and transporting data, maintaining confidentiality and anonymity.*)
3. **Potential Risks and Management of Adverse Events** (*what procedures are in place should adverse conditions arise.*)
4. **Termination Criteria and Protocol** (*under what circumstances will the project be terminated or what steps have you taken to ensure individuals that they can withdraw at any stage without adverse effects to their service*)
5. **Data Analysis** (*how will the data be analysed, what techniques or statistical tests will be employed*)
6. **Reporting Results** (*explain how and where results will be made available, to participants, their families advocates, to the research committee and to the organisation generally, where will results be presented nationally, e.g., seminars conferences, publications etc.*)



7. **Follow-up to research project:** *(describe how benefits to participants can be sustained after completion of project, how will benefits be made available to other groups e.g., control groups after project has been completed, how will benefits be generalised across the organisation, how will adverse effects discovered be minimised in the future).*

Potential Conflicts of Interest:

Any Other Ethical Considerations?

Project Management:

Month	j	f	m	a	m	j	j	a	s	o	n	d
Task												

Application for funding:
(Outline proposed costs in detail)

**I the undersigned have read and understood the research regulations and agree to abide by them. I understand that any breach of best practice as outlined by the Research Department policy document will result in my project being suspended while an investigation is conducted.*

Signed

**Completed proposal forms intended for consideration by the Research Committee must be signed and returned to the Research Department.*



APPENDIX B: STANDARDS AND CONSENT FORMS

Consent Form Checklist (to be completed by the researcher of proposed study)

All research proposals must be made out on official department application forms and should be accompanied by a copy of the information sheet and consent form which will be sent to potential participants and/or their families or advocates.

Please complete the following checklist to ensure that all procedures have been dealt with adequately. You should have marked a yes to each of the following statements.

Items	Yes	No	Comments
1. Does the title of the study appear at the top?			
2. Is the general purpose of the study stated- what is the aim of the study?			
3. What is the purpose of the study (e.g., for completion of a student programme, dissertation etc.). Any sponsorship from government bodies or non-government bodies should also be acknowledged?			
4. Is there a statement included which indicates the persons right to choose to participate?			
5. Is there a statement which explains how the participant was selected?			
6. Is the procedure of the study adequately described, time frame, nature of information, what will be involved...? Will video or audio tapes be used at any stage in the investigation?			
7. Is there a statement which includes the possible discomforts/risk/inconveniences (if any) which will be experienced by the participant? Information about how these will be handled also needs to be supplied			



Items	Yes	No	Comments
8. Are the benefits to participants (if any) described?			
9. Is participant confidentiality and anonymity explained adequately?			
10. Has the Researchers contact details and an alternative person's details (e.g., supervisor, line manager) been supplied should the participant have any queries about the study?			
11. Is it clearly stated that the participant may withdraw from the study at any time without any negative impact to him/her?			
12. Does the letter state that the participant is entitled to a copy of the consent form if requested?			
13. Is there a statement indicating that the signature of the participant indicates a willingness to participate in the project?			
14. Is there a place for the signature of the participant, the researchers signature and parent/advocate's signature if required?			
15. Is there adequate detail on how the findings of the study will be disseminated?			
16. Are there contact details of a person familiar with the research participants' to whom participants or parents'/guardians' can direct their enquiries or concerns they might have about their involvement in the study?			



APPENDIX C: CONSENT FORM

Consent Form

To be filled out with study participant

Project Title:

(please tick as necessary)

	Yes	No
1. Have you read the information sheet about this study?		
2. Have you had an opportunity to ask questions and discuss this study?		
3. Have you received satisfactory answers to all your questions?		
4. Have you received enough information about this study?		
5. Do you understand that you are free to withdraw (your child) from this study at any time without giving a reason?		
6. Do you agree (to allow your child) to take part in this study?		
7. If your answer to (6) is 'Yes': <i>Refer to use of additional material e.g., video or audio tapes and seek permission to use as research data.</i>		

Signed _____ Date _____

Name (in block letters) _____

(Relationship to participant if relevant) _____

Signature of Researcher _____

If you would like to discuss any queries or concerns you have about your child participating in this project, please leave your contact details below (telephone no., address etc.) and you will be contacted as soon as possible.

Queries/Comments

Tel: _____

Address: _____



APPENDIX D: RESEARCH RESUME FORM

On completion of any minor piece of research (e.g., case studies, written reports for internal or external use, evaluations of aspects of a service, pilot projects, surveys, extended essays, observational studies or minor training programmes or any other activities in which data collected and documented would be of interest to others) within COPE Foundation services, this document must be completed and returned to the Research Department.

Title of Project: _____

Name of Researcher: _____

Agency/Organisation/School etc where project is being completed.

Position: _____

Department (COPE Foundation employees)

Contact Telephone number: _____

Description of Project: *This must include a brief overview of the subject area, the purpose for which the project was carried out (e.g., to meet the requirements of a course module), the objectives of the study, the target population involved, a brief description of the methodology involved and time taken to complete the project, staff involved, costs incurred, the relevance of the project to provision of services in your department and any other comments which you feel are relevant to the project.*

Signed: _____ Date: _____



APPENDIX E: RESEARCH REGULATIONS

- Research shall mean the systematic design, collection, interpretation, reporting and/or publishing of any such information relating directly or indirectly to any activity of COPE Foundation from time to time
- Proposals for research within COPE Foundation shall be submitted to the Research Committee for prior approval.
- Minor research undertakings (e.g., single case studies, extended essays etc.) may be granted approval to proceed on the joint recommendations of the Chief Executive and Head of Assessment/Guidance, Training and Employment Division. Reports on all such undertakings will be documented on the Research Resume form (see appendix D) and submitted to meetings of the Research Committee.
- The Research Committee may approve a proposal for research subject to such conditions, as it considers reasonable to advance the objectives of COPE Foundation.
- The copyright and other proprietary rights in any work arising from research shall belong to COPE Foundation
- The protection of confidential information belonging to COPE Foundation and the privacy of COPE Foundation's clients and their families shall be of paramount importance in all research undertaken
- During the course of research the Research Committee shall be entitled to full information as to the progress of the research. On completion all reports shall be presented to the Research Committee for approval.
- Following final approval by the Research Committee, research findings may be made available to 3rd parties outside COPE Foundation.
- Any publications relating to research findings must have the prior approval of the Research Committee.