***A Handbook for BLENNZ Researchers***

***Useful explanations of research concepts and procedures that may assist applicants wishing to carry out research with BLENNZ support and participation***

**1. RESEARCH MERIT**

The study must have clear research goals and potential to contribute to the advancement of knowledge in blindness education that justifies participants time and input. The researcher has an obligation to ensure that the methods are adequate to realise the research aims and objectives.

The risks and benefits for participants should be assessed and include:

* The possible benefits to research participants of taking part in the research
* The possible risks to research participants of taking part in the research
* Whether the participants are likely to experience discomfort (physical, psychological, cultural, or social) and how these can be managed so that they are minimised or prevented.

**2. INFORMED CONSENT**

The principles of informed consent require that people should not be involved as participants in research without understanding and freely agreeing to such involvement.

The researcher must provide adequate information to the prospective participants relating to the purpose of the research, methods of participant involvement, and intended use of the results, with all information relevant to their decision to participate, and invited to take part. This information should be given in plain language appropriate to the participants and in their preferred format (e.g., Braille, print, audio). Where relevant, prospective participants must be given the opportunity to request the services of an interpreter. The researcher must recognise and respect the individual’s right to decline to participate in, or to withdraw up until the time the data is analysed. This includes withdrawal of information they have provided, at any time before data analysis. It is desirable also to submit texts or transcripts of dialogue, or analyses of data, to participants for their approval.

Research is not ethical if coercion of any sort, or inducement beyond reasonable compensation for participating, is used to gain participation.

It is important that researchers recognise the complexities of relationships between individuals and groups and communities. In some cases, cultural mores may make it appropriate for leaders of a group or community to agree to the participation of others. If any individual wishes to decline to participate in the research (in spite of consent given on behalf of the group or community), his or her wishes must be respected, and the greatest care must be taken to prevent consequent retribution by the group or community or others. On the other hand, in some situations the rights of the individual to participate may outweigh a group or community’s decision not to do so. Particular care must be taken in such cases to protect the interests of the participants and be aware of any possible conflicts of interests between participants and those who consent to their involvement.

Information must be given to participants and their consent to participate recorded in written form. Sample consent forms are shown at the end of this handbook.

Where prospective participants are not capable of giving informed consent to their own participation, this must be obtained from other appropriate persons. Special care in preparation of documents is required for children and persons with special needs (refer to Resource 1: 8: Ethical Principles Relating to Children, and 9: Research in Schools). The researcher must not take actions that compromise the voluntary nature of consent.

**3. PRIVACY AND CONFIDENTIALITY**

Researchers must recognise the rights of participants, both individuals and groups and communities, to expect that information which they provide is confidential. The researcher has a duty to ensure such confidentiality.

Identification of participants or informants in any research should not occur without their informed consent. Where informed consent assumes that information will be confidential, the researcher must take all steps necessary to ensure that identities or information acquired in the process of research are kept secure from interception or appropriation by unauthorised persons, or for non-research purposes. This will often require coding of data and removal of names from questionnaires and other documents. Researchers are responsible also for the safekeeping and confidentiality of consent forms as well as the provision of access of participants to their personal data. Due regard must be shown for the relevant legislation e.g., Privacy Act, Freedom of Information Act. Where a third party is involved in the translation or transcription of data he or she should sign a confidentiality agreement.

It is the duty of the researcher to make clear to the participant the extent to which participation will be known to others. In a small population, such as blind and low vision children, it must be noted that while participants may not be named, there may be risk of identification.

**4. MINIMISATION OF RISK AND HARM**

The researcher must make every attempt to identify, and inform the participants of potential risks prior to obtaining informed consent and establish procedures to minimise any risks - physical, psychological, social or cultural – to participation by individuals or groups or communities in research. Risks include pain, stress, emotional distress, fatigue, embarrassment, cultural dissonance and exploitation. Participants must be given the opportunity to raise any concerns with the research process at any time before, during or after the research. Provision of appropriate monitoring and support processes both during and after the research activities must be made with an explanation of the resources available to assist any participant who suffers harm or distress. In addition, the researchers themselves must be mindful of their own safety and well-being.

**5. SOCIAL AND CULTURAL SENSITIVITY**

Research procedures must be appropriate to the participants involved in the study. Adequate steps must be taken to meet social and cultural sensitivity, and language preferences, of all participants.

**Acknowledgement of the Treaty of Waitangi**

Obligations and responsibilities to Māori arise from the Treaty of Waitangi. These relate to the partnership embodied in Articles I and II, and to equity as outlined in Article III. Inherent in these two concepts are:

* respect shown by the researcher for cultural differences and ways of knowing
* regard for participants' physical, mental, spiritual, and social wellbeing
* reciprocity in terms of sharing of knowledge, outcomes, control, and benefits of the research

Researchers who recruit Māori participants should ensure participants’ active involvement in the research at every stage and in a way that empowers and builds capacity. This may be by means of:

* developing a partnership between whānau, hapū, or iwi and the researcher
* involving Māori in the organisation, management, and conduct of the research
* ensuring the outcomes directly or indirectly benefit Māori

For research involving BLENNZ Maori participants, researchers are expected to consult with bodies such as Te Whānau o Homai and Ngāti Kāpō to ensure the integrity of research activity.

Research with, for, or about Maori should include:

* Whether the proposed research impacts on Māori persons as Māori
* How the intended research process is consistent with the provisions of the Treaty of Waitangi
* Identification of the group(s) with whom consultation has taken place, the consultation process, and evidence of the support of the group(s)
* How the research information will be disseminated to participants and the group(s) consulted at the end of the study

**Cultural Sensitivity**

The researcher has a duty to treat all participants with dignity and respect. This may involve providing information in the first language of the participants. When research involves cultural or social groups, the researcher has a responsibility to find and use appropriate channels for permission to work with such groups. The researcher must consider access, safekeeping of information, use of information and intellectual property, and feedback of the results to participants.

Research proposals should include:

* Whether there are any aspects of the research that might raise any specific cultural issues
* What ethnic or cultural group(s) the research involves
* Identification of the group(s) with whom consultation has taken place, the consultation process, and evidence of the support of the group(s)
* How the research information will be disseminated to participants and the group(s) consulted at the end of the study

**6. AVOIDANCE OF CONFLICT OF INTEREST**

It is the responsibility of the researcher to avoid conflicts of interest and to declare anything that could be perceived as a conflict of interest. The purpose and nature of the research should be clearly stated. If the research is funded, the support and its source must be identified. Any sponsorship of a research must not compromise its research merit or ethical acceptability.

In addition, the researcher must be sensitive to possible conflicts of interest between the participants, such as those that might arise between parents and their children, principals, or CEOs and their staff, or teachers and their students.

**7. RESPECT FOR PROPERTY RIGHTS**

Processes of research and publication must not violate or infringe legal or culturally determined property rights. These may cover such things as land and goods, works of art and craft, spiritual treasures, information, and works of the intellect.

**8. RESEARCH WITH PARTICIPANTS AGED LESS THAN 16 YEARS**

**(Children and Other Dependent People)**

Children and people with special needs may be less able to evaluate what participation in research may mean. The following principles apply in addition to the general principles:

* The informed consent of the parents or legal guardians must be obtained.
* The researcher should be sensitive to the possibility of any conflict between the interests and wishes of the dependent person(s) and their parents or guardians
* The agreement of the dependent person should also be obtained as far as possible. Explanations of what is involved should also be provided in suitable terms and accessible format, and agreement to participate sought. Dependent persons should not be involved in research against their will
* Research involving persons who are not in a position to give informed consent for their own participation should not be undertaken unless consent is obtained in a substituted form from a significant other who can represent the interests of the person as if they were their own
* Great care should be taken to avoid any possible harm to dependent persons from their participation in research

Usually it is sufficient for only one of the child's parents or guardians to consent to the child's participation in research. However, the consent of both the child’s parents and all legal guardians may be required in special circumstances. Such circumstances would include, but are not limited to, where the research is on a topic of particular sensitivity to the child and/or the parents or guardians; where there is any risk to the child’s physical, emotional or psychological well-being; or where the child will be asked to discuss any matter relating to their parents or guardians.

Consent and assent

The informed assent of the child is also required if he or she is of an age to understand the research. Because of the conflict of interest involved, parents and guardians cannot give valid consent on behalf of their child aged less than 16 if the parent or guardian is also the researcher. The researcher must be sensitive to potential conflicts of interest between the parent or guardian and the under-age participant.

BLENNZ may accept as sufficient the consent or refusal of a child where the applicant satisfies it with adequate information that the intended child participant will be able to understand their part in the research and the requirements of participation.

In the exercise of this discretion, BLENNZ will have regard to:

* The nature of the research topic and whether it would normally be regarded as being within the comprehension of a child of the age and experience of the intended participants
* Whether the research concerns a topic, or involves ascertaining the child's views on a matter, that a reasonable parent or guardian would wish to have knowledge of because it may affect the child’s relations with his or her parent or guardian, or cause the child some concern
* Whether the research methodology is adequate to ensure that the child participant has the information, time and support required to give informed consent.
* Whether the research is designed or supervised and carried out by people experienced in working with children
* Whether the consequences (educational, social, cultural, emotional, physical) of participation might be of concern to the parent or guardian

Where a child is not competent to give his or her own consent

The consent of the child's parent or guardian must be given before the child is approached for assent.

A child who is able to understand the nature of the research must be asked to give his or her assent to participation. A separate consent form directed to the child should be prepared at the level of language that reflects the child’s age and reading ability. Where appropriate, assent may be given orally. The researcher should check, by asking a few simple questions, that the nature of the research and of the participation is understood. The researcher must keep a record of the written/recorded assent given.

Whether or not the parent or guardian has consented on behalf of the child, the child still has a right to refuse to participate.

Information

Where children are invited to participate in research he or she, and the parents or guardians, must be adequately informed in a manner best suited to their individual needs about the research and what the child will be asked to do.

Each child must be given information about the research in a form that he or she can readily understand.

Each child must be advised of his or her right to decline to participate and his or her right to withdraw from the research at any time without giving a reason.

Researchers must give the child an opportunity to ask questions and to have those questions answered to the child's satisfaction.

The researcher is obliged to obtain the written consent for the child to be a participant.

* The parent or guardian must be given information about the research and be advised of the child's right to decline to participate or to withdraw from the research at any time without giving a reason
* The parent or guardian must be given an opportunity to ask questions and have them answered to his or her satisfaction

Inducements

No financial inducements should be offered to parents or guardians to persuade them to enter a child in their care into a research study. Compensation for expenses incurred by reason of participation may be offered.

### Points to consider

The Research Ethics Committee will consider the following points:

* Does the research have an identifiable prospect of direct benefit to the individual child participant? Can that benefit be achieved through alternative means?
* Does the research have an identifiable prospect of risk to the individual child participant? What safeguards are proposed to minimise these risks? When procedures involving greater than minimal risk to children are anticipated, are convincing scientific and ethical justifications given?
* Are mechanisms in place to ensure that children are involved as research participants in ways that do not undermine their dignity as young persons?
* Are there special problems that call for the presence of a monitor or advocate during consent procedures?
* Are special needs of adolescents such as counselling and confidentiality accounted for in the research design?
* Are there any special problems such as confidentiality and reporting that might arise in sensitive research such as research about child abuse or sexual practices of teenagers?
* If conditions present in children have implications for other family members’ health statuses, are appropriate mechanisms proposed for dealing with the larger family unit (for example, genetic risks)?
* Should parents be required to be present during the conduct of the research?
* Are proposed participants to be very young?

**9. RESEARCH IN SCHOOLS**

Educational researchers need to be careful in working with children in schools given the critical importance of instructional time and activities, as well as the vulnerability of children. In order to make the best use of the time at the school, the efforts of the children and for the research to have maximum relevance and validity, educational researchers need to work cooperatively with schools to ensure that:

* The integrity of ongoing school activities is maintained and that principals are alerted to possible disturbances that may result from the conduct of the research
* The aims of the investigation are communicated as clearly as possible to parents, students, Boards of Trustees and principals, and that they are updated about any significant changes in the research programme
* The findings and the practical significance of the research are communicated in clear, straightforward and appropriate language to relevant research populations, institutional representatives and other stakeholders
* The use of research techniques such as experimental interventions that might deprive students of important parts of the standard curriculum, and in this way have the potential for negative social consequences, are minimised

It is important to note, however, that standards intended to protect the rights of human participants should not be interpreted to prohibit teacher research, action research, and/or other forms of practitioner inquiry, so long as the data are those that could be derived from normal classroom processes, that confidentiality is maintained, the safety and welfare of teachers and students are protected, informed consent is obtained when appropriate, and the use of the collected information is primarily intended to benefit those receiving instruction in that setting.

The following organises and summarises issues and policy that are particularly relevant to conducting research in schools.

**Consent Process**

The Participant Information Sheet must request parents to discuss the research invitation with their child and state that, where parents’ consent to their child participating in research, the final decision typically will be that of the child.

Issues of anonymity and confidentiality need to be clearly specified and differentiated within the Participant Information Sheet. Anonymous indicates that the researcher and those who read the published results cannot identify specific participants, while confidential indicates that the researcher can identify the participants and undertakes not to make the identity of participants public.

Parents and students are to be assured in the Participant Information Sheet that participation or non-participation will not affect the student’s school learning, standing or assessment (if appropriate) and principals should be asked to guarantee this.

It is not acceptable to include children in the absence of written consent being returned by parents. The presumption of consent in the absence of a signed Consent Form is not acceptable. People should not be expected to identify themselves for the sole purpose of refusing consent.

Since much research in schools involves audio and/or video recording, there are special considerations that need to be addressed:

* researchers need to be clear about whether participation in research requires the agreement of the participants to being video or audio taped, or whether they have a choice
* each Participant Information Sheet and Consent Form must indicate clearly whether recording is a requirement of participation or is optional
* when third parties such as transcribers, are involved in the processing and coding of data, that is not anonymous, they need to sign a confidentiality agreement to maintain the confidentiality of participants. This should be clearly indicated on the relevant Participant Information Sheet

Issues related to review, storage, ownership, and disposal of recordings need to be clearly specified within the Participant Information Sheet.

**Research on Teacher Behaviour within Schools**

When the research is focused on observing and describing teacher practice during the course of normal classroom interactions and tasks, there is no need to secure child and parental consent. However, the children, and the parents, should be informed that researchers will be observing the teacher within the classroom and the focus will be on the teacher only.

**Recruitment and participation**

If children in a classroom or other group setting are asked to participate in research, procedures must be put in place to protect the anonymity of those children who do not wish to participate, or whose parents do not wish them to do so.

Prior arrangements should be made with the school to provide alternative activities for students for whom written consent is not received. These should be clearly specified in each appropriate Participant Information Sheet.

If the research topic is of a sensitive nature, then it must be demonstrated that a protocol exists that identifies and caters for students who might suffer emotional harm or psychological discomfort.

The law does not let the school give consent in loco parentis.

**10. ORGANISATION RESEARCH**

Where an organisation or part of its operations is the subject of research, and the research is to be carried out with members of the organisation as participants, it will normally be expected that the researcher will approach the appropriate level of management in the organisation for permission for the research to take place.

When the organisation gives permission for the research to take place, each potential participant has the right to decide whether to participate or not. This condition also applies to all methods of recording the participants. Individual participants have the right to have their participation or non-participation kept confidential from their employers, and the right to have the content of their participation confidential to themselves and the researcher. At all times, the fact that employees are in a dependent relationship with their employers should be borne in mind.

If the organisation or any other party with an interest in the activities of the organisation or participants sponsors the research this must be stated in the Participant Information Sheet. If a report is to go to the organisation this must be stated. Where the statements of participants are reported to the organisation, anonymity should be preserved, however it should be recognised by the researcher, and indicated to the participant, that anonymity cannot be guaranteed

Where several levels of status or authority within the organisation are to be involved, the researcher will need to consider the protocols of the organisation for approach and authority/permission when preparing to meet participants.

In situations involving participant observation, all potential participants must be informed of the observation. They should be given the opportunity to minimise their participation.

**11. RETENTION OF DATA**

Information should be handled in a way that protects the confidentiality of the participant and ensures the safe custody of the data. Care should be taken to protect the legitimate privacy of individuals, institutions, communities and ethnic groups. Where research involves the use of audio, video or electronic recording, special attention is required to protect confidentiality and security of data.

Clear indication should be given to the BLENNZ Research Ethics Committee and to participants regarding the storage and retention of data, which may take the form of documents, tapes, disks, videos, computer files, etc. Storage for the purpose of the original research should be accessible by the researcher only.

If data are to be destroyed subsequently, clear indication should be given to the BLENNZ Research Ethics Committee and to participants regarding the timing and manner of this. If data are not to be destroyed, this must be indicated to participants along with the purpose of retaining them.

The researcher must remain sensitive to the uses to which the research findings may be put, including but not restricted to, publication. Data may only be used for the purpose for which it was collected, which is the purpose understood by participants. Whenever possible, the findings should be conveyed in a comprehensible form to those who participated in the research.

**SAMPLE CONSENT FORM**

 (Address by category, e.g., Student, Parent, Manager)

**Please read this consent form carefully. By signing this form you agree to allow your child to participate in research approved by BLENNZ.**

**Or**

**Please read this consent form carefully. By signing this form you agree to participate in research approved by BLENNZ.**

**This form will be held in a secure location for a period of (timeframe)**

**Title of Research**

**Name(s) of Researcher(s)**

I have read the Participant Information Sheet, have understood the nature of the research and why I have been selected. I have had the opportunity to ask questions and have them answered to my satisfaction.

* I agree to take part in this research.
* I understand that I am free to withdraw participation at any time, and to withdraw any data traceable to me up to a specified date (give an actual date) / period.
* I agree / do not agree to be audiotaped.
* I wish / do not wish to have my tapes returned to me.
* I wish / do not wish to receive the summary of findings.
* I agree to not disclose anything discussed in the focus group.
* I understand that a third party who has signed a confidentiality agreement will transcribe the tapes.
* I understand that data will be kept for (timeframe), after which they will be destroyed.

Signature ……………………………………… Date ………………

Parent / Guardian Full Name ……………………………………………….......

Address ………………………………...…………………………………...……….

Full name of my child ………………………………………………………...

**Approved by the BLENNZ Research Ethics Committee on ….… for (timeframe)**

**SAMPLE CONSENT FORM (Student)**

# Title of Research

**Please read this consent form carefully. By signing this form you agree to participate in research approved by BLENNZ.**

**This form will be kept in a secure location for a period of (timeframe)**

We have read and understood the description of the above-named research. On this basis I consent to participate in the research, and to the publication of the results of the research with the understanding that anonymity will be preserved.

I agree to take part in this research.

I understand also that I may at any time withdraw from the research, including withdrawal of any information I have provided.

Name of participant ………………………………………………..

Signature …………………………………………………

Date ……………………………………

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**Parent/Guardian**

We have read and understood the description of the above-named research. On this basis we give permission for my/our son/daughter to participate in the research, and we consent to the publication of the results of the research with the understanding that anonymity will be preserved. We understand that my son/daughter may at any time withdraw from the research, including withdrawal of any information provided.

**Please read this consent form carefully. By signing this form you agree to allow your child to participate in research approved by BLENNZ.**

Signature ……………………………………… Date ………………

Parent / Guardian Full Name ……………………………………………….......

Address ………………………………...…………………………………...……….

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Full name of my child ………………………………………………………...

**Approved by the BLENNZ Research Ethics Committee on ….… for (timeframe**

 **SAMPLE CONSENT FORM (Teacher)**

**Please read this consent form carefully. By signing this form you agree to participate in research approved by BLENNZ.**

**This consent form will be kept in a secure location for a period of (timeframe).**

**Title of Research**

**Researchers**

I have been given and have read an explanation of this research. I have been given an opportunity to ask questions of the above researchers and have had them answered. I understand the nature of the research and give permission for my responses to be tape recorded. I understand that I can withdraw from the research up until the time the data is analysed and have destroyed any information that I provided.

I agree to take part in this research.

Signed:

Name:

Date:

**Approved by the BLENNZ Research Ethics Committee on ….… for (timeframe**

**SAMPLE CONSENT FORM (Principal)**

**Please read this consent form carefully. By signing this form you agree to allow teachers of your school to be approached and, if they consent, participate in research approved by BLENNZ.**

**This consent form will be kept in a secure location for a period of (timeframe).**

**Title of Research**

**Researchers**

I have been given an explanation of this research. I have been given an opportunity to ask questions of the above researchers and have had them answered. I understand the nature of the research and give permission for the teachers in my school to be approached to participate in the research.

Signed ……………………………………………………..

Name …………...………………………………………….

Date …………………………………

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