Prisoner Based Research Ethics Committee (PBREC) Guidance Document

The PBREC will consider ethical issues arising from research.

Assuming the granting of ethical approval, researchers should note that the Irish Prison Service will separately consider a number of issues such as:

- the value of the research to the Irish Prison Service (IPS)
- the current demands on the time and resources of locations
- the current demands on particular populations in terms of time/effort and volume of research being undertaken.

The PBREC meets four times per year.

Research proposals, on the approved application forms, should be sent to:

Secretary,
Prisoner Based Research Ethics Committee,
Irish Prison Service HQ,
IDA Business Park,
Longford,
Co. Longford.

The closing date for receipt of research proposals is the last working day of April, August, October or December in order to be considered at the next meeting of the Committee.

Role of Supervisor.

Project managers (Supervisors) assume overall ethical responsibility for the scientific and professional activities of those (students, trainees, assistants, supervisees) whose research work they supervise. This responsibility includes monitoring of researchers’ activity, and making them aware of the ethical principles involved.

The Prisoner Based Research Ethics Committee (PBREC) of the Irish Prison Service (IPS) recommend that, because of the complexity of ethical issues that can be encountered, researchers should consult their supervisors or colleagues about ethical issues. This should occur in the planning stage, throughout the project, and in particular when ethical problems present themselves.

Please ensure that the supervisor gives formal written confirmation that he/she assumes overall responsibility for the research application and this should accompany the application.

Ethical Decision Making

The following principles apply when a specific problem presents itself in the course of a project:

Supervisees should consult with a supervisor and/or appropriate groups and committees if faced with a difficult situation or apparent conflict. They should seek consensus on the most ethical course of action and the most responsible, knowledgeable and effective and respectful way to carry it out. Researchers should refer to their discipline's Code of Ethics and Professional Practice Guidelines for guidance on these matters.

Harm [1]

Harm means an injury to the rights, safety or welfare of a research participant that may include physical, psychological, social, financial or economic factors. It is responsibility of the researcher to avoid, prevent, or minimize harm to others.

Physical Harm: Actions or situations may cause bodily harm, in which participants may experience injury or death.

Psychological Harm: Deception or mishandling of information may result in mental or emotional trauma for the participants.

Social Harm: Detailed use of information may be hazardous to the social position of an individual or may be detrimental to groups of people in the participant's community.

Financial/Economic Harm: Loss of privacy may result in a loss of benefits, insurance, or employment for the participant.

Harm to Participants' Rights: Failure to complete the informed consent process or to respect individuals' autonomy could contravene participants' rights.

The principle of minimising harm implies that research will involve the least number of individuals and the fewest number of tests on these participants required to ensure that data is scientifically valid.

Prisoners are vulnerable to exploitation and abuse by research because their freedom for consent can easily be undermined, and because of learning disabilities, literacy difficulties and language barriers prevailing within prisoner populations

There should be an indication that research has to be completed in a prison environment. The PBREC requires an indication that this research cannot be completed in the community with community participants and a rationale for this statement.

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[1] Adapted from UCD Human Research Ethics Committee- Harm, Risk, Deception, Privacy & Confidentiality February 2008.

Risk

Risk pertains to the possibility of harm in terms of magnitude, probability, and permanency. In general, research should not involve more than minimal risk (the threat of magnitude and probability of anticipated harm is not greater than that experienced in everyday life or during routine physical or psychological tests or examinations).

In research involving more than minimal risk, the participation of individuals must be crucial to the achievement of important scientific or societal aims that cannot be accomplished in any other way. All reasonably foreseeable risks should be explained in the process of informed consent. Researchers must consider all risks to participants and present a plan for managing any adverse reactions appropriately.

Deception

In general, research involving deception, concealment or covert observation is not considered ethical because voluntary and fully informed consent cannot be obtained. Exceptional circumstances in some fields of research, such as the study of human behaviour, may require deception, concealment and covert observation. The Research Ethics Committee may consider research involving deception, concealment or covert observation, if specific requirements are met, for example, if:

- The scientific validity of the outcome of the research would be jeopardised if participants were provided with information regarding the objectives, procedures and methods of the research.
- The extent of such activities is specifically defined.
- The desired information cannot be acquired through alternative methods.
- The participants do not experience increased risk due to such activities.
- The disclosure to the participants is adequate and prompt and de-briefing of each participant occurs as soon as possible after participation is completed.
- The participants are allowed to withdraw data which they provided without their knowledge or consent during the research process.
- Such activities will not have a negative effect on the relationship between researchers/research and the community.

In the event that deception is unavoidable a debriefing for research participants is necessary following such studies. The researcher should clarify for the participants the real nature of and rationale for the research and seek to remove any misconceptions.

Privacy

Individuals have a right to keep a part of their lives free from intrusion, and information privacy is an area of particular importance. A fundamental requirement of ethical research is that information disclosed within the context of a research relationship be kept confidential.

The researcher has a duty not to share confidential information with others, without the participant's voluntary, informed consent. However, confidentiality is not absolute; sometimes research values and societal values conflict, in which case, the infringement of privacy and confidentiality may be justified in regard to public interests, due to legal requirements or where other principles may take precedence over privacy as required by law. For example, child protection legislation as outlined in Children First (1999) considers the limits of confidentiality where an adult is concerned that a child (either the participant or someone they refer to) is a risk of harm or abuse.

Confidentiality

It is the duty of the researcher to protect the level of confidentiality agreed in the informed consent process, as far as is legally possible. Research participants must be informed of the extent to which confidentiality can be maintained and the measures taken to ensure this level of confidentiality. This is particularly important when conducting research with children (with informed consent from parents) in situations where complete confidentiality cannot be guaranteed (e.g. when collecting identifiable data).

The following **exceptions to the duty of confidentiality** are considered important in the prison context:

Serious harm: Where there is a grave risk of serious harm to the individual or to others and the individual refuses consent to disclose information to avert such harm, the duty of confidentiality can be overridden by the duty in the public interest to prevent serious harm.

What constitutes 'serious harm' may be difficult to judge. Consultation with appropriate colleagues is advised and researchers may find the following guidance to assess the risk of serious harm helpful: 'a risk which is life-threatening and/or traumatic and from which recovery, whether physical or psychological, can be expected to be difficult or impossible'.

Suicidal intent*:* In such a case relevant authorities, for example, the governor and medical personnel should be informed.

Child abuse: The researcher may be confronted with allegations of child abuse by a research participant. The researcher must have formed an opinion that a child is or has been assaulted, ill treated, neglected or sexually abused, or that the child's health, development or welfare is or has been avoidably impaired or neglected.

Crimes against the person: If the disclosure is necessary to prevent or detect serious crimes against the person and the need to disclose is so serious as to warrant a breach of personal confidentiality.

The researcher should inform a responsible appropriate authority. In the prison setting this implies a designated responsible authority, for example, governor, chief, psychologist, psychiatrist, nurse manager and probation officer.

Information relevant to managing risk should be shared on a need-to-know basis. Unless doing so risks serious harm, the research participant should be informed about who has been told what and why.

Anonymity is the best protection of confidentiality in regard to personal information and records. However researchers should be aware that the public nature of focus group methodology means that neither anonymity nor confidentiality can be guaranteed as the actions of the group members are beyond the direct control of the researcher.

Personal Information

Personal information may be classified into one of three types of data: identified; potentially identifiable; and de-identified.

Identified data refers to information which has identifiers attached to it, meaning that specific individuals could be identified. Identifiers include factors such as the individual’s name, address, city, county, postal code, elements of dates directly related to an individual (such as dates of birth, death, admission, discharge, etc.), phone and fax numbers, electronic mail addresses, account numbers, certificate/license numbers, vehicle and/or device identifiers and serial numbers, web universal locators (URLs), internet protocol (IP) address numbers, biometric identifiers including finger and voice prints, full face photographic or comparable images, and unique identifying numbers (not codes assigned to data by researchers).

Potentially identifiable data is coded information that can be re-identified. Coded means that the identifiers have been removed and replaced by a symbol, such as a number, a series of letters, another name, etc. This is a reversible process of de-identification in which it is possible to use to the code to re-identify specific individuals related to the data. Within qualitative research it is important to remember that recordings of interviews or focus groups can be considered potentially identifiable, even if audio tapes or audio files have no identifiable markings on them. In addition, transcribed qualitative data which has not been thoroughly de-identified can also be considered potentially identifiable data.

De-identified data refers to information that is anonymous, thus not reidentifiable. The data has either never been identified or the identifiers have been permanently removed. De-identification is an irreversible process. It is important to note that data from which only the names are removed is not de-identified; an individual is potentially identifiable due to the presence of other factors (identifiers) such as an address, date of birth, postal code, etc. In addition to ethical considerations, legal requirements, such as those required under the Data Protection Acts 1988 to 2003, apply to personal information.

Informed consent

Informed consent is an ethical requirement for most research and must be considered and implemented throughout the research lifecycle, from planning to publication. Gaining consent must include making provision for sharing data and take into account any immediate or future uses of data.

In the past, researchers have focused primarily on gaining informed consent to enable data collection but researchers should also inform participants about how research data will be stored, preserved and used in the long-term, and how confidentiality, where promised, will be maintained. Contrary to what some researchers or research participants believe, even sensitive materials can be shared ethically.

To ensure that consent is informed, consent must be freely given with sufficient information provided on all aspects of participation and data use. There must be active communication between the parties. Consent must never be inferred from a non-response to a communication such as a letter.

FAILURE TO PROPERLY AND FULLY ADDRESS ISSUES OF INFORMED CONSENT MAY UNNECESSARILY RESTRICT THE OPPORTUNITIES FOR INITIAL USAGE OF DATA, PUBLISHING RESULTS AND SHARING DATA.

Consent procedures must be tailored for the specific research context, methods and sample, the nature of the data (personal, sensitive, level of detail), the format of the data (surveys, written, recordings,) and the planned data uses and handling. This will influence the type of consent and consent process used. More detailed requirements and examples of these are offered in the sections on gaining written or oral consent, and consent forms.

We are aware that informed consent can be a contentious topic and we acknowledge that there are active debates about whether consent is always necessary or even if it is epistemologically possible.

The provisions of both European and Irish law, such as the Data Protection Act, and guidelines of many professional research organisations recommend the following principles be followed to ensure that consent is informed:

- consent must be freely given with sufficient detail to indicate what participating in the study will involve
- there must be active communication between the parties - what is expected from participants and why their participation is required
- documentation outlining consent has to differentiate between consent to participate and consent to allow data to be published and shared
- consent cannot be inferred from a non-response to a communication such as a letter or invitation to participate

Restricting access to data should never be seen as the only way to protect confidentiality. Obtaining appropriate informed consent and anonymising data enable most data to be shared.

Literacy[2]

Participant information and consent form

Offenders and prisoners may have low literacy levels, so documents must be written in plain, concise language that participants will understand.

Informed consent form should explain to the prisoner what the research is about, why the prisoner is involved and what informed consent is about. A sample form is attached at Appendix 1.

Data collection

Individuals involved must consent to access to their personal data (i.e. offender files). If consent is not gained, data will only be provided in de-identified form.

All data collection instruments must be attached to the application. The literacy levels of participants must also be considered in relation to data collection instruments. Long interviews or questionnaires should be broken up to avoid participant fatigue.

Using Plain English

- Use short sentences
- Use active verbs
- Use ‘you’ and ‘we’
- Use words that are appropriate for the reader
- Don’t be afraid to use instructions
- Avoid jargon
- Use lists and bullet points, where possible
- Use Ariel font size 12 and 1.5 line spacing

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[2] Researchers are encouraged to read The Prison Adult Literacy Survey (2003) available on the IPS website. Researchers are also encouraged to use the Plain English website and NALA websites to assist in developing appropriate forms.

Adolescents

Written informed consent is required from parents if research is conducted with individuals younger than 18.

Appeals Procedure

Applicants whose research proposals are not approved by the PBREC on ethical grounds may appeal the decision to an independent appeals board within two weeks of receipt of notification.

Appeals should be addressed to the

Secretary,
Prisoner Based Research Ethics Committee Appeals Board,
Irish Prison Service HQ,
IDA Business Park,
Longford,
Co. Longford.

The application will be reviewed afresh and the appellant notified in due course.

Applicants should be aware that final approval for research resides with the Director General, and access to prisoners is a matter for individual governors for operational and security reasons and in light of available resources in the institutions.

Appendix 1

Consent Form

(Name) has explained to me what this research is about and why I was asked to be interviewed.

- I know what this research is about.
- I have had the chance to ask questions about the research.
- I know I don't have to be interviewed if I don't want to.
- I know that if I sign this form I agree to be asked questions and have my answers recorded/written down.
- If I change my mind during the interview and don't want to be involved, I know I can stop and anything that was recorded or written down will be destroyed.
- I know my real name will not be used at all during this research.
- I know that my answers are confidential unless there is reason to believe that either I or someone else may be in danger.[3]
- I know I can contact (Name) at a later date if I have any queries/concerns about the research or what I said, or if I decide I don't want my answers to be used.

Signed ____________________________________Date __________

Name in block letters____

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[3] In line with Exception to Confidentiality set down by the Research Ethics Committee of the IPS.