University of Malta Ethical Guidelines for Conducting Research with Incarcerated Persons

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The present document complements the "Research Code of Practice" and the "Research Ethics Review Procedures" by providing further guidance regarding ethical issues in conducting research with incarcerated people.
These can be downloaded from: https://www.um.edu.mt/urec

Background:

Research with incarcerated persons is critically important in providing the evidence base for informing progressive prison policy and for increasing the physical, mental and social wellbeing of prisoners. Research with prisoners may also help identify factors that will facilitate the integration of prisoners at re-entry into society. These benefits must however be pitted against the potential risks to prisoners, especially given that the prison environment poses serious risks of coercion.

The Institute of Medicine (US) Committee on Ethical Considerations for Revisions to DHHS (Department of Health and Human Services) Regulations for Protection of Prisoners Involved in Research (2006) has emphasised how "the history of prisoner research is plagued with illustrations of unconscionable abuses" (p. x). It is therefore essential to strike the right balance between the need to engage in rigorous research and the conduct of ethically appropriate treatment of prisoners. Researchers are encouraged to engage in critical research with incarcerated populations in order to identify strategies to ease prisoners' successful re-entry into the community, to reduce recidivism, and to maximise wellbeing in custodial institutions through humane and effective strategies.

This document refers to the process of conducting research within the Correctional Services Agency in Malta (CSA).

The Correctional Services Agency includes:

- The civil prisons in Paola;
- The Valletta Lock-Up below the Malta Law Courts;
- The Forensic Unit (Mount Carmel Hospital) at Attard; and
- The Centre of Residential Restorative Services (CoRRS) at Imtaħleb.

The Correctional Services Agency is regulated as per Chapter 260 of the Prisons Act and its subsidiary legislation.

1.0 Incarcerated populations as vulnerable populations

The history of research involving incarcerated populations leaves much to be desired. Following World War II, experiments held in concentration camps were condemned and resulted in the development of the Nuremburg Code. Despite this, "scientific exploitation by the rapidly evolving biomedical research industry" (Pont, 2009, p.184) continued, encouraged by a philosophy that societal needs override those of the individual. Prisoners were seen to constitute ideal research subjects because they were captive and easy to motivate (Hornblum, 1997).

When developing a research protocol, researchers must be cognizant that prisoners are deemed to be especially vulnerable and subject to potential exploitation from research for the following reasons, as outlined by Pont (2009):

a. They have no liberty;
b. They have impaired autonomy and privacy;

c. Their potential to freely consent is severely undermined by their living conditions;
d. They may have a host of psychosocial difficulties such as "reading and learning disabilities, illiteracy, language barriers, mental impairments and psychiatric disorders, substance use, drug dependency and other chronic health injuries" (p. 190); and
e. They are likely to be ethnic or cultural minorities.

These vulnerabilities place serious doubt on whether prisoners are fully able to voluntarily give consent. There is still considerable discussion on this issue (Elger, 2008; Graebsch, 2002; Institute of Medicine, 2006), which remains unresolved.

2.0 Ethical principles applied to the context of incarceration

The following principles are to be applied to all research carried out with incarcerated persons. Proposals submitted for research ethics review must address how these principles will be adhered to.

2.1 Respect for persons - autonomy

Incarcerated individuals may have limited autonomy. The social psychological dynamics encountered in the prison setting, most notably, the degradation of the inmate's identity through the institutional structure and the power differential between custodial staff and inmates, make it increasingly difficult to determine whether an inmate is able to decide for themselves whether to participate in the study. Such dynamics require that researchers protect inmates in view of their limited autonomy. This has implications for informed consent that is competent and voluntary and is addressed below (4.3).

2.2 Beneficence

The principle of beneficence implies maximising the benefits for the incarcerated research subjects and minimising any possible harms. This requires the researcher to engage in a risk/benefit assessment and an analysis and minimisation of acceptable and unavoidable risks of harm as outlined below (4.1).

2.3 Justice

Researchers should be able to show how their research will distribute burdens and benefits equitably and to provide evidence of how the research has the potential to improve the lives of prisoners when they are in the institution and when they return to the community. The burdens they are likely to experience by participating in the research should be balanced out by the benefits they or future prisoners or society at large may stand to gain. The research protocol should show how within the prison, individuals and classes of individuals will be selected equitably.

3.0 Determining whether a research proposal involving incarcerated persons poses more benefits than costs

In view of the vulnerabilities outlined in the previous section, research undertaken with incarcerated persons must be shown to be necessary and the burdens and benefits must be distributed equitably. Given their vulnerable status, it should be shown that researchers are able to make a case for linking burdens endured by the prisoners to benefits that they or other prisoners may enjoy as well as wider benefits to society at large. When submitting proposals involving incarcerated persons, researchers must provide a rationale for why conducting research with prisoners is absolutely necessary and how they have determined that there is no other suitable research alternative.

4.0 Applications of principles

4.1 Risk of harm to participants

Within the prison context a number of possible harms may emanate from a research endeavour and need to be considered in any proposed research protocol. Below is a guide that may be used as a checklist:

- *Physical harm*: involves procedures or situations that may cause bodily harm and that may lead to injury or death. This is of particular concern to biomedical researchers.
- *Psychological harm*: a research intervention may cause mental or emotional trauma.
- *Social harm*: disclosing identifiable criteria about individuals or communities may cause social harm and facilitate stigma. This is particularly salient in the Maltese context which is characterised by small interdependent communities where many people play a number of roles and know each other well.
- *Financial harm:* if subjects are identifiable, then they may risk economic harm when they leave the custodial institution.
- *Legal harm:* incarcerated individuals may risk disclosure of information about acts for which they may in the future be deemed culpable, which may lead to their future criminalisation.

The research proposal submitted for research ethics review must:

a. Document the potential or risk of inflicting all the five types of harms listed above;
b. Document what safeguards shall be put into place to ensure that the risk of harm will be minimised; and
c. Document how the research participants will be alerted to these risks if the risk of harm cannot be minimised.

University of Malta committees tasked with reviewing research proposals (e.g., Dissertation Committees, Research Ethics Committees) shall adopt a risk-benefit framework when reviewing research proposals dealing with incarcerated persons.

4.2 Risk of harm to researcher

Keeping researchers safe is also an important ethical consideration and researchers need to ensure that they will not be placing themselves in any physical, psychological or economic harm in their research. It is the responsibility of those applying for research ethics review to provide an analysis of such risks and the strategies that will be used to mitigate them. Students should be guided by their supervisors.

4.3 Informed Consent

Prison settings make it more difficult to secure integrity to the process of informed consent. Participants may only participate in a study if they have consented to take part before the study and have understood all the details of the study and what is expected of them.

Potential participants should be given sufficient information about the research as prescribed in the University of Malta Research Code of Practice (Section 3.1.3.). This would include all aspects of the study which may have an impact on their decision to consent to participate or otherwise. This is done by drafting the information sheet and consent form in clear and plain language, using non-technical terms, short words and sentences, to be understandable by all persons, including those of limited literacy competence.

The information/recruitment letter needs to provide all details about participation and should advise potential participants that the Director of Prisons or her/his representative has the right to know who will be participating in the study and that he will be storing their consent forms (see 4.6 below) to secure anonymization of participants at data collection. The information/recruitment letter needs to include what measures shall be in place to ensure that inmates are not adversely affected by participating or by not participating.

Given the reduced or limited autonomy of incarcerated persons, gaining voluntary consent among this population may present a number of difficulties. Researchers must be able to show that these challenges have been mitigated to the best of their ability. The research will not be allowed to proceed should there be doubt as to whether informed consent is able to be sought.

In the case of incarcerated minors, as a general principle, parental authority remains vested in the parents of the incarcerated minor (whether convicted or otherwise) as per the relative provisions of the Civil Code, unless:

a. such authority has been forfeited by the parents;
b. parental authority is deprived by a court of law;
c. following the issuance of any of the protection orders on the minor in terms of article 19 of the Minor Protection (Alternative Care) Act, Chapter 602 of the Laws of Malta; or
d. the minor is still committed to the care of the Minister responsible for Social Welfare under a care order issued in terms of article 3 of the Children and Young Persons (Care Orders) Act, 1980, Chapter 285 of the Laws of Malta, before the Minor Protection (Alternative Care) Act came into force in 2020.

Parental or guardian consent must therefore initially be sought. If this is forthcoming participant assent must also be sought.

4.4 Subtle coercion

The researcher must ensure that incarcerated persons are not:

a. Pressured to participate by those from whom they require services;
b. Afraid of suffering negative consequences if they choose not to participate; and
c. Unduly pressured by the researchers with incentives which, given their deprived situation in incarceration, may appear very attractive.

4.5 Deception

Deception in research is only allowed under exceptional circumstances. Given the lack of autonomy experienced by incarcerated individuals, deception should be avoided whenever possible. If absolutely impossible to avoid, the researchers must ensure that:

a. The research participants will not endure increased risk due to such research;
b. Debriefing is immediate; and
c. Participants can withdraw data which they have not consented to provide.

4.6 Privacy and Confidentiality

Researchers should correctly distinguish between the following categories of data (refer to FAQs for further details):

a. Personal data, which is information relating to an identified or identifiable person;
b. Pseudonymised data, also known as coded or codified data, which is when pseudonyms or codes replace the most obvious identifiers such as names and other personal data, but when collected, processed and stored remains linked with an identifiable person; and
c. Anonymised data, which is when data cannot be linked back to the individual.

Researchers must outline at proposal stage what categories of data they will be collecting and explain how they will make this clear to their research participants.

Researchers should be aware that Art. 10 of the GDPR states that:

> "Processing of personal data relating to criminal convictions and offences or related security measures based on Article 6(1) shall be carried out only under the control of official authority or when the processing is authorised by Union or Member State law providing for appropriate safeguards for the rights and freedoms of data subjects."

This implies that:

a. Personal data of inmates (including consent forms) should only be processed / stored by the Director of Prisons (DoP). Researchers are not permitted to keep consent forms;
b. The researcher needs to collect data anonymously or pseudonymously;
c. The researcher may process the anonymised / pseudonymised data and the participants' codes (if data has been pseudonymised) but not the participants' identifying information (including names and consent forms);
d. The DoP has access to the consent forms, personal data and participants' codes (in the case of pseudonymised data); and
e. The DoP has the right to inspect the research data if they so wish, and may require an embargo on the publication of the dissertation. If participants are identifiable from the data and/or if the research data could subject them to any form of risk or discrimination, the researcher should try to negotiate with the DoP for the research data to remain confidential. However, it is at the DoP's discretion whether this is agreed upon.

The issue of confidentiality is crucial to consider when conducting research with incarcerated persons who have been engaging in illegal and/or harmful activities for which they may not have yet been apprehended. This can result in:

a. Further criminalisation; and
b. Further marginalisation from the community, which could lead to discrimination and the experience of stigma.

Strategies for ensuring confidentiality must be explained in the research proposal, as well as in the information sheet and consent form. Identifiable data on incarcerated persons must be kept in secure cabinets and/or password-protected encrypted data folders. Such data may be requested by the prison director and/or subpoenaed by police or a court of law.

In the prison setting, the only way to guarantee that participants are not harmed in any way through their participation in the research is to store the data in an anonymised format. Anonymisation is designed to sever the connection between the information and the individual, so that the information no longer reveals anything about that person.

Anonymisation can be done:

a. At data collection, by assigning participants a pseudonym or code instead of recording any personal data;
b. At data entry, by erasing the participants' personal data and replacing them with pseudonyms or codes; and
c. At analysis stage.

When a researcher anonymises participants at data collection, this has the advantage of not ever knowing the real identity of the participant and consequently no information about them can be disclosed. For this reason, anonymisation at the point of data collection is the preferred strategy for research with incarcerated persons. In this way, information about

research participants cannot be subpoenaed in court. The consent forms are retained by the prison director who will not, however, be able to match the anonymised data with the consent form of any one particular inmate.

A disadvantage of anonymising participants at data collection is that it precludes subject follow-up. Longitudinal studies requiring the storage of personally identifiable information for follow-up must show that they are stringent in ensuring confidentiality (World Health Organization, 2004).

Once data is anonymised (at whichever point), participants will no longer be able to exercise the GDPR right to access, amend, and erase their data. Before anonymisation, they are entitled to this right, unless restricted by exceptional circumstances of Article 23 GDPR, e.g., national security, public security, etc.

Confidentiality may also be secured at the stage of request for institutional approval whereby the researcher may request specifically in the recruitment form that the institution agrees to not have access to the data collected. The prison director will therefore agree – at institutional approval stage - not to access the data provided by the incarcerated person.

It is not permissible to audio record research interviews within CSA. The researcher would therefore need to record the data collected during the interview in another manner (e.g., handwritten notes).

4.6.1 Limits to confidentiality

The researcher who is conducting research with incarcerated persons must be able to meet the confidentiality agreement set out in the informed consent process (as far as is legally possible).

Research participants need to be clearly advised of the extent to which confidentiality can be kept and the strategies undertaken to ensure confidentiality.

The research on ethical standards in conducting research with incarcerated persons identifies a number of exceptions to the duty of confidentiality. These must be spelled out to the research participants in the consent form and again verbally before the start of data collection.

a. *Serious harm:* Where the researcher identifies risk of serious harm to the individual or to others, the duty to the public interest overrides the duty to confidentiality.
b. *Suicidal intent:* When a research participant discloses such intent, the applicable authorities, such as the prison director and medical professionals, need to be informed.
c. *Child abuse:* The researcher may come into knowledge of current child abuse in the course of research with a participant in the prison context. This would require disclosure.
d. *Crimes against the person:* Breaking confidentiality is required if the research identifies a current or future crime against a person that can be prevented.

e. Abuse of Vulnerable People. The researcher may come into knowledge of current abuse of vulnerable individuals (physically, or mentally challenged persons, and/or elderly) in the course of research with a participant in the prison context. This would require disclosure.

In the instances outlined above, the researcher must inform the responsible authority. In the prison setting this would be the gatekeeper appointed by the Prison Director, or the Prison Director himself should a gatekeeper not have been appointed.

4.7 Right to withdraw

Incarcerated persons should be told that they can withdraw from a study at any time until it is technically possible for them to do so (e.g., before the data are anonymised or the research findings published), and they should be provided with clear instructions on how to withdraw. The researcher needs to ensure that withdrawal will not adversely impact on services participants are receiving.

5.0 Level of qualification

In order to ensure that the cost-benefit ratio of research is respected for persons who are incarcerated, only university academics and students reading for a degree at level 7 or beyond will be allowed to access incarcerated persons for research purposes.

6.0 References

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