Focus Ireland Ethical Guidelines for Conducting Research Involving People at Risk of or Experiencing Homelessness

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Section 1: Introduction

The purpose of this document is to provide ethical guidelines for conducting research which involves Focus Ireland tenants and customers and is carried out either by the organisation's own staff or by an external organisation commissioned by the organisation. It also provides guidance in assessing whether to support or facilitate requests by external researchers.

All Focus Ireland staff conducting research with people experiencing or at risk to homelessness, and external consultants commissioned to undertake research on behalf of the organisation, must fully adhere to these guidelines.

The purpose of Focus Ireland's research programme is to provide further information and understanding on issues surrounding and related to homelessness, in order to improve both Focus Ireland services and public policies. However, when working with people and dealing with sensitive issues in social research, good ethical practice is essential. The complexity of identifying and addressing ethical issues can obviously be a very difficult task, so effective guidelines play an essential role in carrying out research. Research involving human subjects has the potential for being exploitative and damaging, even when the intent is to benefit those who are being investigated. The following guidelines are intended to minimise harm and ensure that the rights, privacy, confidentiality and well-being of participants are fully respected.

Focus Ireland acknowledges that these guidelines do not provide a complete set of rules for resolving ethical choices or dilemmas, but recommend that they should be used as a guide along with the principles and values exhibited in a given context/situation in order to resolve ethical dilemmas and maintain good practice in research. In addition to these guidelines, Focus Ireland's policy in ethical research practice includes an 'Ethics Panel' which is independent of its Research Advisory Group and comprises senior academics with experience in research questions involving vulnerable individuals.

Appendix 1 and 2 provide templates for the 'Consent Form for Research Participants' and 'Receipt Form for Research Participants'.

These guidelines apply to qualitative, quantitative, evaluative, and documentary research.

Section 2: Guiding Principles

Focus Ireland's overarching principles stem from the organisation's belief that 'everyone has a right to a place they can call home'. Focus Ireland believes that good practice in research can be achieved by treating all people equally and with respect, and ensuring a person's safety and well-being at all times. Our work is aimed at achieving honest and accurate results, and in doing so, it is essential not to risk a person's well-being, but rather to ensure that they are treated fairly and competently giving the highest regard to the client rather than the research itself.

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The following principles form a basis on which good ethical practices should be developed:

1. Informed consent
2. Privacy
3. Confidentiality
4. Fairness and equity
5. Avoidance, prevention or minimisation of harm to others
6. Professional competence
7. Integrity
8. Respect for human rights, diversity and equality
9. Social responsibility

Section 3: Relations with Research Participants

3.1 Researchers have a responsibility to ensure that the physical, social and psychological well-being of research participants is not adversely affected by their research activities. They should strive to protect the rights of those they study, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests.

3.2 Research undertaken by, and on behalf of Focus Ireland, is frequently characterised by disparities of power and status between researchers and participants. It is essential that such disparities are recognised and respected. Such disparities will be addressed in relation to research design, methodology, analysis, report-writing and dissemination. Researchers will strive to develop relationships with research participants on a basis of trust, integrity and partnership, whilst maintaining a non-judgemental and professional attitude.

Section 4: Customer Participation

4.1 Participation in research should be based on the freely given informed consent of participants (see Appendix 1). This implies a responsibility on the researcher to explain in appropriate detail (both in writing and verbally), in a language they can understand, and in terms meaningful to participants:

- What the research is about;
- The nature of their participation;
- Who is undertaking and financing the research;
- Implications in terms of risks and benefits of participating in the research;
- Why it is being undertaken/purpose of the research; and
- Information about what will happen to their information, how it will be used and disseminated, stored and when it will be disposed of.

4.2 Invitations to customers or tenants to participate in research should indicate that their participation is entirely voluntary, and participants have the right to withdraw from the study and withhold information at any time without affecting their use of services or need for assistance.

4.3 They should be informed that the researcher will be bound by any confidentially agreement except in cases where information disclosed by the customer/tenant indicates a serious risk to self or to others, or is covered by Children First. Where such issues requiring disclosure arise, they shall be reported to the Focus Ireland Research Officer, who will inform the relevant Services Project Leader in line with Focus Ireland procedures.

4.4 Participants will be informed that they may request that a staff member (normally their key worker) be present at the time of data collection (be that an interview/focus group/completion of questionnaire or other) to provide advice and support. They will also be informed that they can request additional support from their key worker subsequent to the interview of required.

4.5 Research participants should be made aware of their right to refuse participation whenever and for whatever reason they wish, and that there will be no adverse consequences from such a refusal. They should understand how far they will be afforded anonymity and confidentiality; researchers should be explicit in their limits of confidentiality (i.e. if there is a perceived risk to the safety of the research participant or somebody close to them). .

4.6 Research participants should understand that they can reject the use of data-gathering devices such as tape recorders and video cameras. Research data, records or films should not be communicated or used other than for the agreed purposes and with participants' written consent. When making notes, filming or recording for research purposes, researchers should make clear to research participants the purpose of the notes, filming or recording.

4.7 Special care should be taken where research participants are particularly vulnerable by virtue of factors such as age (see Section 6 below) or disability. Researchers will need to take into account the legal and ethical complexities involved in those circumstances where there are particular difficulties in eliciting fully informed consent.

4.8 Researchers should maintain respect for participants in all manners, and pay particular attention to minority ethnic groups, traditions and practices, and ensure knowledge of these practices before conducting research (RESPECT, 2004)[1].

4.9 In cases where written consent cannot be obtained, such as with recorded telephone interviews or where the subjects are illiterate, informed oral consent should be obtained by documenting on the consent form. Where participants have impairments that limit understanding and/or communication to the extent that they are unable to give informed written consent, permission

[1] *RESPECT for research ethics: guidelines*, RESPECT Project, 2004

where possible should be obtained from a family member or other responsible adult, such as a caregiver or guardian, before proceeding with the research.

4.10 Researchers should decide on a project by project basis whether the provision of incentives to recognise and value participants' time and input into research (e.g. giving a token of appreciation) is appropriate (see Appendix 2).

4.11 The signed consent form and the information sheet together are proof of the process of informed consent.

4.12 Research participants should be made aware of the provisions of Focus Ireland's Customer Complaints Policy. Direct the reader to the relevant document?

Section 5: Anonymity, Data Protection and Confidentiality

5.1 The anonymity and privacy of those who participate in Focus Ireland research should be respected whether or not an explicit pledge of confidentiality has been given. In some cases, it may be necessary to decide whether it is proper/appropriate to record certain kinds of sensitive information. Researchers have a duty to ensure that personal information concerning research participants is kept confidential. Researchers must adhere to Focus Ireland's *Data Protection and Customer Confidentiality Policy*.

5.2 Guarantees of confidentiality and anonymity must be honoured, unless there are exceptional, clear and overriding reasons to do otherwise. Colleagues and others given access to the data must also be made aware of their obligations in this respect. By the same token, researchers should respect the efforts of other researchers to maintain anonymity.

5.3 Appropriate measures should be taken to store research data in a secure manner. This includes the removal of identifiers, the use of pseudonyms and other technical means for breaking the link between data and identifiable individuals. All research data should be stored within Focus Ireland's Advocacy Team, and once the research is completed, all sensitive customer information (e.g. interviews, recordings, surveys etc.) should be destroyed. Research data and records should be stored in filing cabinets that can be locked. Information such as names and addresses, and signed consent forms may be held for a period of time for follow-up studies, with the participants permission.

5.4 Extreme care is required when delivering or transferring any confidential material over computer networks (e.g. encryption of data, files etc.).

5.5 Data should be published or released in a form that does not permit the actual or potential identification of research participants.

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5.6 The interviewer should inform the interviewees of their rights under any data protection laws, such as the protection of personal information and the use of personal information by others only through consent (or some other legitimate basis outlined by law), as well as access to this information and right to have it rectified (as outlined in Article 8 of the Charter of Fundamental Rights of the European Union 2000, and the Data Protection Acts 1988 and 2003).

Section 6: Research involving Children and Young People

6.1 Research involving children and young people involves particular care. The consent of all those under the age of 18 years should be sought in addition to that of the parent/guardian. Exceptions to this are detailed in Section 6.2 below.

6.2 The consent of parents or guardians should be routinely sought except:

- Where it is clear that participation in the research involves minimal risk (i.e. risks no greater than those in everyday life) and will not infringe the rights or impact on the welfare of participants
- Where parental/carer permission is impossible or would not protect the child or young person (i.e. where relationships have broken down)
- Where the young people concerned are resistant to parental/carer consent being sought on the grounds of their right to privacy and confidentiality, and where the emotional and social maturity and particular vulnerabilities of the young people have been evaluated and the risks associated with participation in the study are considered to be low.

6.3 Researchers should use their skills to provide information that can be understood by the child, and their judgement to decide on the child's capacity to understand what is being proposed.

6.4 Researchers should have regard for issues of child protection and make provision for the potential disclosure of abuse. Focus Ireland's *Child Welfare and Protection Policy* should be adhered to at all times.

6.5 Young people involved in risky or illegal activities, who are/were incarcerated or have run away from home or care, will have heightened concerns over privacy and may be mistrustful of the confidentiality of their participation. In this context, extra care should be taken to protect their privacy and guarantee confidentiality, insofar as possible?

6.6 Ethical dilemmas should be anticipated and advice sought from those working with the particular population of young people, while taking into consideration what is in the best interests of the child/children.

6.7 Researchers should be cognisant of services relevant to the possible support needs of research participants. A fact sheet detailing services should be prepared.

6.8 Where a child is being interviewed, a second person must always be present during the interview, and it should take place in a location where the child will feel comfortable to talk.

6.9 Where participation in research is liable to be stressful, young people should be asked if they would like to have a friend or advocate with them.

6.10 The limits to confidentiality should be explicitly communicated as follows: 'Whatever you have to say in this interview/focus group/questionnaire is confidential unless you disclose that you, or someone else, are in immediate danger of serious harm. In such a case I would need to report that to someone who might be able to help.'

Section 7: Responsibilities towards Sponsors and Funders

7.1 Research that is unlikely to contribute to Focus Ireland's purpose, or is in contradiction with the organisation's values, will not be undertaken or commissioned.

7.2 The relationship between funders and social researchers should be such as to enable social enquiry to be undertaken as objectively as possible. Research will be undertaken with a view to providing information or explanation, rather than being constrained to reach particular conclusions or prescribe particular courses of action.

Section 8: Other Responsibilities towards Research Participants

8.1 Researchers should carefully consider the possibility that the research experience may be a disturbing one and should attempt, where necessary, to find ways to minimise or alleviate any distress caused to those participating in research. Participants should be made aware that there will be a staff person available at the time of the interview or focus group to provide support and advice, if needed.

8.2 The introduction to the research should state the risks involved in participating in the study, including the consequences involved in revealing personal information on issues relating to personal or public safety (e.g. obligations to report incidents of abuse). These incidents should be considered on an individual basis, and will in the first instance be discussed with a Focus Ireland Services Manager.

8.3 Interviews or focus groups should take place where participants feel most comfortable and familiar, and where both the participants and the researcher feel safe. Interpreter services should be provided when required. Interpreters are also liable to uphold the confidentiality of the research participant.

8.4 Participants should be instructed not to share information from any focus group discussions with outside individuals.

8.5 Interviewers should clarify the extent to which research participants are facilitated to see transcripts of interviews and field notes and to alter content, withdraw statements, and to provide additional information.

8.6 Clarification should also be given to research participants regarding the degree to which they will be consulted prior to publication. Where possible, participants should be offered feedback on findings, for example in the form of a summary report.

8.7 Active participation in the research project should be encouraged, as long as it does not conflict with other ethical considerations (RESPECT, 2004).

8.8 Researchers should be cognisant of any literacy difficulties of participants, and should conduct interviews, questionnaires or focus groups in an appropriate research approach that facilitates literacy issues.

Section 9: Practical arrangements

Research projects which are initiated through Focus Ireland's Research Officer will normally form part of a work programme which is approved by the Research Advisory Group (RAG). When including a project in the work programme the Research Officer will indicate whether a particular project raises, in his/her opinion, potential ethical issues using a 'green', 'yellow', 'red' tagging. The RAG will then decide whether the project should be referred to the Focus Ireland 'Ethics Panel' for consideration. Where a research project is being taken on outside the normal RAG framework, the Research Officer will indicate their judgement on the potential ethical issues (as set out above) and the Chair of the RAG will decide whether the proposal should be referred to the Ethics Panel.

Where research projects are initiated by outside researchers and are seeking Focus Ireland co-operation support in engaging customer or tenant, the request to conduct research must be submitted in writing to Focus Ireland's Research Officer for consideration, along with an explanation of any ethical approval from the research institution proposing the work. The Research Officer will review the research request and all relevant documentation to ensure that it adheres to these ethical guidelines[2]. Taking into account the ethical procedures already in place, the Research Officer will decide whether it is appropriate to submit the proposal to Focus Ireland's Ethics Panel for consideration and final decision. The Research Officer or Ethics Panel may approve a research project subject to specific stipulations as required by these guidelines.

Where it is decided to refer any research proposal to the ethics panel, the Research Officer will select two members from the panel at random from those members who are available to review the proposal within a reasonable period.

[2] The Research Officer will also take into account (i) whether the research proposal fits into Focus Irelands overall research strategy (ii) any additional burden that support for the research proposal will place on Focus Ireland staff (iii) any demands which support for the research proposal will place on the particular customers/tenants who will be part of the research.

Appendix 1 – Template Consent Form for Research Participants

Please read the following statements:

- I understand the information outlined in the information leaflet given to me.
- I agree to take part in the research project named _____
- I have been given the opportunity to ask questions about the research and the information that I will provide.
- I understand that I may decline to respond to any question within the research process but that where I give an answer I understand the importance of providing a true account of the issues covered.
- I understand that the information I give will be treated as confidential and it will not be attributed to me in any way.
- I understand that any decision not to participate in the research will not impact on my access to Focus Ireland services, either now or in the future.

Please sign here if you are willing to participate the interview/research _____

We would like to tape this interview to make sure that everything you say is recorded correctly. Once the research is completed the tape will be deleted.

Please sign here if you agree that the interview can be recorded _____

Thank you,
Focus Ireland

Appendix 2 – Template Receipt Form for Research Participants

Please read the following statement:

- I confirm that I have received a XXX voucher to the value of €XXX from Focus Ireland for participation in the research of XXX.

Name: _____

Signed: _____

Date: _____

Thank you,
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