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

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Contents

Introduction

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

All Focus Ireland staff conducting research with people currently experiencing, have experienced or are at risk of homelessness, and external research 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 evidence and understanding on issues surrounding and related to homelessness, to improve both Focus Ireland services and public policies. 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 people has the potential for being exploitative and damaging, even when the intent is to benefit those who are being researched. The following guidelines are intended to minimise harm and ensure that the rights, privacy, confidentiality, data and well-being of people participating in research 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 each context to resolve ethical dilemmas and maintain good practice in research.

In addition to these guidelines, Focus Ireland's ethical research practice includes consultation with an 'Ethics Panel' which is independent of its Research Sub Committee Advisory Group and comprises senior academics with experience in research involving marginalised groups.

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

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. Focus Ireland's 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 research participant rather than the research itself.

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

- Avoidance, prevention or minimisation of harm to others
- Respecting the rights and dignity of individuals and groups
- Free and informed consent
- Ensuring privacy and confidentiality with regard to data protection
- Fairness and equity
- Professional competence
- Ensuring integrity and transparency
- Social responsibility

Ethical Standards

All research proposals will be assessed for any ethical issues that may arise during or following the research. Depending on the scale and nature of the research, the assessment will be undertaken by Focus Ireland Research Manager or Research Officer and may involve consultation with the Ethics Panel. If any potential ethical issues are identified, the researcher will be asked to provide an ethical statement which sets out assurances on how the research meets the ethical standards required.

Relations with Research Participants

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.

Researchers have a responsibility to ensure that the physical, social and psychological wellbeing of research participants is not adversely affected by their research activities. They should strive to protect the rights of research participants, their interests, sensitivities and privacy, while recognising the difficulty of balancing potentially conflicting interests. Researchers should keep in mind that the research experience may be stressful and/or upsetting for participants and should attempt to minimise any distress for participants, as much as possible.

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 should update research participants with research outputs where appropriate and feasible. Generally, it is good practice to provide research participants with an advance copy of the final draft of the research before it is published.

Researchers should make clear the extent that participants are allowed to see any transcripts, field notes or other productions of data collection, and when they are allowed (if at all) to alter or remove information. Participants should also be informed how much (if at all) they will be consulted prior to publication.

Researchers should be conscious of any literacy difficulties of participants, and should conduct data collection in an appropriate research approach that facilitates literacy issues. When reading and writing is necessary in data collection, participants should be given alternative methods (e.g. they can dictate and the researcher can transcribe; the researcher will read a piece of writing aloud so the participant doesn't have to read it).

Interviews or focus groups should take place in a location where participants feel most comfortable and familiar, and where both the participants and the researcher feel safe. When conducting telephone-based surveys researchers should prepare to be accommodating toward a participant's schedule, and offer callbacks at a time that suits them where required. Participants should be informed that they can take a break during the data collection process.

Informed consent

All prospective participants in Focus Ireland research must give their informed consent before taking part in any research. They should be offered an information sheet and a consent form, which must be signed. The information sheet and consent form should be written in an accessible way, with easy to read language. Researchers should be mindful of different literacy levels and dedicate time to go through any information sheets and consent forms with participants when necessary.

Information sheets

All participants should receive - either a physical/digital copy or read aloud - an information sheet about the research being conducted. An information sheet should contain the following information[1]:

- Who is conducting the research
- Who is funding it
- The purpose or objectives of the research
- The voluntary nature of participation and the right to withdraw participation at any time without penalty
- Who will use/have access to the data and for what
- What participation will entail (e.g. a 30 minute interview about their experience with homelessness; a survey about their opinions on Focus Ireland)
- Who will have access to the research data including participant data
- What are the risks (if any) as a result of participating in this research

Additionally, participants must be made aware of the following, either verbally or in the information sheet:

- Those who *do consent* to participation may, in turn, 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.
    - Researchers should additionally make clear the extent that participants are allowed to see any transcripts, field notes or other productions of data collection, and when they are allowed (if at all) to alter or remove. information. Participants should also be informed how much (if at all) they will be consulted prior to publication.

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[1] Social Research Association, *Research Ethics Guidance* (2021).

- A participant's data may potentially be withdrawn, but may not be possible after a certain point (e.g. after data has been anonymised). Participants must be told if and when they can withdraw their data after participating in research.
- All researchers involved in the project will be bound by any confidentiality agreement except in cases where information disclosed by the customer/tenant indicates a serious risk to self or others, or is covered by Children First[2]. Where such issues requiring disclosure arise, they shall be reported to the Focus Ireland Research Officer or Research Manager, who will inform the relevant Services Project Leader in line with Focus Ireland procedures.
    - There may be some situations where a participant asks to be contacted by a member of Focus Ireland staff (e.g. for support around an issue they are facing). Where this happens, the researcher must ask for the participant's explicit consent before sharing their contact details with the relevant persons.
- Research participants may request additional support during the data collection, and researchers will aim to accommodate this insofar as possible.
- Research participants can also request additional support from their keyworker after the interview, if required. Researchers will make participants aware of any additional support they can ask for after participation is complete.
- If necessary, Research participants should be made aware of Focus Ireland's Customer Complaints Policy.
- Research participants should not share any information from any focus group discussions with outside individuals. They should not take any photos or videos during the research, unless explicitly told that they can.
- Research participants should be respectful of both the research team and other participants where relevant.

Researchers have a duty to:

- Inform participants of all the information above
- Ensure that participants are aware that there will be no negative repercussions for refusing to participate or withdrawing consent after they have previously given consent.
- Create a space that is comfortable and feels safe for participants

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[2] Children First training has been created by Tusla, the Department of Children, Equality, Disability, Integration and Youth, and the HSE. It is an e-learning programme that has been written to support people of all backgrounds and experience in recognising concerned about children and young people and reporting such concerns if they arise. The programme is based on Children First: National Guidance for the Protection and Welfare of Children and the Children First Act 2015.

- 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
- As much as possible accommodate participants in any way that they need or request

A sample information sheet can be found at Appendix A.

Consent forms

All participants should give consent via use of a consent form. A consent form can be given in a number of ways, including:

- A physical consent form which outlines everything they are consenting to, where a participant must check each item they're consenting to. Both the participant and the researcher must sign this.
- A checkbox on a survey that must be ticked 'yes' to give consent after reading an information sheet in full. This can be ticked either by the participant or the person administering the survey, where relevant.
- Where a participant may struggle with reading and writing verbal consent may be given, but all information must be clearly stated to this participant.

Consent forms must be stored securely and destroyed one year after publication or conclusion of research. A sample consent form can be found in Appendix B.

Marginalised communities

Special care should be taken where research participants are particularly vulnerable by virtue of a variety of factors. This includes, but is not limited to:

- Children and young people (<18)
- Those with a language difficulty
- Persons who have an intellectual or mental impairment or neurological condition
- Older people
- Those who are incarcerated

The researcher/s must consider the legal and ethical complexities involved in those circumstances where there are difficulties in gaining fully informed consent.

Where research participants have impairments that limit understanding and/or communication to the extent that they are unable to give informed written consent, permission where possible should be obtained from a family member or other responsible adult, such as a caregiver or guardian, before proceeding with the research.

In cases where written consent cannot be obtained (e.g. telephone-based data collection or where there are literacy barriers) informed oral consent should be obtained by documenting on the consent form.

Focus Ireland will endeavour to provide translation services where necessary.

Research involving children and young people

Focus Ireland rarely undertakes research involving people under 18 due to ethical complexity. However, should research with the group be approved the following guidelines are paramount.

Research involving children and young people requires particular care. The consent of all those under the age of 18 should be sought in addition to that of the parent/guardian.

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

- Where parental/guardian permission is impossible or would not protect the child or young person (e.g. where relationships have broken down)
- Where the children or young people concerned are resistant to parent/guardian consent being sought on the grounds of their right to privacy or confidentiality. In this case the emotional and social maturity and particular vulnerabilities of the young people must be evaluated and the risks associated with participation in the study must be low.

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

Researchers should have regard for issues of child protection and make provision for potential disclosure of abuse. Focus Ireland's Child Safeguarding policy[3] should be adhered to at all times.

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 interest of the young person/people in question.

Where a child or young person is being interviewed or is participating in a focus group, a second adult must always be present during the interview. Where possible, the second adult should be known to the child/young person or work with children/young people regularly, so as to provide a safe space.

As much as possible, in-person data collection should take place in a location that is familiar to the child or young person.

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

The limits to confidentiality must be explicitly communicated, as is the case with adults. This must be communicated in an age-appropriate way, such as below:

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[3] This can be provided upon request

“Whatever you have to say in this [DATA COLLECTION] is confidential and nobody will know that you said anything that you will say to me today, unless you tell me that you, or someone else, is in immediate danger of serious harm. If that happens, I would need to report it to someone who can help”

Data Protection, Anonymity and Confidentiality

Data Protection

All research conducted must abide by GDPR rules as set out in the Data Protection Act 2018. This includes the 7 key principles of GDPR as listed below:

1) **Lawfulness, Fairness and Transparency:** clearly inform participants about how their data will be used such as what data will be collected, how it will be used and who it will be shared with. Have a clear lawful basis for data collection such as consent and ensure consent forms meet the conditions for valid consent under GDPR[4].
2) **Purpose Limitation**: use data only for the specific research purposes stated.
3) **Data Minimisation:** collect only the data necessary for the research.
4) **Accuracy:** ensure data is accurate and up to date.
5) **Storage Limitation:** retain data only for as long as necessary. The Focus Ireland Research team will store data in accordance to Focus Ireland's record management policy and destroy any research data one year after publication or completion of research.
6) **Integrity and Confidentiality:** protect data against unauthorised access and data breaches.
7) **Accountability:** Maintain documentation to demonstrate compliance.

Additionally, if the researcher/s wishes to incorporate new types of platforms of systems including online systems (e.g. new type of survey collection), they must inform the Data Protection Officer to ensure that it follows all GDPR laws in place.

Anonymity and Confidentiality

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 appropriate to record certain kinds of sensitive information.

Research participants will be granted anonymity unless explicit consent is given to waive that anonymity, or if the participant or another person is in danger. For example:

- If a participant wants to be contacted by a Focus Ireland staff member about an issue and explicitly consents to having their contact details shared.
- If a participant expresses suicidal thoughts or the researcher is concerned about their welfare.
- If there is mention of abuse currently occurring.

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[4] See Customer Participation and Informed Consent above

Any potentially identifying information (e.g. age, gender, sexuality, ethnicity) should only be collected on a *need to know basis* – i.e. if it will benefit the research being undertaken.

Any quotes from participants must be completely anonymised, and any potentially identifying information stated in quotes (e.g. a location or a name) must be removed.

Compensation for participation in research

Where relevant, compensation will be paid to research participants in the form of gift cards/vouchers, to acknowledge the time taken to participate in the research, An amount of between to €20 to €50 will be paid in respect of the amount of time a research participant dedicates to a task e.g. survey, interview, focus group, or dissemination activity.

In some cases where data collection involves a large number of participants (e.g a satisfaction survey) the Research team may decide to raffle off a number of gift cards (i.e 1 voucher per X number of participants). This decision is at the discretion of the Research team and is on a case-by-case basis.

Compensation should be based on acknowledgement of time taken to participate in the research project and not the risk involved.

Compensation should be scheduled on a per task basis and not dependent on completion of the research. This will ensure that subjects will not be unduly influenced to complete the research.

Compensation of time should not be listed as a benefit in the participant information leaflet.

The use of the words “payment”, “inducements” or “reward” should not be used in information leaflets or consent forms, but the terms “expenses” and “compensation” are more suitable.

The decision to allow compensation or reimbursement to research participants for particular studies rests with the Focus Ireland Research Manager who may on occasion consult with the Ethics Panel for guidance.

Appendix

Appendix A: Sample Information Sheet

What is this research?

[This section should contain information about what the research being undertaken is]

Why is this important?

[this section should contain information about why this research is important and its potential benefits]

Who can take part?

[This section should contain information about the research sample]

What would participation involve?

[This section should contain information about what the participant will be doing, if they consent to being a part of the research – e.g. a 30 minute interview about their experience of homelessness, a 10 minute survey about their experiences of the Focus Ireland website]

Who will know what I've (said/answered/etc)?

[This section should contain information about confidentiality and anonymity, as well as Focus Ireland's GDPR policy]

Further information on Focus Ireland's Data Protection Policy can be found on the website (focusireland.ie)

Can I review what I've said?

[This section will contain information about whether the participant can review what they've said after participating. E.g. in a survey the answer is probably NO after submitting, as these surveys are anonymous. If it is an interview etc, the answer may be YES up to a certain point]

What if I don't want to take part?

[SAMPLE TEXT: You do not have to take part in this (data collection method). It is completely up to you whether you decide to take part or not, and there will be no consequences if you decide not to take part]

What if I change my mind?

[This section contains information about how they can withdraw from the research, and when it's no longer possible to withdraw (e.g. after an anonymous survey has been submitted]

Are there any risks if I take part?

[This section should contain any information about potential risks, including if the content of the research is potentially upsetting. For any risks listed, information about support offered should also be included]

Will I be compensated for this?

[This section should contain information about compensation, if relevant. If the participant is being compensated it should be clearly stated exactly what compensation they're receiving, as well as how and when it will be received]

What else do I need to know?

[This section should contain any other relevant information. If the research is an interview or focus group there should be information about recordings, etc.]

Who can I contact for more information?

[List the email addresses and/or phone numbers for the relevant people that participants can contact]

Appendix B: Sample Consent Form

Tick or signature next to each that you consent to

1. I understand the purpose of this study and have been given the opportunity to ask questions. [ ]
2. I have been given and read an information sheet about this research
3. I understand what is being asked of me to participate. [ ]
4. I understand that refusing to participate or withdrawing consent will have no negative consequences and that it will not impact on the services I receive from Focus Ireland either now or in the future. [ ]
5. I understand that I may decline to respond to/refuse to answer any question within the research process. [ ]
6. I understand that Focus Ireland may use my anonymised quotes in the final research.
7. I understand that any identifying information given will be removed. [ ]
8. I understand that my participation in this research will be anonymous, unless I or somebody else is at risk of severe harm or I give my explicit consent to waive anonymity. [ ]
9. [IF RELEVANT] I consent to this interview/focus group being recorded for transcription and data analysis purposes. [ ]

For more information about how Focus Ireland uses your personal data please see our Data Protection Notice on our website or ask your support worker for a copy.

Participant Signature	**Date**
________________________________	__/__/____
Researcher signature	**Date**
________________________________	__/__/____