

SURVEY, QUESTIONNAIRE, INTERVIEW AND FOCUS GROUP ETHICS APPLICATION GUIDELINES

PREAMBLE:

The purpose of this document is to provide guidelines for researchers who anticipate using questionnaires, surveys, interviews, and focus groups to gather data. The intention of these guidelines is not to prescribe methods and designs for research tools, but to emphasise which aspects Ethics Committees would need to see in place to enable them to make effective Ethics clearance decisions.

Thus, it is a given that researchers will be familiar with the definition of concepts such as 'research population', 'sampling', 'sampling size', 'types of sampling methods' *et al.* It is also considered a given that a researcher knows that the survey, questionnaire, interview schedule and focus group probing questions will be presented to the Ethics Committees for scrutiny, and captured in the appropriate Research Ethics Application form.

This document sets out to illustrate the 'nuts and bolts' of these data gathering methods, as envisaged and required by ethics committees. In these guidelines the persons and target groups, who possess or are able to provide the information sought by the researcher, are referred to as 'participants'. In alternative research literature such persons or groups may sometimes be referred to as 'subjects' or 'informants'.

1. GATEKEEPERS:

In many cases, access to the participants, and the environment in which the participants operate, will need to proceed through some form of gatekeeping. **Gatekeepers** are those who oversee, or carry the responsibility for, the participants in the research ambit. Examples of these might be the CEO of a company, University Management, the MEC for education, school principals, parents, Governing Bodies, proprietors of businesses and enterprises *et al.* In certain communities 'gatekeepers' might refer to the cultural or clan leader, and, in other communities, to the head of the household.

Golden rules:

- In all cases it is incumbent upon the researcher to determine who the relevant gatekeeper is.
- Having established this, it is the responsibility of the researcher to get permission from the gatekeeper to access the domain where the participants operate, and then from the participants themselves.

This important task is generally accomplished by making use of an Information leaflet which facilitates Informed Consent.

The Information leaflet, together with the request for permission to access the domain and the participant, needs to contain, at least, the following information:

- ✓ What the study is about.
- ✓ Why that organisation has been selected.
- ✓ If permission is granted, what the gatekeeper will be giving permission for.
- ✓ How the organisation, to be reported on, is going to be protected.

- ✓ A directive that the permission of the gatekeeper needs to include an acceptance that the participants will be protected.
- ✓ Confirmation that the participants will be informed that the gatekeeper has given permission, subject to the conditions outlined in the Information Leaflet.
- ✓ What the benefits for the organisation might be.
- ✓ Confirmation that the researcher's organisation has granted ethical approval for the research.
- ✓ Who can be contacted for further information, the availability of such person/s and the necessary contact details.

Ethics Scrutiny:

The Ethics Committee needs to see the Information Leaflet and Informed Consent document **before** they are presented to the organisation and the gatekeepers.

The Ethics Committee will check the ethics of the Information Leaflet and ensure that it correlates with the science of the project.

The Ethics Committee will furthermore correlate the gatekeeper Information Leaflet with the Information Leaflet which is attached to the relevant data or information gathering instrument.

2. (ELECTRONIC) QUESTIONNAIRES:

This section deals with questionnaires that are to be administered electronically. *Questionnaires that are to be administered through participant self-completion but have been handed out through fieldworkers, or through fieldworker verbal question and answer, will be dealt with under the following section, appropriately headed 'SURVEYS'.*

All questionnaires need to contain an Information leaflet (see the guidelines).

A questionnaire does not require an Informed Consent signature. It is taken as a given that proceeding to answer the questionnaire constitutes an acceptance of the conditions laid out in the Information leaflet. The researcher may, however, wish to add a section that advises the reader that by ticking the box the participant accepts the conditions presented in the information leaflet. This would be followed by a box that can be ticked/activated electronically.

Ethics Scrutiny:

Besides scrutinising the information contained in the Information leaflet, and the questionnaire itself, the Ethics Committee also requires the following information, which may be contained in the proposal (a practice to be recommended) or in the Application form or, preferably, in both:

- ✓ Precisely how the participant is to be recruited. The Ethics Committee needs to know how the questionnaire will be delivered to the participant for completion. The Ethics Committee will also need to see a written undertaking that the gatekeepers have given permission for such access.

- ✓ The Ethics Committee needs to know that the participant has been informed that the gatekeeper is aware of the entire process and has given permission for the participant to proceed, should he or she wish to do so.
- ✓ The Ethics Committee needs to know how the participant will return the completed questionnaire to the researcher. It is imperative for the Ethics Committee to know that the system of return ensures full confidentiality and anonymity. *It is for this reason that the use of university email addresses, or even personal email addresses, will only be sanctioned under extraordinary, and fully justified and motivated, circumstances.*
- ✓ The Ethics Committee needs to know how the returned questionnaires will be dealt with. It is not enough to state that the 'data will be analysed'. If there is a statistician involved, the Ethics Committee needs to know that there is a confidentiality agreement in place with such a statistician. It also needs to know where and how the raw data will be stored and, once the research is completed, what will happen to the raw data. It needs to know whether any portion of the data will be converted from electronic to paper format and, if so, where both will be stored. The Ethics Committee furthermore requires a declaration of password protection.

It should be noted that the use of social media for data gathering is still under scrutiny. It needs to be handled with ethical care. This is especially important after the passing of the Protection of Private Information Act. Guidelines will be forthcoming in this domain.

3. SURVEYS:

For the purposes of this document, a 'survey' means that the participant and the researcher or researcher's assistant/field worker are working synchronously and in the same environment, whether face-to-face, telephonically, or via any other electronic medium, such as Skype or Zoom or related media. In essence, the data gathering is done one-on-one, whether the questions are asked verbally, or the questions are provided in written form where the participant completes the form, and then hands it back.

Ethics Scrutiny:

Besides scrutinising the information contained in the Information Leaflet, and the questionnaire itself, the Ethics Committee requires the following information, which may be contained in the proposal (a practice to be recommended) or in the Application Form or, preferably, in both:

- ✓ The Ethics Committee needs to see an undertaking that permission will be sought to enter the domain or environment where the survey is to be conducted. This is the gatekeeper's concern.
- ✓ The Ethics Committee needs to understand the process or procedures for recruiting the participant who will participate in the survey. To this end, the Ethics Committee needs to be convinced that there is no element of possible coercion to complete the survey.
- ✓ The Ethics Committee needs to understand how the survey will be administered and what exactly will transpire between the potential participant and the researcher/field worker. Included in this concern is the presence of possible processes of beneficitation.

- ✓ Once the survey has been completed, a description of what will happen to the completed documents needs to be given to the Ethics Committee. This may include details concerning the transportation of the documents, the centralisation of the documents, the analysis of the documents *et al.*
- ✓ The Ethics Committee needs to see the confidentiality agreement that should be setup between the researcher and any other body that will be actively involved in the handling of the documents, whether field worker, statistician, transcriber or any other person or organisation.
- ✓ In the case of telephonic surveys, the commitment to safeguard the recording and the storage of the recording must be explained and guaranteed.
- ✓ In the case of face-to-face data gathering, through electronic means, the Ethics Committee needs to know how access to the participant's site is to be protected. It also needs to know how the participant will be informed about this protection. The Research Ethics Committee requires a declaration that the researcher/field worker will not pressure the participant in his/her domain to provide information. The participant has the right to not answer any question without consequences.

4. INTERVIEWS

For the purposes of this set of guidelines, an interview is defined as an in-depth pursuit of information from a participant, where the interviewer and the interviewee are present at the same time in the same environment, and where that environment is deemed to be safe and protected. The information is captured through field notes, audio recordings or video recordings, or a combination of these methods.

Ethics Scrutiny

The Information leaflet and Informed Consent for interviews are often complex and will not be dealt with here. These aspects will be attended to in another set of guidelines. The concern in this set of guidelines is about recruitment and participation of participants.

- ✓ The Ethics Committee needs to know what the specific procedure is that is to be undertaken to recruit interview participants.
- ✓ The Ethics Committee needs to know that permission will be sought to access the participants, via the gatekeepers or similar authority, and also what undertakings have been given as part of that permission.
- ✓ The Ethics Committee needs to have accurate knowledge of the parameters of the 'safe places' that are to be sought and in which the interview will take place.
- ✓ The Ethics Committee needs to know who will handle the data once it has been gathered (transcribers, coders *et al.*).
- ✓ The Ethics Committee needs to know how the raw data (recordings, transcriptions, notes *et al.*) are to be stored.
- ✓ Where translators or interpreters are required by the researcher in the study the Ethics Committee requires confirmation that a confidentiality agreement will be concluded with the translator/interpreter.

- ✓ Where applicable, the Ethics Committee needs to know what plans are in place to provide emotional or psychological support should such support become necessary as a result of the interview process.
- ✓ In studies where extremely sensitive interviews are contemplated, and the researcher is of the opinion that the interviewer should be assisted by a suitably trained specialist, this procedure needs to be specified. The necessary confidentiality agreement with such specialist must be formulated and in place.
- ✓ Where telephonic interviews are to be conducted, the commitment to safeguard the recording of the conversation, and ensure the safe storage of the recording, must be defined and prescribed.
- ✓ Should face-to-face interviews, with the assistance of electronic apparatus, be envisaged during the study, the Ethics Committee needs to know how exclusive access to the participant's site is to be managed and protected. How the participant will be informed about this protection must also be specified. Furthermore, the process of Informed Consent needs to be undertaken verbally, in the presence of witnesses. The Ethics Committee needs to know how the researcher plans to comply with this requirement, while ensuring confidentiality.

5. FOCUS GROUPS

For the purposes of this document, a focus group consists of several participants who meet and are led through a discussion that is generated by the researcher and guided by ethically cleared parameters of exploration. In general, focus groups foster debate and dialogue of less emotional or psychological engagement than interviews do. They are usually convened to gain and refine opinions or to solve problems.

Ethics Scrutiny

- ✓ The Ethics Committee needs to know what the specific procedure is that the researcher will adopt to recruit focus group participants.
- ✓ The Ethics Committee needs to know that permission will be sought, from gatekeepers, or persons in authority, to access the participants and what undertakings have been given to enlist that permission.
- ✓ The Ethics Committee requires a detailed description of the selection parameters of the safe places that are to be sought, in which the focus group will convene.
- ✓ The Ethics Committee requires precise details specifying who will handle the data, once it has been gathered. These persons may include transcribers, coders, and similar research assistants.
- ✓ The Ethics Committee needs to know how the raw data, such as recordings, transcriptions *et al*, are to be stored.
- ✓ Where translators or interpreters are to be engaged by the researcher the Ethics Committee requires confirmation that a confidentiality agreement will be concluded with these translators/interpreters.
- ✓ It is understood that confidentiality can be adequately maintained during an interview. In a focus group, however, although the researcher may declare confidentiality, there is no guarantee that the focus group members will not engage with persons outside of the focus group. The Ethics Committee requires a comprehensive plan, formulated by the researcher, as to how the researcher will manage the focus group to ensure maximum confidentiality.

- ✓ It is possible that solutions offered by the focus group may culminate in the creation of some form of Intellectual Property. The Ethics Committee requires the researcher to consider this possibility and state how such an eventuality would be managed.

Focus groups that convene 'electronically' (by adopting internet platforms and aspects of social media) present serious confidentiality concerns. When people meet in one venue, the recording, for example, is centralised. During a 'virtual meeting' there is far less control over the recording. There is also the possibility of outsiders being erroneously incorporated or invited. Implications inherent in 'verbally' signing confidentiality undertakings and Informed Consent are legion. These are new developments and, as such, are not yet adequately formalised and benchmarked.

FINAL NOTE:

These guidelines are not exhaustive. Situations may arise where other concerns come to the fore. There are also instances where some of the conditions may be superfluous. The nature of the research will determine the researcher's management obligations. It is hoped that, as the researcher maps the research path, these guidelines will assist the researcher to adequately incorporate these important aspects in that design.