

**AGST Alliance**

**Human Participants  
Research Ethics  
Handbook**



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ALLIANCE

## Companion document to this handbook

**Human Participants Research Ethics: Document Templates and Examples** is a separate document designed to complement this handbook: It provides templates and examples to help you create the necessary forms, letters, etc. required for a complete ethics application – and, most of all, for an ethically sound research project.

## Human Participants Research Ethics courses – ICETE Academy

This handbook details the practicalities of completing a HPEP application.

However, we strongly recommend that AGST Alliance researchers and their supervisors complete the ICETE Academy *Human Participants Research Ethics* courses to gain a good grounding of the rationale of ethical research with human participants – the ‘whys?’ and ‘whats?’.

There are two ICETE Academy courses available:

1. [Human Participation Research Ethics](#). This is a course written for students undertaking research that need ethics approval, for faculty or staff members who want to make sure that research meets the expectations for best ethical practice and for members of human research ethics committees who are tasked with reviewing research projects. The course gives an overview of the ethics framework and what researchers might need to be alert to for their particular research projects. Duration: Up to 10 hours.
2. [Preparing a Research Ethics Application](#). This is a nanocourse for researchers which gives specific guidance in preparing research ethics applications. The main assignment work for this course is getting a research ethics application approved by HPEP. Duration: Up to 2 hours

AGST Alliance students and supervisors are able to complete these courses free of charge.

The ICETE Academy (<https://icete.academy>) is a global educational partnership providing certified professional training for theological educators.

## Contact details

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Further details about ethical issues and informed consent covered in these guidelines may be found in reputable books on research in education and the social sciences. Websites also provide samples, etc.

We are grateful to the following institutions for their human research ethics resources which have been drawn on and adapted for this handbook: the University of Auckland Human Participants Ethics Committee, Laidlaw College and Carey Baptist College.

## Contents

Companion document to this handbook .....	2
Introduction.....	4
What research qualifies for ethics approval? .....	4
Responsible research practice .....	4
Ethical research.....	5
Key terms in research ethics applications.....	8
Completing the HPEP Application .....	9
Elements to note in the application form.....	10
Questions and concerns.....	18

## Introduction

Internationally there is an enhanced awareness of the ethical responsibilities of researchers towards research participants. Issues of integrity, respect for persons, beneficence (promoting the good of people) and justice lie at the heart of this concern as theological issues too. So AGST Alliance seeks to ensure that people undertaking research in its programs reflect these values also.

If you are involved in research which gathers 'live' data – the views of living people – then ethical issues relate to such areas as:

- Aspects of anonymity and confidentiality
- Care for research subjects/participants
- Protocols for selection of samples
- Informed consent and rights of research subjects/participants

'Live' data sources may include the administration of questionnaires, interviews, focus groups, observations, drawing information from current administrative records of an institution, etc.

Data collection for your research cannot proceed until ethics clearance is received from the AGST Alliance Human Participants Ethics Panel. Research conducted without prior ethics approval is a significant failure, and may result in disciplinary action, and any data gained not allowed to be used. Retrospective approval (approval after data have been gained) is most unlikely to be granted.

This handbook is written specifically to provide guidance to researchers – both students and faculty members – on the ethical conduct of their research projects and on the process of applying for ethics approval. It notes especially issues/areas to which particular attention needs to be paid.

### What research qualifies for ethics approval?

All research involving living human participants undertaken for AGST Alliance programs requires ethics approval unless specifically exempted.

Ethics approval may not be required in these situations:

- Surveys or interviews by AGST Alliance students or faculty designed to help improve their teaching, management or leadership activities.
- Course evaluations that are not for the purpose of research.
- Observations in public spaces where the people are not identified.
- Research using only already published or publicly available data.

However, the best rule to apply is: 'If in doubt, request ethics approval'.

## Responsible research practice

All AGST Alliance students and faculty are expected to undertake research that reflects the highest standards of professional conduct.

This will mean research will be conducted

1. with honesty and integrity
2. employing appropriate research methodology
3. in accordance with ethical guidelines
4. with appropriate records being maintained

### 1. Research conducted with honesty and integrity

Researchers take responsibility for the integrity of their research by:

- obtaining and presenting facts and interpretations in an objective and open manner.
- being fair and unbiased in all aspects of their research.

- honestly representing their goals and intentions participants in the research process.
- fairly, fully and truthfully presenting their results.
- correctly acknowledging the work of others (i.e. not plagiarising).
- complying with all legal requirements.

## **2. Employing appropriate research methodology**

Research undertaken will use appropriate research methods. Findings need to be fully and objectively reported, with conclusions based on critical analysis of the findings.

## **3. In accordance with ethical guidelines**

Researchers need to be aware of best practice for the ethical details of their research. Fuller details come later in this handbook.

## **4. With appropriate records being maintained**

Researchers will maintain clear and accurate records of their research and its processes. This will enable verification of their work by others, and protect their intellectual property.

# **Ethical research**

There are a number of principles underlying ethically sound research with human participants:

1. The merit of the research
2. Participant's informed and voluntary consent
3. Respect for participant's right to privacy and confidentiality
4. Minimisation of risk of harm to research subjects
5. Respect for the potential vulnerability of participants
6. Truthfulness, including the limitation of deception
7. Social and cultural sensitivity in the research
8. Appropriate compensation for participation
9. Avoidance of conflict of interest

### **1. The merit of the research**

Each research project must have a serious purpose or value, and have the potential to contribute to human knowledge. It needs to have clearly defined goals to achieve its purpose, and be designed in such a way that it can meet those goals.

### **2. Participant's informed and voluntary consent**

The participation of anyone in a research project must be voluntary, and based on a clear understanding of what their participation will involve. Participants must not be coerced to participate in a project, either by the researcher or in other ways.

The information provided to potential participants must be written in clear and easily understood language. This may require translation of participant information and consent documents into different languages.

Potential participants need to be advised of:

- The names and roles of the people who are conducting the research.
- The purpose of the research, and possible benefits of participation.
- The procedures they are being asked to agree to participate in (e.g. interviews, focus groups, observations).
- How the information gained from the participants will be used (e.g. in a thesis or dissertation, journal article, conference presentation).
- Their right to withdraw from the research process at any time and without disadvantage; and at what point in the research process it is no longer possible to withdraw their data.
- Their right to decline to participate without adverse consequences.
- How confidentiality of their data and/or anonymity of themselves and their data will be protected.
- What will happen to their data once the research is completed.

- The opportunity to have any questions which they have about the research answered, and a summary of the results when the project is complete.
- Assistance that may be available in case of discomfort or distress during and after their participation.
- The financial implications for participating in the research (e.g. honorarium/reimbursement).

Written consent is the norm. In some situations information may be given, and consent gained, orally rather than in written form, but this is the exception. Also, sometimes the consent of collective groups may be necessary rather than just from individuals.

### **3. Respect for participant's right to privacy and confidentiality**

Respect for participants' right to privacy and confidentiality is very important. So applications for ethics approval must identify procedures for:

- the protection of the identity of participants.
- keeping information relating to the research confidential.
- the secure storage of participants' consent forms and other identifying information.
- informing the participants of their rights to access and to edit/correct their personal information and/or data provided.
- ensuring the confidentiality of participants' personal or private information that is not directly related to the research but which might emerge in the course of the research.
- (where culturally appropriate) acknowledging the collective ownership of information gained (i.e. it might not belong just to the researcher).
- informing participants how long their data will be kept for, and then what will happen to it.
- assuring participants that their data will be used only for the stated purpose it has been acquired, unless participants have authorised it to be used for other purposes.

There may be situations in which participants are willing for their information to be disclosed and made public, but this needs to be clearly and explicitly consented to.

### **4. Minimisation of risk of harm to research subjects**

Researchers need to identify where there may be a risk of harm to participants, and ensure that all such risks are identified and minimised.

Risks may include pain, stress, emotional distress, embarrassment, guilt, tiredness, and cultural discomfort. Potential harm from these risks may be physical, psychological, emotional, social, cultural or spiritual.

Minimising risk of harm may require the researcher to balance inconvenience and discomfort to participants (e.g. in data collection methods) against the benefit of the research to the participants and to society, and the importance of the knowledge gained.

### **5. Respect for the potential vulnerability of participants**

Participants, by virtue of their age, social status, setting and other factors, may be vulnerable. Examples include children, church members, disabled persons, students and prisoners.

It is very important for the researcher to identify potential power and authority relationships, and address how these will be handled appropriately. Examples of settings in which people have an unequal power relationship may be students in an educational setting being participants in research conducted by a member of the faculty or staff; or church members being recruited for research conducted by a church leader. In such cases strategies for obtaining data without the participants feeling under an obligation to assist in the research will need to be set in place, e.g. by using an independent interviewer or focus group facilitator.

In cases like these, special attention must be given to what informed consent and participation will be like.

So, for example, if children (typically, under 18 years old) are being recruited as research participants:

- They will need to give their assent to participate.
- A parent or legal guardian will need to give consent.
- A parent or guardian (or someone the child or parent/guardian nominates) has the right to be present when data is collected from the child.

In some cultures, women may need to be interviewed by women, and men by men – or another person invited by the participant may be allowed to be present.

### **6. Truthfulness, including the limitation of deception**

There are occasions in which a researcher may seek to justify less-than-full disclosure of the purpose of the research and the procedures to the participants. For example, it may be felt that full information about the purpose of the research needs to be withheld from the participants before and during their participation so that the information they provide is unbiased.

In these cases, researchers will usually be required to disclose the full purpose to participants once participants have provided their data (e.g. at the end of an interview or focus group). And full disclosure must be made in the ethics application.

### **7. Social and cultural sensitivity in the research**

Researchers must ensure that their actions are appropriately sensitive to the participants' cultural and social frameworks, and ethical values enmeshed in them.

So a research project must ensure that:

- there is culturally appropriate consultation in the development of the research processes.
- data collection is sensitive to the cultural and social beliefs and practices of the participants.

### **8. Appropriate compensation for participation**

Participants must not be induced or coerced to participate in the research. It is appropriate for researchers to compensate participants for their involvement. This may be in the form of an honorarium or a small gift of gratitude for the participants' willingness to be involved in the research, and/or reimbursement for their out-of-pocket expenses (e.g. travel).

The amount of compensation needs to be such that:

- it doesn't induce or coerce participation
- it doesn't discriminate between different participants

If participants withdraw from a research project after it has begun, reimbursement may be proportional to their participation (e.g. if 3 sessions are involved, they receive one third of the compensation per session). If participants commence a session and then withdraw part way through it for whatever reason (which they don't need to give the researcher), they should be given the full compensation for the session.

### **9. Avoidance of conflict of interest**

Researchers are responsible to identify any potential conflict of interest that may arise for them in relation to the proposed research and to any participant. In their application, researchers must explain the nature of the potential conflict, and what actions (if any) they propose to take to minimise, avoid or resolve that conflict.

For example, a researcher may be a senior leader in an organisation, and she is planning to interview staff members about the efficiency of the organisation. Staff members will be put in a potentially awkward, even difficult, situation if they are being interviewed by someone whom they perceive to impact on organisational efficiency, and so may not respond freely or honestly. Conflict of interest on the part of the researcher will be avoided by getting an independent person to conduct the interviews, and for the data to be anonymized before being given to the researcher.

## Key terms in research ethics applications

Researchers need to be familiar with the terms which are commonly used in the research ethics application process. Key terms include these:

### Participant information sheet (PIS)

In order for participants to be able to make an informed decision on whether to participate in research, researchers provide them with a PIS. This sheet gives details of the nature and methodology of the research, the rights and responsibilities of participants and the researcher, the name and contact details of the researcher and supervisor, and contact details for the Human Participants Ethics Panel, should a participant have any concerns about the ethical issues they wish to discuss with someone independent of the research.

### Consent form (CF)

Participants sign a CF to indicate their willingness to participate, based on the information given in the PIS. This document is purposely brief and specific in nature. A copy of the signed CF is usually given to each participant and a copy is also held by the researcher, separate from the research data.

### Anonymity

This term is normally reserved for situations in which neither the researcher nor the readers of the researcher's report know who the participants are. So a response is anonymous when the researcher and those who read the published results of the research cannot be identified as belonging to a particular respondent. For example, participants in on-line surveys are anonymous if the survey doesn't ask for identifying information (e.g. name, date or birth, IC, specific role in an organisation, etc.).

### Confidentiality

In research ethics situations, confidentiality is used when matters referred to are known only to the participant and the researcher, and are not revealed in any way. Confidentiality may be expressed in one of two ways:

- *Confidentiality of participation*: The researcher undertakes to keep both the identity of the participants and the fact that they have taken part confidential. Only the researcher (and usually the supervisor) will know this information, or have access to it.
- *Confidentiality of data* (information provided by a participant): Data provided by the participant is kept between the participant and the researcher, and will not appear in any report.

It is misleading to describe information collected during research as confidential if it is reported or published. An appropriate sentence to use in the PIS will be: "If the information you provide is reported/published, this will be done in such a way that does not identify you as its source."

### Research participant (or respondent)

Research participants are people from whom the researcher obtains data – they are participating in the research. They may be called respondents when the data they provide is obtained by means of such data-collection methods as surveys and questionnaires (e.g. they are responding to a survey).

### Withdrawal of participation

Participation in research is voluntary, and participants are free to withdraw from the research, without needing to give a reason. Withdrawal of participation may take two forms:

- Participants are entitled to withdraw themselves at any time from a research process (e.g. ending an interview early, not participating in the second of two planned sessions, etc.).
- Participants are entitled to withdraw the data they have provided for the research. Usually there is a timeframe by which this right may be exercised (e.g. before the data is analysed).

The PIS (and usually the CF) will include details about the right to withdraw and the timeframe for participants to request to do so.



## Completing the HPEP Application

Ethics clearance from the AGST Alliance Human Participants Ethics Panel (HPEP) must be obtained **before** you commence data collection for your research.

### The application timeline

The application process follows these steps:

1. Complete the application form, and submit it, with the supporting documents, to the AGST Alliance Human Participants Ethics Panel.
2. The application is reviewed by the members of HPEP.
3. HPEP gets back to you with its response.
4. If amendments are required, make these and resubmit the required application and/or documents.
5. Full approval is given by HPEP.
6. You commence your data gathering, using the approved forms and processes.

### Timing for approval

If the research is considered low risk, a decision is likely to be made more quickly than if the research is considered to have a higher level of risk and so requires a HPEP full review.

**A low-risk project** is one which is considered to have a very low risk of harm or adverse effects. It may be reviewed and approved by the chair of HPEP.

A project which is deemed to have more than a very low risk of harm or adverse effects is given a **full review** by all the members of HPEP.

Whether a project is considered low risk or requires full review is determined by the answers to questions in the application form.

Generally, well-prepared applications will take 2-3 weeks to be considered by HPEP and be approved. But the time taken to get approval is dependent upon whether amendments and changes are needed to the application and the associated documents.

### HPEP application responses

HPEP will respond to your initial application with one of these responses:

- *Approved:* All ethical issues are properly dealt with and no changes are required. Your research can proceed.
- *Conditional approval:* The application is approvable, but there are some issues that need to be addressed before approval is granted. The application must be resubmitted to HPEP to show that the changes have been made.
- *Pending resubmission:* There are substantial ethical concerns or insufficient information for HPEP to make its informed decision. The application needs to be resubmitted for a full review before a decision can be made.
- *Declined:* The application cannot be approved for some reason(s) which will be conveyed to the researcher.
- *Noted:* No approval is granted, but the research may proceed because the proposed collection of data doesn't require HPEP approval.

### Translations of documents

The ethics approval process of HPEP is conducted in English medium. Translations of documents (e.g. PIS, CF) into other languages are to be provided to HPEP where they are prepared. However, they may be presented to HPEP after the English-language version has been approved.

### Duration of ethics approval

Once research is approved by HPEP, the approval is valid for up to three years.

**Amendment requests**

If researchers wish to make changes to the application and/or the research process after the original application is approved, they must make an amendment request, using the *Ethics Amendment Request* form.

Amendment requests need to be made for such matters as:

- Changing any aspect of the approved research processes.
- Changing the criteria or number of approved participants and how they will be recruited.
- Modifying the documents for participants – PISes, CFs, etc.

To make an amendment request, the researcher needs to inform HPEP of what the requested amendments are and give a rationale for the requested changes. Amended drafts of documents (PIS, CF, etc.) need to be included with the request.

## **Elements to note in the application form**

As you fill out the application form, note these points on various items in the form.

**Section B: Research focus and design*****B2: Plain title (English)***

This is the title that will appear in material provided to the research participants, so it may be a simplified version of your full research project title. Write this plain title in English, even though it may be translated into a different language for the research participants.

***B4: Summary of the project***

This item requires a summary of your research project, indicating how it relates to other research or practice. What is the knowledge/practice 'gap' that it is designed to fill?

***B6: Description of the research design***

This is a detailed outline of your research design. What are you planning to do, and in what ways, with the research participants? Make sure this is a full description of the processes.

***B7: Methods to be used for obtaining information***

This section requires details about the methods you propose to use for data collection. You need to include with your application at least reasonable drafts of documents like proposed interview or focus group questions, questionnaires, etc.

***B8: Who will carry out the research procedures?***

Keep in mind possible conflict of interest that you as a researcher may have with the participants. Consider whether you need someone else to undertake aspects of the data-collection process. For example, an independent person rather than you may need to request potential participants to indicate their willingness to find out more about the research, with a view to signing up to your research.

Or, an independent interviewer or focus group facilitator might be required.

Or, an independent person might need to administer a survey, and then anonymise the response sheets before passing them to you.

***B9: Where will the research procedures take place?***

If you plan to conduct your study at a specific location, then a separate PIS and consent form will likely be required for the leader/person with the authority to allow you access to that location. A letter granting authority rather than a consent form may be adequate, but it will still need to include the key elements of consent.

For example, if you wish to conduct your research with a Sunday School class, then you will require a PIS for the Sunday School superintendent or the church leader overseeing the Sunday school, stating what you are intending to undertake.

Wherever the research procedures/data collection takes place, the safety of both the research subjects and the researcher needs to be carefully considered. For example in-person, face-to-face interviews (especially with a member of the opposite gender) will usually be conducted in an open, neutral space rather than in a closed room. In some situations (e.g. with children) the presence of an independent person or a child's parent may be appropriate. (See also comments on G2, below.)

### ***Internet-based research***

If you plan to use the internet as a 'research site' involving human participants (e.g. data collection through social media, or drawing data from elsewhere on the internet) you need to be aware of the ethical implications for doing so.

Note that material in the public sphere (i.e. visible to a public audience) is not necessarily material in the public domain (where intellectual property rights have expired or are not applicable). Resources in the public sphere may still be subject to copyright and intellectual property rights by the creator of the resources – and these rights need to be respected.

Issues of consent and confidentiality need to be carefully considered for data drawn from the internet (e.g. through social media sites). Examples of issues you need to be alert to include these:

- When on-line consent is required, issues relating to the identity of participants may arise (e.g. their age, vulnerability, etc.).
- A guarantee of confidentiality may be an issue, as it may be relatively easy to track the source of text.
- Sensitive and highly personal data transferred via the internet is not usually encrypted, raising security issues.

### ***B10: Your institutional role***

It is important to note if you have a role or position in the institution/setting from which your research participants will be drawn. If you do, this heightens the possibility of conflict of interest, and the possible impact on your research of aspects such as power imbalance, dependency and objectivity.

### ***B11: Conflict of interest***

Note the comments on B8 (above), and further detail on p. 7.

## **Section C: Research participants**

### ***C1: Who are the participants in the research?***

#### **Children or young people**

The United Nations *Convention on the Rights of the Child* recognises a child as a person under the age of 18 years old, unless national laws recognise an earlier age of majority. It is important to be aware of what the age is in your country, and to base your research ethics requirements on the rights of the child in your country.

If children are considered old enough to be able to understand the project and their role in it, they will be required to give their assent to participate. Usually this age is about 7 years, but children younger than 7 years old may be able to understand a simple explanation of what you would like them to do and to agree (or not) to it.

But only assent from the children is not sufficient. When children are proposed participants in research, informed consent must be gained from the parents or those legally designated to act in place of the parents (e.g. guardians). The parents/guardian have the right to refuse consent, and this needs to be respected.

Children/young people in your country may be able to give consent without parental approval. For example, in some countries persons over the age of 16 years are permitted to give consent to participate in research. But this will need to be justified in your application.

It is important that the language used in the PIS and CF forms for children/young people is able to be readily understood by them. It cannot be just a 'cut and paste' from the adult informed consent documents.

### **Vulnerable participants**

People you wish to use as participants in your research may be considered to be vulnerable, for a number of reasons (see p. 6).

- Proposed participants may have limited mental capacity, and so not able to give informed consent. We have already mentioned children. Elderly people sometimes could fit this category too.
- Proposed participants may be in a dependent situation, and feel unable to resist participation for fear that some of their rights or privileges might be taken from them. Dependency could include physical, social and spiritual elements.
- Proposed participants may be people with whom the researcher has a special relationship, e.g. family members, colleagues, or close friends.
- A special context for research by AGST Alliance students is church settings, in which there is a heightened dependency (or spiritual differential) at work between pastors/church leaders and the members of their church. Similar dynamics may be at work in seminaries also.

Research with vulnerable people requires special care with respect to obtaining informed consent, and also to lessen the possibility of harm. People who are vulnerable shouldn't be excluded from research simply because of the challenges of ensuring freely-given and informed consent. Participation in the research may benefit them in some way. But recognise that the possibility of coercion to participate in research with such people is heightened, as well as the potential for harm, and so extra caution is required in the consent process.

Note also that the ability to give consent is not 'all or nothing' with potentially vulnerable people: people may be able to give consent to some kinds of research participation but not other kinds.

### ***C4: How will you identify potential participants and invite them to take part in your research?***

Once you have decided the population from which you will recruit participants, the call for them to offer to participate may be made in a variety of ways, e.g. by means of an advertisement, through social media, by word of mouth, in an email sent by you or someone other than you, etc. You will need to provide copies of any advertisements and the text of emails/letters you plan to use.

### ***C5: Will access to participants be gained with the permission/consent of any organisation?***

When conducting research with people drawn from an organisation or institution, it is important to determine whether organisational/institutional authority for the research is required before the participants are recruited. Usually the chief executive (e.g. the pastor of a church or principal/president of a Bible college) approves the researcher approaching members of their organisation to participate in the research.

Note that the head of an organisation gives permission for members to be recruited into the research. Only the participant members of the organisation/church can give consent for their own participation.

### ***C6: Will information on the participants be obtained from a third party (i.e. people other than the participants)?***

It is possible that a researcher may want to access information on participants from a source other than the participants themselves. An example is a researcher seeking the views of participants in a seminary course, and wanting to get from the seminary administration the students' grades from their previous courses.

If you plan to get information from third parties you need to explain why, and how you propose to do this. The participants in your research will need to be aware of this (detailed in the PIS), and consent to it.

***C7: Will participants receive any payment, reimbursement or other benefit from participating in the research?***

An important principle for ethical research relates to payments to, or benefits for, participants (see p. 7). Participants must not be induced or coerced to participate in the research, but it is appropriate for researchers to show their appreciation to participants for their involvement. This may be in the form of an honorarium or a small gift of gratitude for the participants' willingness to be involved in the research, and/or reimbursement for their out-of-pocket expenses (e.g. travel).

Remember that the amount given participants needs to be such that:

- it doesn't induce or coerce participation
- it doesn't discriminate between different participants

No payment that could be perceived to be an inducement should be made to parents/guardians to persuade them to allow their children to participate in a research project. Children and young people may be offered a small gift to show your gratitude for their participation.

Generally it is preferable to offer a voucher of some sort or a small gift than to give cash to participants (except perhaps for reimbursement of direct expenses). Sometimes it may be sufficient to offer participants a summary of your final report (in non-technical language).

**Section D: Socio-cultural issues**

While much research is socio-culturally generic, i.e. the participants are not selected on the basis on their ethnicity or social factors, research may be undertaken that does involve people specifically from a particular socio-cultural group or which has clear implications for people in that group. Common socio-cultural aspects could include culture/ethnicity, geographical location, special interests, and shared experiences (e.g. church denomination or tradition).

In such cases the research processes should be developed and conducted in socio-culturally appropriate ways. Researchers must ensure that their actions and intentions are sensitive to participants' cultural ethical values, social practices and expectations. This will be reflected in such questions as:

- Who needs to be consulted about how the research will be conducted, to seek advice from, and (if appropriate) to get permission/approval to work with the group and its members?
- Is it appropriate for consent to be group consent given by leaders of the group rather than individual consent?
- Do information for participants and the consent form need to be in their first language?

**Section E: Information and consent**

Review the informed consent details on p. 5 above.

***E1: How and by whom will information about the research be given to potential participants?***

Once you have identified potential participants (detailed in C4), how will you inform them about the details of your research and what is expected of them? This may be conveyed to them by you or by someone else (especially if there is potential conflict of interest). Usually a detailed written PIS is used as at least part of the information given to them to help them make an informed choice about participation.

***E2: How and by whom will consent for participation be obtained?***

Explicit, informed and voluntary consent is required from research participants. Usually, a participant will be asked to indicate their consent after you (the researcher) have made sure that the participant understands what they are committing themselves to and have had an opportunity to ask questions. Most often this will be immediately prior to commencing an interview or focus group. It is not appropriate to get signed consent forms from potential participants at the same time as they express early interest in participating (e.g. when contacting the researcher as a result

of an email invitation from an church/organisational leader), as they will not have had opportunity to get any questions answered or concerns addressed.

For internet-based interviews or focus groups, the logistics for getting the consent form signed and given to the researcher immediately prior to starting the interview/focus group is different to a face-to-face situation. Instead in on-line cases, on-line but prior to starting the interview questions or focus group discussion, researchers may review the research process with the participants, get their oral consent to proceed, and ask them to transmit the signed consent form as soon as possible after the interview/focus group. Researchers should not use any on-line data until they have the signed consent in hand.

In some situations (especially where some conflict of interest is identified), an independent person will need to take consent from the participant.

In the case of anonymous data collection (e.g. a paper or on-line survey/questionnaire in which respondents don't give any information that identifies them to the researcher), consent is implied when the person submits the survey/questionnaire – so they don't need to sign a separate consent form.

***E4: Will participants have difficulty giving informed consent on their own behalf?***

There are some research situations in which participants (other than children) might not be fully competent to give their informed consent. In such cases, it may be possible for someone to give consent on behalf of the participant, e.g. someone with legal authority to act on behalf of the potential participant. Where possible, participants unable to give consent should be asked to assent to their participation.

***E5: Does the research involve participants giving oral consent rather than written consent?***

There are some situations in which oral consent is possible. If you choose to obtain oral consent, you will need to give your reasons for doing so. You will also need to include a procedure for documenting that consent has been obtained (e.g. recorded consent, a signature).

***E6: What period will you allow for participants to change their mind about involvement and/or their data being used?***

Participants have the right to withdraw from participation at any time without needing to give a reason. This means, for example, that they could terminate an interview partway through, or leave a focus group session.

Participants can also request to withdraw any/all of their data from the research up to a specified date or period of time. Commonly the period of time is 2-4 weeks after an interview. If participants are given the opportunity to review the transcript or researcher's notes of their interview, then the time they have to withdraw their data will usually be about two weeks from the time they have reviewed their data.

It is not possible for a participant in a focus group to withdraw their data, because its removal will likely affect the meaning of the data as a developing conversation among the group members. Participants in this situation may request that any quotations of their data not be used in the research report.

A participant who has completed an anonymous questionnaire cannot request to withdraw their data, as the researcher won't know which response is from that person.

***E8: How will consent forms be stored securely?***

The researcher needs to keep the consent forms in a secure place separate from the research data, so that no-one can match the consent form with the data.

Electronic copies of completed paper consent forms may be made and the paper copies then destroyed (shredded or burnt, not just put in a wastebin). In this case, the computer/storage device used to store the electronic copies of the forms must be at least password protected.

## Section F: Storage and use of results

### ***F1b: If recordings are made, will participants be offered the opportunity to edit the transcripts of the recordings?***

Commonly, interview participants may be offered the opportunity to review and edit the transcript/summary of their interview. Editing of transcripts is not usually appropriate for participants in focus groups.

If you make this offer to participants, give a specific timeframe for them to complete their review and edit of the transcript, e.g. up to two weeks after they receive the transcript. Allow another 1-2 weeks after they have returned the transcript to you for them to request that their data not be used.

### ***F5: How will the data (including any recordings) be stored, and for how long?***

All data collected about, and from, research participants must be stored and later disposed of securely. This is to protect participants' confidentiality and to better ensure the authenticity, integrity and safe-keeping of the data.

Stored/saved research data should be accessible only by the researcher (and supervisor). So think carefully about where and how you store your research data, especially for data in electronic format.

- Paper-based data and other documents (e.g. signed consent forms) should be kept in a locked drawer or cabinet.
- Data and documents in electronic format should be kept only on computers or other e-storage devices that are password protected (and, ideally, with encrypted drives).
- ... and make sure you have a separate back-up(s) of all your electronic data, in case of failure ('crash') of your storage drives.
- Storage of data 'in the cloud' has significant security issues, and so should be used cautiously, and with appropriate safeguards (password protected access, etc.)
- Signed consent forms should be stored separately from your research data (e.g. completed surveys, interview transcripts, etc.)

Data should be kept at least until sometime after the research has been completed (and the study program completed). So suggest a fixed term (e.g. two years after the research report has been completed).

Data may be kept indefinitely, but if you plan to do so, your reasons for doing so should be made clear in the PIS. Also, generally data kept indefinitely will be de-identified (the names and other identifying features of participants removed from the stored data).

### ***F6: How will the data (including recordings, consent forms, etc.) be destroyed?***

Disposing of data needs to be undertaken securely.

- Shred or burn hard-copy (paper) data, not simply dump it into a wastepaper bin.
- Full destruction of electronic data involves more than simply deleting files. Get advice about the best method to use for full destruction.

### ***F7: Who will own the data and results of your research?***

The data and results of research may be the intellectual property of the researcher. However, researchers' institutions usually have clear policy relating to this (especially if the research is funded by the institution and/or the researcher has an official role in the institution). Check this carefully.

## Section G: Risks and benefits

### ***G1: What are the possible benefits to participants by taking part in your research?***

Any research project must have the potential to contribute to human knowledge, and so to benefit people and society in some way. Your research may result in direct benefit to the participants, or to wider society through the results of your research. Make sure that you don't overstate the possible benefits to the participants (e.g. in the PIS).

***G2: Is the research likely to place the participants and/or you as researcher at risk of harm beyond that normally encountered in everyday life?***

Recall (p. 6) that 'risks may include pain, stress, emotional distress, embarrassment, guilt, tiredness, and cultural discomfort. Potential harm from these risks may be physical, psychological, emotional, social, cultural or spiritual'.

What potential harm could there be for participants and their communities in your research, and what steps will you take to ensure that you minimise the risk of this happening? Researchers cannot completely guarantee the safety of research participants, so you need to make them aware of the possibility during the consent process. Some form of monitoring may be appropriate, and/or suggesting resources to participants if you sense they are experiencing distress or harm. In some situations the location for interviews may need to be carefully considered, or what on-line software/apps are used because of security concerns.

Also, be mindful of your own safety and well-being as researcher. Strategies to ensure this may include such things as debriefing after interviews you have conducted, with your supervisor or a respected confidant.

***G3: Does the research involve processes that could disadvantage participants?***

Respect for participants (see pp. 6f) means that researchers need to be careful that their participation doesn't disadvantage the participants. If there is potential for being disadvantaged in some way, the researcher needs to give a rationale for this, and/or indicate how it will be lessened.

***G4: Does the research involve deceiving the participants, or lack of full disclosure to them?***

See p. 7. Some research requires deceiving participants about the purpose of the study until after it has been completed. If you think your research requires deception (or lack of full disclosure of the purpose of the study), then give your reasons and say how you plan to limit the impact (e.g. by a debriefing). Include a copy of your debriefing material for the participants.

Note that it is not appropriate to deceive participants about the time their involvement will take or the methods to be used to get data from them.

***G5: Will your data be kept confidential?***

Confidentiality in research (see p. 8) means that information is private to the researcher and the participant: only the researcher (and supervisor) can link the data to individual participants. Do you plan to keep information (data) from participants confidential, or will your report(s) name the participants or identify them in some other way?

In this question, outline the strategies you plan to use to protect confidentiality. This includes how you will present data in your report and how you will manage the data (e.g. making sure you store identifying material separate from coded/de-identified data). If you intend to use participant names and identifying data in your report(s), you need to state this clearly in the PIS and CF.

If potential participants cannot be guaranteed confidentiality, this should also be clearly stated in the PIS. For example, the PIS for participants in focus groups will state that confidentiality cannot be guaranteed in that setting, even though every endeavour will be made to ensure that it is preserved. This is because in a focus group confidentiality of information relies on the participants – and the researcher cannot promise that.

Remember that it is misleading to describe the information collected during the research as confidential if it will be reported or published. So use wording like this in the PIS: "If the information you provide is reported/published, this will be done in such a way that does not identify you as its source."

Note also that researchers can only give an assurance of confidentiality to the extent allowed by the law of your country. Some government departments and the courts of law have a legal right of access to certain information. A disclaimer should therefore be included in that confidentiality will



be maintained to the extent allowed by law. This may be necessary if the life and health of a participant (or someone named by a participant) may be at risk as a result of information given.

**G6: Will you anonymise your data?**

Ensure you appreciate the difference between anonymity and confidentiality (see p. 8). Anonymity in research means it is impossible for a researcher or anyone else to link any data to an identifiable person (e.g. the data a participant has provided).

In the PIS state whether or not potential participants can be guaranteed anonymity. Anonymity is unlikely where there is only a small number of participants, or they are drawn from a recognised group (e.g. an organisation, church, seminary, etc.)

It is common practice in research projects for the researcher to assign a code name or number to participants. But if the researcher does this, the data is not anonymous. To ensure anonymity, a third party (who signs a confidentiality agreement) may need to assign codes to completed surveys, and separate the personal identifiers from the data before passing the data to the researcher.

Normally, participants may be assured of anonymity when they complete an internet-based questionnaire that doesn't ask for respondents' identifying information or an unnamed paper-based survey. But note that when respondents are drawn from a small population, or only a small number of people are completing the survey, even though their name are not requested, answers to a combination of other questions in the survey could enable the researcher or others who know the setting to reasonably accurately guess who respondents are.

Research design may also need to address how to protect the anonymity of non-participants. For example, if a questionnaire is completed in a group setting, those who decline to participate could be asked to return a blank questionnaire.

**G7: Will your research raise privacy issues?**

A principle relating to ethical research is respect for participants' right to privacy (see p. 6). Privacy is different from confidentiality. It relates to how participants' personal information that is sensitive is disclosed and used.

In many countries there are privacy laws, and your research needs to be undertaken within the parameters of those laws to ensure and protect the privacy of participants.

**G8: Is it possible that your research could give rise to incidental findings or adverse events?**

Research occasionally results in findings that are unexpected and unrelated to the original purpose of the research, and which may impact on the well-being and interests of participants and or the duty of the researcher. For example, a participant being interviewed might mention the actions of a person that are illegal or which involve harm to others (e.g. violence or abuse). Adverse events during the research can arise too. In educational and social science research these might include psychological or emotional disturbance, or infringements of privacy or other rights (for example, from unauthorised access to identifiable personal information or disclosure of confidential information). Serious adverse events may be life-threatening.

Where there are incidental findings or adverse events, the first priority of the researcher is to ensure that the affected participant(s) immediately receives care and assistance appropriate to the event or outcome, but to respond within the limits of their expertise and within the parameters of participant confidentiality and privacy. Then, consult with a trusted adviser (e.g. research supervisor, seminary principal, senior church leader) on the steps to take to address the issue.

If researchers believe there is a reasonable probability of incidental findings, they have a responsibility to inform the participant of this in the PIS, stating also that if a participant does not want to be informed of any such findings, they should not participate in the research.

## **Section H: Ethical issues**

In this section, summarise the main ethical issues arising in your research and how you plan to resolve them. Review your responses to the questions in the earlier sections – there may be some repetition of what you have included earlier.

### **Questions and concerns**

For further details about ethics approval issues for your research, contact the Chair of the AGST Alliance Human Participants Ethics Panel ([ethics@agstalliance.org](mailto:ethics@agstalliance.org)) the Dean of AGST Alliance ([dean@agstalliance.org](mailto:dean@agstalliance.org)), or your program director.

Especially, contact any of these people or another informed person about the ethics requirements if you plan to invite children or potentially vulnerable groups of people to be participants in your research, or if you plan to conduct your research on a sensitive topic (e.g. conversion of a particular group of people, sexual attitudes and practices, etc.)

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