

Research Ethics Policy

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Introduction

1.1 This handbook is designed to outline policies and provide guidance for the development and maintenance of appropriate ethical approaches to the conduct, supervision and utilization of research in NANA girls and women empowerment initiative. As such, it underpins, supplements and enhances the principles and operational requirements flowing from the need to work within professional codes of conduct and relevant legislation.

1.2. In line with definitions adopted by the Quality Assurance Agency (QAA), ‘research’ “comprises creative work undertaken on a systematic basis in order to increase the stock of knowledge, including knowledge of [people], culture and society, and the use of this stock of knowledge to devise new applications”. The word research is used in an inclusive way to accommodate the range of activities that support original and innovative work in the whole range of academic, professional and technological fields, including the humanities, and traditional, performing, and other creative arts.

1.3. Research is generally understood as an enterprise invested with mutual respect and trust between researchers, participants, stakeholders, academic and public audiences. As such it is subject to ethical review to ensure that it is conducted in accordance with its responsibilities to individual participants and the wider public. Most particularly the ethical review of research is intended to:

- Ensure that any foreseeable harm to the physical, psychological, social well-being, health, values and dignity of participants, researchers and other stakeholders is minimized; and that
- Ensure the rights of participants, researchers and other stakeholders are upheld, including participants’ right to informed consent, privacy, confidentiality and anonymity.

NOTE:

Researchers: denotes all staff of the NANA Girls and Women Empowerment Initiative who are undertaking research, and encompasses anyone involved in conducting research in collaboration with staff of NANA Girls and Women Empowerment Initiative.



Participants: usually understood to be individuals or groups, animals and plants who directly provide the data for a study.

Stakeholders: individuals or groups with a vested interest in the research, e.g.: family members, local communities, funding agencies, employers and/or the wider research community.

1.4 The ethical dimensions of research relate to issues of research integrity and as such involve more than these specific responsibilities to take into account the interests of the public and the researchers to incorporate the credibility and standing of research. Some of these dimensions include:

- The collection, use, and interpretation of research data
- Methods for reporting and reviewing research plans or findings
- Relationships among researchers and community
- Relationships between researchers and those that will be affected by their research
- Means for responding to misunderstandings, disputes, or misconduct
- Options for promoting ethical conduct in research

1.5. Ethical review is intended to be a constructive and collaborative enterprise that promotes valuable research in the interest of the common good. The NANA Research and Publication Unit is responsible for reviewing applications for ethical approval. This document sets out the NANA's policy and practice on the ethical conduct of any research carried out under its name.

1.6 Professional and academic communities are placing increasingly exacting responsibilities on their members to improve the ethical standards of research and practice within their disciplines, and journal editors may require evidence that research projects have secured formal ethical clearance before agreeing to publish their findings.

1.7. NANA research and ethic policy comprises two parts: Ethical principles and procedures
Part A is a statement of ethical principles, designed to articulate a common set of values to guide and support the professional conduct of research and research-related activities. It is based on the statement of ethical principles which has been in use and applies principally to all research involving human subjects and participants as well as animal research

Part B contains the procedures by which research proposals can be assessed and, where necessary, given ethical clearance

20. Part A: Ethical Principles

2.1. The primary responsibility for the conduct of ethical research lies with the researcher. It is a fundamental principle that staff engaged in research adopt a continuing personal commitment to act ethically, to encourage ethical behaviour in those with whom they collaborate, and to consult where appropriate concerning ethical issues.

This section outlines some general ethical principles NANA consider in conducting or supporting research. The principles are at a relatively general level include community based participatory research, with the bullet points offering brief illustrations of what each principle might include. The bullet points are not meant to be an exhaustive list. More detailed practical principles and guidance are offered in Section II.

Mutual respect: developing research relationships based on mutual respect, including a commitment to:

- Agreeing what counts as mutual respect in particular contexts
- Everyone involved being prepared to listen to the voices of others
- Accepting that there are diverse perspectives

Equality and inclusion: encouraging and enabling people from a range of backgrounds and identities (e.g. ethnicity, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part in the research, including a commitment to:

- Seeking actively to include people whose voices are often ignored
- Challenging discriminatory and oppressive attitudes and behaviours
- Ensuring information, venues and formats for meetings are accessible to all

Democratic participation: encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need, including a commitment to:

- Acknowledging and discussing differences in the status and power of research participants, and working towards sharing power more equally
- Communicating clearly using language everyone can understand
- Using participatory research methods that build on, share and develop different skills and expertise

Active learning: viewing research collaboration and the process of research as an opportunity to learn from each other, including a commitment to:

- Ensuring there is time to identify and reflect on learning during the research, and the on ways people learn, both together and individually
- Offering all participants the chance to learn from each other and share their learning with wider audiences sharing responsibility for interpreting the research findings and their implications for practice



Making a difference: promoting research that creates positive changes for communities of place, interest or identity, including:

- engaging in debates about what counts as 'positive' change, including broader environmental sustainability as well as human needs or spiritual development, and being open to the possibility of not knowing in advance what making a 'positive difference' might mean
- valuing the learning and other benefits for individuals and groups from the research process as well as the outputs and outcomes of the research
- building the goal of positive change into every stage of the research

Collective action: individuals and groups working together to achieve change, including a commitment to:

- identifying common and complementary goals that meet partners' differing needs for the research
- working for agreed visions of how to share knowledge and power more equitably and promote social change and social justice
- recognizing and working with conflicting rights and interests expressed by different sections of communities or by different communities

Personal integrity: participants behaving reliably, honestly and in a trustworthy fashion, including a commitment to:

- working within the principles of communitybased participatory research
- ensuring accurate and honest analysis and reporting of research
- being open to challenge and change and prepared to work with conflict

2.1.1. The NANA's approach to research ethics is consistent with European Commission's

Twelve Golden Rules to Ethical Research Conduct:

2.1.2 You must ensure that your research:

1. Respects the integrity and dignity of persons (that this intrinsic worth protects them from being used for greater perceived benefits);
2. Follows the "Do no harm" principle. Any risks must be clearly communicated to subjects involved;
3. Recognizes the rights of individuals to privacy and personal data protection;
4. Honours the requirement of informed consent and continuous dialogue with research subjects;
5. Treats animals with respect and work under humane conditions before, during and after the research;
6. Designs animal research in accordance with the 3 Rs: Replacement, Reduction, and Refinement;



7. Respects the principle of proportionality: not imposing more than is necessary on your subjects or going beyond stated objectives (mission creep);
 8. Treats societal concerns seriously - a researcher's first obligation is to listen to the public and engage with them in constructive dialogue, transparently, honestly and with integrity;
 9. Tries to prevent being openly available for misuse or malignant dual use by terrorists or military organizations.
 10. Recognizes the wholeness of an individual and that any modification (genetic or technological) does not interfere with this principle;
 11. Respects biodiversity and does not impose irreversible change that threatens the environment or ecological balance;
 12. Builds on the understanding that any benefits are for the good of society, and any widely shared expressions of concern about threats from your research must be considered (with the acceptance that perhaps certain research practices might have to be abandoned).
- 2.1.3 All research conducted under NANA auspices is expected to be consistent with these provisions, and researchers are expected to take account of them in their research design.
- 2.1.4 Six Principles governing research at the NANA Girls and women empowerment initiative:
1. Autonomy/respect – participants' ability to think, decide and act freely.
 - i) Autonomous individuals are able to make independent decisions, while those with diminished autonomy are entitled to protection;
 - ii) This principle of respect underpins core practices including informed consent, protection of vulnerable participants' rights to privacy, anonymity and confidentiality;
 2. Beneficence – to do some good.
 - i) Noting that benefits may be direct or indirect, and may including contributions to knowledge
 3. Non-maleficence – to do no harm.
 - i) Noting that the risk of harm is often balanced against other principles, especially beneficence, and
 - ii) that at best the risk of harm in research can be minimized, not guaranteed



4. Justice – fairness and equity

- i) This usually requires an assessment of who benefits from the research, who bears the burdens or takes the risks, and
- ii) requires research designs that ensure equity of treatment of participants.

5. Fidelity – honesty, integrity, trust.

- i) All research is a collaborative venture, whether it is with participants, other researchers or other source material; fidelity therefore incorporates other principles such as integrity, trustworthiness and honesty.

6. Academic freedom.

- i) That is, the right of the researcher to design, conduct and disseminate their research freely and without interference including from funders, commercial companies, governmental or institutional pressures.

2.2 General Responsibilities

2.2.1. Towards research participants

NANA researchers have a responsibility to ensure as far as possible that the physical, social and psychological well-being of their research participants is not detrimentally affected by the research. Research relationships should be characterized, whenever possible, by mutual respect and trust.

2.2.2. Towards other researchers

NANA researchers should avoid, wherever possible, actions which may have deleterious consequences for other researchers or which might undermine the reputation of their Organization. Those directing research should bear in mind their responsibilities towards members of their research teams and should aim to anticipate and guard against the possible harmful consequences of the research for team members.

2.2.3. Towards themselves

NANA researchers should avoid, wherever possible, actions which may have deleterious consequences for themselves. In many research settings researchers are vulnerable to various forms of harm, including physical, psychological and reputational harm.

2.3. Informed Consent

2.3.1. Research should be based, as far as possible and practicable, on the freely given informed consent of those under study and is the principal means by which participant's autonomy is recognized and given meaning. However, it is recognized that in some cases it may be necessary to employ covert methods should these constitute the only means to obtain the required data. In such cases, please refer to the information below.

2.3.2. It is the responsibility of the researcher to explain as fully as is reasonable and appropriate, and in terms meaningful to the participants: the aims and nature of the research, who is undertaking it, who is funding it, its likely duration, why it is being undertaken, the possible consequences of the research, and how the results are to be disseminated. The research should also make sure to explain what happens to the data once the research project is completed.

2.3.3. The power imbalance between researcher and researched should be considered. Care should be taken to ensure that the latter are not pressurized into participation. Research participants should be aware of their right to refuse participation at any time, including withdrawal from a research project at any stage, and should not be given the impression that they are required to participate. This is a particular concern in projects where researchers play other roles, including but not limited to being a worker, in the research site. It should also be recognized that research may involve a lengthy data-gathering period and that it may be necessary to regard consent not as obtained once and for all, but subject to re-negotiation over time.

2.3.4. The researcher should explain how far research participants will be afforded anonymity and confidentiality and participants should have the option of rejecting the use of data-gathering devices such as video cameras and audio and digital recording devices. Participants should also be made aware during the consent process whether the data set will be made publicly available and the implications of that availability: this is a requirement for many publicly funded projects, and in many disciplines, especially in the experimental sciences, is becoming considered best practice. In cases where data sets will be archived, in repositories or elsewhere, researchers should pay careful attention to issues of anonymity and confidentiality, including in respect of anyone who might be identifiable from the data set.

2.3.5. If there is a likelihood of data being shared with or divulged to other researchers, whether through archives, repositories or other means, the potential uses of the data should be discussed with the participants and their explicit agreement to such use should be obtained.

2.3.6. Researchers should be aware of additional data protection legislation and the responsibilities they have towards the collection, storage and use of data.

2.3.7. Where access to a research setting is gained via a 'gatekeeper' the researchers should also obtain the informed consent of research participants, while at the same time taking account of the gatekeeper's interests. It should be borne in mind that the relationship between research participant and gatekeeper may well continue long after the research has been undertaken. Where researchers are studying in locations where they also occupy other roles; the potential for misinterpretation by the participants should be considered. This may be significant

where the researcher also has organizational power over the participants.

2.3.8. Where research participants are young children or other groups that may be made vulnerable in or by specific social conditions relevant to the research such as elderly, disabled or sick people, or people with learning difficulties whose understanding is impaired in some way so that they are unable to give full informed consent, it may be necessary to use a proxy in order to gather data. In this case great care must be taken not to intrude upon the privacy of the vulnerable participants.

The researcher should consult relevant professionals, care-givers, parents/guardians and relatives, as appropriate.

2.3.9. In some cases when working with people with diminished autonomy, such as young children or people whose understanding is impaired in some way so that they are unable to give full informed consent, a system of informed assent may be possible: that is, in these cases agreement to participate does not need to be verbal or written, but it does need to be explicit and evidenced. Assent, that is non-verbal or non-written agreement to participate, may only be used in projects **approved under the terms of categories identified in Section 2.6 of this handbook.**

2.3.10. Researchers should obtain the informed consent of children and their parents in relation to School children who are in loco parentis.

2.3.11. In addition to obtaining the informed consent of those under study, researchers should attempt to anticipate and guard against the possible harmful consequences of their research on

participants.

2.3.12. In cases where a researcher may have professional obligations, such as through professional registration provisions, additional to those expected by best practice, research participants should be made aware of those obligations.

2.5. Confidentiality and Anonymity

2.5.1. The anonymity and privacy of research participants should be respected and personal information relating to participants should be kept confidential and secure. Researchers must comply with the provisions of current data protection and privacy legislation and should consider whether it is proper or appropriate even to record certain kinds of sensitive information.

2.5.2. Where possible, threats to the confidentiality and anonymity of research data should be anticipated by researchers and normally the identities and research records of participants should be kept confidential, whether or not an explicit pledge of confidentiality has been given.

2.5.3. Whilst the researcher should take every practicable measure to ensure the confidentiality and anonymity of research participants, s/he should also take care not to give unrealistic assurances or guarantees of confidentiality. Research participants with easily identifiable characteristics or positions within an organization should be reminded that it may be difficult to disguise their identity totally without distorting the data.

2.6. Approval Requirements

2.6.1. Research subject to approval at NAAN Girls and women empowerment initiative

2.6.1 All research involving human must demonstrate ethics approval by relevant authorities through NANA research and publication Unit.

2.6.1.4. Certain classes of research where procedures vary from standard procedures in particular, covert research and research where the data are not recorded in a manner that protects the anonymity of subjects or participants;

2.6.1.5. Research where the research topic is dealing with sensitive aspects of the subject's or participant's behaviour, or where proposals for research involve vulnerable populations. With the exception of children and young people (below), in all cases 'sensitivity' shall be a judgement determined by an assessment of:

i) the research questions

ii) the research design

iii) the recruitment procedures;

2.6.1.6 Proposals for research that involve vulnerable populations. With the exception of projects where participants are children and young people (see below), in all cases ‘vulnerability’ shall be a judgement determined by an assessment of:

i) the research questions

ii) the research designs

iii) the recruitment procedures;

2.6.1.9. Research involving assent-based participation, as defined in section 2.3.8 above. For the NANA Girls and women empowerment initiative purposes, assent is when verbal or written agreement to participate is not feasible. Assent is therefore always implied and not stated.

2.6.1.10. Procedures for gaining approval are contained in section 3.0.

2.6.3.1. Generally, decisions shall be made at a schedule NANA Research and publication unit meeting for review and approval of any research as well as follow up with other authorities in case of external approval.

2.6.3.4. In reviewing applications for ethical approval, NANA Research and Publication Unit (NRPU) will:

i) Review and approve, or withhold proposals for proposed research projects;

vi) NANA Research and Publication shall provide a quarterly report to the NANA Research and documentation Department.

vii) Oversee a data base of submitted proposals and NANA research activities aswell as formally document the final report. this database should include a record of all interviews audio, video, consent, assent and other research activities.

2.6.4 Researcher obligations

2.6.4.1. In making a submission for ethical approval, NANA team/researcher should not undertake and/or begin the proposed research until it has been approved; to adhere to the project design and principles as approved.

3.0. Part B: Ethical Procedures

3.1. Introduction

Following the principles that underpin the NANAs general quality assurance systems, responsibility for ensuring that research is conducted in an ethical way lies at the closest point possible to its actual conduct. Responsibility for the ethical conduct of research, therefore, rests primarily with the department who is planning and undertaking the project, supported by the NANA research and documentation department

3.2. Practice Principles and Guidelines

This section focuses on how to put the ethical principles presented in Part A into practice and offers some brief guidance. It is not designed to offer comprehensive practical guidance about how to conduct a community-based participatory research project, but rather to outline some of the ethical issues that NANA staff should think about.

3.2.1 Preparing and planning

Before starting out to do research, NANA shall involve the parties and go through the preliminary phase of checking out expectations, including considering whether the proposed research project and/or research partnership is a good idea at all.

3.2.1.1 Why work together? At the start, NANA shall involve all stakeholders to get to know each other, discuss their hopes and fears for the research and share what they want to get out of it. What are the commonalities and differences? Is it going to be practical and productive to work together? At this point it might be decided that the research or proposed partnership is not going to work or that some expectations need to be changed. Sharing experiences and stories can be a useful part of the process to find out common values and aspirations.

3.2.1.2 Who should be involved? Given the purpose of the proposed research, are there certain people or groups with expertise, experience or interest in the topic who should be invited and what might be the barriers to their participation? Is there a group of people that deliberately or unintentionally excludes others for no good reason? Some people may have the capacity and desire to be heavily involved whereas others may dip in and out. Anticipating and managing the different levels of involvement is important to ensure nobody feels either pressured to contribute, or deliberately excluded.

3.2.1.3 What are the aims and objectives of the research? Are all parties clear about why they want to do the research and what they want to get out of it? It is important to involve as many people as possible in the process of designing the research and to take account of different expectations of the purpose of the

research – being clear which aims and objectives can be agreed by all and which may need to be modified or changed.

3.2.2.1. Doing the research

Having established that there is potential to work together, decided who to involve and agreed a set of aims and objectives, it may be useful to develop a ‘working agreement’ about how to work together. This need not be regarded as fixed or unchangeable – as community-based participatory research is not always controllable and may develop in unexpected ways. For this reason, it may help to provide a framework that can be reviewed and revised on an ongoing basis. This may include practical details of working relationships, as well as an outline of how to ensure that people who provide research data are protected and credited.

3.2.2.2. How will the participants work together as research partners? The working agreement might include:

- Agreed ethical principles, such as those listed on the previous page
- Protocol for communications, including preferred ways of communicating (e-mail, skype, face-to-face meetings), expected frequency of communications and meetings, how to ensure that a few participants do not dominate and that people speak in plain language
- Protocol for safety, including procedures for researchers working on their own
 - Protocol for handling difficulties and conflict, including ways to sort things out if people disagree, fall out and things go wrong
- Agreed aims and objectives of the research
- Methods to be used, including how these will reflect a commitment to participation
- Management of research, whether by a research team, partnership, steering group or other means, including acknowledgement that leadership roles may change throughout the research process
- What funding is available to whom, for what, and who will allocate and be accountable for the budget. If some researchers are volunteers, it will be important to agree payment for time and expenses
- Any training required for the research partners (e.g. professional researchers needing training in the specialist field of the community partner or community partners in specialist research methods)
- Practical details of who will take responsibility for what, e.g. research design, data collection, analysis, interpretation and dissemination when and where meetings will be held



- Processes for reflection, evaluation and learning from each other and from the research throughout the process

3.2.2.3. How will researchers handle information and treat people who provide it? The working agreement might include more details about handling and using information of the kind usually required by research ethics committees (indeed, the following might provide the basis for a submission to a research ethics committee):

Informed consent: NANA staff shall ensure as far as possible that people who provide information or allow access to aspects of their lives as part of the research are given information about the purpose and uses of the research data. As they need to know enough about it to be able to decide whether to participate (or for their parent/guardian/ consultee to agree). In NANA's research approach those who may need to give consent might include community and professional researchers (who may be both collectors of information from others and providers of information themselves), as well as people who are invited to participate in information-collection aspects of the research only. Sometimes it is not only the consent of individual people that is required, but also collective consent (e.g. of a community, group or organisation). It is also important to acknowledge that the purpose and uses of the research may change and develop over time, so consent may need to be continually reviewed and renegotiated, especially as specific plans for publication and dissemination are developed.

Handling personal information: In all NANA's research, it is important to ensure that identifying information (e.g. names and addresses) is stored separately from other personal information collected as part of the research (e.g. interview transcripts, questionnaire responses) and securely (e.g. in a locked filing cabinet, password protected computer). In NANA's research it is vital that researchers who are also community members, neighbours or relatives take particular care in safeguarding personal data that may be stored in community centres or neighbourhood projects.

Confidentiality: In Nana's research when community researchers are collecting data from and about people they know, or live near, they are trained and advised to be very careful about confidentiality. If someone tells a researcher something that is personally compromising or that they do not wish to be passed on to others, it is important to honour this. It may mean that information cannot be directly used in the research, and should not even be passed on to other members of the research team. Alternatively, it might mean the information can be used, but people's names and other identifying features of the situation shall be removed. NANA understand social media (eg facebook and twitter etc) affects issues of confidentiality, at early stage NANA research team shall be as clear as possible about how confidentiality will be handled in order to avoid causing harm or embarrassment to people. Usually, in social research, a limit is placed on confidentiality in circumstances where researchers get to hear about unlawful or risky behaviour, suspected child/ adult abuse and/or where there may be a risk of serious harm to other people. The circumstances of disclosure should be made clear to those participating in the research in advance.

Anonymity: It is a good idea to discuss in the research team and with others involved in the research the advantages and disadvantages of identifying people, places and organisations (by their real names, appearances or voices in written, visual or audio records or social media) – whether this is in team discussions or dissemination of the research. If research relates to sensitive topics or contexts (e.g. household debt, mental health, domestic violence, public protest, crime), it is often important not to name or give identifying features of individuals. It may also be advisable to give organisations and places



different names, as using real names may help identify people. However, in some cases, individuals and organisations may wish to be named, to have their opinions, achievements or challenges credited or highlighted. Yet naming some people needs to be discussed fully and consideration given to the implications for the anonymity of others.

Ownership, control and use of the research data and findings: When research is a collaboration between several people or partner organisations it is important to be clear who ‘owns’ any data, new knowledge or collaborative outputs that have been produced. ‘Ownership’ in this context means the right to use it and pass it on. If it is jointly owned, then it is important to decide what rights each partner has to use the data to inform their work or produce publications and whether the permission of all partners is required. Sometimes a funder may control the use of data and findings, and all parties need to be clear about the implications of this from the outset. It is particularly important that recognition is given to new knowledge made by communities and that when appropriate they receive financial rewards and have the right to own and use it.

3. Sharing and learning from the research During the course of the research, or once the findings have been drawn together, the research team will usually want to share the research with others – people in the locality, community organisations, policy makers, politicians, academics and others.

3.1 How to analyse and interpret research data and findings? There is often a tendency for professional researchers or more experienced community members to take responsibility for analysis and interpretation of the research data. However, involvement of a range of people in analysis and interpretation of findings can be an opportunity for the development of new skills. It may require more time, training and creative thinking about inclusive processes, but may add valuable alternative perspectives on what some of the findings mean and contribute to the thinking about problems and solutions.

3.2 How to share the research? In CBPR the process and findings may be shared with others as the research progresses, and there may be a wide range of different audiences and research users to consider.

What to share?: Sharing research findings can have both positive and negative effects on communities. For example, sharing accounts and analyses of social problems of particular groups or neighbourhoods might be expected in a report to research funders or service providers, and may result in heightened awareness of inequalities and/or improved services. But this may have a negative effect on the self-esteem of community members. Open, honest discussions and negotiations about what to share, how to share it, desired outcomes and possible negative impacts should be an ongoing part of the research process.

Formats for dissemination: If a range of different audiences is anticipated, it is important to consider the most accessible format to reach people, e.g. visual materials including film, art, cartoons and photos; performance arts including theatre and music; written reports, magazine articles, academic papers and books; conferences, workshops and celebratory learning events; or web-based materials. It is also important to consider what formats may suit the skills of different members of the research team, and several different types of outputs geared to different audiences might be produced.



Authorship and credits: It is a good idea to discuss in advance who will be responsible for compiling or writing the outputs, when decisions will be made about the nature and formats of outputs and how the responsibility can be shared and skills developed by those who are not used to doing this. Although it may be time-consuming, holding writing, editing, film or photography workshops, where people work and learn together, can be an empowering and satisfying process for all concerned. Agreeing who will be credited and how is also important – ensuring that the variety of contributions is recognized.

3.3 How to make an impact? Once a particular research project has been written up or when the funding runs out, this is not necessarily the end of the process.

Implementation: It can be useful to think about how to use or implement the findings and followup any recommendations for change in practice, policy and ways of working.

Producing useful outputs: Consideration should be given to ensuring that any reports or other products of the research are made accessible to other researchers, policy-makers, service providers, community members and organisations for future use. Additionally, it is important to ensure that the skills and knowledge gained by all of the partners is capitalised upon in further research or action projects.

Learning from the research: It can be very productive for the research partners to reflect on what they have learnt. Not just from the research findings, but also from the process of doing the research and working together. If the relationship has gone well, or has potential to go well, then a longer term research partnership may develop.

Good endings: At some point the relationships that were formed around the research may have to end (funding ends, people move on). So it is worth thinking about how endings should be negotiated to ensure the benefits of the research can continue into the future and some participants do not feel let down