



DFID ethical guidance for research, evaluation and monitoring activities











Foreword

DFID is committed to supporting the generation and use of rigorous evidence, to drive the effectiveness of our and others' development work. This means a strong commitment to research, and also to the rigorous monitoring and evaluation of our programmes. It is crucial that activities conducted are fully in line with DFID's stated values and adhere to established international standards in research ethics.

In universities and many other research organisations, Institutional Review Boards (IRBs) and Research Ethics Committees (RECs), alongside national ethical review boards, are responsible for ensuring that research activity is conducted in a manner consistent with established ethical standards. However, some research, monitoring and evaluation work may fall outside of the remit of such bodies.

In an effort to ensure that the collection and use of all data commissioned by DFID is conducted in a manner that adheres to appropriate ethical standards, we have prepared this guidance, based around the project planning and implementation cycle. We hope that this will be a useful tool both for those commissioning and those implementing research, evaluations and monitoring, to ensure that they reflect on their responsibilities to ensure that ethical issues are appropriately considered in their work.

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This guidance and FAQ was prepared for DFID by IOD PARC in May 2019, for DFID to use as a working document.





Purpose of the guidance

The Department for International Development (DFID) leads the UK's work to end extreme poverty. DFID's work is framed by the Sustainable Development Goals (SDGs), which tackle global challenges, including those related to poverty, inequality, climate, environmental degradation, prosperity, and peace and justice. The purpose of this ethical guidance is to enable DFID's research, evaluation and monitoring activities to support its work in addressing these global challenges.

Who and what is this guidance for?

This guidance is for all DFID staff, contractors and subcontractors who undertake or commission research, monitoring or evaluations. The guidance is structured by the different stages of the research, evaluation and monitoring lifecycle set out below (Commissioning, planning and design; Data collection and analysis; Reporting and dissemination; and Monitoring and follow up). For each stage the guidance shows the most relevant DFID ethics standard(s).

Ethical dilemmas can arise at any point in the lifecycle. Researchers, evaluators and commissioners must keep DFID's ethical principles and standards in mind across all of the lifecycle stages. Use these guidelines thoughtfully and intelligently. They are not just a checklist. Working ethically requires you to reflect regularly on the ethical questions raised by your work and adopt a culture of dialogue and learning. It requires you to take personal moral responsibility for acting with honesty, integrity and respect for others.











DFID's ethics principles and standards for research, evaluation and monitoring





DFID's ethics principles

This guidance is based on clear ethical principles. These are the values which inform DFID's research, evaluation and monitoring activities.

- Seek to maximise benefit and minimise harm.
- Respect people's rights and dignity.
- Act with honesty, competence and accountability.
- Deliver work of integrity and merit.

All research, evaluation and monitoring decisions must be aligned with these four principles.

They are consistent with the Civil Service's core values of **Honesty, Integrity, Impartiality and Objectivity** and the humanitarian principles of **Humanity, Neutrality, Impartiality and Independence**.











DFID's ethics principles and standards for research, evaluation and monitoring





DFID's ethics standards

DFID's ethics standards set out what is required for the ethical conduct of research, monitoring and evaluation activities. They are aligned with the four ethics principles on the previous slide.

- Research, evaluation and monitoring is useful and necessary.
- Design and conduct of research, evaluation and monitoring work is sensitive to cultural, socio-economic, environmental and political context.
- Harms to individuals and communities are minimised and benefits maximised, risks are identified, and mitigating actions are taken.
- Identity and confidentiality is protected and data are secure.
- Participation is based on informed consent.
- People's rights and dignity are respected and there is equitable participation.
- Findings are disseminated to intended beneficiaries and used appropriately.











DFID's ethics principles and standards for research, evaluation and monitoring





DFID's expectations

- DFID expects research and any other forms of data collection and analysis conducted on DFID funded projects to be guided by the ethical principles and standards stated in this guidance.
- For research studies, it is expected that alignment with these principles and standards will normally be assured by submission of relevant protocols for review by the researchers' Institutional Review Board (IRB)/Research Ethics Committee (REC) and the relevant regulatory authority in the country where the research is to be completed.
- For evaluations, monitoring and other activities where submission to an IRB/REC is not generally required, DFID expects the planning of data collection and analysis to reflect active consideration of these principles.
- DFID has prepared this guidance to prompt consideration of ethical issues at each stage of the project cycle.











Guidance across the research, evaluation and monitoring cycle

Monitoring and/or follow up

Commissioning, planning and design

Reporting and dissemination

Data collection and analysis

Click the segments in the wheel to reveal more information...











Commissioning, planning and design

Is the research, evaluation or monitoring work useful and necessary?

Do commissioning processes ensure high ethical standards are followed?



Is the design fit for purpose and appropriate to context?



Are robust safeguarding policies and processes in place?



Are there robust processes in place to manage and mitigate risks and maximise benefit?













Data collection and analysis

Are identity and confidentiality protected and data secure?



Is participation based on informed consent?



Does the method and implementation respect people's rights and dignity?



Is participation supported by a two-way feedback process?











Reporting, dissemination and use of evidence

Is the utilisation of learning and evidence products maximised?





Does the evidence and learning have integrity and merit?













Monitoring, follow up and data use

Is the use of research and evaluation data collected ethical?



Is ongoing monitoring governed by DFID's ethical principles and standards?

















Is the research, evaluation or monitoring work useful and necessary?

Ethics Standard: Research, evaluation and monitoring is useful and necessary?

- How will the evidence and learning generated be of utility to different audiences, including international, national, institutions, local communities and the intended beneficiaries of a given intervention?
- Are the timeframe and resources realistic to achieve the intended purpose and outcomes, including good quality dissemination of findings?
- Have the potential benefits been weighted up carefully against potential harms to individuals and communities, particularly in conflict and humanitarian settings?
- What are the benefits to the public and participants?
- Is there a risk of harm to people not involved in the work or from its findings?
- Will it provide value for money for tax payers? Are there other or more cost-effective ways of obtaining the
 evidence you require? Have you checked that others are not doing or have not already commissioned similar work
 with a similar group of people?
- Has an evaluability assessment been made? Are expectations of the work reasonable in view of the resources and timeframe available?
- Have you planned and budgeted for the dissemination of the research/evaluation findings? Is the budget sufficient to fund different ways of communicating findings to different stakeholder groups, including beneficiaries?



















Is the research, evaluation or monitoring work useful and necessary?

Research Ethics tool for humanitarian settings, <u>ELHRA</u>. This tool shows guidance in relation to ethics and research in humanitarian contexts.

Guidance on conflict sensitivity. A website with many useful links and guidance on conflict sensitivity.

Hunt, M. (2017) Ethics of and ethics in humanitarian research. This discusses the ethics of humanitarian research, and how to effectively engage with communities.

<u>Guidance to carrying out an evaluability assessment</u>, Useful information and tools for considering and assessing evaluability before undertaking a potential research or evaluation project.

<u>WHO - Code of conduct for responsible research</u>: link has two helpful guides, one of which discusses the WHO's code of conduct for responsible research, with the other discussing misconduct in research. Other ethical issues are also discussed, for example ethical principles and the WHO's work on preventing sexual exploitation and abuse.

DFID Supply Partner Code of Conduct. This gives information on the standards of conduct that DFID expects from its suppliers.

<u>Australian Council for International Development, Principles and Guidelines for ethical research and evaluation in development.</u> Discusses ethical guidelines in research and evaluation. It covers all stages of the research/evaluation cycle and also has some useful resources and supporting documents.



















Is the research, evaluation or monitoring work useful and necessary?



Is the work necessary and good value?

Dilemma: There has been a request to conduct an evaluation of a programme. The programme is similar to other programmes carried out in the last ten years, each of which has already been evaluated. It is not clear what the additional benefits of this evaluation will be. There are costs associated with carrying out the evaluation to DFID, the relevant country(ies), evaluation participants, and UK and country tax payers – is the evaluation good value for these constituent stakeholders?

- Before commissioning the evaluation, carry out a review of other relevant evaluations, to identify their evidence, learning and gaps in evidence. From this, identify where the evaluation can add value/fill gaps.
- Develop a term of reference informed by the review, tailored to gaps and new learning, and building on existing data and analysis.
- Note that in an ideal world, such a review would precede the programme design so that opportunities for learning are maximised.
- If there is no clear benefit, consider not undertaking the work.



















Is the research, evaluation or monitoring work useful and necessary?



Deciding whether to carry out research in a conflict/fragile situation

Dilemma: Research is proposed which will take place in a refugee camp. This will inevitably pose an extra demand on people living in the camp as well as the people managing it. The research is interesting, but findings will not necessarily benefit the refugees directly.

- Assess the benefit to people who are currently living in the refugee camp and people who may need to live in the camp in the future. Is the research likely to enhance lives or wellbeing? If not, are there other ways of obtaining the information that you need that avoid the need to go into the camp? What other data sources are there, or ways of obtaining information for example secondary data?
- If the research will have a direct impact on people living in the refugee camps, it is important to give intended the beneficiaries an opportunity to feed into the research so that it is participatory. This will need to be done with care and according to the standards pertaining to: respect, dignity, informed consent, data protection, beneficiary feedback, sensitivity and risk mitigation.



















Is the research, evaluation or monitoring work useful and necessary?



Inadequate budget for the work required

Dilemma: The terms of reference do not allocate enough time or resources for the evaluation, including planning, dissemination and use of the findings. This will seriously limit our capacity to gain robust evidence and learning in a way that engages stakeholders appropriately. There is a risk of substandard work. This could potentially have a negative impact on the programme, as well as having potential for reputational damage to both DFID and contractors. What do we do?

- Highlight your concerns and request that the proposal is reviewed by the commissioners.
- Options for them would include finding more budget and time or changing the scope of the terms of reference, (in discussion with stakeholders) so that a more limited evaluation can be delivered within budget and time.
- Another option is to decide to discontinue the evaluation.



















Do commissioning processes ensure high ethical standards are followed?

- Do you as a commissioner or contractor have the necessary skills? For instance have you received ethics training?
- Do contractors have ethics guidelines in place acceptable to DFID?
- For a research proposal, will it be submitted to a Research Ethics Committee (REC) or Institutional Review Board (IRB) for approval? (All research proposals should be.) Have you explored use of local RECs/IRBs or the contractors' own REC/IRB?
- For an evaluation, does the quality assurance process include an explicit assessment of ethical risks and mitigation proposals? Would it benefit from a REC/IRB assessment?
- For a monitoring and data management contract, does the quality assurance process include an explicit assessment of ethical risks and mitigation proposals?
- Is regular reporting of ethical challenges and mitigating actions planned across the life of the research, evaluation or monitoring project?
- Have you explicitly considered and addressed DFID's ethics standards in drafting the terms of reference and in the assessment of proposals?



















Do commissioning processes ensure high ethical standards are followed?

<u>Building ethics into the research design, Research Ethics Guidebook, ESRC</u> provides a guide to ethics in relation to sampling, consent, confidentiality and research methods in social science research.

<u>Getting approval for research with human participants – research ethics committees</u> (RECs), Epigeum Ltd 2012: Explains the process of getting ethical approval for research with human participants, it highlights issues pertaining to health research and when research requires ethical clearance.

<u>UNICEF Introduction to Ethics in Evidence Generation</u>. This is an online course provided by UNICEF. Primarily for UNICEF staff, it is also for anyone who is interested in knowing more about UNICEF's approach to ethics and evidence generation that involves children. It takes 90 minutes to complete.



















Do commissioning processes ensure high ethical standards are followed?



We are required to use two RECs – how can we do this well?

Dilemma: The research is due to be reviewed by two research ethics committees - one in-country REC and the REC of the academic institution that the researchers are employed by/affiliated to. This may lead to making different recommendations from each REC, how do we avoid this?

- Speak to both REC leads to see whether there is scope for avoiding duplication and/or contradictions, and opportunities for alignment of questions and timescales.
- If the REC leads do not agree to use each other's processes, ask them to agree to coordinate over timescale to reduce delays; and to discuss any differences in finding an aligned approach and report.



















Do commissioning processes ensure high ethical standards are followed?



Does an evaluation require approval by a REC/IRB?

Dilemma: Does the evaluation require approval by an REC/IRB? It is a large, complex evaluation; although we are told that REC/IRB approval is not required, we think that it may be helpful.

- The primary reason for exempting evaluations from REC/IRB scrutiny and approval is that evaluations are not seen as developing or contributing to generalisable knowledge, rather that they are undertaken to improve a specific practice or programme. You will need to consider whether the evaluation confirms to this rule of 'thumb'; and may decide that it would benefit from REC/IRB approval. Larger and more complex evaluations, especially if they use quasiexperimental methodologies are more likely to be suitable for REC/IRB submission. Quality assurance mechanisms for large evaluations should also, ideally be in place.
- You could identify a REC/IRB from a local institution such as a university and obtain guidance from them.



















Do commissioning processes ensure high ethical standards are followed?



We do not have an ethical quality assurance process in place

Dilemma: We are due to undertake an evaluation, but we do not have an ethical quality assurance process in place. Is there anything that we can do to ensure that we meet DFID's standards?

- Ask DFID if you can use the EQuALS checklist prior to developing the inception report.
- Approach an IRB/REC, to see if they can give you guidance on the work proposed.
- Review the standards in this guidance and apply them systematically.



















Is the design fit for purpose and appropriate to context?

Ethics Standard: Design and conduct of the work is sensitive to cultural, socio-economic, environmental and political context

- Does the proposed design address the objectives, context and intended use of the research/evaluation/monitoring well?
- Are beneficiaries and stakeholders clearly defined?
- Has the design been developed collaboratively with stakeholders, including female and male beneficiaries?
- Are feedback processes to and from participants included?
- Does the method demonstrate how contractors will give due regard for the age, gender, abilities, background, culture, values and beliefs of participants?
- Do methods show awareness of local context (social, cultural, religious values and beliefs), and how these will be addressed and respected?
- Does the design and methodology address environmental impact both on the local context such as use of scarce water and power resources and on the global scale, such as minimising carbon emissions?



















Is the design fit for purpose and appropriate to context?

- DFID EQuALS review templates
- <u>University of Sheffield: Ethical Considerations in research with children and young people</u>: The University of Sheffield paper discusses in detail the ethics of working with children and young people as well as people with learning disabilities, research with people who lack the ability to consent and risks to the researcher.



















Is the design fit for purpose and appropriate to context?

Ensuring culturally sensitive methods

Dilemma: Study participants were children who did not speak English, and lived in a culture of high obedience and unquestioning respect to adults. The study required children to give frank answers, but this concerned the adult interpreters as it breached their expectations of children's behaviour. How can we get the data we need in a way which is sensitive to local attitudes?

- Using professional interpreters, with a traditional cultural approach may prevent the children speaking freely. Recruiting others, such as bilingual students, as interpreters avoids this problem.
- The local bilingual students should be trained on safeguarding issues, interview methods and on how to interpret with young children.



















Ethics Standard: Harms to individuals and communities are minimised and benefits maximised, risks are identified, and mitigating actions are taken

- Are safeguarding policies and processes for adults and children, staff contractors and sub-contractors in place that meet DFID's due diligence standards?
- Is there evidence that contractor staff are trained and aware of safeguarding policies and processes?
- Have safeguarding issues that affect vulnerable groups been identified e.g. people with cognitive impairments, socially or economically marginalised groups, people with disabilities, people with stigmatising conditions such as HIV or mental illness?
- Do contractor safeguarding policies and processes address:
- Sexual exploitation and abuse and other potential direct and indirect harms to individual and community wellbeing from research/evaluation implementation, dissemination and use of findings.
- The different situations and needs of children, women and men and vulnerable groups who are directly or indirectly affected by the research/evaluation.
- The evaluation/research team's safety and wellbeing.
- The specific needs of participants and staff in humanitarian and conflict situations.
- Processes for reporting and acting on information on any abuse/harm/exploitation disclosed.
- How differences between DFID's and local safeguarding standards and legislation will be addressed.



















<u>Child Safeguarding Standards, Keeping Children Safe 2014</u>: This guidance discusses four key standards on how to keep children safe: building child safe projects and programmes; reducing the risk of harm by staff, volunteers and associates; running safe events and activities for children; and ensuring good practice when using media.

<u>DFID's guidelines on Safeguarding see DFID Due Diligence guidance</u>: This guidance provides partners with details of the new standards and how they will be used in enhanced due diligence assessments (DDAs) to assess an organisation's ability to protect from sexual exploitation and abuse and harassment, children, young people and vulnerable adults they work with as well as their own staff and volunteers.

<u>Girl Effect (2018) Digital Safeguarding Tips and Guidance</u>. Girl Effect give 10 ways on how to ensure digital safety for children in the digital age in different contexts.

<u>UKCDR- International Development Research Funders Statement on Safeguarding, 2018</u>: Statement on a joint commitment to safeguarding by DFID, Department for Business, Energy & Industrial Strategy, the Department of Health & Social Care, UK Research and Innovation, Wellcome Foundation. It clearly states what is and is not acceptable in the development arena.





















Participant discloses experiences of gender violence

Dilemma: During a Mid-Term Evaluation of a Women's Economic Empowerment Programme, an evaluator is interviewing a female farmer. Although the semi-structured interview questions do not ask specific questions about violence, she tells the evaluator that her husband hospitalized her recently after she challenged him about sexually abusing their child. She explains that she is fearful for their safety. What are the evaluator's next steps?

- The evaluator should be clear in her/his introduction that if an interviewee reveals something to the researchers that raises concern, then confidentiality will need to be breached. They should have been clear about this and the implications of any disclosure. This would inform any consent obtained.
- The evaluator's company should have adequate safeguarding processes in place. These should require the evaluator to report the information confidentially to a designated safeguarding lead, without disclosing personal details of the woman and the child. Information and any subsequent actions can only be shared with the woman's consent.
- The safeguarding lead should provide specialist advice on next steps; safety and possible onward referral pathways should be identified and offered to the woman, for instance information on support for women and children facing violence and abuse.
- All communications with the woman must be handled with complete confidentiality and care for the safety of the woman and her child.





















Team members harassing or abusing beneficiaries

Dilemma: During the course of undertaking an evaluation with vulnerable women, a member of the project team made sexual advances and innuendoes towards beneficiaries of the project. The person who has told us about these alleged instances did so because they felt that they had no one else to confide in.

Guidance:

This information should be reported promptly to the contractor's lead for safeguarding/company who should suspend the person pending investigation. If the person has behaved inappropriately, e.g. harassing or abusing beneficiaries, they should be dealt with using the contractor's own code of conduct and disciplinary process, and removed from the evaluation. The issue should be reported promptly to DFID.





















Team members harassing other team members

Dilemma: A well-respected national consultancy firm is contracted. The Principal Investigator is responsible for hiring a mixedsex team of enumerators to collect survey data. Two of the female enumerators contact the DFID country evaluation lead to say that in the coach on the way to the field work, the Principal Investigator and one of the male enumerators were watching pornography on their phones and the enumerator later asked the woman questions about her sexual history. They ask the DFID evaluation lead what they should do, as they do not want to continue working with these men.

Guidance: The DFID lead identifies sexual misconduct and reports it to a DFID Safeguarding Lead and the contractor company's director. The DFID lead should ensure that the women affected are supported, are safe and not at risk of harm. Other potential actions include:

- Suspension of evaluation activities.
- Breach of code of conduct may lead to individuals being removed from the contract and potentially termination of contract.
- Review of whether adequate hiring checks were completed by DFID.





















Safeguarding the participation of vulnerable groups

Dilemma: The community participating in the evaluation includes people with disabilities. Local researchers and community leaders are dismissive of the value of the inputs of disabled people, who occupy a low status position in local culture. The evaluators want to include the disabled people's views, however the evaluators are aware they may need support and the confidence to do so safely and without negative repercussions from their community. (This dilemma could apply to other disadvantaged or vulnerable groups.)

- Influence local leadership behaviours by discussing with local community leaders the value and importance of the input of people with disabilities and how they can show good leadership through supporting wider community participation, and engage them in preventing any subsequent negative behaviours.
- Suggest to the disabled or vulnerable person that the interview could be undertaken in a place of their choosing, somewhere where they feel comfortable. This could be their home or in a social setting of their choice where they feel safe.
- Ensure that the people with disabilities are comfortable with whatever questions are asked (as in all interviews they can stop the process at any time).
- Whatever choice is made guard people's confidentiality stringently both in the field and in sharing findings as you do not know what may happen following your engagement.



















- Is there an active risk assessment and mitigation plan, including ethical, safeguarding, environmental and human rights risks?
- Are ways of maximising benefits to different stakeholders clearly identified?
- Have national/local stakeholders been consulted on risks, benefits and mitigations to check their accuracy and completeness in the local context?
- Are staff including subcontractors adequately trained in ethical behaviour?
- Are there processes for confidentially alerting accountable managers of safeguarding risks and incidents in place? Are there clearly identified accountable managers?
- Are there mechanisms in place for the provision of a timely remedy if ethics principles have been breached?
- Do contractors have the processes and skills to address ethical dilemmas as they arise through dialogue and negotiation with different stakeholders?
- For a research proposal, will it be submitted to a Research Ethics Committee (REC) or Institutional Review Board (IRB) for approval? (All research proposals should be.) Have you explored use of local RECs/IRBs or the contractors' own REC/IRB?
- For an evaluation, does the quality assurance process include an explicit assessment of ethical risks and mitigation proposals? Would it benefit from a REC/IRB assessment?



















Assessing risk and harm, ESRC Research Ethics Guidebook, provides an overview of approaches to assessing risks that arise in social research, definitions of benefits, risk and harm, with more detailed underpinning guidance.

Child Safeguarding Standards, Keeping Children Safe 2014: although focused on children's safeguarding processes, the guidance is relevant to wider risk management and mitigation for all age groups.

DFID's guidelines on Safeguarding see DFID Due Diligence guidance: These provide a summary of processes that should be in place to mitigate safeguarding risk.

DFID's Supply Partner Code of Conduct: This gives information on the conduct and standards that DFID expects from its suppliers.





















How do we put together an adequate risk management and mitigation plan?

Dilemma: There are potentially so many risks – how do we distinguish what to include? How do we assess risks?

- It can be helpful to develop a risk identification, assessment and mitigation plan as a team to ensure there is a common understating of risks and what can be done to mitigate them. Structure a plan and begin to populate it, revising iteratively with colleagues. Points in the plan could include, e.g. risks to implementation, risks to safeguarding, risks to ethics, risks to reputation, risks to security.
- Consult on the draft plan with the commissioner and with country/programme stakeholders who may identify other risks, or provide more information.
- Ensure you all have a common understanding of the impact and likelihood of the risks, and how to mitigate them
- Risk assessment should start from day one of the proposal and be actively reviewed and managed throughout the work as risks and their potential impacts evolve. Convince the commissioner that this is important – an actively used risk management plan will help both commissioner and contractor to ensure a high-quality process and product as well as an ethical one.





















What risks do we need to consider in conflict situations?

Dilemma: Conflict situations present a number of risks of harm to communities, research teams, the research methodology and ethical integrity.

Possible risks to consider include:

- How far are you prepared to put an evaluation team at risk? How do you deal with the need for data collection when working in communities experiencing trauma? How do you "do no harm" when even talking to a researcher can put someone at risk?
- Do you have the expertise to vet proposals, which are not subject to an ethics review board? Where an ethics review board is available, do they have the necessary understanding of the methodological, logistical, and political context within which such work is undertaken?
- How will political interests be balanced against ethical principles?





















What we do when an ethics standard is breached, for instance informed consent?

Dilemma: Often there is a strong commitment to ethics, but no underlying procedures for taking action in case of breach or clear accountability for ensuring compliance.

- · Identify what needs to be done in the case of potential ethics breaches and how they can be mitigated. Ensure there are clear processes for alerting the accountable manager and that there are whistleblowing guidelines to protect confidentiality.
- Ensure processes for reporting and acting on reports of breaches of confidentiality are publicly available and that staff, including subcontractors are aware of these and trained in their use.
- Allocate overall responsibility for ethical conduct for the work to the project lead, but also identify a different senior individual in the company to be accountable for ethical conduct, to whom any breaches should be reported.





















How do we ensure that we address beneficence and inclusivity?

Dilemma: How do we fully include the beneficiaries of the work and ensure that we avoid reinforcing existing power structures?

- When you organise venues, consider who is excluded through lack of consideration of inequalities and power relations in the local context.
- When you write up your analysis, whose voices dominate? Who has the final say when there are choices about what to include and what to leave out?
- Who receives the results of the evaluation and research? Who does not see them? Do we reinforce vulnerability and discrimination through our own approaches by failing to acknowledge the individual's knowledge and agency?
- In terms of research and evaluation with persons with disability (or other disadvantage), could you engage people with disabilities (or other disadvantage) as evaluators and agents of change?
- Be aware of the specific sensitivities that may apply in a conflict/post conflict setting.



















Are there robust processes in place to manage and mitigate risks and maximise benefit?



When do we prioritise duty of care to the individual over the greater good of the research learning?

Dilemma: A researcher gathering data in a randomised control trial notes a harmful practice in one of the households. The example is a gas servicing engineer, who was also a researcher, who spotted a fault with a gas meter looking at energy consumption in a control group. Should she raise this, although it was a pre-existing condition, or should the commitment to the integrity and value of the research mean she prioritises the research methodology?

Guidance:

Despite the risk to the completeness of the control group data, the researcher's duty of care to households is a higher order ethical responsibility, In such a case she should report the faulty gas meter. Similar issues might arise in a health study, where a person in a control is found to have a health condition/disease which requires treatment, although the treatment will mean the person is no longer suitable to be part of the control group



















Are there robust processes in place to manage and mitigate risks and maximise benefit?



Are we letting budget constraints limit our commitment to social justice and rights?

Dilemma: Limited funds and time mean difficult choices. Are we prepared to pay for our ethical commitment to social justice and rights or do we exclude them because of value for money considerations? For instance, to be inclusive, you may need to visit an indigenous community, this could require an additional day of travel away. Or you may need an interpreter to access some groups.

- Consider how you can reallocate funding to prioritise inclusion. Can you prioritise the extra costs of inclusion over, e.g. speaking to a larger number of people?
- Can the evaluation team be divided to ensure different groups are included at no extra budgetary/time costs?



















Are identity and confidentiality protected and data secure?

Ethics Standard: Identity and confidentiality is protected and data are secure.

- Is identity and confidentiality protected across the research, evaluation and monitoring cycle including qualitative and quantitative data collection, data storage, analysis and reporting?
- Are questions on socially or politically sensitive issues such as violence towards women, political views, HIV/AIDS, sexual and mental health, framed to avoid personal identification and/or by masking the purpose of the inquiry within a broader set of questions?
- Are any risks to confidentiality posed by use of web-based platforms identified and mitigated?
- Some participants, including children and young people, adults and people with impaired cognitive abilities will say they are happy to be identified. They might even offer to share their images and/or identity. Have you fulfilled your responsibility to minimise harm and ensured that this does not put them at risk?



















Are identity and confidentiality protected and data secure?

The General Data Protection Regulations (GDPR), guidance in brief to Data Protection Impact Assessments (DPIA) provides a quick overview of DPIAs and when you need to use them. There is a link to more detailed guidance if needed. The GDPR applies to all data which is processed in the UK and EU, so must be considered at an early stage.

<u>PIM (Protection Information Management) Framework for Data Sharing in practice, 2018</u>. The PIM Framework discusses responsible handling, sharing, and use of data and information how to protect people's data when data sharing.

Keeping Children Safe Online: A guide for organisations, 2014. This guide gives advice on how to keep children safe online.

<u>UNICEF procedure for ethical standards in research, evaluation, data collection and analysis</u>. The UNICEF guidance is comprehensive and covers the research/evaluation cycle. It gives clear definitions of what is assent and confidentiality as well for example, privacy. It also provides a tool that will help an organisation to ascertain if the UNICEF ethics procedure is applicable.

Children and the Data Cycle: Rights and Ethics in a Big Data World Innocenti Working Paper 2017-05, Gabrielle Berman and Kerry Albright provides an analysis of the risks to children from big data.

The UK Statistics Authority Data governance section of the Code of Practice for Statistics: these are the professional ethical standards that UK statisticians work too. The code guides working practice and addresses the requirements of partners in data collection.

The Open Data Institute Data Ethics Canvas: A useful tool to help explore the ethics around collecting, sharing and working with data. The canvas is designed to help identify potential ethical issues associated with a data project or activity and helps to promote understanding around the issues it raises and identifies the steps needed to act ethically in relation to data.



















Are identity and confidentiality protected and data secure?



A national government request for data sets

Dilemma: The evaluation team for a job creation programme working with small and medium enterprises received a request from the government line ministry for access to the full unanonymised set of evaluation data. The request was received after the baseline data had been collected.

Guidance:

Although DFID has an open data policy, the country office involved should decline the request to share the full unanonymised dataset. Providing the data would breach the ethical standard of protecting identity and ensuring that informed consent had been given by participants.



















Are identity and confidentiality protected and data secure?



Sharing photographs/images

Dilemma: Consent has been given by beneficiaries to use their photographs in publications and materials. However, you have a concern that photographs will identify people and there may be a risk of them experiencing negative consequences due to a potential perception that they may have benefitted from the evaluation/programme, or if they are thought to have provided information which has had a negative impact. What should you do?

- Using photographs must always be with the informed consent of subjects. The evaluator has a duty of care to
 consider whether there is a risk of negative future impacts on the subjects from publication, and should err on the
 side of caution. In the UK, it is standard practice to use models from an image library to illustrate evaluations and
 campaigns about people; this approach could also be considered.
- Consideration also needs to be given to whether images might be shared digitally on the web and then extended to social media, and the potential for exploitation of images especially of children and women and the consequent risks of harm. If this is assessed by your safeguarding lead as a risk, you should not use the photographs.



















Are identity and confidentiality protected and data secure?



Avoiding identifying individuals

Dilemma: Although the data that has been collected is anonymised, it is possible that the data may be used to identify the individuals who have been involved in the work, due to the small sample size and the known location where data collection took place. Our concern is how to ensure individuals' identities are protected.

- Data analysis and reporting need to ensure that identities are not revealed, for instance avoiding direct attribution to individuals or locations. It can also be addressed by only reporting sufficiently large samples within the data set to conceal any individual responses/personal data.
- It may be possible to provide fictitious names for people or places so that it prevents identification. If there is likelihood that people can be identified, the right ethical decision will be not to report the data that identifies them.



















Are identity and confidentiality protected and data secure?



Is data secure and protected?

Dilemma: The work requires us to collect small data sets which collects personal information. There is also other information (names, addresses of interviewees) on our laptops/tablets/phones which would allow a third party to link the two so that anonymity was breached, for instance if the devices were stolen. This is a risk, what needs to be done?

Guidance:

• All data must be encrypted and devices password protected. Where possible, a touch ID device should be used. Handwritten notes, if used, should be destroyed once they have been entered into a device.



















Ethics Standard: Participation is based on informed consent.

- Is the information given to participants sufficient and accurate to enable them to give informed consent? For example does the information include the purpose of the research/evaluation/monitoring; what data will be collected about participants and how it will be used, disseminated and shared; data archiving; the risks and benefits to them; the requirements of participants; arrangements for guarding confidentiality and identity; safeguarding arrangements and procedures in place; how they can feedback during the research/evaluation?
- Does the information for consent include options and processes for giving consent and for withdrawing consent at any point? Does it give people the option to raise questions and give them enough time to decide whether to take part?
- Are there options for informed consent to be obtained either by a written signature or by audio recording their verbal assent for people who cannot read/write?
- Children under 18 (unless local law gives majority earlier) can only give informed assent; consent is also needed from their parent/guardian. For assent to be valid the child must show evidence of understanding the purpose of the research, what he or she is to expect, and what will be expected of them.
- Participants should be informed of safeguarding policies and that if they disclose information concerning abuse or harm to themselves or others, how this will be reported, and to whom.



















Building ethics into the research design, ESRC The Research Ethics Guidebook, provides guidance on informed consent, and the Nuremberg Code and Helsinki declaration. It provides further guidance on compensation, defining competence to consent, and opt-in, opt-out sampling.

For children, see Ethical Research Involving Children (ERIC) Compendium: A comprehensive guide published by UNICEF on undertaking ethical research with children. The guide covers the fundamental principles of ethics in research as well as payment and compensation for participation. It includes a number of relevant case studies.

For general guidance and people with cognitive disabilities, see <u>Australian Council for International Development (ACFID) Principles and Guidelines for</u> ethical research and evaluation in development 2016.

For people with cognitive disability see (disregarding New Zealand specific legislation references unless relevant): This guidance provides information on how to engage with people who have a cognitive disability and how they may need support so that they might engage in a research process.

For women and girls at risk of gender based violence, see Ethical and safety guidelines for research on gender based violence, Partners for Prevention, no date: This is a comprehensive tool that draws on the work of the UN. It discusses the provision of crisis intervention and how to report safeguarding issues.





















There has been a failure to gain informed consent from participants

Dilemma: The Principal Investigator has learned that researchers have not consistently been gaining people's consent prior to interview or participation in focus groups.

- The Principal Investigator should report the issue to the contractor and alert DFID as commissioner. The contractor needs to contact researchers immediately and ensure they use proper consent procedures, including training where needed.
- Where data has been collected without consent, it is not valid; it may be possible to use it if interviewees are asked retrospectively, with a clear option for withholding consent to use of the data once they have a full understanding of the implications.
- Consent should include consent to all planned future uses of data. If there is an intention to share the data or for wider research purposes, this must be stated.





















Options for gaining consent with groups with low literacy and no audio equipment

Dilemma: Gaining consent in an area with low literacy required people to give their consent orally. The researcher wanted to leave participants with a record of what they had consented to, so that they could refer back to it during the project implementation. The researcher wanted to ensure that participants wanted to continue after they had given consent. However, the locality had no electricity or audio devices for them to keep a recording to listen to.

Guidance example:

The researcher developed a pictorial account of the work, using photographs illustrating the research and its process. She also included some written text to avoid assumptions about participants' literacy levels and to add an extra layer of communication. This was put onto a form on one page so that it was concise, cheap and easy to retain. She copied the forms and left them with people. Many participants brought the form to each research workshop, and many kept the form - along with the photographs they took - as evidence of their participation in the project.





















Gaining consent for children where there are no adult guardians

Dilemma: The study is in Sub-Saharan Africa, where the AIDS epidemic has left children living in child-headed and youth-headed households. There are homes where all the adults have died, and the oldest caregiver is a child themselves, or a sibling aged 18-25 years. There is no parent or legal guardian able to give consent for the child to participate. There is a group of children who want to participate in the research, but who said that their guardians would not let them participate because the guardians themselves were abusing the children and did not want this to be exposed by the research. How do we obtain consent from these children in an ethical way?

- An option could be to allow children to identify another trusted adult, such as a teacher or social worker, (in situations where caregivers were abusing or exploiting children) or an aunt or grandparent, (in situations where children had no legal guardian) who can give consent for the children to participate. It should be noted that this approach should never be used as a substitute for acquiring guardian consent simply because it is perceived as being more convenient.
- Children should be informed as part of the consent process that if they report any kind of abuse or exploitation, referrals will be made to health and social services. This means that any referrals will be made with the child's full knowledge and consent.
- Consent and information forms should be in people's first languages, and written in clear simple language without technical terms. At each stage in the research, children and their guardians or nominated adults should be asked again for their consent to participate.





















Gaining consent for unaccompanied adolescents aged under 19

Dilemma: The study explored the experiences of unaccompanied adolescents seeking asylum living in a hostel. Gaining guardian consent was either impossible due to a lack of adult caregiver, or because adults were protecting their own interests at the expense of the children in their care. But these adolescents represent some of the most vulnerable groups, and it was essential to include and represent their needs in the research. (A similar issue is raised in another study on how to gain consent from street homeless children/adolescents.)

Guidance example:

- All the residents were asked if they wished to be participants in the study. The young people were informed that participation could involve allowing the researcher to take field notes in relation to them and/or participating in an interview. They were informed that the researcher would not take notes in relation to anyone who did not wish to be a participant. A majority gave written consent to their participation in the research.
- Informed consent is increasingly recognised as a process which needs to be revisited during a project. In this project, the researcher regularly asked residents in the hostel about whether their consent had changed. Some residents who had originally not consented to participation changed their mind and consented to be interviewed. Others who had consented to participation subsequently decided that they did not want to be interviewed.



















Does the method and implementation respect people's rights and dignity?

Ethics Standard: People's rights and dignity are respected and there is equitable participation.

- Do contractors follow international human rights conventions and covenants that the UK has signed up to? How will they
 address any human rights violations?
- Does the research/evaluation/monitoring have representation from groups with less access to power such as women, disabled people, children, poorer people, people with minority languages; how will they be facilitated to take part? How will these groups be included to avoid bias?
- Does the method identify how local issues such as land rights, water conflict, ethnic tensions, will be addressed to avoid potential bias towards different interests?
- Does the method identify and mitigate indirect risks to specific groups, e.g. if women or people with stigmatised conditions or social groups are known to have taken part in focus groups or surveys, will this put them at risk?
- Have you contacted local support groups/experts to ensure that your proposed methods/target groups /sample are appropriate?
- Have contractors budgeted with facilitating the specific needs of different stakeholders in mind to ensure that the process is sensitive to and inclusive of the voices of those who are often excluded?
- If payments, reimbursements or gifts are used to increase participation, are these ethically acceptable?



















Does the method and implementation respect people's rights and dignity?

Universal Declaration of Human Rights

International Covenant on Civil and Political Rights

Convention on the Rights of the Child

Convention on the Elimination of all Forms of Discrimination Against Women

United Nations Commission on Population and Development

Declaration on the Rights of Indigenous Peoples



















Does the method and implementation respect people's rights and dignity?



Should we use payment for participation?

Dilemma: Members of community groups were reluctant to talk to us or be involved in the research because they felt that it was only right that they were paid for their time. As researchers, we were reluctant to pay to avoid influencing results or being perceived to have done so. Payment could also lead to ill feeling in the community from those who did not take part, and therefore had no reward. Incentive payments to encourage participation are contentious since paying for someone to participate in the research process can mean people feel coerced to take part, (or family members coerce them) since they want the money, so that consent is not genuinely given. Or people may feel that having been paid they need to provide positive feedback in their contributions to an evaluation. How do we avoid these pitfalls?

- Payment can be given to reimburse people for costs incurred, such as travel and child care. Tokens of appreciation, for example, staple foods, or toiletries to compensate for loss of income due to potentially missing work can also be considered. When the research involves children, pens could be given. You will need to take into consideration the local context. For instance, in some contexts when a gift is given it must be reciprocated, leading to a situation where a family in poverty feels obliged to give the researchers something in return.
- At the design phase of the research it is important to ensure that a budget has been allocated for any potential tokens of appreciation. Information about tokens of appreciation and payment for expenses will also need to be communicated with potential research participants and the wider community.



















Does the method and implementation respect people's rights and dignity?



Mitigating risk to stigmatised groups

Challenge: HIV is amongst one of the most stigmatized health conditions globally, this is especially the case in Sub Saharan Africa (SSA). The research is with, and about people who are living with HIV (PLWHIV), with the purpose being to understand more about what it means to be living with HIV in a remote village. The aim of the research is to inform the design of future projects. How should the researcher undertake research with PLWHIV so as to ensure that they do not cause harm? How can they access PLWHIV?

- In many places in SSA, even in remote areas, there are likely to be informal or structured support groups for people who are living with HIV. Access to these could be gained with the help of health care professionals from local clinics.
- Alternatively, after having considered any local risks, you could ask the clinic if they could be a gate keeper to the research, or a local community based organisation. Employing a peer researcher could also help to access people who are positive so as to ensure confidentiality.



















Does the method and implementation respect people's rights and dignity?



Engaging participants in different ways to ensure representation

Dilemma: In the local community, women and a minority ethnicity group are not given equal status with dominant ethnicity men. However, it is important to gain their views, and support their engagement. This is a basic right and will enrich the findings and give them more credibility and legitimacy. It will also support us as we seek to maximise the benefits of this work. How best to bring these views to the table?

- Ensure that sampling of interviewees, focus groups and any survey clearly includes representation from the different groups and women/men, rather than making samples proportionate to the aggregate population.
- Discuss separately with women and people from the minority group what their concerns and needs regarding participation are in a confidential setting before the evaluation begins.
- Focus groups will need to be held with the different groups separately to ensure participants can speak freely. Consider holding interviews and focus groups in different venues, depending on where different groups feel safe, and where they can go safely; for instance the village meeting place may not be suitable for all groups.
- Women's focus groups and interviews to be undertaken by women team members.



















Does the method and implementation respect people's rights and dignity?



Legal redress in the case of different legal systems

Dilemma: Which countries' laws prevail and who provides legal redress in the case of a Tanzanian data collector, contracted by an Indian company, who has been commissioned by DFID in the UK? There is a potential for an individual in Tanzania to be put at risk through a failure to protect a respondent's privacy?

Guidance:

Every contractual situation needs to be considered on its own merits. However, the rule of thumb for DFID is to refer to the wording of the contract (DFID) Terms and Conditions) agreement made with the commissioner when a contractual guery arises. The Terms and Conditions will clarify the responsibilities.



















Is participation supported by a two-way feedback process?

- Are processes for systematic two-way participant feedback in place? i.e. soliciting participants' feedback to you
 and with you ensuring feedback to participants after their participation.
- Is participant feedback asked for during the research/evaluation/ monitoring? Is it used to improve implementation processes for participants?
- Do processes facilitate feedback by local people? For instance processes could include invited group feedback sessions, providing a (non- personal) phone or email contact; a hotline; a box for comments?
- Do these processes allow groups with less access to public spaces to provide feedback, such as children, women, minority groups?



















Is participation supported by a two-way feedback process?

<u>Groves, L. (2015) Beneficiary Feedback in Evaluation</u>. This report highlights the challenges of providing beneficiary feedback and why it is important to provide feedback to beneficiaries.

<u>The Research Ethics Guidebook, ESRC Dissemination and 'impact</u>': An overview that discusses dissemination and impact. It addresses the relevance of ensuring that there are resources for dissemination activities, that interested parties are involved and clarity on the intended audience for reports/products of research and evaluation.



















Is participation supported by a two-way feedback process?



How can we design feedback into the implementation process?

Dilemma: Evaluations and research are often undertaken with short timeframes and with limited budgets. Once methods are set, it often feels, or is, difficult to vary them. However, it may add value to the quality of the work if there are opportunities for participants to feedback. For example, they might be able to identify groups or issues that have not been included to date, or to highlight ethical or implementation risks. They may also be able to improve the way that the field work is conducted in other ways.

Guidance:

Find ways to seek feedback during the research (see next example) and build in review points during the work timed according to the overall time period for the field work. Even a very short field presence can benefit from review by the team and any input from other stakeholders. Review could be daily, weekly, or for example fortnightly. The critical point is that the team and method can respond appropriately to feedback.



















Is participation supported by a two-way feedback process?



Making sure participants can feedback during the evaluation/research

Dilemma: Beneficiary feedback methods need to ensure that all groups can use them, and be inclusive. However, practical issues can mean that some methods exclude people. Comments boxes will exclude those who are less literate; however they provide anonymity. Focus groups identify participants, so are less useful for those who are reluctant to identify themselves due to social position or potential stigma. Mobile phones and hotlines may support inclusion through being a more anonymous tool for giving feedback and for managing people's fear of reprisals. However, they may also increase exclusion, where women, for example, may not have access to the household/mobile telephone.

- Evaluators will need to reflect on what the position of participants is, their literacy levels and their access to phones.
- Different population sub groups may need different methods to be put in place. You may need to use several methods.



















Does the evidence and learning have integrity and merit?

Ethics standard: Research, evaluation and monitoring work is useful and necessary.

- Are the dissemination products clear, accessible and relevant to the purpose of the work?
- Have you prevented stakeholders dismissing or suppressing findings or using them selectively?
- Have you preserved the integrity of evidence and learning against possible bias or external influence?
- Have you maintained vigilance in protecting participants' identities in findings?
- Are dissemination products disseminated promptly to optimise their use and relevance?
- Are the dissemination products in a format that makes them accessible and relevant to different audiences, including participants?

DFID's policy is to publish all findings from research and evaluation unless there is a compelling reason to withhold findings. DFID should approve any decision not to publish findings.



















Does the evidence and learning have integrity and merit?

The Research Ethics Guidebook, ESRC Reporting



















Does the evidence and learning have integrity and merit?



Can we stop the research/evaluation mid way?

Dilemma: The research/evaluation consultants wanted to halt the research at the mid-term, saying that the findings were already clear. Commissioners pushed back, and said it was too early to decide this. They were proved right, as the findings of the end evaluation were very different to those of the mid-term.

- In this case, DFID pushed back and challenged the contractors from a technical perspective as well as from a wider ethical perspective, as it was too early to end the project when the evidence was not conclusive.
- DFID recognised the importance of strong research governance it turned out that the contractors wanted to stop early due to budget constraints, so that DFID's intervention assured the integrity and validity of the research.
- There are occasions when research should be stopped for ethical reasons, for instance if there is significant risk of harm to participants, or the research will no longer produce evidence that will be used. (Also see research and evaluation cycle stages of commissioning, planning and design, and data collection and analysis.)



















Does the evidence and learning have integrity and merit?



A commissioning decision not to publish findings

Dilemma: A commissioning decision has been made not to publish the findings.

- To identify possible actions, you need to clarify the reasons for the decision.
- The reasons may be political, for example concern about the impact of the evaluation findings. This is not an acceptable response, as publication is key to the integrity of the work. It may be possible to modify slightly the presentation of findings, but the key findings and conclusions must be retained to preserve the integrity of the research. In principle, any potential political risks should have been identified and addressed during inception or during reviews of risks during implementation.
- The reasons may be budgetary. This should have been addressed in the commissioning and design stage (see above). But if there have been unexpected budget cuts or changes, explore other means of dissemination through country stakeholders or using local media. Some budget will be needed to support this; can an NGO or academic or media organisation assist with this? Can the commissioner find funds from elsewhere?



















Does the evidence and learning have integrity and merit?



Country stakeholders and partners want to suppress publication/amend findings

Dilemma: Country or partner stakeholders want to suppress publication, or change findings which they do not agree with.

- Providing there is robust evidence for the findings, this needs to be strongly defended against. If there is a valid point being made, this will need to be listened to.
- Discussing draft findings at an early stage with stakeholders can help identify and mitigate potential conflicts. Commissioners (and other allies) need to be enlisted to defend the findings.
- Refer all parties to the DFID ethics principles of: Act with honesty, competence and accountability; Deliver work of integrity and merit and the UK Civil Service principles of: Honesty, Impartiality, Objectivity and Integrity.



















Is the utilisation of learning and evidence products maximised?

Ethics Standard: Findings are disseminated to beneficiaries and used appropriately.

- Have you implemented the costed and budgeted communication and dissemination plan that you identified in the design phase? Have you ensured that there are different products for different groups, including beneficiaries?
- Have you reviewed what formats and languages will meet the needs of different groups and consulted on formats with different audiences, including beneficiaries?
- Have you revisited your planned reporting formats in line of the reality of your implementation process. For example considered pictures or cartoons, videos, group briefings, braille and audio materials for e.g. illiterate people, children, people with disabilities?
- Have you identified appropriate platforms to reach the audiences? These could include local media (radio, newspapers, TV); online publications and local websites; social media.
- Have you ensured that the principles of minimising harm and respecting people's rights and dignity (see <u>Data collection and analysis</u> stage above) are not breached by disclosing identity or by breaking confidentiality in reports?



















Is the utilisation of learning and evidence products maximised?

<u>Guidance note on developing an evaluation dissemination strategy, UNIFEM 2009</u>. The guidance notes explains how to incorporate the dissemination strategy into the various stages of your work, and its importance.

Formats for children: After Yolanda – what children think, need and recommend, Save the Children UK, 2014.



















Is the utilisation of learning and evidence products maximised?

Sharing information with affected populations

Dilemma: Ensuring accountability to affected populations and that evaluation outcomes are communicated to community members involved in the intervention/research/evaluations is important. Research respondents who host researchers in their community often participate in research activities, yet often researchers fail to ensure that findings are shared with the community. Sometimes this is due to failing to budget for this; sometimes due to not planning for information sharing activities in the methodology and timeline.

- There should have been sufficient budget included in the contract for participant feedback at the start of each project, accompanied by a costed dissemination plan (see the Commissioning, planning and design stage). This plan should include the budgeted time required from the contractors to undertake dissemination. If this was not done is there a way to raise the issue with commissioners or other stakeholders to fund dissemination?
- If you only realise at a late stage how important feedback is, can you find a way to build feedback to participants into existing dissemination plans? Can stakeholders, programme staff or local media platforms assist with this?



















Is ongoing monitoring governed by DFID's ethical principles and standards?

Ethics standard: All standards are relevant.

- Have you ensured that the data collected are necessary for monitoring the project/programme? Are they used as intended, and producing the evidence needed?
- Have beneficiaries been included in the design of the monitoring content and process?
- If data are recorded which can be linked to individual identity, has informed consent been given?
- Have you ensured that identity is protected and confidentiality preserved in the management of data collection, storage, sharing, analysis, reporting?
- Does the monitoring/data activity include a process for regular review and reporting of ethical challenges and mitigating actions, for instance as part of an annual review?
- Does the activity include a process for regular review of the continued relevance and utility of the data collection activities, analysis and reporting?
- Is data collection, analysis and use still compliant with legal requirements? These can change, as can techniques for accessing and using data so legal compliance needs to be checked regularly in a longer time frame project.



















Is ongoing monitoring governed by DFID's ethical principles and standards?

<u>Building ethics into the research design, ESRC The Research Ethics Guidebook</u>, provides guidance on informed consent, and the Nuremberg Code and Helsinki declaration. It provides further guidance on compensation, defining competence to consent, and opt-in, opt-out sampling.

Consent to data archiving or data sharing, ESRC The Research Ethics Guidebook

<u>Privacy and data confidentiality methods: a National Statistician's Quality Review (NSQR)</u> provides a link to the NSQR website with a wealth of information; two selected articles of interest are below. The website has other very relevant material.

<u>Privacy, confidentiality and practicalities in data linkage, Kerina Jones and David Ford, 2018</u> explores data linkage methodologies with particular focus on privacy and confidentiality

<u>The future of statistical disclosure control, Mark Elliot, Josep Dimingo-Ferrer</u>, describes the state of the art for statistical disclosure control, which is part of the anonymisation process, and discusses the core issues and future challenges



















Is ongoing monitoring governed by DFID's ethical principles and standards?



Do the same ethics standards apply to regular programme monitoring?

Dilemma: Monitoring is often under-resourced, and managed by relatively inexperienced staff, including programme staff who are running projects as managers or practitioners. They don't have ethical or research training, and see monitoring as a (possibly secondary) add on to their main jobs. They are not well supported in doing it, and are not involved in using the data beyond a basic level. What to do?

- Clarify to monitoring staff that DFID's ethics principles and standards apply to regular programme monitoring.
- Ensure staff collecting data are trained in: data collection and data ethics; understanding the planned use of data collected; informed consent; and the importance of monitoring as a part of programme management and adaptation.
- Resources need to be adequate to the needs of the monitoring required, and their adequacy reviewed regularly to ensure that data is of good quality, valid and sufficient for needs, and ethically collected and used.



















Is ongoing monitoring governed by DFID's ethical principles and standards?



Informed consent for ongoing monitoring data

Dilemma: Data required for monitoring a health service improvement programme includes data on peoples' use of health clinic services with personal data (village, age, gender, presenting issue). Monitoring analysis anonymises these data by removing names. Is informed consent required?

- As with any personal data collected and stored, informed consent is required. People using the clinic should always be told that their data will be collected and analysed, have the reason for doing this explained, and asked for their consent before data is added to the database. Given the potential for emergency clinic admissions, verbal consent may be accepted.
- Staff are trained in informed consent, and in how to ask people for it, and explain the purpose of the monitoring.
- Notices can be posted round the clinic explaining that data will be collected and used, what its purpose is and clarifying a commitment to maintaining people's anonymity and confidentiality.



















Is ongoing monitoring governed by DFID's ethical principles and standards?



Use of monitoring data to support other research/evaluation activities

Dilemma: Data from a local programme on livelihoods is requested by a researcher for a larger research project/different evaluation. However given the localised nature of the programme and rich data, even anonymised data will enable individuals to be identified. There is also a concern that, once data is shared the responsibility for maintaining anonymity becomes less clear, and subsequent data analysis may breach anonymity. There is also an issue of consent, since the original data was provided for the purposes of programme monitoring, unless consent for any wider use of data was specified.

- Programme participants are informed of the potential for wider use of the data when they provide their consent to providing monitoring data.
- The data set is cleaned of potential identifiers, before providing it to the researcher.
- Some data sets may not be capable of anonymisation in which case they should not be shared.



















Is ongoing monitoring governed by DFID's ethical principles and standards?



Ensuring monitoring data is necessary for users and/or has public benefit

Dilemma: The programme has been running for two years, so some of the data is no longer useful or relevant to monitoring reports, since the programme has evolved. However, some research staff want to continue collecting the same data, though it is no longer used as originally planned. Collecting the data uses resources, and also requires participants to share data about their participation.

- Any collection and use of data must be based on a clear user need, and/or with public benefit. DFID's current guidance covers this point, clearly stating that "the value of any research/evaluation being proposed[must] be greater than the burden imposed on participants". Identify what data is no longer necessary or used and stop collecting it.
- If there is a robust argument that the original data should be collected e.g. for the purpose of longitudinal analysis against baselines, this could be considered. The costs (to the programme and to participants) and utility of doing so need to be carefully balanced.
- Participants must give informed consent to providing any different information now required.
- Participants must give informed consent to the data collection if its intended use is now for wider research purposes.



















Is the use of research and evaluation data collected ethical?

- How will the research/monitoring and its findings help build and sustain local research capacity?
- Are data used through data sharing platforms to maximise their benefits and value?
- Have you assessed plans to share personal data within DFID, or externally under DFID's Open Data Policy, to
 ensure that agreed levels of confidentiality and anonymity are not breached?
- Where stakeholders such as governments ask for data to inform their work, did participants agree to this use of their data when they gave their informed consent?
- Have you considered how anonymised data could subsequently have identifiers added with the use of big data sets collected by other researchers, which may then enable individuals to be identified?
- Have you considered how sharing small/localised samples or rich qualitative data may potentially allow identification – now or in future?
- Is the use of publicly shared data monitored to ensure it is used ethically and its integrity maintained?
- Are data analysed to provide knowledge of the specific issues facing women, children and other disadvantaged or vulnerable groups?



















Is the use of research and evaluation data collected ethical?

The General Data Protection Regulations (GDPR), guidance in brief to Data Protection Impact Assessments (DPIA) provides a quick overview of DPIAs and when you need to use them. There is a link to more detailed guidance if needed. The GDPR applies to all personal data which is processed in the UK and EU, so must be considered at an early stage.

PIM (Protection Information Management) Framework for Data Sharing in practice, 2018, OCHA Humanitarian Data Centre.

DFID Open Data Policy 2013. This is DFID's open data policy, it explains it and why open data is important to DFID. It also discusses potential limitations

Helping organisations navigate ethical concerns in their data practices, Open Data Institute 2017. A guide to using data ethically which sets out some common issues and challenges including legal issues, data protection and transnational sharing of data

The Data Ethics Canvas guide, Open Data Institute, 2017.

Greenleaf, G., (2013) Data protection in a globalised network, in Research Handbook on Governance of the Internet, ed. lan Brown



















Is the use of research and evaluation data collected ethical?



How do I know the plan for data collection and sharing is ethical and legal?

Dilemma: We want to promote the use of innovative data collection and use of personal data. However we are unclear on how an individual's identity will be protected, nor what the relevant regulations are.

- This is a fast changing issue; data regulations in the UK, G20 and in the countries DFID works in are evolving rapidly to adapt to new data extraction and management technologies. This requires DFID as well as contractors to ensure that they are aware of the current state of play to ensure compliance, and ethical use of data.
- Seek up to date guidance using the links to materials, both on UK and national guidance.



















Is the use of research and evaluation data collected ethical?



Country where the research/evaluation is based has weak data protocols

Dilemma: The relevant country has weak data management protocols. Researchers are concerned that data provided under conditions of anonymity will be used by government or others it shares the data with, in a way which allows individual identification. For example by linking data to common identifiers or by use of very localised data which potentially identifies individuals or communities.

- Given the risk of inappropriate use by third parties, data should first be fully cleaned to ensure anonymity, for instance by removing data which could identify individuals.
- Cleaning needs to consider how the data set could be combined with other data sets to allow identification.













