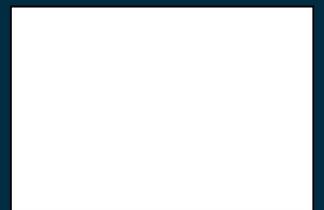


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Government Social Research Unit

GSR Professional Guidance

Ethical Assurance for Social Research in Government



GSR Guidance

This guidance note is one of a series produced by GSRU. Other titles are:

1. Government Social Research Competency Framework; July 2005
2. GSR Professional Guidance: Procurement of Government Social Research; February 2006
3. GSR Professional Guidance: Release Protocol for Government Social Research (in press).

They can be downloaded from the GSR website on www.gsr.gov.uk

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Foreword

The purpose of this document is to set out the key principles which should be upheld in the conduct of social research for government. The principles reflect the standards accepted by the wider profession, but take particular account of the responsibilities of those conducting social research for government.

Part One summarises the content; Part Two sets out the principles and Part Three addresses governance arrangements to safeguard adherence to the principles. **All** social research conducted for government should adhere to the principles. The precise governance arrangements to ensure government social research upholds the principles are a matter for individual departments, but they should be clearly set out and responsibility for oversight should be clearly assigned to named individual(s) or nominated post(s). Part Three sets out good practice governance arrangements designed to ensure the principles are upheld; alternative arrangements which achieve the same end are also acceptable. The procedures in place should address the particular risks faced by individual departments in commissioning and conducting social research; these may differ depending on policy area and customer base.

This is the first in a series of GSR Professional Guidance notes; copies can be downloaded from the GSR website at www.gsr.gov.uk

Paul Wiles

Head of Government Social Research Service

1. Introduction and Summary

- 1.1. Social science research may involve participants or subjects directly as the source of primary data, or indirectly via access to secondary data already secured. There is a need to ensure that researchers attend to all ethical issues and principles relating to the potential risks of the research to all involved¹. All members of the Government Social Research (GSR) service, and others with responsibility for commissioning social research on behalf of government, must be aware of and uphold basic ethical responsibilities (as well as their legal obligations) throughout the life of any research project conducted or commissioned for government.
- 1.2. The Government Social Research Unit (GSRU) has reviewed existing arrangements to manage the conduct of ethical review in departments and has also consulted other funders, who are similarly seeking to ensure research they fund is conducted ethically. This guidance on the ethical assurance of government social research both draws upon, and is aligned with, this body of knowledge – especially the Economic and Social Research Council (ESRC)'s Research Ethics Framework; the Social Research Association (SRA)'s Ethical Guidelines; and the MRS's Code of Conduct. The guidance is also consistent with the values contained within the Civil Service Code.
- 1.3. The guidance:
 - summarises the key principles which those commissioning or conducting social research for government, whether members of the Government Social Research service or not, need to uphold
 - sets out the responsibilities of departments in developing governance procedures for use in central government
 - clarifies the future role for the Government Social Research Unit in maintaining appropriate ethical standards.
- 1.4. All staff commissioning or conducting social research for government have a responsibility to uphold five key ethical principles:
 - Principle 1: Sound application and conduct of social research methods and appropriate dissemination and utilisation of the findings
 - Principle 2: Participation based on valid informed consent
 - Principle 3: Enabling participation

¹ This would include: research subjects and any wider social groups or organisations they may represent, the researchers themselves, their employing organisations and funding agencies.

- Principle 4: Avoidance of personal and social harm
- Principle 5: Non-disclosure of identity and personal information.

Responsibilities of departments

- 1.5. It is the responsibility of individual government departments to put in place suitable systems and processes to ensure that appropriate ethical standards are met. In particular, government departments have a responsibility to ensure that for all research projects they conduct or commission:
- systems are in place to assess, throughout the life of the project: the appropriateness of proposed research methods; the ability and capacity of contractors to undertake the research to appropriate quality standards; the anticipated risk to researchers and participants at the outset of the project; and unanticipated ethical problems which emerge during the project. Systems and protocols will need to be reviewed/audited on a regular basis to ensure they continue to be fit for purpose;
 - the importance of good ethical practice is set out in departmental skills/competency frameworks, and that training/development needs for individual staff are identified and met to ensure that staff are aware of and can implement their ethical responsibilities; and
 - appropriate management and quality assurance arrangements are in place for ensuring in-house research is conducted ethically including systems for monitoring and responding to complaints for both internal and external projects.
- 1.6 Individual staff responsible for conducting or managing social research for government must ensure they are aware of their ethical responsibilities, and of any local (departmental) protocols on how to put these into practice. Those commissioning research need to ensure that the potential ethical issues presented by a project are assessed at the outset, that appropriate arrangements for ethical scrutiny are in place; and that the organisation undertaking the research has appropriate arrangements in place to ensure the day-to-day management of these risks. Those conducting research (including secondary analysis) must additionally ensure they comply with the department's arrangements for management and quality assurance.

Support from the Government Social Research Unit

1.7 The Government Social Research Unit will provide the following to support individuals and departments in meeting their obligations:

- **Keep the guidance under review**, to ensure it is kept up-to-date.
- **Keep a watching brief on ethical developments** and provide ad hoc advice on specific ethics issues emerging in departments, including facilitating sharing of information on difficult cases and their resolution.
- **Support departments** in sharing good practice and promote consistency in the development of local protocols, and supporting proforma.
- **Ensure competencies** within the GSR Competency Framework incorporate ethical standards.
- **Provide training** for GSR staff to help them develop ethical expertise.

2. Ethical Responsibilities

2.1. It is important that government-sponsored research practice facilitates general acceptance and understanding of research processes and so enables rather than hinders future research. Those conducting, commissioning or managing government social research have a responsibility to ensure that research is conducted using appropriate methods and that the rights and interests of all those involved in the research process are protected. Government social research should be conducted in a manner that:

- ensures valid, informed consent is obtained before individuals participate in research
- takes reasonable steps to identify and remove barriers to participation
- avoids personal and social harm
- protects the confidentiality of information about research participants and their identities.

All processes should also protect against distortion and bias in the interpretation of findings.

2.2. Commissioners of social research for government should ensure that these principles, together with legal obligations² are upheld when designing and conducting research studies. Departments are responsible for putting in place arrangements to ensure this happens. Where projects are externally commissioned, it is the research manager's responsibility to check that ethical issues have been identified, and that the contracted organisation(s) have suitable arrangements for addressing them and keeping them under review as appropriate over the life of the project.

Principle 1: Sound application and conduct of social research methods, and interpretation of the findings

2.3 Social research conducted by or for government should be based on sound research methods that are appropriate to the research question and carried out to the highest standards of quality. Social research conducted by or for government should aim to meet a clearly defined, legitimate and unmet need to inform the conduct of government business. Those responsible for conducting or commissioning government social research

² The main relevant legislation is summarised in Appendix B, but legal advice should always be sought if there is any uncertainty regarding legal rights and obligations.

should avoid placing an unnecessary burden on respondents. The evidence emerging from government sponsored social research should be brought to the attention of policy makers and other users in a way that is clear and accessible, as well as conforming to professional and ethical standards to protect against distortion and bias in the interpretation of findings.

Principle 2: Participation based on informed consent

- 2.4 Participants in any research study involving primary data collection must be asked for their consent to take part unless the law **requires** participation, as with the Census. In other cases, it should be clear that participation is voluntary and that they have the right to refuse to answer individual questions or to withdraw from the research process at any point, for whatever reason. Potential participants should not in any way feel pressurised to take part in social research³. They must be given sufficient information to enable them to make an informed decision. Participants' agreement should also be sought before equipment (such as a video or a tape recorder) is used. In some contexts, additional consent may need to be obtained after the completion of research fieldwork if, for example, presentation of raw data is necessary and warranted at a conference, or if additional research is to be conducted that goes beyond the use for which informed consent was given. Covert research raises particular ethical and legal concerns and should be approached very carefully. Where covert research is planned it must be subjected to rigorous independent ethical review, and legal advice should be sought before it is conducted.
- 2.5 Consent may need to be renegotiated where respondents are being re-interviewed, and researchers must disclose the source of the original sample if respondents request this. Special considerations apply to interviewing children and vulnerable adults who may not have capacity to give valid, informed consent.
- 2.6 The Information Commissioner advises, in relation to obtaining consent for the purposes of the Data Protection Act 1998, that there should be some active indication that consent has been given. As a minimum, researchers must ensure that they can demonstrate that they have fully informed potential respondents about the nature and purpose of the study, that

³ Given concerns about declining response rates, many research organisations are understandably firming up their activities at initial contact, to maximise response rates by converting potential non-responses into interviews. Those responsible for commissioning or undertaking research on behalf of government need to satisfy themselves that these activities do not leave potential participants feeling pressurised.

- consent is voluntary, and that they can withdraw at any time. One method of achieving this is through leaflets. Researchers should also consider whether written evidence of consent is appropriate. Participants may request that their personal data be destroyed and may in some cases have the right to have it destroyed, under the Data Protection Act 1998. Participants may also request copies of research data relating to them via Subject Access Requests under the Data Protection Act 1998, or a request under the Freedom of Information Act, 2000.
- 2.7 Secondary data analysis, including systematic reviews and research synthesis, must be conducted in a way that is consistent with the respondent consent given in the original study.
- 2.8 If individuals choose to take part in research, their consent should be freely given. Any information likely to affect a respondent's willingness to participate should be provided. Participants should be neither overwhelmed nor inadequately informed. Relevant information includes the purpose and nature of the research, who is undertaking it, who the sponsor is, and plans for dissemination/feedback. Participants should be informed of any features which might particularly affect them. Any consequences of participation should also be explained. Written information that is intended for participants' use should be produced in 'plain English' and in an appropriate font size (size 14+ for those with visual difficulties). Where relevant, potential participants should also have access to material produced in minority ethnic languages, Braille or on audiocassette.

Consent via gatekeepers or proxy

- 2.9 Where possible, participants should be approached directly for consent. Consent should only be accepted from a gatekeeper or proxy after a reasonable attempt has been made to explain to the intended participant the purposes and implications of the research, and to secure his/her consent directly. When negotiating consent via gatekeepers or proxies, reasonable care should be taken to safeguard the relationship between gatekeeper/proxy and participant and protect the participant's privacy.

Children

- 2.10. Legally, the age at which a child has capacity to consent will depend on the circumstances. For government sponsored research, parents or legal guardians must be approached for consent for children aged under 16 to participate in research. In addition to parental consent, reasonable efforts must be made to inform children under 16 about the purpose of

the research and seek their consent to participate. Children under the age of 16 should be accompanied during interviews.

- 2.11 Children who are 16 or over will usually be able to give their own consent but even where this is so, researchers should consider whether it is also appropriate for parents, guardians or other appropriate gatekeepers (e.g. schools) to be informed when their child has been invited to participate in research.

Principle 3: Enabling participation

- 2.12 The potential impact of choices in research design (such as sample design, data collection method and so on) on participation should be considered. In particular, the effect of research design on such groups as ethnic minorities, those with caring responsibilities, and those with physical or mental impairment should be considered. Consideration should be given to issues likely to act as a barrier to participation, and reasonable steps taken to address these. Possible measures include:

- Assistance with costs incurred in research participation: - e.g. help with childcare, or transport costs etc.
- Provision of services: e.g. transport to and from the venue for those with accessibility/mobility problems; provision of interpretation facilities/foreign language interviews; induction loops for those with hearing impairment etc.
- Methods of data collection: e.g. offering a choice between self completion and interviewer assisted interviewing in projects where respondents have difficulty reading or comprehending written material.
- Sample design: e.g. considering the implications of excluding sparsely populated areas in highly clustered sample designs; and considering the case for over-sampling under-represented or hard-to-reach groups.
- User-involvement: e.g. consulting hard-to-reach groups and/or their representatives on research design to ensure that possible barriers to participation are identified and minimised.

Principle 4: Avoidance of personal and social harm

- 2.13 Individual research subjects⁴ (and the wider social groups or organisations to which they belong) and researchers should have their

⁴ Including those who opt out.

physical, social and psychological well-being protected at all stages of the research process. A research participant may feel wronged if: the research is inappropriately intrusive (in terms of method, relevance to the research question, or time commitment); it raises false hopes; their reputation is adversely affected; or if they experience avoidable anxiety or distress. The risk of perceived intrusion can be minimised by avoiding unnecessarily long interviews (although this needs to be balanced against the need to give adequate time on sensitive topics and/or to vulnerable participants), ensuring the research methods are appropriate to the research question being addressed, and ensuring that the time participants give to government research is spent providing information that is clearly needed and not available from other sources. The conduct of research should be sensitive to participants' 'private space', particularly when undertaking observation studies, and should respect participants' privacy.

- 2.14 Researchers should try to anticipate and guard against any possible harmful consequences of participation in research. This includes ensuring that interviewers have been properly trained and appropriate employment checks (ie Criminal Records Bureau/Disclosure Scotland) have been undertaken, especially where research involves vulnerable respondents. Relevant checks must be undertaken where research involves children⁵.
- 2.15 Those conducting or commissioning research on behalf of government should minimise – and avoid where possible – any likely annoyance or distress resulting from the research process. Where there is a high potential risk of distress (e.g. interviewing victims of crime), it is particularly important to ensure that the information is clearly needed and cannot be obtained by other means. In cases where there is high risk of distress, consideration should be given to provision of post-interview support for respondents and interviewers. The impact of the research on non-participating members of the target group should also be considered.
- 2.16 An objective assessment of potential personal or social harms should be included in the research proposal. This assessment should, where relevant, include: procedures for dealing with disclosures of abuse; means of protecting participants and researchers from undue stress, loss of self-esteem, or psychological injury; and procedures for assessing interview sites, recruitment methods and whether potential participants are under the influence of alcohol or drugs at the time of interview.

⁵ This is defined as under 18 in the Protection of Children Act 1999.

Principle 5: Non disclosure of identity

- 2.17 The identity of, and data belonging to, participants and potential participants (including information about the decision whether or not to participate) should be protected throughout the research process – including respondent recruitment, data collection, data storage, analysis and reporting. Even if research participants are not concerned about data disclosure, researchers should uphold principles of confidentiality and data protection and maintain the security of personal data and participants' anonymity (e.g. by ensuring that participants are not identified or identifiable in the outputs of research). Clear and transparent procedures should be developed to protect the identities of those who are identified through third parties (e.g. in snowball sampling, or sampling from administrative records). Participants' names and addresses should be kept secure and separate from their responses to help reduce the likelihood of breaches of security and anonymity⁶.
- 2.18 Research findings must not be used for purposes other than those they were collected for – e.g. marketing, advertising, and training. Where anonymous data is to be used for secondary data analysis, particular care must be taken to ensure that the further analysis retains the anonymity of respondents. Special care should be taken with small or very localised samples, and with the rich data generated by qualitative research, which may enable individuals to be identified from their characteristics alone.
- 2.19 If in any case there is doubt as to whether consent is sufficient, whether further consent is required, or about the purpose for which data can be used or disclosed, it is recommended that legal advice is taken.

⁶ Researchers should be alive to the risks of including full postcodes with survey data, as this can have the effect of identifying individuals or households in sparsely populated areas.

3. Departmental governance arrangements

- 3.1 Government departments have a responsibility to ensure that their project management and quality assurance arrangements enable all those in government commissioning or undertaking social research to uphold the ethical responsibilities set out above. In particular, departments must be able to satisfy themselves, their ministers, the external research community and the public that appropriate systems are in place for:
- assessing, throughout the life of the project: the appropriateness of proposed research methods, and the quality of research execution, analysis and reporting; the anticipated risk to researchers and participants at the outset of the project; and unanticipated ethical problems which emerge during the project. Systems and protocols will need to be reviewed/audited on a regular basis to ensure they continue to be fit for purpose
 - setting out the expected competencies for each grade in relation to upholding ethical principles, and identifying training/development needs for individual staff to ensure they meet these competencies
 - ensuring in-house research is appropriately scrutinised, to ensure ethical principles set out in Part Two are upheld
 - monitoring and responding to complaints for both internal and external social research projects.
- 3.2 Individual staff responsible for conducting or managing social research for government must ensure they are aware of their ethical responsibilities, and of any local (departmental) protocols on how to put these into practice. Those commissioning research need to ensure that the potential ethical issues presented by a project are assessed at the outset, that appropriate arrangements for ethical scrutiny are in place; and that the organisation undertaking the research has appropriate arrangements in place to ensure the day-to-day management of these risks. Those conducting research (including secondary analysis) must additionally ensure they comply with the department's arrangements for management and quality assurance.
- 3.3 Research project managers in departments should ensure that all their key stakeholders, including policy customers, are aware of ethical issues likely to arise in the course of a project, and the proposed means of managing these.

- 3.4 It is for departments to decide how they wish to develop or refine management arrangements to meet these needs, but some possible options are set out below. The obvious point of accountability, in most cases, will be the departmental Head of Profession (HoP) for Government Social Research, in consultation with the departmental HoP for the Government Statistical Service. They have responsibility for the ethical conduct of staff and their activities, within their professional specialism, but departments will need to ensure that government social research adheres to ethical principles, whoever in government conducts and commissions it.

Departmental Ethics Sponsors

- 3.5 Departments may wish to consider nominating one or more Ethics Sponsors, who would be responsible for acting as champions for ethical research practice within their departments by:
- maintaining expertise on research ethics
 - scrutinising research proposals considered to be relatively high risk
 - identifying action needed to reduce/manage that risk
 - providing specialist advice and support to internal research teams (and non-specialist commissioners of research) on an ad hoc basis.
- 3.6 Ethics Sponsors will need to be equipped to monitor and manage ethical issues that emerge during the course of a research study and to justify and document the reasons for their level of input. Ethics Sponsors will therefore need to be sufficiently senior to make and defend these decisions, but also to be accessible to staff as required. The Ethics Sponsor could be the Head of Profession for GSR or their nominee.
- 3.7 Ethics Sponsors should have an up-to-date awareness and understanding of ethical issues. Their role should be formally reflected in job descriptions and work plan objectives, and reported on in departmental appraisal processes.

Assessing and Managing Risk

- 3.8 All social research projects conducted for government, whether internal or external, must be subjected to an initial risk assessment – to be undertaken by the departmental project manager – at the earliest possible stage of project development. Ideally this would be at the project planning stage, but may need to be delayed to post-tender stage

for some forms of external competition. Departments may wish to classify projects according to their level of anticipated harm (emotional, physical, and psychological) or risk to participants, their wider communities/organisations and researchers at this stage, perhaps using a variant of the system suggested below.

- 3.9 Projects which are regarded as presenting 'more than minimal risk' to participants or others directly affected by the proposed research need to be formally reviewed. A formal review process must incorporate the following principles:
- *Written record* of the potential risks and harms and how it is proposed they will be handled.
 - *Independent scrutiny*, by a research professional outside the immediate research team, of the risk assessment and proposed arrangements for managing these. For the scrutiny process to be respected and seen to be impartial, it would benefit from a review by at least one expert from outside the department commissioning or undertaking the research. A number of departments already achieve this by arranging for proposals to be peer reviewed as part of the commissioning process. This could be a member of GSR from another government department or an expert from the external research community. Legal advice needs to be taken where there is any uncertainty regarding legal rights and obligations.
 - *Monitoring and continuing ethical review*. Procedures should be in place to monitor the conduct of research which has received ethical approval until it has been completed, and to ensure appropriate continuing review, where the research design is emergent.
- 3.10 Projects regarded as presenting 'minimal risk only' do not need to be subjected to formal ethical review, but departments should ensure that clear criteria for identifying projects which are 'minimal risk' are in place. Ideally, the decision to classify a project as presenting 'minimal risk only' should always be checked by a research professional outside the research team, but at a minimum there should be systems in place to periodically audit risk classifications.
- 3.11 Proposals that represent 'more than minimal risk' would include those that by virtue of the topic, vulnerability of the potential participants, or proposed methods - or a combination of these - present a greater challenge in upholding the stated ethical principles. These projects require greater vigilance with respect to ethical issues throughout their lifespan. In departments where a high proportion of research is likely to be ethically sensitive by virtue of subject matter or client group,

departments need to identify appropriate ways of managing this higher level of risks, for example by developing more detailed protocols to support project managers in assessing and managing the potential risks of harm raised by the subject matter (e.g. crime or immigration at the Home Office) or client group (e.g. vulnerable older people or those in receipt of benefits at DWP) and ensure that staff are trained to an appropriate standard.

- 3.12 In practical terms, topics, participant groups or methods that might of themselves be considered high risk include the following:

Sensitive topics

- Illegal behaviour and contact with criminal justice system
- Experience of violence, abuse or exploitation
- Health (including behaviours detrimental to health, mental health, loneliness, pregnancy and death, sexual behaviour, ageing, cognitive impairment, genetics)
- Income, unemployment and benefit receipt
- Children and family life circumstances.

Participant groups

- **Vulnerable participant groups** – including children and young people; vulnerable older people; those with a learning disability or cognitive impairment; individuals in a dependent or unequal relationship
- **Groups accessed via gatekeepers** – including ethnic or cultural groups, especially where English is not the first language.

Methods

- Covert and/or participant observation (especially where it is not proposed to seek full and informed consent at the outset of a study)
- Accessing/combining data from multiple sources – especially where this involves personal or confidential information of identifiable individuals
- Intrusive interventions – including the collection of biological samples
- Use of ‘practitioner’ researchers
- Experimental and quasi-experimental designs.

- 3.13 The above list is not prescriptive or exhaustive; in practice, it is often the context of the research or the combination of factors that results in a project being judged as presenting 'more than minimal risk'.
- 3.14 When embarking on new research, project managers need to ensure that appropriate scrutiny arrangements are identified. For external projects, this means:

Either:

- a) Ensuring that projects (whether internal or external) falling within the remit of the DH Research Governance Framework for Health & Social Care are scrutinised by one of the NHS Research Ethics Committees. These include research projects in NHS settings, those that use NHS records, those that require access to NHS staff and research projects with NHS patients (whether for sampling purposes or as research data). Further information on the DH Governance Framework can be found at www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4108962 The project manager on behalf of government should check whether this process has satisfactorily resolved all the ethical issues identified in the initial risk assessment.

Or

- b) For other external projects (as part of the procurement process for a particular project⁷, or as part of the process of setting up framework agreements) departments must satisfy themselves that arrangements are in place for the organisation to subject project proposals to an appropriate process for ethical scrutiny. Arrangements which can be shown to comply with the ESRC Research Ethics Framework, or the MRS Code of Conduct, can be considered to be appropriate. Again, the project manager on behalf of government should check whether this process has satisfactorily resolved all the ethical issues identified in the initial risk assessment. For projects presenting more than minimal risk, departments should ensure a formal ethical review has been undertaken in accordance with the principles set out in paragraph 3.9 above.

⁷ Invitation to Tender (ITT) documents should request that applicants address all identified risks as well as any others they consider might arise and require that tenderers/applicants identify proposed arrangements for initial scrutiny and ongoing monitoring of ethical issues. The ITT should make it clear that appropriate handling of ethical issues is part of the tender assessment exercise and proposals will be evaluated against an 'ethical standards' dimension in addition to others already used by departments, such as value for money. Some departments find it useful to peer review project proposals - ethical dimensions should ideally be considered as part of this process.

- 3.15 For internal projects, and external projects where the contracted organisation does not have satisfactory arrangements for ethical review, departments need to ensure that project proposals are scrutinised by one or more independent research professionals, according to the level of ethical risk.
- 3.16 It is advisable for all substantial and/or higher risk projects to have a steering or advisory group. Included in the role of steering/advisory groups should be a requirement to ensure that initial scrutiny procedures are undertaken and emergent ethical issues are monitored, and the membership of steering/advisory group needs to reflect this need. Line managers of project managers are expected to maintain ethical standards of projects carrying 'minimal risk only'.

Sanctions and redress

- 3.17 Where a participant complains of a breach of ethical procedures, the complaint must be fully investigated by the department and if justified, a letter of apology and explanation sent to those concerned. Wilful misuse of data or abuse of the research relationship – whether it is unlawful or simply breaches ethical principles – should be brought to the attention of the appropriate part of the department so action can be taken. Departments should have specific policies and processes to deal with these situations.
- 3.18 Each department should require that contractors notify them of complaints and have specific policies and procedures to help them deal with such complaints. Details of all complaints, along with departmental responses should be collected and reviewed regularly so appropriate remedial action can be taken, where necessary.

4. The Government Social Research Unit's Role & Responsibilities

- 4.1. The role of GSRU in promoting ethical standard across GSR is to:
- **Keep the guidance under review**, to ensure it is kept up-to-date.
 - **Keep a watching brief on ethical developments** and provide ad hoc advice on specific ethics issues emerging in departments, including facilitating sharing of information on difficult cases and their resolution.
 - **Support departments** in sharing good practice and promote consistency in the development of local protocols, and supporting proforma.
 - **Ensure competencies** within the GSR Competency Framework incorporate ethical standards.
 - **Provide training** for GSR staff to help them develop ethical expertise.

Appendix A: Links to other sources of ethical guidance

Please note GSRU is not responsible for the content of these internet sites.

- Data Sharing for Statistical Purposes; A Practitioners' Guide to the Legal Framework. Legal and Data Sharing Branch of National Statistics and International Division, Office for National Statistics (ONS).
http://www.statistics.gov.uk/downloads/theme_other/NSDataSharing.pdf
- Doing the Right Thing. Working Paper 11 (2003) The Department for Work and Pensions. HMSO London. <http://www.dwp.gov.uk/asd/asd5/WP11.pdf>
This is a discursive document with practical advice for researchers on a wide range of topics. This document is especially useful for discussions about the pros and cons of random assignment, incentive payments and data sharing.
- Further information on the Department of Health's Research Governance Framework for Health and Social Care is available at:
www.dh.gov.uk/assetRoot/04/01/47/57/04014757.pdf
- For guidance on FOI, see the Department for Constitutional Affairs (DCA) website at www.foi.gov.uk/guidance/proguide
- There is a range of guidance on the ONS website. See http://www.statistics.gov.uk/about/national_statistics/cop
- The Cabinet Office has prepared guidance on the conduct of social research and statistics during Elections and the Civil Service Code. The latest versions are available at www.cabinetoffice.gov.uk/conduct.aspx
- Research Ethics Framework (2005) Economic and Social Research Council (ESRC).
www.esrc.ac.uk/ESRCInfoCentre/Images/ESRC_Re_Ethics_Frame_tcm6-11291.pdf This document details the minimum standards required of all ESRC funded research. It also contains a useful discussion on the relationship between research governance and ethics.
- Ethical Guidelines (2002) Social Research Association (SRA). London.
<http://www.the-sra.org.uk/publications.htm>
- RESPECT, a project funded by the European Commission's Information Society Technologies (IST) Programme, to draw up professional and ethical

guidelines for the conduct of socio-economic research.
www.respectproject.org/code/index.php

- Guidelines for good practice in Evaluation (2003). United Kingdom Evaluation Society. www.evaluation.org.uk
- The Market Research Society (MRS) has developed guidelines on the conduct of social and market research, including research among children and young people, and the implications of the Data Protection Act, 1998
www.mrs.org.uk/standards/codeconduct.htm
- British Standards Institution (BSI) has developed standards on data security (ISO 17799) and also provides useful guidance on data protection.
<http://www.bsi-global.com/>
- The European Society for Market Research (ESOMAR) has also developed a Code of Marketing and Social Research to ensure its members adhere to high professional and ethical standards. The site also includes useful updates on data protection www.esomar.org.

Appendix B: Legal Context

The main areas of law that are likely to be relevant to the ethical considerations are set out below. Legal advice should always be sought if there is any uncertainty regarding legal rights and obligations.

- B1 Confidentiality: A duty of confidence may arise either expressly or by way of implication. For information to be subject to a duty of confidence it must have the necessary quality of confidence and not be a matter of public knowledge. There may be a public interest in disclosing information which is held subject to a duty of confidence which overrides the public interest in keeping the information confidential. However this is a complex and developing area of law and legal advice should be sought if it becomes an issue.
- B2 Consent: For consent to be valid it must be freely given by a person, acting voluntarily, who has the necessary capacity and is sufficiently informed. The age at which an individual has capacity to consent (or refuse consent) will depend on the circumstances. In this context, persons with parental responsibility should generally be asked to consent on behalf of children under the age of 16. Children who are 16 or over (i.e. those aged 16-18) may be able to give their own consent although it may also be appropriate for parents to be informed. However each case must be considered on its own facts.
- B3 The Human Rights Act 1998: This incorporates the rights and freedoms guaranteed under the European Convention on Human Rights (the Convention) into domestic law. A public authority must not act in a way which is incompatible with a Convention right unless it cannot do otherwise as a result of a provision of primary legislation. Of particular relevance in this context is Article 8 of the Convention, which guarantees the right to respect for private and family life, home and correspondence.
- B4 Data Protection Act 1998: This makes provision for the regulation of the processing of information relating to individuals including the obtaining, holding, use or disclosure of such information. It implements the EC Data Protection Directive ([95/46/EC](#)). The Act gives individuals rights of access in relation to personal data which is about them, and provides that their personal data must be processed in accordance with the data protection principles. There are exemptions from some of the provisions of the Act in certain cases. The exemption in section 33 which applies to data processed only for research, statistical or historical purposes may in particular be relevant.

B5 The Freedom of Information Act 2000: This provides a right of access to information held by a public authority. There are a number of exemptions to this right, the majority of which are not absolute (that is, they are subject to a balancing act as to whether the public interest in providing the information outweighs the public interest in maintaining the exemption). The exemptions in section 40 (which relates to personal information) and section 41 (which relate to information provided in confidence) may in particular be relevant.

Other provisions that may be relevant are:

B6 Crime and Disorder Act 1998: Section 115 of the Crime and Disorder Act 1998 gives power to disclose information to specified relevant authorities (e.g. those engaged in Crime Prevention Work) where the disclosure is necessary or expedient for the purposes of that Act.

B7 Health and Social Care Act 2001: Section 60 of the Health and Social Care Act 2001 enables the Secretary of State to make regulations for and in connection with requiring or regulating the processing, including for research purposes, of patient information in prescribed circumstances. Under Section 61 the Secretary of State has established the Patient Information Advisory Group to provide, *inter alia*, an additional safeguard for patients as regards the use of the power provided by section 60.

B8 Anti-Terrorism, Crime and Security Act 2001: Section 17 of the Anti-Terrorism, Crime and Security Act 2001 extends certain existing disclosure powers to include specified purposes relating to criminal investigations and proceedings.