# BSG Ethical Guidelines

## BSG Guidelines on ethical research with human participants, updated March 2012

## Background

Researching later life engages us with people living in all situations including some whose concerns relate to their health, housing and social care. Regardless of whether they are receiving or providing services or have some other interest, inviting them to participate in research is a serious matter. We should approach them only after giving careful consideration to what it is we will be asking them to do. We may see them as research participants or co-producers of research. The following guidelines relate to research projects of all forms – including undergraduate and postgraduate research (see also Gilhooly, 2002).

## Preliminary questions

Early in the planning of your project, you should address two questions.

### 1) What might it be like to take part in the research?

Many people really enjoy taking part in research projects finding them an opportunity to say positive things and make a contribution. But sometimes the experience is not so positive and the possibility of causing harm, distress or anger, may be unavoidable but it must be minimised. If your fieldwork is to be undertaken in complex or dangerous settings you should spend time beforehand simply observing what goes on and perhaps you should consult individuals or organisations with relevant experience. It is important to consider whether consent is needed to observe these settings. Often it is sensible if you work through possible fieldwork strategies. Your aim should be to check out what might be asked of the prospective research subject, and how different people might feel about this.

You should also assess the position of the researcher who may be putting themselves in a vulnerable position. In participatory research this may be an older person and you should consider the expectations that you have in involving them (see Barnes & Taylor, 2007). In seeking ethical approval, you may be asked if you have undertaken these kinds of check – a form of 'risk assessment'.

**2) As a result of your enquiries or observations, might you come across individuals with needs requiring treatment or attention?**

If so, you should decide in advance what actions you should take. This may entail consulting service providing agencies. It is particularly important that you think through how you introduce yourself, how you will be perceived and the limits of what you will feel able to do. In order to avoid situations where you are expected to take actions for which you are not prepared, you will need to explain clearly what your research aims to do and should consider whether you should inform participants of the circumstances under which you would need to involve a third party.

## Undertaking ethical research

Before you begin fieldwork you must consider the ethical implications of your research. If you will be including participants who are connected to the health services as service users or workers then ethical approval may be required. All NHS-based research must be submitted to an NHS research ethics committee (REC) (further details are given below). In all cases you should obtain ethical approval from your institution's Research Ethics Committee (REC) or equivalent (University Research Ethics Committee – UREC). You may find that approval by an REC is accepted by the UREC and further review is not required but do remember to ask.

This document is intended to provide guidance and information on this procedure which involves developing an Ethical Statement concerning the research and an Agreement to Participate for all respondents.

**Basic principles**

- A first basic principle for research is that the human rights of the individuals who participate or who are observed are recognised and respected.

- Those you invite to participate should be given full details of what will be asked of them, leading to a signed Agreement to Participate. These details should be given in a written form translated as necessary (font pt.14 as a minimum) or using alternative formats. You should provide clear written information even if individuals are not able to read or to understand this. This is because they may wish to consult others (advocates, family, carers, etc.) who, in turn, may be concerned to know more about what might be involved. It is essential that you inform people in advance of what you will be asking of them so that they can give their consent. This consent may need to be re-negotiated throughout the research process. The Mental Capacity Act, 2005 states that intrusive research carried out on, or in relation to, a person who lacks capacity to consent to it is unlawful unless the research is approved for meeting certain requirements. It also outlines issues regarding consultation of carers on behalf of a person who cannot give consent to taking part in the project (see sections 30-34, The Mental Capacity Act, 2005).

- The researcher may need to confirm their suitability for working with vulnerable adults by having a criminal records bureau check – see www.crb.org.uk for details.

- You should inform prospective participants about the known and possible consequences of your research: what might be done with the resulting data and how your recommendations might affect services. You should include assurances about levels of confidentiality, anonymity, accessibility and information about how your research evidence will be presented. If it is proposed that research data should be archived, this should be discussed in detail. Consenting to secondary use of data is a way of doing something useful for posterity. In the case of participative or emancipatory research, it may be that your participants will have some control or ownership of the research material. If so, this needs to be negotiated and clearly agreed. You will need to assign copyright at the time of interview. This is important if any recording or writing by a participant is to be published and there is an example of a consent form on www.oralhistory.org.uk (also given at the end of this document).

- Researchers have obligations in observational studies to respect the privacy and psychological well-being of individuals taking account of cultural issues. 'Unless those observed give their consent to being observed, observational research is only acceptable in situations where those observed would expect to be observed by strangers'. (British Psychological Society, p11).

- You should offer something in return, making dissemination as inclusive as possible. Here are three ways in which you might do this. First, you should send a letter, thanking people for their participation. Although purely symbolic, this may be sufficient and widely appreciated. Second, you might send them a report summarising the findings and/or recommendations, plans for dissemination and references to other publications. A third option is for you to offer to acknowledge their contribution by naming them in the concluding report. Often, without asking them, researchers assume that participants wish to remain totally anonymous. In this participatory age, however, some may welcome a public acknowledgement of their contribution to education or to the development of services.

- Sometimes participation might involve payment (either monetary or in kind, such as a shopping voucher), or it may be subject to a prior agreement with a participating organisation (as might be the case in interviewing service providers, for example). Such arrangements may place a certain obligation upon the participant and you may have a different relationship as a consequence. In such situations, there are other ethical issues to be addressed regarding the level of payment and the risks of exploitation – these should be discussed with those involved with ethical committees. Some believe the limit to an incentive should be that participants are not persuaded to undertake something they would not normally do – rather, the

incentive should act as an encouragement to give priority to participation over other possible uses of a participant's time.

- When no such obligation arises from an agreement to participate – i.e. participation is perceived to be purely voluntary – then you should not apply any pressure to those individuals who have doubts or reservations about participation. Moreover you should make it clear that, should they agree, they will be free to drop out at any time or to refuse to answer a question or whatever.

- Participants should be provided with information about how to complain or comment: they need to be able to contact the Principal Investigator or Supervisor for postgraduate students.

- The researcher should tell someone the address and time of interviews, recognising their own need for security.

- Research is often undertaken in teams and principles of good practice need to be agreed between members.

- Researchers should protect the rights of participants between projects, guarding against dissemination of confidential information.

It is important that you endeavour to adhere to these principles, but there may be occasions when this is not possible. Providing detailed information, for example, in itself increases stress among some people.

Despite having endeavoured to minimise the risks entailed in fieldwork, you may still face distress, anger or other kinds of ethical dilemmas. You are then expected to exercise professional judgement and to seek a solution that is in keeping with your conscience. If possible you should raise these matters with those involved in ethical committees or research governance within your own establishment.

## Ethical research practice

There is no one way of doing ethical research. In practice, researchers have to take different approaches to different issues. There are however three key aspects to the organisation of fieldwork that you should carefully consider.

### Teamwork

There is no guarantee that teamwork is more ethical in practice but all too often research is undertaken by an individual researcher in isolation. This can be the cause of stress and anxiety which in turn can lead to poor practice. One of the benefits of teamwork is for the group to provide suitable advice and support to each other. This should be the rationale behind supervisory teams for postgraduate work just as much as research teams for project work.

In addition you might decide to set up an Advisory Group for your project that includes people from other organisations. It is important to recognise that your prospective research participants may be able to offer you invaluable comment on the acceptability of your methods and the risks that you are running. You may be able to consult some and then invite them to join your Advisory Group. This is one of the most important aspects of participatory research.

Not only does teamwork help to ensure that research practice is of a high quality, but it can also serve as a sounding board when you have to handle ethical issues that arise in the course of fieldwork. Through such teamwork, you can develop a fund of experience of sustaining ethical research practice.

## Piloting research methods

Frequently it is the case that, prior to fieldwork starting, neither you nor any of your advisors can know what risks are being run in practice. Methods should be piloted, not only to ensure that they are effective in regard to the aims of the research, but in order to check their acceptability. Participants in the pilot stage should be asked if they consider any of the methods potentially distressing or annoying. In this way piloting can strengthen the ethical basis of the project.

### Interpersonal fieldwork

Often research entails interviewing or some similar form of personal interaction. The ethical principles guiding such fieldwork require you to:

- do no harm, treat those participating with respect and dignity, and work within a framework that acknowledges privacy, justice, human rights, and non-discriminatory practice,

- be appropriately equipped and supported (and supervised, if you are a research student, research assistant, interviewer or fieldworker),

- recognise the agency of the research participants and their freedom at all times to refuse collaboration,

- adopt non-oppressive strategies free of prejudice and discrimination,

- abide by the requirements of the Data Protection Act, and the Copyright and Licensing Act,

- respect the assurances given to the participant; for example, regarding confidentiality,

- adopt the principles of honesty and integrity in scholarship and research.

## Procedure

In order to obtain ethical approval you should prepare an *Ethical Statement*.

Your *Ethical Statement* should:

- be based on the basic principles listed above,

- include any further information about how ethical issues might be handled in the proposed fieldwork,

- identify any specific risks that might be encountered, and indicate how these will be minimised,

- include or append the letter or leaflet to be used in recruiting participants and the *Agreement to Participate* form,

- indicate how participants will be supported, particularly in the event of distress being caused.

You should think positively about the task of preparing your *Ethical Statement*. If done carefully, it should prove useful to you in underpinning your subsequent research practice.

Below is a model *Agreement to Participate*.

Agreement to Participate (434k)

## New ways of working

### Ethical Clearance and the NHS

Whilst these guidelines refer to all research undertaken by social gerontologists, we will often find ourselves involving older people who are service users within the healthcare system. This has involved quite complex procedures with local and multi research ethics committees but since the mid 2000's the procedure has been streamlined leading to the introduction of the National Research Ethics Service (NRES) in April 2007 and since 2009 part of the Integrated Research Application System (IRAS), see below. National Research Ethics Advisors will ensure that full research ethics committee consider only those studies needing intensive scrutiny. A screening function will identify at an early stage applications which may need further development, fall outside the scope of NHS Research Ethics Committees or demand intensive scrutiny. Contact details, application forms and advice on completion are available from the National Research Ethics Service (NRES) and comprises the former Central Office for Research Ethics Committees (COREC) and Research Ethics Committees (RECs) in England (www.nres.npsa.nhs.uk).

Those wishing to undertaken research within the NHS who are not employees will also need to acquire a 'Research Passport'. The NHS – Human Resource (HR) Good Practice Resource Pack describes the Research Passport system whereby honorary research contracts can be issued to researchers with no contractual arrangements with the NHS, and who wish to carry out research in the NHS that affects patient care – (see http://www.nihr.ac.uk/systems/Pages/systems_research_passports.aspx)


**Social Care Research Ethics Committee**

The Department of Health (DH) asked the Social Care Institute for Excellence (SCIE) to appoint a new national Social Care Research Ethics Committee (REC) which has been operating since June 2009. It adheres to the DH Research Governance Framework for Health and Social Care and covers the conduct of research in the NHS and adult social care.

The Social Care REC meets monthly and is expected to deliver an opinion to applicants applying for ethical review within 60 days of receiving a valid application. The Social Care REC reviews adult social care research, intergenerational studies involving adults and children or families, use of social care databases and some proposal for social science studies situated in the NHS. This REC also reviews applications involving the social care section e.g. in local authority, private and voluntary care settings) not suitable for review by other NRes RECs or which cross boundaries see http://www.screc.org.uk

**Integrated Research Application System (IRAS)**

The Integrated Research Application System (IRAS) is a single online system for applying for permissions and approvals for health and social care/community research in the UK. It streamlines the process for seeking relevant approvals, as researchers no longer need to enter the details for a single project in separate application forms.
**IRAS can be accessed at www.myresearchproject.org.uk.**

Since 1 April 2009, all applications to NHS Research Ethics Committees are made using IRAS (see).

http://www.nres.npsa.nhs.uk/applications/integrated-research-application-system

**ESRC – Framework for Research Ethics (FRE)**

Your attention should be drawn to the Research Ethics Framework (REF) for social science research introduced by the ESRC in January 2006 and revised as the Framework for Research Ethics (FRE) in 2010. See:

http://www.esrc.ac.uk/about-esrc/information/research-ethics.aspx

Since 2006 ESRC will only fund research where consideration has been given to ethical issues. It is therefore important that you are aware of your institutional procedures for ethical clearance for Research Councils through your UREC.

**The RESPECT Code Of Practice**

The RESPECT Project is funded by the European Commission's Information Society Technologies (IST) Programme to develop professional and ethical guidelines for the conduct of socio-economics research. This programme has produced the RESPECT Code of Practice intended to aid responsible and informed decision-making. It is a voluntary aspirational code, and is not prescriptive and based on three main principles:

- Upholding scientific standards
- Compliance with the law
- Avoidance of social and personal harm

(See – www.respectproject.org/code/index.php)

## Other ethical guidelines

Finally, you will find that many professional associations across the range of disciplines have developed ethical guidelines and we recommend the following:

British Sociological Association – statement of ethical practice - see www.sociology.org.uk/as4bsoce.pdf

British Psychological Society – code of conduct - see www.bps.org.uk/the-society/code-of-conduct/code-of-conduct_home.cfm

British Educational Research Association, Guidelines for Educational Research (20054) http://www.bera.ac.uk/publications/pdfs/ETHICA1.pdf

Social Research Association - see http://www.the-sra.org.uk/ethical.htm

## Useful references

Barnes, M. & Taylor, S. (Summer 2007) Summary Guide of Good practice for Involving Older People in Research, ERA-AGE.
Gilhooly, M. (2002) 'Ethical Issues in researching later life' in Jamieson, A. and Victor, C. (eds.) Researching Ageing and Later Life. Buckingham: Open University Press, pp211-225.
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Kayser-Jones, J. & Koenig, B.A. (1994) 'Ethical Issues' in Gubrium, J.F. & Sankar, A. (eds.) Qualitative Methods in Aging Research. Thousand Oaks, California: Sage Publications, pp.15-32.
Iphofen R. (2009) Ethical Decision Making in Social Research. Basingstoke, Hampshire: Palgrave Mcmillan.