75-monitoring-equality-developing-gender-identity-question). The initial judgment about whether or not questions are sensitive and likely to cause harm or discomfort rests with the lead researcher. For advice in such cases, the lead researcher should initially consult their departmental Ethics Administrator.

Finally, researchers should give appropriate consideration to the potential risks to themselves and to others who may be involved with, or affected by, the research. Appropriate steps should be undertaken to mitigate these risks (e.g. undergoing a risk assessment process, implementing a lone work policy – further guidance may be found on the University's Health and Safety webpages, and departments may have their own policies and procedures in place).

The University of Sheffield
Research Ethics Policy Note no. 4

PRINCIPLES OF ANONYMITY, CONFIDENTIALITY AND DATA PROTECTION

For a detailed discussion of the law on which University policy in this respect rests, see the Specialist Research Ethics Guidance Paper, 'Principles of anonymity, confidentiality and data protection', of which the following is no more than a brief summary.

A researcher who collects, stores, uses, discloses or destroys identifiable personal information - as defined as in the next paragraph - about living individuals, must comply with the requirements of the Data Protection Act 1998 (DPA) and the Common Law duty of confidence. A researcher who collects, stores, uses, discloses or destroys identifiable personal information about deceased individuals, must still consider the requirements of the Common Law duty of confidence. The collection, storage, use, disclosure or destruction of anonymised personal information, whether relating to the living or the deceased, falls outside the scope of these legal requirements.

The DPA applies to 'personal data', which are data that relate to a living individual who can be identified either from those data alone or from those data taken in conjunction with other information that is available to the Data Controller. 'Available' here means that the 'other information' needed to enable an individual's identification is either in the possession of the Data Controller or is likely to come into the Data Controller's possession. The Data Controller in this context is usually the University of Sheffield rather than any particular individual or team, although collaboration with other institutions may result in joint Data Controllers.

In practice, in the case of discrete research projects, it is highly unlikely that members of the research team will come into contact with data from other parts of the University that may result in the re-identification of participants whose data has been anonymised. However, researchers should think carefully about this possibility when seeking to anonymise their data; strictly speaking, if there is any possibility that anonymised data could be traced back to the individual who provided it via any other data held by, or likely to come into the possession of, the Data Controller, then the data has in fact only been 'pseudonymised'. This means that it would in fact still be classed as personal data. Two examples of situations in which this problem is more likely to arise include:

- administrative research, in which research staff may have access to central University records that may link data to the participants that provided it;
- types of research which there are particular identifiers that are widely used outside the research team (e.g. health research involving NHS numbers).

The use of identifiable personal information in research should be reduced so far as possible consistent with achievement of the research aims. Thus researchers should always think carefully about (a) whether it is necessary to use identifiable personal information, (b) what is the earliest stage at which de-identification might be possible without compromising the integrity of the research and (c) how full, robust anonymisation can be achieved. All uses of personal information should be defensible as accurate, relevant and not excessive.

If it is necessary to use identifiable personal information, then this should generally only be done with consent. It may be possible to use such data without consent - when the material is already in the public domain, for example - but consent is to be preferred, unless it can be shown to be inappropriate for some reason. If a researcher intends to process data without

consent, then further advice should be sought.

When gathering identifiable personal information researchers should aim at all times to ensure that its processing is defensible as both 'fair and lawful'. This requires as much transparency as possible about the uses to which data will be put and any risks that might be involved.

Personal information must be kept secure at all times. The level of security should be proportionate to the risks inherent in the nature of the data, but all personal information should be kept securely e.g. portable devices should be encrypted. Although personal information should not be retained for longer than necessary, it is recognised that, as long as relevant conditions are satisfied, research may require the retention of data for long periods and that this may be justified.

Personal data that are processed for research purposes may be exempt from a DPA subject-access request. In general, the disclosure of identifiable information, including information that may be identifiable to others, should be avoided wherever possible. If it is necessary to disclose personally identifiable information, or information that may be potentially identifiable, then this should usually only be done with the consent of the individuals involved.

Finally, the common law duty of confidence applies to research, as to all other activities. Individuals have a reasonable expectation of privacy with respect to confidential information that refers to them. Any use of such confidential information that exceeds that which an ordinary person could reasonably be said to expect constitutes a breach of confidence.

For further discussion, see the separate Specialist Research Ethics Guidance Paper entitled: 'Principles of anonymity, confidentiality and data protection'

NB. The University has a separate policy covering the transfer of research data which relates to human participants between Principal Investigators within the University of Sheffield.

The University of Sheffield
Research Ethics Policy Note no. 5

ETHICS REVIEW OF HEALTH AND SOCIAL CARE RESEARCH IN THE UK

The University of Sheffield's Research Ethics Policy is intended to complement the long-established National Health Service (NHS) ethics review system (overseen by the Health Research Authority (HRA) and incorporated into the HRA Approval process), and the procedure established by the national Social Care Research Ethics Committee. The University's Ethics Review Procedure does not duplicate the functions, or overlap with the remit, of the NHS ethics review system or the national Social Care Research Ethics Committee.

It should be noted that, in addition to the requirement for ethical review, health and social care research in the UK is subject to additional research governance requirements. For more details refer to the following webpage: https://www.sheffield.ac.uk/ris/other/gov-ethics/governancehttps://www.sheffield.ac.uk/ris/other/gov-ethics/governance.

It should be noted that in the UK, for clinical trials of Investigational Medicinal Products (IMP-trials) or Medical Devices, and for research involving the use of human tissue, there are specific legal and regulatory requirements which must be considered alongside the requirements for ethical review. Further information relating to the requirements for IMP-trials and Medical Device trials can be found in sections 1.2 and 2 of this Policy Note, and the MHRA's website (https://www.gov.uk/government/organisations/medicines-and-healthcare-products-regulatory-agency). Further information relating to the use of human tissue in research is provided in section 2 of this Policy Note and in Research Ethics Policy Note no. 11.

In addition, there is a legal requirement for social care research involving adults in England and Wales who are deemed to be lacking in capacity to be reviewed by a recognised Appropriate Body under the Mental Capacity Act 2005. Appropriate Bodies include certain NHS Research Ethics Committees and the Social Care Research Ethics Committee; for full details see section 3 of this Policy Note and the Specialist Research Ethics Guidance Paper entitled 'Research involving adult participants who lack the capacity to consent'.

1 DEFINITIONS

1.1 Research

The University's Research Ethics Policy defines research as 'a process of investigation leading to new insights, effectively shared'.

The HRA defines research as 'the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods'.

Thus the University's definition of research is broader than that of the HRA. This means that some studies which are not considered research by the HRA, and which therefore do not require ethical review by an NHS Research Ethics Committee, may still require ethical review via the University's Ethics Review Procedure (e.g. studies classed as service evaluation by the HRA, but which are undertaken by a student as the research element of a University degree award).

1.2 Health care research

The Department of Health's *Research Governance Framework for Health and Social Care Research* (2005), the 'RG Framework', defines health care research as:

> All research that relates to the responsibilities of the Secretary of State for Health. That is, research concerned with the protection and promotion of public health, research undertaken in or by the Department of Health, its non-Departmental Public Bodies and the NHS, and research undertaken by or within social care agencies. It includes clinical and non-clinical research, research undertaken by NHS or social care staff using the resources of health and social care organisations, and any research undertaken by industry, charities, research councils and universities within the health and social care systems that might have an impact on the quality of those services (The RGFramework, p. 2).

In practice, the University considers research that requires review by an NHS Research Ethics Committee to be health care research (see section 2 of this Policy Note for more details).

Clinical trials of investigational medicinal products (IMP-trials), which are one type of health care research, are defined by the International Conference on Harmonisation Guideline on Good Clinical Practice (ICH-GCP) as:

> Any investigation in human subjects intended to discover or verify the clinical, pharmacological and/or other pharmacodynamic effects of an investigational product(s) and/or to identify any adverse reactions to an investigational product(s) and/or to study absorption, distribution, metabolism, and excretion of an investigational product(s) with the object of ascertaining its safety and/or efficacy. The terms clinical trial and clinical study are synonymous.

Research involving human tissue is one type of health care research. The Human Tissue Act (2004) defines human tissue as 'relevant material that has come from a human body and consists of, or includes, human cells'.

1.3 Social care research

Social care research refers to research that is undertaken in or with bodies (either independent or statutory) that provide personal social services.

Local social care providers will have their own research governance requirements, and researchers will need to refer to the relevant provider in order to determine which types of project will be affected. For example, the definition of social care research applied by Sheffield City Council is 'research that involves human participants who have been identified through the social care services of Sheffield City Council with the aid of Council resources'.

It should be noted that not all social care research requires access to human participants via statutory social care services.

2 ETHICS REVIEW PROCEDURE FOR HEALTH CARE RESEARCH

Health care research is reviewed by an NHS Research Ethics Committee (NHS REC). Review by an NHS REC forms part of the HRA Approval process. The remit of NHS RECs is defined by the Department of Health's policy document *Governance arrangements for research ethics committees.*

In general, review by an NHS REC will be required for research that involves participants identified from, or because of, their status as patients of the NHS or other Department of Health Services, and/or the relatives of such patients. There are also specific types of health

care research that will require review by an NHS REC (e.g. a clinical trial of an Investigational Medicinal Product and research involving human tissue). Research involving only the premises and/or staff of the NHS or other Department of Health services does not require review by an NHS REC. Researchers should refer to the HRA's ethics decision tool for full details:

http://www.hra-decisiontools.org.uk/ethics/

The University requires all research involving human participants, their data or their tissue to be ethically reviewed. This means that research that falls outside the remit of NHS RECs, but which involves human participants, their personal data or tissue must be reviewed via either the University's Ethics Approval Procedure or an Alternative Ethics Review Procedure (for further information about the latter, see section 4 of the University's Research Ethics Approval Procedure). It should be noted that this may include studies that the NHS considers to be service evaluation, and those which involve NHS staff or premises.

3 ETHICS REVIEW PROCEDURE FOR SOCIAL CARE RESEARCH

The national Social Care Research Ethics Committee (SCREC) is part of the HRA. The University's Ethics Review Procedure does not duplicate the functions, or overlap with the remit, of SCREC. SCREC generally expects to review particular categories of social care project, including social care studies funded by the Department of Health, and social care research that involves people lacking capacity in England and Wales and requires approval under the Mental Capacity Act 2005; full details can be found on the HRA's website:

http://www.hra.nhs.uk/resources/before-you-apply/non-nhs-recs/national-social-care-research-ethics-committee/.

The SCREC does not review studies involving clinical interventions. Such research should be reviewed by an NHS REC.

If social care research does not require review by an NHS REC or SCREC, but involves human participants, personal data or human tissue, it must be reviewed using the University Ethics Review Procedure, on the proviso that the requirements of the ESRC *Framework for Research Ethics* are met. This means that the ethical scrutiny of social care research projects of this kind will be undertaken by a sub-committee of the UREC, comprising two ethics reviewers from the project's department of origin, one lay member from the UREC, and additional members of the UREC as required on a case-by-case basis in order to meet the requirements of the external body. The departmental Ethics Administrator should be notified of social care research projects, so that they can liaise with the UREC Minute Secretary to arrange appropriate ethical review.

3.1 Mental incapacity

The University's Ethics Review Procedure cannot review research that involves adults in England or Wales who are defined as lacking mental capacity. Only Research Ethics Committees that are recognised as *Appropriate Bodies* for this purpose can do so under the Mental Capacity Act (MCA) 2005 (these are also sometimes known as 'flagged committees' for the purposes of such reviews). SCREC as well as NHS RECs established in England and Wales are recognised for this purpose. The MCA applies only to people aged 16 and over.

The MCA does not apply to Scotland. In Scotland medical research which involves people aged 16 or over who lack capacity requires approval from an NHS REC. There is currently no

equivalent law on mental capacity in Northern Ireland.

For further information, see the Specialist Research Ethics Guidance Paper dealing with 'Research involving adult participants who lack the capacity to consent'.

The University of Sheffield
Research Ethics Policy Note no. 6

RESEARCH INVOLVING VULNERABLE PEOPLE

From the initial research design stage onwards research involving human participants must prioritise how the research process and results are likely to impact upon those who will be directly involved as participants as well as those for whom the research has relevance. This is part of the duty of care owed by the University's staff and students to all people affected by the University's research.

The responsibility for conducting research rigorously, respectfully and responsibly, from start to finish, is magnified when undertaking research with people who are considered to be vulnerable. However, the term vulnerability is open to many interpretations. Certain people or groups of people are potentially more vulnerable than others.

The degree of vulnerability of an individual will depend on a range of factors, some of which can be anticipated and some not. Therefore researchers should take particular care to:

- anticipate and prepare for foreseeable ethical challenges, in order to protect the participant(s) and themselves;
- adhere to recognised research ethical principles and any associated legislative requirements (e.g. consent, confidentiality, etc.); and
- remain pragmatic and flexible in ensuring these principles are applied rigorously.

The type of participants, the research methods employed, and the sensitivity of the subject being researched will all play a part in determining the degree to which participants are vulnerable.

1 THE CONCEPT OF VULNERABILITY

All human participants in research may be potentially vulnerable. Some participants may, however, be particularly vulnerable (as described below). Some people may not perceive themselves to be particularly vulnerable. However, there are certain groups that must be considered as vulnerable and appropriate steps taken to account for this.

There are three basic kinds of vulnerability:

- vulnerability to physical harm;
- vulnerability to damage to social standing or reputation; and
- vulnerability to psychological and emotional distress.

These types of vulnerability may occur in combination. People may be vulnerable in different ways and to different degrees at different points in their lives, due to the circumstances in which they find themselves at a particular time. However certain vulnerable individuals may be at more risk of harm when taking part. Accordingly, researchers cannot take it for granted that standard procedures (e.g. for seeking consent) will be appropriate and for some vulnerable groups it is essential that their specific requirements are taken into account and addressed when designing and undertaking research including information sheets.

Among the categories of people who are perceived to be likely to be vulnerable in a research context are:

(a) People whose competence to exercise informed consent is in doubt, such as:

- infants and children under 18 years of age;
- people who lack mental capacity, may be at risk of losing capacity or have fluctuating capacity for example people with learning disabilities, people with dementia or conditions that give rise to cognitive impairments such as stroke;
- people who suffer from psychiatric or personality disorders, including those conditions in which capacity to consent may fluctuate; and
- people who may have only a basic or elementary knowledge of the language in which the research is being conducted.

(b) People who may socially not be in a position to exercise unfettered informed consent, such as:

- people who depend on the protection of, or are controlled and influenced by, research gatekeepers (e.g. school pupils, children and young people in care, members of the armed forces, young offenders, prisoners, asylum seekers, organisational employees);
- family members of the researcher(s); and
- in general, people who appear to feel they have no real choice on whether or not to participate.

(c) People whose circumstances may unduly influence decisions to consent, such as:

- people with disabilities;
- people who are frail or in poor health;
- elderly people;
- people who are in care;
- relatives and friends of participants considered to be vulnerable;
- people who feel that participation will result in access to better treatment and/or support for them or others;
- people who anticipate any other perceived benefits of participation; and
- people who, by participating in research, can obtain perceived and/or benefits to which they otherwise would not have access e.g possibility of a new medication being available, payment for participation.

The above is not intended to be a comprehensive list, it is merely indicative of the range of situations in which questions about the vulnerability of research participants must be addressed.

Vulnerability should not simply be seen as a property or characteristic of individuals or categories of people. The research process may increase the potential vulnerability of participants, of a participant's relatives, friends and others who have a relationship to the participant, and of the researchers themselves. Similarly, research into sensitive topics may also increase a participant's vulnerability to harm or distress.

What is perceived as vulnerability in one research discipline may not be perceived as vulnerability in another; some disciplines and research areas also have specific legal, regulatory and/or governance requirements relating to vulnerable participants which must be met (e.g. for health and social care research). The type of research method and the subject matter of

the research also affect the nature and degree of participant vulnerability.

Different research methods present different risks to participants; these may be risks that increase the vulnerability of the participants. Researchers should put in place measures to manage and to mitigate foreseeable risks. This may include, for example, research which involves in depth qualitative enquiry and/ or requires the participant to use or recall experiences or incidents that may cause distress. The sensitivity of the subject matter being researched is also significant in this respect. For example, a research project focusing on any of the following subjects may increase the vulnerability of participants: 'race' or ethnicity; political opinion; religious, spiritual or other beliefs; physical or mental health conditions; sexuality and/or gender identity; abuse (child, adult); nudity and the body; criminal activities; political asylum; conflict situations; personal violence; and terrorism or violent extremism.

Conducting research ethically is not, however, a matter of avoiding potentially high-risk research. It is, rather, about preparing for and managing risks; it is a matter of being risk aware, not risk averse.

2 SOME IMPLICATIONS FOR RESEARCH

All research should be conducted as skilfully and as carefully as possible. Researchers must ensure that they themselves, and any collaborators or members of a research team or students under their supervision, comply with legal requirements in relation to working with infants or children or vulnerable adults.

The principles that govern all research involving human participants should be adhered to with even greater diligence when research involves vulnerable participants. When designing the research, including the informed consent process, and when conducting, communicating and publishing research the researcher should consider the perspectives of actual or prospective participant(s). Depending on the nature of the research, the researcher should also give consideration to how to manage the relationships with participants post-research, for example by offering to send them a summary of the results.

Researchers who collect information about the characteristics and behaviours of individuals and groups should where possible avoid using classifications or designations that give rise to unreasonable generalisations, resulting in the stigmatisation of, or prejudice towards, the group(s) in question.

3 THE IMPORTANCE OF CONTEXT

It is important to be *aware* that prospective participants *may* be vulnerable, but not to *assume* that they *are* particularly vulnerable. Each person is unique with a distinct personality. Therefore, it is worth reflecting that within groups defined as vulnerable there may be significant variation in degrees of vulnerability.

Context is an important factor in influencing vulnerability, such as, for example, the location in which the research is undertaken, the social-economic background of the participants, or the culture and living conditions of the participants. The combination of the research context and the particular research design has the potential to increase the vulnerability of participants.

4 GENERIC PRINCIPLES FOR CONDUCTING RESEARCH INVOLVING VULNERABLE PEOPLE

The following are useful generic principles that should be taken into account when doing research that involves vulnerable people:

- Be perpetually reflective about one's research actions and research decisions.
- Be aware that the particular characteristics of a research project can affect the nature and degree of participant vulnerability.
- In designing the research seek to minimise the potential risks to prospective participants.
- Be aware of the possible need to support participants on completion of the research, and prepare for this accordingly (not least with respect to an exit strategy).
- Where appropriate offer prospective participants as many choices and options as possible.
- Be aware of the risks to researchers themselves, as well as to participants, and minimise the potential risks in the research design.
- Show respect for the potential diversity of prospective participants in designing and undertaking the research.
- Pay attention to communication and prepare to meet support requirements in this respect, if necessary.
- Consider consent as an ongoing process.
- Be aware of power relationships in research (e.g. when undertaking research with people in care).
- Listen to participants and do not make assumptions about what participants want.

For further discussion of related issues, see Research Ethics Policy Notes nos. 2 (Principles of Consent), 3, (Participant Safety and Well-being), and 4 (Principles of Anonymity, Confidentiality and Data Protection), and the following Specialist Research Ethics Guidance Papers:

- Doing research with people with learning disabilities;
- Research involving adult participants who lack the capacity to consent;
- Ethical considerations in research with children and young people; and
- Ethical considerations in research involving older people.

The University of Sheffield
Research Ethics Policy Note no. 7

ADMINISTRATIVE RESEARCH WITHIN THE UNIVERSITY

In 2009, the University's Senate approved a proposal by the University Research Ethics Committee (UREC) that all empirical investigations, other than audits and evaluations, carried out by, or on behalf of, professional service departments of the University (i.e. 'administrative research') should be subject, as research, to research ethics review. This also applies to administrative research undertaken within academic departments, faculties or research centres, and aims to guarantee consistency across the full spectrum of the University's activities. It should also be a useful contribution to ensuring that whatever inquiries the University makes are of the highest possible quality.

Procedure aside, administrative research undertaken within, or on behalf of, the University is subject to the same research ethical requirements as academic research undertaken within, or on behalf of, the University. This principle applies whether the work is undertaken in- house, by University staff or students, or contracted out to an external research organisation (such as a market research company, for example).

The University has implemented two procedures for handling the ethics review of administrative research within the University:

1. Ethics Review Procedure for research undertaken within the Student Services Department;
2. Ethics Review Procedure for other administrative research.

1 ETHICS REVIEW PROCEDURE FOR RESEARCH UNDERTAKEN WITHIN THE STUDENT SERVICES DEPARTMENT

In September 2011, the UREC approved a procedure, developed in conjunction with Student Services, for the ethical review of research which is undertaken within the Student Services Department (as the department within the Professional Services which conducts the most research).

1.1 Applying for ethics review

This procedure applies to research undertaken within Student Services which involves human participants or personal data(it is assumed that research with human tissue will not be applicable). The first stage is for the project leader to complete the University Research Ethics Application Form for Staff in Student Services (guidance on deciding whether the project constitutes research can be found in a suggested 'pre-ethics review process', which is included in the application form) (NB. This form is currently available on paper only). The project leader then assesses whether the project presents a low or potentially high risk and proceeds to the appropriate procedure below (a suggested risk assessment checklist has been developed to assist project leaders in this decision, and is included in the application form).

1.2 Ethics review procedure for low risk projects

The project leader submits the ethics application form and any other supporting documentation to their line manager for ethical review. The line manager reviews the application and informs the project leader of their decision (in line with the potential outcomes outlined in section 3.1.6 of the Research Ethics Approval Procedure for academic

departments). If the line manager considers the project to represent a potentially high risk, then the procedure for high risk projects should be followed instead. Copies of all the documentation should be kept by the project leader and Student Services Ethics Administrator.

1.3 Ethics review procedure for high risk projects

The project leader submits the ethics application form and any other supporting documentation to the Student Services Ethics Administrator. The Ethics Administrator arranges for three departmental ethics reviewers to review the application and reach a decision (in line with the potential outcomes outlined in section 3.1.6 of the Research Ethics Approval Procedure for academic departments). The Ethics Administrator should confirm the decision to the applicant, and keep a record of the application and the decision made. In the event of a significant, fundamental difference of opinion between ethics reviewers, then the application should be reviewed by the independent members of the Student Services Ethics Review Panel. If members of the Ethics Review Panel cannot reach a consensus, then the UREC will undertake an ethics review of the application. The UREC's decision is final.

2 ETHICS REVIEW PROCEDURE FOR OTHER ADMINISTRATIVE RESEARCH

The following ethics review procedure applies to research which involves human participants, personal data or human tissue, undertaken within all Professional Services departments, except for Student Services. It also applies to administrative research that is undertaken within academic departments/faculties/research centres.

2.1 Is it research?

Since, for administrative work, it is not always clear whether a particular inquiry constitutes research, the first stage is to determine whether or not ethical review will be required. Should the member of staff who is taking the lead on the work require advice on this, they may contact the Ethics Administrator for administrative research, who is also the Minute Secretary to the UREC. The Minute Secretary will consult with the Chair of UREC in order to decide whether ethics review is necessary. If necessary, at this stage the Chair shall also take soundings within the Committee.

2.2 Ethics review

The second stage, should it be decided that ethics review is necessary, will involve the member of staff who is taking the lead on the project submitting an ethics application using the online Ethics Application System (refer to the Research Ethics Approval Procedure section of this Policy for full details). For administrative research taking place within an academic department, the project will be reviewed in line with the standard University Ethics Review Procedure (i.e. the review will be undertaken within the department). For other administrative research, three ethics reviewers will be appointed by the Ethics Administrator for administrative research. Since the number of ethics applications of this type is very low, a pool of ethics reviewers has been identified from across the Professional Services. Should the reviewers be unable to reach a consensus on the decision, the UREC will undertake an ethics review of the application. The UREC's decision is final.

The University of Sheffield
Research Ethics Policy Note no. 8

USING EXTERNAL RESEARCH ORGANISATIONS

From time to time research involving human participants is carried out on behalf of the University of Sheffield by external organisations: market research organisations, private- or public-sector social research organisations, voluntary sector organisations, and so on.

Many of these organisations have their own research ethics guidelines or policies. However, in all cases it is the University of Sheffield's Ethics Policy Governing Research Involving Human Participants, Personal Data and Human Tissue that should govern the conduct of the research. The University of Sheffield is the contracting body and the University's Policy applies to any research that is carried out on its behalf. The contract under the terms of which such research is undertaken must stipulate this clearly and unambiguously. Research contractors must be made aware of the Policy's details.

Such research must be approved in accordance with the University of Sheffield's Policy and the details of the research ethics stipulation(s) in the contract with the external organisation should form part of the documentations submitted for ethics review.

The University of Sheffield
Research Ethics Policy Note no. 9

ARCHIVAL RESEARCH

1 PERSONAL DATA IN ARCHIVES

All archival research that involves 'personal data', whether in public or private archives, requires ethics review and approval via the Research Ethics Approval Procedure. The University's Research Ethics Policy uses the Data Protection Act's (1998) definition of personal data:

> 'Data which relates to a living individual who can be identified from those data, or from those data and other information which is in the possession of, or is likely to come into the possession of, the data controller, and includes any expression of opinion about the individual and any indication of the intentions of the data controller or any other person in respect of the individual.'

Archival research involving personal data is subject to all the strictures and principles of the Ethics Policy Governing Research Involving Human Participants, Personal Data and Human Tissue.

2 OTHER ETHICAL ISSUES IN ARCHIVAL RESEARCH

Notwithstanding the above, much archival research relates to individuals who are not living and, therefore, does not involve 'personal data', thus defined. This does not, however, mean that there are no ethical issues involved in this kind of archival research.

Public archives are generally straightforward, in that the material in them can be considered to be in the public domain already. Even here, however, there may be issues about ownership, publication and confidentiality that require explicit agreements.

The following ethical issues should be considered when undertaking research in private archives (which should be taken to mean everything from modest files of individual or family documents to large, managed documentary repositories, and to include on-line material as well as hard copy).

First, there is a responsibility to treat ethically the owner(s) or controller(s) of the archive. Explicit agreements should ideally be entered into, and recorded, about:

- the uses to which archival material will be put;
- if relevant, the nature of any anonymising strategies that will be employed;
- the ownership and copyright of the material; and
- the rights of approval of publication (if any) of the owner(s) or controller(s).

There may, depending on circumstances, be other matters to consider in this respect. It is important, and in the best interest of all parties, that factors such as these be dealt with explicitly and recorded appropriately.

Second, the competence and legal right of ownership (or control) of those with whom access to archival material is negotiated should not merely be assumed. It is a researcher's responsibility to satisfy her/himself of the propriety and legality of her/his actions in this respect.

Finally, it should be remembered that the dead may have living relatives, whose sensitivities should at least be explicitly considered. This does not mean that those sensitivities should always be able to prevent research or publication. It does mean that researchers should be clear and transparent about their reasons for setting such sensitivities aside, should they deem this to be necessary or appropriate.

The University of Sheffield
Research Ethics Policy Note no. 10

RETROSPECTIVE RESEARCH ETHICS REVIEW

It is fundamental to the spirit of the University Research Ethics Policy that research involving human participants, human tissue or personal data should not begin before research ethics review has taken place, according to the Research Ethics Approval Procedure, and ethics approval granted. Retrospective ethics review is, therefore, not permitted. It is the responsibility of the principal investigator or, in the case of a student project, the supervisor, to ensure that ethics review is undertaken in good time. There are no exceptions to this principle.

However, there may be circumstances in which there is legitimate uncertainty about when research begins (or has begun). In particular, scholars may accidentally, or unexpectedly, come across materials or events that subsequently become of research interest (i.e., they could be used as data within research).

The following examples may serve to illustrate the kinds of circumstances in which this may, with the best of intentions, happen:

- Attendance at a public occasion generates notes and observations that, subsequently, contribute to the framing of a research problem. For the sake of illustration, the occasion in question might, for example, be a political meeting, an academic conference, or a sporting occasion.
- An historian may come across documents that deal with living individuals and which set off a train of research thought. The expression 'come across' can cover a variety of eventualities: someone may send them, unsolicited, to the scholar concerned, for example, or the researcher may find them in an archive while investigating another, unrelated matter.
- A routine Internet search for material of interest with respect to ongoing research, or even undertaken for unfocused curiosity, may throw up something unexpected that stimulates the development of another line of research.
- Data collected as part of routine student module evaluations may show some interesting trends which the module leader would like to develop into a publishable piece of research.

These examples are simply chosen to illustrate the role of serendipity in the genesis of research, and do not exhaust the possibilities.

Taking the first paragraph of this Research Note completely literally it might be thought that in all three cases the initial material would be unusable as data, because it was noted or collected prior to ethics approval.

However, it is not the purpose of the Policy to discourage or prevent ethically defensible research from taking place. So, in cases such as the above, as soon as the researcher in question decides either (1) to develop a research project on the basis of the original materials or (2) to publish an account or analysis of the material in question, without further research, ethics review must take place immediately. No further work on the material will be permissible until ethics review has taken place. The research ethics application must make it clear that research ethics approval is being sought for existing material, that might already be in the researcher's possession, to be used in research, and that retrospective research ethics

approval is not being sought.

These limited exceptions cannot be used to permit retrospective ethics review for a project that could, and therefore should, have been reviewed through the normal procedure. Therefore, applications of this, exceptional, kind must initially be referred to the University Research Ethics Committee (UREC), together with details of how the materials were originally generated, and the original intention of these materials. UREC will determine whether it would be legitimate for a research ethics application to be made for these materials to be used for research and thus, decide whether they should proceed to ethics review within the department concerned. Only once this process has been undergone, and research ethics approval has been obtained, can research on the materials commence.

The University of Sheffield
Research Ethics Policy Note no. 11

RESEARCH INVOLVING HUMAN TISSUE

In the United Kingdom, the use of human tissue or primary cells for research purposes is legally regulated; primarily by the Human Tissue Act 2004 (HTA). The Act makes it a criminal offence to engage in various activities involving human tissue and cells, such as storage without a licence (issued by the Human Tissue Authority) or using human tissue or cells outside a research project that has been authorized and approved by a 'recognised ethics review committee' (RERC).

University research ethics committees are not 'recognised' committees for this purpose and researchers will therefore have to seek approval from a RERC prior to commencing research in order to ensure that the research complies with all the ethical and legal requirements. Currently, RERCs are all Research Ethics Committees under the auspices of the National Research Ethics Service (NRES) within the National Research Ethics Service (NRES) for England or within the wider UK Health Departments' (UKHDs) Research Ethics Service, together with all ethics committees recognised by the United Kingdom Ethics Committee Authority (UKECA) under the Medicines for Human Use (Clinical Trials) Regulations 2004.

The types of human tissue and cells that are covered by the HTA are referred to as 'relevant material'. The relevant materials covered by the HTA include materials that have come from a human body, whether living or dead, including body parts, organs and human cells. Established cell lines are not relevant material, but primary cell cultures are. Storage of established cell lines for research does not require a licence, nor does research using cell lines require ethical review (except in the case of human embryonic stem cell lines – see next paragraph).

The storage and use of human reproductive cells and embryos outside the body is regulated separately, by the Human Fertilization and Embryology Authority (HFEA), under the Human Fertilization and Embryology Act (2008). All research involving human reproductive tissue requires a research licence from the HFEA and must undergo ethical review. The use of stem cell lines, derived from human embryos (human embryonic stem cells), in research requires approval from the MRC UK Stem Cell Bank Steering Committee to ensure that research performed is in keeping with HFEA Regulation. The process of obtaining approval does require institute signature which states they will abide by the "Code of Practice for the Use of Human Stem Cell Lines".

The HTA does not cover hair and nails from a living person. However, the HTA makes it a criminal offence to hold human tissue - including hair, nail, and gametes (i.e. cells connected with sexual reproduction) – for the purpose of DNA analysis, without the consent of the person from whom the tissue or cells came (or of those close to them if they are deceased). Medical diagnosis and treatment and criminal investigations are excluded.

It is important to distinguish between the *licensing* by the Human Tissue Authority of premises as approved storage facilities for human tissue - for further details of which consult the Specialist Research Ethics Guidance Paper, 'Human tissue research' - and the *ethics approval* of research involving human tissue.

Ethics approval by a RERC for human tissue research is a legal requirement under the HTA in the following circumstances:

- if a specific research project involves the storage or use of relevant material on premises without a licence from the Human Tissue Authority to store relevant material for scheduled purposes;
- if the research involves the storage or use of relevant material taken from a living person without their consent for the research (in which case, in addition to ethics approval, the research must be conducted such that the donors are not identifiable to the researchers); or
- if the research involves the storage or use of bodily material from a living person with the intention of undertaking DNA analysis without consent for such analysis (in which case, in addition to ethics approval, the research must be conducted such that the donors are not identifiable to the researchers).

Relevant material – human tissue or cells – can be obtained for research purposes in two ways:

First, it can be obtained from a human tissue bank that is licensed by the Human Tissue Authority to house tissue for unspecified research. The research purpose(s) must, however, be specified prior to the use of the tissue or cells, and must comply with the human tissue bank's conditions, which will include:

- evidence of independent scientific approval;
- compliance with the terms of the donor's consent;
- anonymisation of the relevant material at the point of release; and
- compliance with a supply agreement.

Second, it can be obtained by application to a RERC for ethics approval for a specific research project that will include the collection of human tissue or cells. At the end of a research project the relevant material must be handled in one of the following three ways: deposited in a human tissue bank licensed by the Human Tissue Authority; used for a new research project (after new RERC ethics approval); or destroyed.

The regulatory framework on human tissue and cells is in a state of development, with continuing revisions and updates of the guidance by regulators to ensure that the regulations keep abreast of fast-moving technology. If a researcher is in any doubt as to whether her/his research project requires ethical approval from any of the above bodies, or the University's Ethics Review Procedure s/he must seek guidance from UREC.

For further information and discussion, see the Specialist Research Ethics Guidance Paper, 'Human tissue research'.

The University of Sheffield
Research Ethics Policy Note no. 12

RESEARCH INVOLVING ILLEGAL ACTIVITIES

This is a complex area. There is a long tradition of social science research into illegal activity that has enriched public debate about crime and a range of other public issues. Similarly, researchers in psychology or medicine, for example, might in the course of their research learn about criminal activity. But what is the legal and ethical position of the researcher in such circumstances?

1. LEGAL RESPONSIBILITIES

Researchers have the same legal obligations that they would have in any other context, as citizens or legal residents. As a private member of society, there is, however, no *general* legal obligation in the United Kingdom to report to the relevant authorities all illegal activity that one observes or learns about.

However, there may be *moral* obligations to report in the following circumstances:

1. It may be a requirement of access, imposed by any relevant gatekeeper;
2. It may be a condition of research funding;
3. It may be a tradition within the specific discipline and/or research context (for example, in criminology there is a tradition of warning convicted offenders that confidentiality will be breached should the participant reveal a previously undetected offence); and, perhaps most importantly;
4. The researcher might see certain circumstances as requiring disclosure as a matter of personal morality and/or professional ethics.

The important thing to emphasise here is that researchers MUST be clear to their participants from the start as to the circumstances in which they will breach the confidentiality of the data that the participant provides.

The definite obligations to disclose that exist in United Kingdom law relate to child protection offences such as the physical or sexual abuse of minors, the physical abuse of vulnerable adults, money laundering and other crimes covered by prevention of terrorism legislation. These obligations are concerned primarily with serious and immediate harm to others.

These obligations aside, research is not covered by any legal privilege. Although there has been a long tradition of academic research into illegal activities, the courts have never considered whether or not one might lawfully refuse to disclose confidential information on 'public interest' grounds – i.e. on the basis that the benefits of completion of the research to society at large outweighs any harm caused by the failure to report individual offences.

That said, researcher knowledge of illegality has not historically and is not (at the time of writing) seen as grounds for rendering a researcher liable for prosecution; this does not, however, mean that it never will be. Researchers and ethics committees are encouraged to keep abreast of developments in this area.

Lastly, it should be remembered that there is a huge difference in the evidential standards of social science research, for example, and the sterner demands of a court of law, particularly in criminal proceedings. Unless a researcher has actually seen an offence being committed,

or can offer other hard proof of criminality - such as knowledge of the location of proscribed drugs, illegal weapons or stolen goods, for example - then most information that is garnered as research data would probably fall into the category of hearsay, if tested in court. At best it would be likely to be considered as 'intelligence' rather than admissible evidence.

Disclosure to the Police would only generally be useful for the prosecution of the (alleged) offender-participant if it led to the discovery of clearer evidence of criminal wrongdoing, and the researcher (and ethics committee) in question ought to:

1. Factor this into any decision as to when to breach confidentiality; and
2. Ensure that prospective participants are fully informed of the circumstances in which confidentiality will be breached, and what the researcher will do to avoid having to disclose confidential information, as mentioned above.

2. RESPONSIBILITIES TO THE UNIVERSITY

As employees of the University of Sheffield, researchers have a professional duty to refrain from doing anything that would bring the University into disrepute. However, the issue of disrepute is neither obvious nor straightforward. What counts as 'disrepute' is not settled, and will depend very much upon the individual circumstances of the research project in question. These issues are particularly emphasised by research into illegal activities, such as 'joy-riding' and drug dealing. On the one hand, the value of understanding these forms of criminality more fully, and the concomitant utility of such research for those drafting better laws or designing more effective policies, is likely to boost the perceived value of the research, and thus the reputability of the University. However, on the other hand, if such research seems to condone the activity in question, either for the duration of the project or in general, then that could be seen as research tending to bring the University into disrepute. The issue, in other words, is very much a matter of context, and is often in the eye of the beholder.

The researcher and their host department ought to be very clear, and very careful, about making claims using data drawn from illegal activities. Researchers should generally refrain from: (a) participating in illegal activities themselves, and (b) encouraging others to participate in illegal activities, for the purposes of providing research data.

3. SUMMARY POLICY AND GUIDANCE

As a general principle, researchers, as University employees and as citizens or legal residents of the United Kingdom, have a responsibility to report to the relevant authorities any actions or planned actions, discovered during the course of research, which they believe are likely to result in serious and immediate harm to others. Beyond that, however, much will depend upon a researcher's own moral compass and judgment.

Researchers have responsibilities to participants, too, as outlined in this Policy. Participation in research should not place people in greater hazard than they would otherwise be. Researchers should, if they anticipate that they may become aware of illegality, tell actual and potential research participants about the requirements of the Policy, as spelled out above, and about the nature and limits of whatever confidentiality they feel they can offer. This should be part of negotiations about consent.

Researchers also have a responsibility to themselves and their research collaborators, to avoid, where possible - and it may not always be possible - acquiring information that is likely to

prove dangerous, compromising or otherwise problematic in the senses discussed in this Policy Note. If possible, erring on the side of caution and avoidance is a sensible basic principle.

In observing the above responsibilities, caution is particularly indicated with respect to what is recorded audio-visually, digitally and in writing.

Finally, a principled and defensible ethics approval procedure is impossible in the absence of proper information. If a researcher anticipates encountering any of the issues discussed in this Policy Note, s/he must disclose this in the ethics approval application. If such issues are encountered after the initial ethics approval, the researcher should approach their departmental Ethics Administrator for advice.

The University of Sheffield
Research Ethics Policy Note no. 14

RESEARCH INVOLVING SOCIAL MEDIA DATA

1. BACKGROUND

Social media are communication tools that allow users to share information and communicate online. The content they create may be publicly available, or access may be restricted to specific individuals or members of a group or community. Examples of social media platforms include Facebook, Twitter, Weibo, blogging sites (e.g. Wordpress), video sites (e.g. Youtube), online messaging services (e.g. Whatsapp), online dating services (e.g. OK Cupid, Grindr), discussion forums etc.

The data generated by users of these tools is a rich data source that is used by researchers across sectors. Social media data includes:

- content users create (e.g. a comment, Tweet, video, blog post etc)
- data that records users' engagement with content and other users (e.g. likes, shares, retweets, followers, friends etc)
- other user data that is collected by the social media company possibly without the user being aware e.g. location data.

Depending upon the nature of the research, social media data might be used for different purposes e.g.

- Observing social media users to gain insight into a social or socio-technical phenomenon
- Using social media data to develop and test a new tool e.g. a new interface for visualising social media content related to a particular topic

In all cases where social media data is being used for research purposes, ethical approval must be gained prior to collecting and analysing data.

Social media users are defined as **human participants** if you are observing them or using their data for research purposes

Most social media data is defined as **personally identifiable data** under the Data Protection Act.

Due to the complex and evolving nature of social media platforms, it is not possible - or desirable – to provide strict rules regarding the ethical use of social media data. However, a number of organisations and networks have published more general guidelines and frameworks for assessing the ethical issues related to research using social media data which the UREC recommends for further reading. For example:

- AOIR Association of Internet Researchers (2012). Ethical decision-making and Internet research 2.0: Recommendations from the AoIR ethics working committee. Available at: http://aoir.org/reports/ethics2.pdf
- British Psychological Association (2013). Ethics Guidelines for internet-mediated research. Available at: http://www.bps.org.uk/system/files/Public%20files/inf206-guidelines-for-internet-mediated-research.pdf

6. IS INFORMED CONSENT REQUIRED?

Assessment of the public/private nature of the post will impact upon whether informed consent should be sought and, if so, who from. As stated by the British Psychological Association (2013):

> "Where it is reasonable to argue that there is likely no perception and/or expectation of privacy (or where scientific/social value and/or research validity considerations are deemed to justify undisclosed observation), use of research data without gaining valid consent may be justifiable."

Whether informed consent is needed or not does not impact upon the need to get ethical approval. The ethics application should explain decision making with respect to whether or not to gain informed consent.

Observation of online public spaces

As with all research involving observation of public space it is recognised that it is often infeasible and unnecessary to gain the consent of all that may be observed. However, as stated in Research Ethics Policy Note no. 2 (Principles of Consent), if researchers are observing individuals in public places then unless consent is gained "specific individuals should not be identified, explicitly or by implication, in any reporting of the research, other than public figures acting in their public capacity (as in reporting a speech by a named individual, for example)". This aligns with recommendations in a number of social media research ethics guidelines. In such cases, if appropriate anonymisation is used (see section 7 below) then it may be appropriate to argue that consent is not required.

Observation of online spaces that may be perceived as not fully public by social media users

In cases where social media users may perceive their posts as not fully public, it may be necessary to gain appropriate consent. What is appropriate will depend on the nature of the research in question. For example, if the social media data is likely to be perceived by users as fairly public, the research is low risk, and the analysis is at the population level and no users will be identified, it may be appropriate to check that the terms and conditions of the platform state that the users have agreed to explicitly allow research use of data and/or to get consent from a gatekeeper (e.g. forum moderator, group administrator).

However, the less public the data, the higher risk the research and/or the more individual the analysis becomes, the more it will be necessary to consider how to gain informed consent from gatekeepers and/or individual social media users for:

1. Data harvesting and/or analysis;
2. Quoting or reproducing social media posts;
3. Identification of social media users in publications and tools.

Dependent upon the nature of the research it may be appropriate to get consent from gatekeepers and/or individual social media users for some or all of the above.

In making a decision about how to gain informed consent the following should be considered:

- Explicit statements on the website or in the terms and conditions of the platform

- The perspective of gatekeepers (e.g. forum moderators, group administrators) regarding the social media users' preferences about the use of their data
- The researcher's level of engagement with the social media users (i.e. will they observe/analyse data without interacting, or will they engage directly with users?) (see Research Ethics Policy Note no.2 (Principles of Consent) with respect to consent in participant observation (section 7) and the Specialist Research Ethics Guidance Paper entitled 'Ethical considerations in autoethnographic research')
- The potential harm to the community if they become aware of a researcher observing their interactions (see British Psychological Association (2013) Principle 3: Social Responsibility p. 6)
- Whether the nature of the research means that it is appropriate to engage in covert observation of a non-public space (see Policy Note no. 2 (Principles of Consent) with respect to research involving principled deception (section 6))
- How practically to gain consent from the appropriate people (e.g. could individuals be directed to a website that contains information about the research? Can consent be gained directly within the platform e.g. via a direct Tweet, Facebook message etc?)
- Should participants be offered the opportunity to consent (or not) to different things e.g.
    - Having their interactions observed;
    - Being identified in reports and publications;
    - Being directly quoted;
    - Having posts reproduced in publications.

Deleted posts

A significant issue arising in social media research is how to handle deleted posts. If the researcher collects their data before the post is deleted, the researcher may be unaware of the deletion and analyse it alongside other still existing data.

If a user deletes a comment this suggests they do not want others to see it, and this might be interpreted as equivalent to a request to withdraw consent for use of data (whether or not direct consent was obtained). It is therefore important to ensure that ethical decision making around reporting social media data takes into account such an eventuality whilst maintaining the integrity of the research, and that researchers consider what they will do if they become aware that there are deleted posts in their dataset.

Research by IPSOS MORI (2015) suggests that the public in general are uncomfortable with researchers' use of social media data.

Only 38% of respondents were aware that social media companies share individuals' social media data with third parties, such as the government or companies, for research purposes - and 60% of respondents believed this should not be happening.

Whilst the public were more favourable towards university researchers analysing social media data (more so than researchers based in government departments and companies), rates of acceptance were still low (approx. one third). Out of a number of scenarios presented to respondents, the one rated most favourably in terms of ethicality was still only deemed ethically acceptable by 50%. This scenario involved the following conditions being met:

- The researchers were based in a University or similar organisation
- They were only using the data of social media users who had **opted in to their data being used for this specific project**
- They were collecting data related to use of a specific word, hashtag or phrase relevant to the project
- The researchers were aiming to review or act on **comments about a product or service they deliver.**

(IPSOS MORI, 2015)

These findings suggest a lack of awareness and consent for academic use of social media data for research purposes, and challenge assumptions of implied informed consent to conduct research using social media data.

Whilst these findings should not necessarily stop social media research being conducted, they do suggest that issues of consent need to be thoroughly considered, and that ethical practice may also involve more open and public discussion about social media research methods, and the contribution that such research makes to society.

7. CONFIDENTIALITY AND ANONYMISATION

Unless a researcher seeks explicit consent from a social media user to identify them in the research, **steps should be taken to anonymise individuals in publications and other outputs, unless the individual is a public figure acting in a public capacity** (see Research Ethics Policy Note no.2 (Principles of Consent)). This is the case whether the social media data is perceived to be public or private. The need to anonymise applies both to individual social media users, as well as other individuals that they mention or depict in their posts.

In the case of photographs of people which have been shared on social media, the researcher should consider whether the person depicted has consented to their photograph been taken and shared. For example, for a stock image of a model, we can assume consent has been gained from the model for taking and reproducing the image – although the researcher may need to check whether the image is protected by copyright. On the other hand, in the case of a photograph of an individual taking part in a protest, we cannot assume the individual has consented to the image being taken and shared, and furthermore its reproduction could cause harm to the individual in some social contexts.

How to anonymise social media data

- The researchers should only collect the identifying information that they need to do the research (is the collection of usernames, profile descriptions, profile photos, date of birth, location etc. really necessary?).
- The researcher should consider replacing identifying information (e.g. usernames) at the earliest opportunity. Remember that such datasets are often re-identifiable using the correct techniques, so they should still be treated as though they were identifiable data, and in line with the Data Protection Act.
- If potentially identifying information (e.g. usernames, locations) needs to be retained in order to conduct the analysis then, unless the researcher has gained consent to identify users in reports, in most cases users should be anonymised in the reporting of research e.g. by using pseudonyms and image editing software such as Photoshop to hide identifying information and images in screenshots.
- Beyond using pseudonyms and removing identifying information, it is also recommended that if the researcher wants to report direct quotations that they paraphrase the quotation in a way that retains meaning. For higher risk research this should be standard practice. Advice on anonymization practices can be found here (British Psychological Society, 2013 p. 18; Townsend and Wallace, 2016, pp. 11-12). Paraphrasing is used because it is fairly easy to trace the source of direct quotations using a search engine.

Anonymization practices sometimes go against the Terms and Conditions of some platforms e.g. Twitter states Tweets must be given in their original form and attributed to the individual who posted the Tweet. In such cases careful consideration needs to be given as to what is ethically appropriate.

8. DATA STORAGE, SHARING AND RE-USE

As with all research consideration needs to be given to how to store, share and archive social media datasets. As discussed above, potentially identifiable social media data is regulated under the Data Protection Act, and researchers are advised to follow University of Sheffield Research Data Management guidelines in relation to handling such data. The terms and conditions of the relevant social media platform, and if relevant commercial data provider, should also be checked for requirements relating to data storage, sharing and archiving. In the case of contradictory demands, advice can be sought from UREC.

Some social media data providers allow researchers to analyse data online, rather than needing to download and store it themselves. If these tools are provided legally and in line with the terms and conditions of the social media platform, they may be a suitable alternative to downloading and storing data. However, such tools are not always transparent in relation to how data are collected, analysed and presented, which can raise separate research integrity and ethical issues as discussed in section 3 above.

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