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Special considerations when gaining consent

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Table of contents

Data collection

There are situations where special considerations are needed when seeking consent. We highlight just a few of them and explain some implications for data sharing.

Personal data

Researchers must adhere to data protection requirements when managing or sharing personal data. The General Data Protection Regulation (GDPR) applies, if:

- a researcher based in the EU collects personal data about people anywhere in the world.
- a researcher outside the EU collects personal data on EU citizens.

Personal data is defined within the legislation as ‘any information relating to an identified or identifiable natural person’ whereby the person can be identified directly or indirectly.

It is important to remember that not all research data obtained from people count as personal data. If data are anonymised and an individual is no longer identifiable then the Act and Regulation will not apply, as the information no longer constitutes 'personal data'.

Audio-visual recordings

As audio-visual recordings or photographs are likely to be classified as personal data, explicit consent should be gained for any onward data sharing of unaltered data. It may be tempting to explore digital manipulation as a way of removing personal identifiers to anonymise audio-visual material, but there are some disadvantages to this:

- Techniques such as voice alteration and image blurring are labour-intensive and expensive to apply for large quantities of data.
- Data alteration is likely to damage the research potential of data, for example distorted speech can significantly reduce the research value of a recorded interview and blurring faces represents a major loss of information where facial expressions might be of interest.

Our model consent form and this example consent form shows how you can seek consent for the sharing of audio-visual data, which will fall under the GDPR.

Medical research

Where research involves medical matters, medical Research Ethics Committees will need to be involved to approve the methodology and consent forms. The researcher should also be aware of the standards traditionally asserted by such committees, and at times, committees can be sceptical about data. Researchers will need to fully document procedures for safely handling data, especially personal data, when sharing. All applications to research NHS patients are done through a standard application form used by all NHS Research Ethics Committees across the UK.

For further information see:

- NHS National Research Ethics Service application and support.
- Medical Research Council Ethics and Research Guidance.

Internet research

Increasingly, researchers gather data from online discussion groups, blogs, social media and websites. The separation between public domain and private space may be blurred. The question to ask is whether to seek consent to gather and use such materials from the individual, the moderator or the webmaster. There are no absolute answers.

Permission from the webmaster or copyright owner should be sought if text from a (public) web page is used for research, mainly for copyright reasons.

If information is taken from a restricted environment where members contribute information that is therefore not considered to be in the public domain (chat room, forum, discussion group), then good ethical practice is to inform and seek consent for research and sharing from each individual providing information and show that this has been obtained. For further information:

- MRS guidelines for online research.
- Association of Internet Researchers Ethics guidance.
- BPS Ethics Guidelines for Internet-mediated Research.

Research with children and young adults

Research participants must be provided with full information about the research in order to give their informed consent to take part. Careful thought needs to be given to translating this into practice when the participant is a child.

The clearest guidance on consent from children can be found in advice for clinical practice which presumes, based on a legal ruling, that young people aged 16 years and above can give their own consent. For younger children, a judgement must be made about their ability to understand what is being asked of them. Information must be given in clear language at a level that the child can understand, using visual aids if necessary. In this way they can be asked for their individual voluntary consent, in addition to that of a parent/guardian and/or the head teacher.

Due to their legal status as a minor and the implied vulnerability that this status confers, the researcher often has to negotiate access to children via gatekeepers (e.g. teachers or carers), who through their relationship with the child are assumed to have a protective role.

The gatekeepers will require information about the research, how consent will be obtained from the children and responsible adults and the extent of confidentiality, prior to approving access to children. In other situations gatekeepers control physical access to children, such as in schools, where permission is needed to make the initial contact with parents. Again, in order to gain access to the children, researchers may be asked to make changes to their data collection instruments or to require parents to take positive action, i.e. elect for their child to 'opt in' to the research.

Confidentiality, anonymity, storage and sharing of personal data should be explained in a way that children can understand. It should also be made clear who will have access to the information and what will happen to it when the research is complete. Information can be given about how data will be used, in the same clear language as used about the research. It is recommended that written information should always be provided for the child and responsible adult, including a contact telephone number, should they wish to contact the researchers. See an example consent form for research with children.

For further information see:

- Informed Consent, Gatekeepers and Go-Betweens: Negotiating Consent in Child- and Youth-Orientated Institutions.
- Informed consent and the research process: following rules or striking balances?
- Guidelines for Research with Children and Young People.

People with learning difficulties

Research with people who have learning difficulties raises questions of ownership, power and exploitation which reflect the ethical concerns of much general research but which can be more problematic and therefore need special consideration. Revealing sensitive material in the records, or the stirring of painful memories of the past during interviews also raises another ethical issue about the need to provide support for those who are involved in this type of research. Extra time needs to be built into the project for these concerns.

Particular attention should be paid to discussion of the purpose and implications of the research and data sharing and to ensuring that these have been understood. The use of any documentation or consent form needs to be appropriate, recognising adult status, but at the same time being accessible. Careful attention should be paid to the use of language. Cartoons or drawings run the risk of being patronising, whereas appropriate photographs or diagrams combined with clear statements in large print and double spacing can create an attractive and informative form to be referred to by the participants. One way of enabling people to understand as clearly as possible the implications of their named participation in research is to discuss with them who is likely to read the published research, and who will have access to the archived material. Examples of such literature can be shown and discussed. Books are significant and powerful examples of the public realm even for those who cannot read. In cases where the researcher finds it difficult to understand the participant, it is important to find an interpreter i.e. a friend, relation, or long-term carer.

Research within organisations or in the workplace

Research with people within an organisation or workplace will need additional consent if work is to be discussed. Information given by an employee in an interview which takes place during the course of employment (typically on the work premises) should not be used unless the employer has given consent. This is because employees may be seen to owe a duty of confidentiality to their employer. Indeed employment contracts may contain confidentiality clauses. It is always advisable when carrying out research with someone in the workplace, in working hours, to discuss whether consent from employers is necessary. It is the responsibility of the researcher to be aware of the policy of each organisation.

See an example consent form for use with interviews in the workplace.

Researching crime

Research into crime may require a different form of consent. Participants should be made aware that a researcher may under some circumstances need to disclose information relating to criminal activity. Normally, there is no legal obligation to disclose information relating to criminal activity - unless legal proceedings or an investigation are underway. Even then, confidants will only be guilty of perverting the course of justice if they deliberately evade questioning. They are therefore unlikely to be under a legal duty to disclose unless actually approached by the police with regard to the specific information or case in question.

For further information see: British Society of Criminology Code of Ethics for Researchers in the Field of Criminology.

Secondary analysis

Secondary data provide the research community with rich and unique material that can be reanalysed, reworked, used for new analyses, and compared or combined with more contemporary data.

Linking to administrative data

Understanding Society is a large-scale longitudinal household panel survey, in which participants are interviewed each year. Each participant completes an individual questionnaire, but they are also asked if they consent to the survey team linking to a range of administrative data records (such as their health, education, employment and pension records). Both elements of the survey have different consent procedures.

For the annual household and individual questionnaire, the participants are sent an advance letter shortly before the interviewers contact them. This letter reminds them about the purpose of the survey and asks them to participate again. People joining the survey are also given an information leaflet which explains more about the aims of the study, what is entailed in joining the study and emphasises the voluntary nature of their participation. This voluntary participation is also re-emphasised at key points throughout the interviews. No written consent is sought, rather it is implied through their participation in the interview.

For the administrative data linkage, participants are given an information leaflet during the interview which explains the important aspects of data linkage. The leaflet contains information on what data the study is interested in, who will use the data, data security, what their consent covers and how long it lasts and how to withdraw their consent. Participants are given time to read this leaflet, and then asked to read and sign the consent form.

See information leaflets and the consent forms used in wave 4 of the study.

Use of X (formally Twitter) data

Public posts may appear similar to public space, but there are legal and morally significant factors to consider. Firstly there are constraints from X’s Terms and Conditions of Use. Posts may not be anonymised and authors must honour requests for change or deletion. This can become problematic if a paper based on quoted posts has already been published or X data is shared.

Researchers have a duty of care to the author, whether content has been made public or not. For small scale data projects, consent can be sought by:

- contacting the author directly to request permission to use the posts in research
- providing full information via a website
- making it clear to authors they will not be anonymous.

When consent is not possible there may be alternatives, and in selected cases, consent may not be necessary. For example, consent is not necessary where the data is aggregated and no identification is possible, or where the posts are from public, official or institutional accounts.

It should be noted that even if a post ID is not a real name the post text can be searched and re-linked with the author.

See the Social Data Science Lab Ethics Statement.

Consent in surveys

For surveys, where personal identifiers such as people's names are not collected or are easily removed from the data file, written consent is often not gathered. Instead, the information sheet given to participants or the survey introduction would state that consent for the data being used for specified purposes is implied from participating in the survey, with a clause stating that an individual's responses would not be used in any way that would allow his/her identification. The information sheet should also provide details about any plans for sharing the data.

This is the usual practice for most large-scale surveys such as those undertaken by government departments in the UK.

If a survey extends beyond asking questions, to include activities such as a nurse visit, taking samples, making physical measurements, etc. then written consent is recommended. If personal data, sensitive data or confidential data are gathered during a survey, the use of written consent forms is recommended to assure compliance with the Data Protection Act and with ethical requirements.

For guidance, see our example survey consent statement as well as an example information letter from the British Household Panel Survey. You can view consent for other surveys in the UK Data Service data documentation attached to catalogue records in our Data Catalogue.

You might also wish to look at Understanding Society as an example of how consent is dealt with in large, complex quantitative studies. There is also a discussion of consent for linking Understanding Society with administrative data in the Special Cases section.

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