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Methods used to obtain consent

There are several methods available for obtaining consent, including:

- signing a consent statement on a paper form
- ticking an opt-in box on paper or electronically
- clicking an opt-in button or link online
- selecting from equally prominent yes/no options
- choosing technical settings or preference dashboard settings
- responding to an email requesting consent
- answering yes to a clear oral consent request.

When it comes to participating in research and collecting personal data, a clear affirmative statement through consent **must** be included. This should include a statement indicating risks, benefits, voluntary participation, right of withdrawal and how data (anonymised or not will be shared).

Record keeping when processing personal data

It is essential that researchers are able to demonstrate that data subjects have consented for their personal data to be processed, so records must be kept and used as evidence or for reviewing, if and when required.

Good record keeping should include the following:

- Who consented: name or other identifier.
- When they consented: dated document for written or oral consent and a time stamp for online records.
- What they were told at the time: for written consent, a copy of the consent form used to demonstrate the consent statement and for an oral consent a document with the script that was used at the time of data collection.
- How they consented: written, online, oral Have the consent withdrawn: if so, when.

Language to avoid

Consent forms should not preclude sharing of research data. So, promises to destroy any data or that data will only be seen or accessed by the research team should be avoided.

Terms such as 'fully anonymous' or 'strictly confidential' should be avoided, as they are often impossible to define. Better is to indicate how data will be anonymised (e.g. by removing all personal information that could directly identify an individual) and that whilst data will be made available to other researchers, confidentiality will be protected.

Example of wording that does not preclude sharing from the <u>Interuniversity Consortium for</u> Political and Social Research (ICPSR) adapted for the UK:



Study staff will protect your personal information closely so no one will be able to connect your responses and any other information that identifies you. National laws may require us to show information to university or government officials (or sponsors), who are responsible for monitoring the safety of this study. Directly identifying information (e.g. names, addresses) will be safeguarded and maintained under controlled conditions. You will not be identified in any publication from this study.

<u>Examples with detailed wording</u> are available that address specific concerns, such as being clear who will have access to any personal data during and after the project.

Consent form revisions and renewal

As research is a dynamic process the original consent may not be informed 'enough', that is, contain sufficient and up-to-date information about the aims of the research. Therefore, so it is always advisable to keep any consent forms under constant review.

When consent becomes invalid

Best ethical practice indicates that consent becomes invalid:

- If there are doubts over whether someone has consented.
- If a person doesn't realise they have consented.
- There are no clear records to demonstrate participants had consented.
- No genuine free choice over whether to opt in was given.
- There was a clear imbalance of power between a researcher and the individual.
- The consent request was vague or unclear.
- Pre-ticked opt-in boxes or other methods of default consent were sued.
- The researcher's organisation was not specifically named.
- Subjects were not informed about their right to withdraw.
- Subjects cannot easily withdraw consent.
- The research purposes or activities have evolved since the original consent.

Destruction of consent forms

Consent forms should be kept for as long as the research data are retained (by the researcher or an archive). The original consent forms can be digitized and stored securely (encrypted), permitting the originals to then be destroyed securely by means of shredding.



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