Consent for data sharing

A practical guide for researchers

This document is designed to offer guidance to researchers who wish to gather informed consent for research projects that collect data from people using questionnaires, observations, interviews, diaries, focus groups, video recordings, etc. It pays particular attention to ensuring the ethical collection, use, and onward sharing of data.

There is no one-size-fits-all consent form. The consent process must be tailored to the type of data being collected, how it will be used for the project and how it will be shared for future research. Therefore, this guidance should be adapted to create an informed consent form using the notes and suggestions provided.

It is also important to note that a consent form should:

- Be accompanied by and align with a clear participant information sheet.
- Set out what participation involves, including any recordings or observations.
- Specify how personal data will be processed, anonymised, and stored.
- Explain how the data will be used during the project.
- Detail data sharing and reuse, including archiving in a data repository.
- Provide participants with meaningful choices and ensure their rights under UK GDPR or any other applicable legislation.
- Use plain, accessible language and avoid jargon.

For ease of understanding, the consent form can be separated into three sections:

1. Taking part in the study.
2. Use of the information in the study.
3. Future use and reuse of the information by others.

Below are example consent statements that researchers can adapt, combine, and contextualise according to the specific nature of their study. Researchers are encouraged to use only the statements relevant to their study, adapt the phrasing to suit their participants (e.g. language level, context) and align their final consent form with institutional ethics and data protection guidance.

Section 1: Taking part in the study

This section of the consent form should be designed to ensure that participants are fully informed about the study and their rights before agreeing to participate. It outlines the key aspects of the study, including the opportunity to ask questions, the voluntary nature of participation, and potential risks and benefits. It is crucial that participants understand the study's purpose and the scope of their involvement.

Example statements

Purpose	Example text	Yes	No
Ensure understanding of the study details and provide the opportunity to ask questions	I have read and understood the participant information sheet for the above study, dated DD/MM/YYYY, or it has been read to me. I have had the opportunity to ask questions about the project, and my questions have been answered to my satisfaction.	☐	☐
Establish voluntary participation and the right to withdraw	I consent voluntarily to participate in this study and understand that I can refuse to answer questions and withdraw from the study at any time without having to give a reason.	☐	☐
Describe what participation involves	I understand that taking part in the study involves [audio-recorded interviews/video-recorded focus groups/completing a questionnaire].	☐	☐
Obtain consent for audio/video recording	I agree for my [interview/focus group] to be audio/video recorded.	☐	☐
Clarify the handling and processing of recordings	I understand that the recordings will be transcribed by a third party, as described in the participant	☐	☐

Purpose	Example text	Yes	No
	information sheet, and that the (optional: recording will be securely destroyed or… once the transcription has been completed).		
Acknowledge potential risks or discomforts	I understand that taking part in this study may involve [include here for example discussing sensitive topics about or emotional subjects such as] and that the potential risks have been explained to me.	☐	☐
Request agreement for possible future contact	I agree to be contacted for follow-up interviews or to provide additional information if needed.	☐	☐

Key considerations

- Use plain, non-technical language that is easily understood by your target participant group. Avoid jargon and long sentences. Ensure translated versions are available if needed.
- Ensure participants have had sufficient time to read the Participant Information Sheet and ask questions. Verbal explanations should be offered, especially for participants with low literacy or additional needs.
- Clearly reinforce that participation is voluntary and that withdrawal is possible at any time without penalty. Avoid language that could be perceived as coercive or imply consequences for non-participation. Consider and adapt accordingly to what you would like to offer here. For example, *'I can withdraw from the study and all information collected before my withdrawal can be used, but no additional data will be collected.'* or *'If I withdraw, my data will be removed from the study and will be destroyed.'*
- Accurately describe what taking part in the study involves (e.g. type of data collection, duration, format). This helps manage expectations and supports genuine informed consent.
- Consider describing in a few words how information is captured, using the same terms as you used in the information sheet, for example: an audio-recorded interview, a video-recorded focus group, a survey questionnaire completed by the enumerator, an experiment, etc. For interviews, focus groups and observations, specify how the information is recorded (audio, video, written notes). For questionnaires, specify whether the participant or the enumerator completes the form. For audio or video

recordings, indicate whether these will be transcribed as text and whether the recording will be destroyed.

- Explaining risks and benefits is context-specific, so this is an optional statement. If there is any potential risk associated with participating in the study, please include a clear statement describing the nature of the risk, along with information about the support or resources available to participants (e.g. counselling services, medical assistance, or contact details for support personnel).
- You could explain either in the information sheet or verbally the benefits of taking part in the study. For example, *'By participating in this study, you may contribute to a deeper understanding of [insert study topic]. While direct personal benefits are not guaranteed, the insights gained from this research could lead to [specific potential benefits, e.g. advancements in science, improved practices, policy changes, or community support]. Additionally, you may gain personal satisfaction from contributing to research that aims to benefit [specific group, field, or society].'*
- Make it clear that agreeing to future contact is entirely optional and will not affect current participation. Provide a separate tick box to avoid confusion or implied obligation.

Section 2: Use of information in the study

This section explains how the information you provide during the study will be collected, used, stored, and protected. It ensures that you understand what types of data will be gathered (including any recordings), how personal information will be handled, and the legal basis under which it is processed. It also outlines the steps taken to protect your privacy and maintain confidentiality throughout the research process.

Purpose	Example text	Yes	No
Inform how the information or data will be used	I understand that the information I provide will be used for [list the planned outputs, e.g. reports, publications, website, video channel, etc., using the same terms as you used in the study information sheet].	☐	☐
Describe formats and type of data being collected	I understand that the information I provide will include (e.g. interviews or focus groups being recorded, format of recording audio/video, completing a questionnaire).	☐	☐

Purpose	Example text	Yes	No
Describe how identifiable information will be used	I understand that personal information collected about me that can directly identify me (such as my full name, address, NHS number etc.) will be used for the purposes explained to me/stated in the information sheet.	☐	☐
Ensure confidentiality and privacy	I understand that and every effort will be made to protect my identity as explained to me/stated in the accompanying information sheet.	☐	☐
Clarify who may access data for oversight	I consent that the relevant sections of data collected during the study may be reviewed by authorised people from the [organisation name] for monitoring or auditing purposes.	☐	☐

Key considerations

- Ensure the terms used in the consent form (e.g. planned outputs, data types, legal basis) match exactly with those in the Participant Information Sheet. Inconsistencies can undermine informed consent and ethical approval.
- Clearly specify how the participant's information will be used (e.g. reports, publications, websites). Avoid vague terms — participants should know where and how their data might appear, especially in public-facing outputs.
- Clearly describe the format and nature of data being collected (e.g. audio/video recordings, surveys). Participants must understand what participation involves and how their contributions will be documented.
- Make sure participants know what personal data is being collected, how it will be used, and why it is necessary. Only collect the minimum personal information required for the study.
- Explain how personal data will be kept confidential, including security measures (e.g. password protection, anonymisation, access restrictions). If there is a risk for participants to be identifiable within the sample given the methodology used, this should be disclosed clearly. For example, for focus group: *'I understand that while the researchers will make every effort to maintain confidentiality, anonymity cannot be guaranteed due to the nature of focus group discussions, where other participants will*

be present and may hear my contributions.' or *'I confirm that participants will be identified using pseudonyms in any publications resulting from the research.'*

- When collecting data from public figures the option of waiving anonymity might be beneficial. For example, *'I agree to waive anonymity for the purposes of publication'.*
- Explain whether recordings will be kept or transcribed. How long recordings will be kept and how will these be stored?
- If personal information is being collected as part of the study, researchers must specify the lawful basis under which the data is being processed. This could include consent, contractual necessity, legal obligations, vital interests, public tasks, or legitimate interests. Clearly state the chosen lawful basis in the participant information sheet to ensure transparency and compliance with data protection regulations.
- For example, the Information Commissioner's Office (ICO) advises that for the majority of research undertaken within the UK, organisations should rely on the lawful basis of public task for public entities, such as the NHS, HSC, universities, and UKRI, or legitimate interest for non-public entities, including charities and private companies. Researchers must consider the specific circumstances of their projects to ensure compliance with all applicable legal and ethical obligations.
- Reinforce that participants can withdraw their data if they choose, particularly before data has been anonymised or publicly shared. Explain how they can request this and what the limits of withdrawal are (e.g. after publication).
- Ensure that participants are clearly informed about who will have access to their data for monitoring or auditing purposes (e.g. authorised staff, ethics committees, regulatory bodies). Specify the role and responsibilities of these individuals to ensure transparency and maintain trust.

Section 3: Future use and reuse of the information by others

This section outlines how your data may be accessed, shared, and reused beyond the current study. It explains who may review your data for monitoring purposes, how your contributions may be stored for future research and learning, and your rights regarding copyright over materials you provide. These measures ensure transparency, ethical data handling, and enable valuable contributions to future research.

Example statements

Purpose	Example text	Yes	No
Inform about data archiving for future use	I give permission for the (e.g. de-identified, anonymised, pseudonymised audio/video, transcripts, etc.) that I provide to be deposited in [name of data repository, or if unsure if the data collection is suitable for a specific repository specify or an alternative suitable place of deposit] so it can be used for future research. For any materials provided that are protected by copyright whereby I am the copyright holder, I agree to permit the researcher to reuse those materials for research and learning purposes, and to publish (optional: anonymised/de-identified/pseudonymised versions of) those materials in a responsible repository for future research and learning.	☐	☐
Explain ownership/permission for future reuse of information	For any materials provided that are protected by copyright whereby I am the copyright holder, I agree to permit the researcher to reuse those materials for research and learning purposes, and to publish (optional: anonymised/de-	☐	☐

Purpose	Example text	Yes	No
	identified/pseudonymised versions of) those materials in a responsible repository for future research.		

Key considerations

- Specify in which form the data will be deposited, e.g. de-identified, anonymised transcripts, audio recording, survey database, etc. and if needed repeat the statement for each form of data you plan to deposit. Specify whether deposited data will be de-identified or anonymised, and how. Make sure to describe this in detail in the information sheet.
- Specify whether use or access restrictions will apply to the data in the future, e.g. exclude commercial use, conditions of access placed on the data, etc. and discuss these restrictions with the repository in advance. Please note conditions of access could be explained in detail in the accompanying PIS.
  (Optional) Explaining the benefits of data sharing may help in increasing confidence and trust to agree to data sharing (e.g. data sharing helps advance research, fosters collaboration, and accelerates discoveries that can lead to meaningful solutions for global challenges).
- Clearly identify the data repository where participants' data will be stored for future use (e.g. specific academic or public repositories such as [insert examples]). This ensures transparency about where the data will be held and made accessible. If you are uncertain about the specific repository at the time of consent, you can state that the data will be deposited in a "responsible repository".
- Provide clear explanations about why data is being deposited in a repository and how it will be used for future research and learning purposes. This helps participants understand the long-term value of their contribution and assures them their data will be used ethically.
- Informing participants about the copyright is an optional statement and must be adapted based on the research context. However, informing participants about the future uses of data such as depositing it in a responsible repository so that other researchers can use it is essential.

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We are supported by the Universities of Essex, Manchester, Edinburgh, University College London and Jisc. We are funded by UKRI through the Economic and Social Research Council.