

Researchers wishing to utilize participant focus group sessions as part of their studies are asked to be particularly cognizant of **consent** and **confidentiality issues** as they pertain to multiple participants **sharing potentially personal information**, within a group setting.

As the researcher you will need to take special efforts to emphasize and ensure that confidentiality is respected by each of the participants in the focus group; this should be clearly communicated in two ways (detailed below):

1. In writing, in the informed consent document
2. Orally, at the beginning of the focus group session

**Communication of Confidentiality in the Written, Informed Consent Document:** When describing the proposed research and participation in focus group meetings, a statement such as the following should be included:

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“Your agreement to participate in a focus group means that you may be disclosing personal information or other sensitive information to other participants in the group. You are asked to not share with anyone else the identity of others in this group (in other words, to maintain their anonymity), to keep confidential what people say during the focus groups, and to not share what was discussed in this meeting with anybody outside of this group. Audio/ video recording is not allowed, nor is the use of cell phones.”

The researcher should also outline procedures for maintaining the confidentiality of participants, in your role as researcher in the consent document.

*In the Protocol Summary and the Written Informed Consent Documents:*

Add to the sections on “Potential Risks to Participants” that there may be potential risks involved for the participants if other members should choose to disclose information from or about another participant. Although the researcher is committed to following procedures for maintaining confidentiality of participant identity, ultimately the researcher cannot control what focus group participants will choose to share or not share outside the parameters of the focus group meeting itself.

**Communication of Confidentiality at the Beginning of the Focus Group Meetings/sessions:**

The facilitator of the meeting should orally preface the discussion by informing participants of their responsibility to maintain confidentiality with respect to other participants. A sheet containing the following points (but not requiring a signature) should be handed to participants and orally presented and discussed by the researcher:

- As part of this group meeting, you may be disclosing [personal] information to other participants in the focus group.
- Please only use first names to address other members of the group, if necessary.
- Audio/video recording is not allowed. Please do not use cellphones.
- We ask that participants respect the need for confidentiality regarding other participants’ identities, and regarding what people say during the focus groups. There are potential

## IRB Guidelines for Research Involving Focus Groups

risks involved for the participants if other members should choose to disclose information from or about another participant.

- *[briefly state/remind participants what you will do as a researcher to maintain confidentiality of information/identities]*
- You may opt out of the study now, or at any time during the discussion if you feel uncomfortable with the topic, without penalty.
- If you decide to participate you indicate that you understand these risks, and are willing to continue participation. At any time during the discussion if you feel uncomfortable with the topic you may choose to remain quiet or to discontinue your participation.

For example, the facilitator might state, *“As part of this group meeting, you may be disclosing [personal] information to other participants in the focus group. We ask that what people say during the focus groups be kept confidential and not leave this room and that the participants in this group will remain anonymous and not be talked about to anybody outside of this group.”* (etc.)

Participants should be asked to orally acknowledge their understanding of this informed risk: after doing so, participants can either indicate their agreement to continue participation, or chose to opt out of their participation in the study without penalty.

If the researcher chooses to take attendance at the meeting, it should be coded in accord with confidentiality procedures.