

Privacy in Research

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Confidentiality

Privacy in research refers to the confidentiality afforded to participants in the research.



The banner features the Explorable logo and the text "Quiz Time!" in a white, handwritten-style font on an orange background. Below the text are three quiz cards, each with a different image and title:

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Quiz:
Psychology 101 Part 2
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Quiz:
Psychology 101 Part 2
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Quiz:
Flags in Europe

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Why is Confidentiality Important in Research?

Science depends on research participants to volunteer information regarding individual beliefs and actions on a host of topics. A participant or subject is more likely to provide honest responses when their identity is not going to be exposed.

Considerations for confidentiality should be given to the following:

- Nature of the response.
- Possible punishment for the response.
- Possible punishment for participation.
- Perceived punishment for the participation.
- Fear of embarrassment
- Participants answer differently if they think that privacy may be compromised

The research may focus on topics that are taboo in society and it would be difficult to illicit honest responses to some of the questions posed when a participant did not feel secure in

knowing that their identity is protected.

There also maybe some personal liability involved depending on the topic of the study. If the study involved cheating on testing at the university they attended and a guarantee of anonymity could not be provided, the likelihood of honest answers being given would be very low, for fear of retaliation.

Bias in employment although illegal is very real, if confidentiality is not upheld and if the wrong information is passed around regarding a participant it could very well effect the ability of the participant to maintain employment and be employed in the future.

In addition there are other negative responses that a participant may face if the research is on an unpopular topic, or a controversial issue. If the group involved in the research all works for the same organization and the study is to determine the employer's unethical practices, participants if not kept confidential could suffer great consequences for their responses.

In some cultures a subject's participation alone could result in public punishment, being excommunicated from the community or even death.

There may only be a perception of punishment for participation if confidentiality is not guaranteed. The perception alone will keep potential subjects from participating in the research, and will also prevent honest answers.

Research is never meant to punish anyone, it's only goal should be greater knowledge and understanding working toward a positive goal.

Privacy matters should be addressed from the inception of the research to the publication of the results. There should be safety nets put in place to guarantee confidentiality. The only amount of personal data that should be collected for the research is the minimal amount needed to insure a proper sampling of the population. Personal identifiable information should not be collected nor maintained unless absolutely necessary. Research staff should be properly trained in procedure to maintain confidentiality.

Informed Consent

Informed consent ^[1] is required in all studies and research using human participants. The consent to participate should clearly outline the purpose of the study and what the information gathered will be used for.

When is Confidentiality not an Issue

Confidentiality is not an issue when observing large groups, where individual responses or actions are not considered or when participants' identifiable information is not involved. Even in cases where there are large groups being assessed it is up to the researcher to use good judgment in making decisions regarding what information should be shared.

A Legal Breach

There is a sticky area when it comes to confidentiality. If a participant in a research event or a

study falls into any of the below categories than the researcher is legally compelled to report the participant.

- Risk of bodily harm - if there is a potential that a violent act will occur against someone else or the participant at his/her own hand.
- Cases of child abuse - sexual misconduct with a child, or there is imminent danger to a child that has been disclosed.
- Terrorism - there is a terrorist act or plan in place that the participant has disclosed.
- There is a eminent threat to public health.

There is some ethical concern by being required to report someone in any of the categories above. Let us look at these few examples to review the ethical quandary.

Sample A

A study is being conducted looking at the effectiveness of a drug on depression. The participants are asked to record feelings of violence, suicide, anger and despair, both before they began taking the medication and after three weeks of being on the medication.

Each category is assigned a numerical value to display a range of feelings from very likely to least likely. The study is dependent on honest answers, the participants have been promised confidentiality.

If 30 of the 100 participants report that they feel more suicidal since taking the medication, is the researcher required to report all thirty of the participants?

Sample B

AIDS patients have been asked to participate in a study to gauge sexual habits since being diagnosed. 60% of the participants report that they have adjusted their sexual habits to include safe sex practices or abstinence, but 40% report that they still sometimes do not practice safe sex.

Should they be reported?

They are a definite threat to public health, but the study depends on honest answers, once that confidentiality has been breached it certainly will sour future participants from being honest. How can we ever gauge the effectiveness of programs and education within certain communities if participants have to fear potential criminal charges?

Should Science Be Required to Act As a Step in the Penal Process?

A Real Life Story

A woman in Florida is expecting baby number 3. She appears at a public health department for prenatal care and agrees to participate in a study for drug use and pregnancy.

She confesses that she has an addiction to cocaine (a known teratogen). She also answers yes to one of the questions asking if she would accept rehabilitative services if they were

available. The information is passed on to the local authorities, her existing children are turned over to the state, and her in utero child is taken upon birth and placed in foster care while the mother is forced into treatment so she can get her children back.

The case goes to court; the mother sues the state of Florida and its public health system for breach of confidentiality. She loses, based on the required reporting of suspected child abuse. The case has gone to the Supreme Court.

There are a few ethical issues that are evident in this brief breakdown of this story.

1. Mom disclosed willingly the information, she evidently had not acted in a manner to bring attention to herself, she disclosed the information believing it would be kept confidential.
2. The case was brought to court and the argument was that the mother was abusing her unborn child by snorting cocaine while pregnant hence the defense in reporting based on the abuse that was purportedly to her unborn child. Can we mandate good health practices by a pregnant women or risk being charged with child abuse and neglect?
3. Should willing disclosure be punished especially when it is a part of research?

There are many instances of ethical concerns when it comes to confidentiality and privacy matters in research. As a result of allowing a participants information to be revealed there can be insurmountable damages, it should only be done when absolutely necessary.

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Links

[1] <https://www.explorable.com/informed-consent-policy>