



Ethical Considerations in Data Collection

Data collection is central part of community health improvement efforts. Sometimes, the aim is to learn more about a problem as it is experienced by a specific group of people; other times it is to see if people are better off after participating in an intervention. Most data is collected through surveys, interviews, or observation. It's important to keep in mind the following when you collect data:

Please note, the considerations listed below were adopted by the North Jersey Health Collaborative. They are not meant to replace your organization's guidelines pertaining to research or data collection. If your organization has an institutional review board (IRB), ethical review board, or research ethics committee, please consult your organization prior to beginning any data collection.

- It is good practice to let people know who you are (your name, organization and reason for collecting data when you ask them if they would like to participate).
- You should have permission from participants (people providing the data) and they should be made aware that their involvement is voluntary. Participants are free to withdraw from any active data collection or intervention program at any point without pressure or fear of retaliation.
- Avoid or minimize anything that will cause physical or emotional harm to participants. Make participants aware of any potential harms prior to their participation.
- Try to remain neutral and unbiased. Don't let your personal preconceptions or opinions interfere with the data collection process.
- Collecting data (i.e. through surveys) is often done under the assumption that information provided is confidential and the findings will be anonymous. You should let participants know when you will have to break confidentiality (e.g. in the case of harm to themselves or someone else) and whether results will be anonymous or not.
- When collecting data, try to avoid taking advantage of easy to access groups simply because they are there (this is called "convenience sampling"). Data should be collected from those that most help us answer our questions.
- Be respectful of people's time and when possible, compensate them for it.
- Be sure to protect the data you collect from people. Do not leave anything with personal information in a place that can easily be accessed by people who do not need to see the data (e.g. the back seat of your car). If possible, keep the information in a secure, or locked location.
- After data are analyzed it is always good to share the results back to the participants.
- If anything on these guidelines is new to you, please consult with the NJHC's Data Committee. They can help design data collection activities that comply with these guidelines, and set you up to produce meaningful information for your workgroup.