DEFINITION OVERVIEW

This issue reviews common terms used when completing your application for human subjects research. There are some clarifications which will go into effect July 1, 2022, so take a look and stay current!

Anonymous
- Identities are unknown to investigator (not requested, not given). Data do not contain any information that would permit identification of the individual subjects.
- Note: Subjects cannot be anonymous if the research involves audio/video recordings, in-person interviews, etc.

Confidentiality
- Identities are known to the researchers and/or data contain information that **would allow** for identification. Data are transmitted and stored in a manner that protects the information from unauthorized release.
  - Information will not be divulged without permission (disclosed to subject).

Individually identifiable
- Identity of the subject may be ascertained by the investigator; identity may be associated by the information collected.
- Example: a College of Nursing student whose age is being collected but falls outside of class median/mean (19 years of age).
- Identifiable information is not limited to name, date of birth, or contact information.

Indirect Identifiers
- May be combined to identify individuals in certain circumstances (place of birth, race, ethnicity, religion, weight, activities, employment information, medical information, education information, and financial information)
- Data that do not contain direct identifiers, but include a sufficient number of indirect identifiers may not be considered anonymous or de-identified
  - According to Sweeney et al*, 87% (216 million of 248 million) of the population in the United States had reported characteristics that likely made them unique based on the combination of: 5-digit ZIP, gender, date of birth.
  - Half of the U.S. population (132 million of 248 million or 53%) are likely to be uniquely identified by: place, gender, date of birth. Place is the city, town, or municipality in which the person resides.
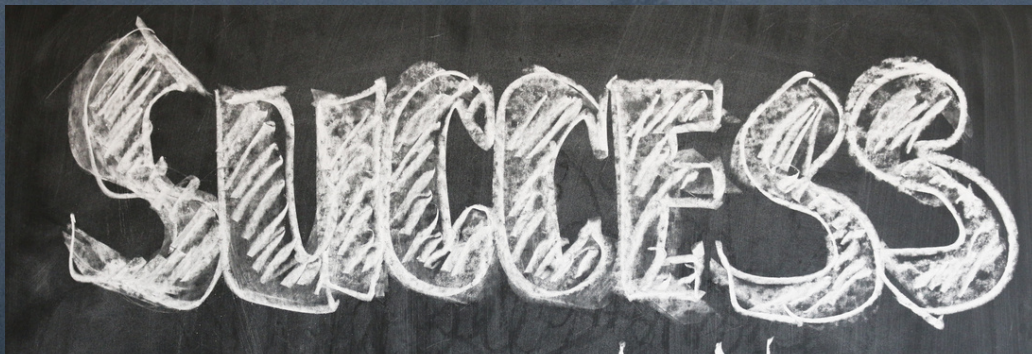
DEFINITION OVERVIEW (CONT.)

De-identified variables

- When collected, the data contained identifiers or information that would permit identification of the individual about whom the data were collected; however, the identifiers or indirect links to identity have been removed and no longer exist anywhere in any form.

- If you have questions about how these apply to your project... reach out and let us help!

*L. Sweeney, Simple Demographics Often Identify People Uniquely. Carnegie Mellon University, Data Privacy Working Paper 3. Pittsburgh 2000.

DOS AND DON'TS

PLEASE DO...

Based on successful submissions

- Use the templates for Informed Consent, Recruitment script, etc.
  - If you want to be creative by changing the font size or style, feel free.

PLEASE DON'T...

Based on submissions that were not successful the first time

- Utilize figures who are authoritative to recruit subjects for research.
  - Example: faculty member recruiting students, physician recruiting patients, etc.