# De-identified vs. Coded Data

The terms "**coded**" and "**de-identified**" describe ***different types of datasets***. The distinction hinges on whether **there is a key** linking subjects to their identifiable data and whether anyone involved in the research has **access to that key.**

## Coded Data:

Coded data are created when direct identifiers (e.g. name, MRN, dates, etc.) are removed and replaced with a **code**; a **key exists** that **can link the code back to the individual**.

- Identifiers are removed and replaced with a code
- A key exists that can link codes back to individuals
- If anyone on the research team can access the key, the data remain identifiable

***Note:*** *Whether or not researchers intend to use the key does not change the identifiable status of the data.*

## De-identified Data:

Data are considered **de-identified** only when **no one on the research team has access to any key or mechanism that could re-identify subjects.**

- Identifiers have been removed
- The key is not accessible to the research team
- The research team is unable to re-identify subjects

## In conclusion:

**Coded data are not the same as de-identified data.** If a key exists and the team can access it, the data are *coded*—not "de-identified".

# Understanding "Coded" vs. "De-Identified" Data

*Pertains to data that previously contained identifiers at some point during its life cycle.*

**Q: Does a key exist linking data to subjects' identities?**

**YES**

Does the study team have access to the key?

**YES**

**"CODED"**
- Key accessible
- Subjects CAN be re-identified

**NO**

**"CODED", BUT…**
- Key exists (but outside of study team purview)
- Data recipient CANNOT re-identify subjects
- Becomes *de-identified* to *recipient* of data

Represents re-identification risk

**NO**

**"DE-IDENTIFIED"**
- No key exists
- No one can (re-)identify subjects
- When the key is destroyed, the data become *anonymous*

**Did you know?**

Studies that are FDA-regulated, even when the data being used are de-identified, may require submission to the IRB.