A VISUAL GUIDE TO PRACTICAL DATA DE-IDENTIFICATION





What do scientists, regulators and lawyers mean when they talk about de-identification? How does anonymous data differ from pseudonymous or de-identified information? Data identifiability is not binary. Data lies on a spectrum with multiple shades of identifiability.

This is a primer on how to distinguish different categories of data.



DEGREES OF IDENTIFIABILITY

Information containing direct and indirect identifiers.

POTENTIALLY

IDENTIFIABLE

PARTIALLY MASKED

INTACT

LIMITED or

NONE IN PLACE



PSEUDONYMOUS DATA

Information from which direct identifiers have been eliminated or transformed, but indirect identifiers remain intact.



DE-IDENTIFIED DATA

Direct and known indirect identifiers have been removed or manipulated to break the linkage to real world identities.



ANONYMOUS DATA

ANONYMOUS

ELIMINATED or

TRANSFORMED

Direct and indirect identifiers have been removed or manipulated together with mathematical and technical guarantees to prevent re-identification.



DIRECT IDENTIFIERS

Data that identifies a person without additional information or by linking to information in the public domain (e.g., name, SSN)



INDIRECT IDENTIFIERS

Data that identifies an individual indirectly. Helps connect pieces of information until an individual can be singled out (e.g., DOB, gender)



SAFEGUARDS and CONTROLS

Technical, organizational and legal controls preventing employees, researchers or other third parties from re-identifying individuals

> SELECTED **EXAMPLES**

Name, address, phone number, SSN, government-issued ID (e.g., Jane Smith, 123 Main Street, 555-555-5555)

EXPLICITLY

PERSONAL

INTACT

INTACT

NOT RELEVANT

due to nature of data

Unique device ID, license plate, medical record number, cookie, IP address (e.g., MAC address 68:A8:6D:35:65:03)

Same as Potentially Identifiable except data are also protected by safeguards and controls (e.g., hashed MAC addresses & legal representations)

NOT READILY

IDENTIFIABLE

PARTIALLY MASKED

INTACT

CONTROLS IN PLACE

KEY CODED

ELIMINATED or

TRANSFORMED



CONTROLS IN PLACE

Clinical or research

datasets where only

curator retains key

diabetes, HgB 15.1

(e.g., Jane Smith,

g/dl = Csrk123

INTACT

Unique, artificial

pseudonyms replace

direct identifiers (e.g.,

(unique sequence not

used anywhere else)

HIPAA Limited Datasets,

John Doe = 5L7T LX619Z)

PSEUDONYMOUS

ELIMINATED or

TRANSFORMED

LIMITED or **NONE IN PLACE**

> Same as Pseudonymous, except data are also protected by safeguards and controls

PROTECTED

PSEUDONYMOUS



DE-IDENTIFIED





Data are suppressed, generalized, perturbed, swapped, etc. (e.g., GPA: 3.2 = 3.0-3.5, gender: female = gender: male)



PROTECTED

DE-IDENTIFIED

TRANSFORMED



CONTROLS IN PLACE

Same as De-Identified.

protected by safeguards

except data are also

and controls

ELIMINATED or **ELIMINATED** or TRANSFORMED TRANSFORMED



NOT RELEVANT due to nature of data

For example, noise is calibrated to a data set to hide whether an individual is present or not (differential privacy)

-1-1-**ELIMINATED** or TRANSFORMED

AGGREGATED

ANONYMOUS



ELIMINATED or TRANSFORMED



NOT RELEVANT due to high degree of data aggregation

Very highly aggregated data (e.g., statistical data, census data, or population data that 52.6% of Washington, DC residents are women)