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.



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.

PROTECTED

DE-IDENTIFIED

×...•

ELIMINATED or

TRANSFORMED

-×...

ELIMINATED or

TRANSFORMED

CONTROLS IN PLACE



Produced by

ANONYMOUS DATA

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



phone number, SSN, (e.g., Jane Smith, 123 Main Street, 555-555-5555)

EXPLICITLY

PERSONAL

INTACT

INTACT

1

LIMITED or

NONE IN PLACE

POTENTIALLY

IDENTIFIABLE

PARTIALLY MASKED

PARTIALLY MASKED

NOT READILY

IDENTIFIABLE



INTACT



-X

ELIMINATED or

TRANSFORMED

KEY

CODED





PSEUDONYMOUS

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×

ELIMINATED or

TRANSFORMED



LIMITED or

NONE IN PLACE



PROTECTED

PSEUDONYMOUS

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ELIMINATED or

TRANSFORMED

except data are also



DE-IDENTIFIED







Same as De-Identified, except data are also protected by safeguards and controls



ELIMINATED or **TRANSFORMED**



ELIMINATED or TRANSFORMED



ELIMINATED or

TRANSFORMED

ELIMINATED or

TRANSFORMED

NOT RELEVANT due to nature of data

due to high degree of data aggregation Very highly aggregated

For example, noise is calibrated to a data set data (e.g., statistical to hide whether an data, census data, or individual is present or population data that not (differential privacy) 52.6% of Washington, DC residents are women)

Name, address, government-issued ID

NOT RELEVANT

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)

CONTROLS IN PLACE

Clinical or research datasets where only curator retains key (e.g., Jane Smith, diabetes, HgB 15.1 g/dl = Csrk123

CONTROLS IN PLACE

Unique, artificial pseudonyms replace direct identifiers (e.g., HIPAA Limited Datasets, John Doe = 5L7T LX619Z) (unique sequence not used anywhere else)

protected by safeguards and controls

INTACT

Same as Pseudonymous, Data are suppressed,

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

NONE IN PLACE