



DE-IDENTIFICATION Tool

Checklist of Review Criteria for Public Health Agencies to Evaluate Proposed Collection, Access and Sharing of De-identified Data

After the public health attorney or privacy officer collects all of the facts involving the proposed data collection, access or sharing, review criteria are addressed. Privacy requirements must be determined at each data transfer point, so that all governing laws are identified. Laws may specify whether the proposed action with de-identified data is lawful, as well as how it must occur. Factual information may reflect increased risk to individuals or the public health agency and application of additional privacy controls may be appropriate. Collection of a new data stream should be evaluated in light of Freedom of Information laws, particularly where the proposed data stream is highly sensitive or potentially stigmatizing to a community. The checklist below is intended to guide public health practitioners in identifying appropriate review criteria to analyze factual information concerning de-identified data collection, access and sharing.

1. Have all laws that apply to each data type and source been identified?

Laws may be both general and specific, and enacted or promulgated by both the federal and state levels of government. Map the proposed data collection through to use and then to disclosure, if applicable, identifying every transfer point. Every transfer point for data, is a decision point with regard to law, regulation and policy (hereinafter law). Does HIPAA apply? If public health is covered by HIPAA, ensure that questions of legal preemption are addressed.

2. Does law allow disclosure of de-identified information?

Does law prohibit disclosure of de-identified information? Does the Freedom of Information law compel disclosure of the data?



3. Does law include provisions for determining whether data are de-identified?

Are there specific standards, criteria or procedures that must be followed to ensure that the data are legally de-identified? Are there any court decisions that provide guidance? For example, see [Table of Cases](#) that is part of this toolkit.

4. Has the public health privacy officer or attorney reviewed the de-identification method against law to confirm that it meets all legal requirements?

Has the public health privacy officer or attorney determined that the data set does not identify or tend to lead to the identity of an individual (substitute appropriate legal standard if different)? Did the data manager take into account publicly available data as well as the possibility of the mosaic effect?

5. What are the competing interests that must be balanced? How should benefits be maximized and privacy risks minimized?

Has the data manager given consideration to the following:

- How will the data be used? What are the benefits to public health or others in collecting, accessing or sharing the data?
- What is the availability of the data; is public health the only source?
- What is this data action's impact on informing the public? Is the disclosure necessary for the reasonable and appropriate response to a public health emergency or other action? Is there a compelling public health or state purpose?
- Could less data be adequate to meet the need?
- What is the risk to privacy? What is the potential impact on the community, including stigma?

The public health attorney should evaluate whether there is any impact to public health with regard to ongoing litigation.

6. Has public health adequately documented the de-identification process with respect to both the law and the resulting data set, or the decision not to release the data?

Prior to sharing de-identified data, has the proposed data set been validated as meeting criteria, standards or policy? Is there adequate documentation? If public health finds that the data requested is identifiable and determines that it should not release the data set, has it stated a particularized and specific justification for denying access? This analysis should be performed on a case-by-case basis.

SUPPORTERS



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