



DE-IDENTIFICATION Tool

Checklist of Factual Information Needed for Public Health Agencies to Address Proposed Data Collection, Access and Sharing

Public health attorneys and privacy officers provide advice to public health agencies on an array of questions about collecting, accessing, and sharing information. Questions may involve oral, written or electronic data. Responses must consider whether a public health agency has the legal authority to collect, access, or share information, and if so, what are the conditions and limitations for data sharing. In addition to legal considerations, policy and ethical concerns may be relevant. In some situations - for example, urgent threats of communicable disease – the public health agency might face competing interests of protecting individual privacy and protecting the public's health. Certain factual information about the data to be shared and the circumstances and conditions for sharing is needed to evaluate proposed data sharing. The checklist below is intended to assist public health practitioners in providing relevant factual information to resolve questions about proposed data collection, access and sharing.

WHAT?

- What information do you want to obtain or share? Identify data elements.

WHY?

- For what purpose is this information needed? Clearly articulate the public health purpose.

HOW MUCH?

- Will de-identified information or a limited data set (that includes demographics but not personal information) serve the purpose?

FROM WHOM?

- What are the sources for the information? (e.g. health care providers, schools, other business, and individuals that provided/will provide the information to public health).
 - Under what terms or conditions, if any, was this information provided to you?
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WITH WHOM?

- Who will have access to this information?

CONDITIONS?

- Acceptable uses and linkages of the information?

HOW? WHERE?

- How will the information be transferred/shared/stored?

PROTECTIONS?

- What privacy and security measures are in place to protect information during transfer, storage, use and disposal?

AND THEN WHAT?

- Retention, reuse, further sharing, disposal of the data?

ASSURANCE?

- Audits or other mechanisms to monitor proper receipt, storage, access and use?

ACCOUNTABILITY?

- What are the terms of data use and means to enforce for violations?
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SUPPORTERS

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This document was developed by Denise Chrysler, J.D., Director, at the Network for Public Health Law – Mid-States Region. The Network for Public Health Law provides information and technical assistance on issues related to public health. The legal information and assistance provided in this document does not constitute legal advice or legal representation. For legal advice, please consult specific legal counsel.