# Checklist of Factual Information Needed to Address Proposed Data Collection, Access and Sharing to Improve the Health of Communities

Attorneys and privacy officers provide advice to public health agencies and other organizations 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 or other organization 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, threats of communicable disease or environmental hazards – a public health agency might face competing interests of protecting individual privacy, protecting the public's health, and avoiding stigma of communities or individuals. 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 and advocates and community organizations in providing relevant factual information to resolve questions about proposed data collection, access and sharing.

# What?

What is the purpose of the data request? What do you want to do with the data?

What data do you need to accomplish your goal? Identify data source(s), data type(s) and data elements.

# From whom?

From whom might you obtain these data? Identify each data provider.

# With whom?

With whom do you want to share these data? Identify each data recipient.

# Why?

Why are you sharing these data with these partners? What is the connection between these data and what you want to accomplish? Ensure that the stated purpose is consistent with the described proposed use.

# How Much?

How much data do you need to accomplish your goal? Will de-identified information or a limited data set (that includes demographics but not personal information) serve the purpose?

# Conditions?

Under what terms or conditions, if any, was this information provided to you? 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?

**Tool available to download at:** <https://www.networkforphl.org/wp-content/uploads/2020/01/Checklist-of-Information-Needed-to-Address-Proposed-Data-Collection-Access-and-Sharing-final.docx>

**SUPPORTERS**



**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.**