

Model Data Use Agreements: A Practical Guide

Amy O'Hara

amy.ohara@georgetown.edu

October 26, 2020



McCourt School of Public Policy

Scope

Objectives – data sharing that is efficient, secure, equitable, and transparent

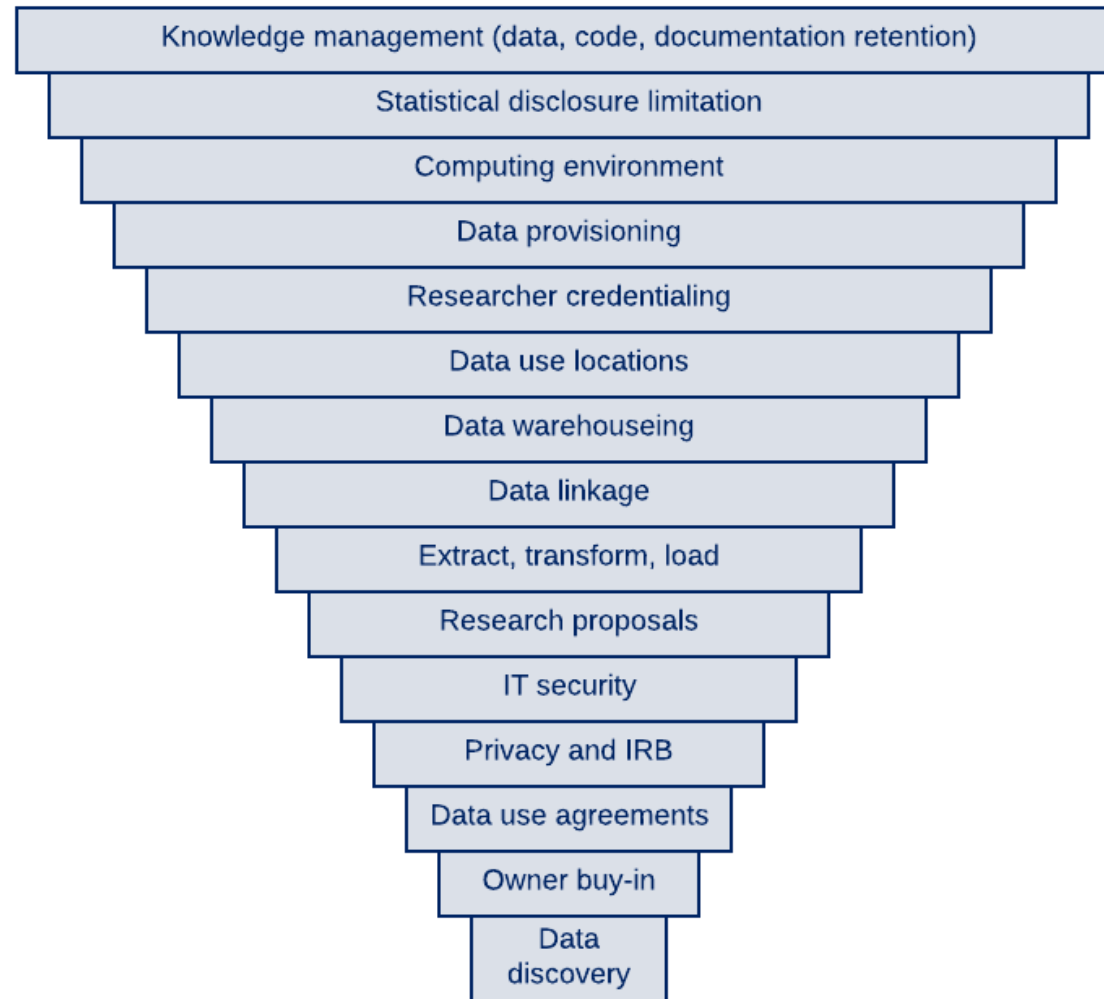
Not just data sharing – data exchange and data access

Outcomes – knowledge production, more data access, building trust

Data Use Agreements

- Documents that describe what data are being shared, for what purpose, for how long, detailing access restrictions or security protocols
- Related to Memoranda of Understanding, Data Use Licenses, Data Exchange Letters, Non-Disclosure Agreements
- Parties include data provider and data requestor

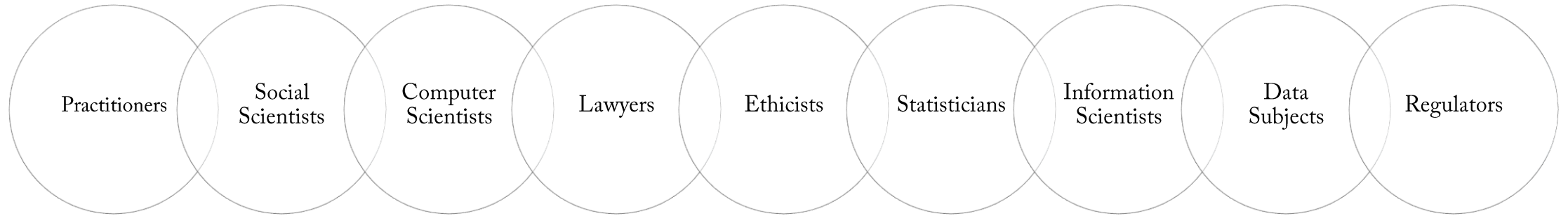
Balancing Act



What is Required

- Clear vision, objectives
- Understood vocabulary
- Coordination across sectors and organizations
- Collaboration across roles and disciplines

Examples: Roles and Disciplines



- Some are already working together
- Need to have better information transmission

The Goal

**MODIFICATION 1 TO THE
MEMORANDUM OF UNDERSTANDING
THROUGH WHICH THE U.S. CENSUS BUREAU IS ACQUIRING
PRISONERS DATA
FROM THE DEPARTMENT OF JUSTICE, UNITED STATES MARSHALS SERVICE**

0071-FY18-NFE-0010.001/M0001

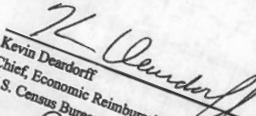
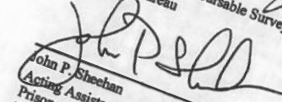
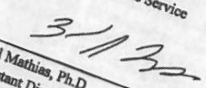
This document constitutes a modification to Agreement No. 0071-FY18-NFE-0010, an agreement between the Department of Justice, US Marshals Service (USMS) and the U.S. Census Bureau (Census Bureau) dated May 31, 2018. The purpose of this amendment to allow for the transfer of additional data to the Census Bureau and to document necessary updates to security language.

The purpose of the amendment is to:

1. Add the following paragraph to the end of the BACKGROUND section:
The Census Bureau requests additional data requested in Modification 1 in order to incorporate information the USMS collects on citizenship for the Census Bureau's Decennial program.
2. Add the following paragraph to the end of the USMS RESPONSIBILITIES section:
 - i. To transfer to the Census Bureau via secure method such as Secure File Transfer Protocol (SFTP) or appropriately encrypted, FIPS 140-2 compliant CD-ROM or DVD-ROM, administrative data on prisoners held. Records will be transferred as soon as possible after signing of the MOU but no later than December 31, 2019. A second transfer with any records pertinent to the MOU will be created with a vintage of April 1, 2020 and sent to the Census Bureau as soon as possible but no later than July 31, 2020. Variables required:
 1. Name
 2. Date of Birth
 3. Sex
 4. Social Security Number
 5. Pre-incarceration Address
 6. Citizenship Status
 - ii. To provide adequate documentation and support of transferred files for the

1

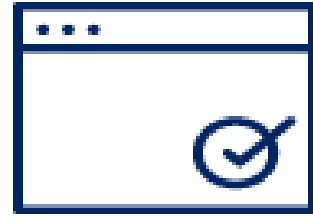
APPROVALS

 Kevin Deardorff Chief, Economic Reimbursable Survey Division U.S. Census Bureau	9/16/19 (Date)
 John P. Sheehan Acting Assistant Director Prisoner Operations Division United States Marshals Service	8/26/19 (Date)
 Karl Mathias, Ph.D Assistant Director Information Technology Division United States Marshals Service	8/9/19 (Date)

5

Framework: Five Safes

- Safe Projects
- Safe People
- Safe Settings
- Safe Data
- Safe Outputs



Embedding the Five Safes into DUAs

- Intended data uses
- Terms for data access and handling
- Describe project outputs and expected publications
- Acceptable data uses, linkages, and topics of analysis
- Roles and responsibilities for the provider and researchers
- Metadata
- Reporting or disposition requirements

Preparation

- What data are available?
 - Is quality known? Is there documentation? Have other researchers used the data? What elements are captured or retained?
- How long will it take?
 - Negotiating and then getting the data. Is there an established data request process?
- Adherence to laws, regulations, and policies permitting data use
 - Are there templates or existing agreement to follow? What data sharing has been permitted before?

Needs and Wants of Both Parties

- Researchers
 - Preparation
 - Negotiation
 - Responsibilities
 - Transparency

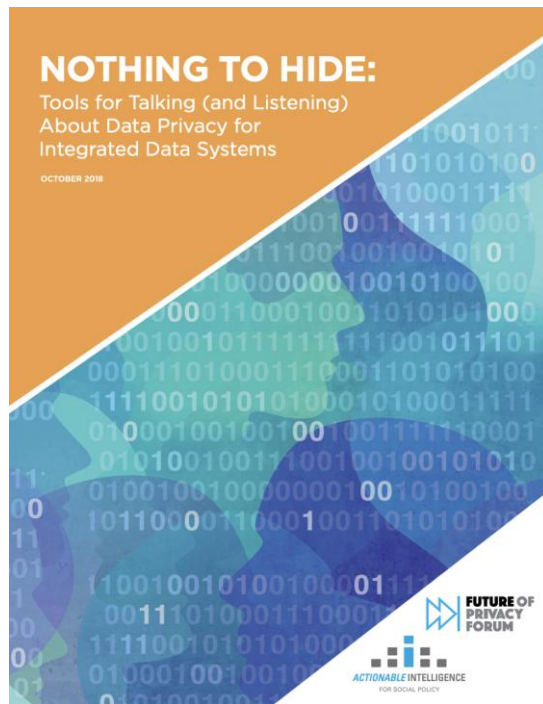


- Providers
 - Incentives/needs
 - Documentation
 - Extraction
 - Sharing/hosting



Consideration for Data Subjects

- What are the potential benefits, costs, and risks for the data subjects?
- How will these be communicated to them?



	<i>Active engagement</i> ← ———— → <i>Passive engagement</i>			
	<i>Co-creation</i>	<i>Reviewing</i>	<i>Commenting</i>	<i>Reporting</i>
Project conception				
Accessing and/or collecting data				
Cleaning, linking, and de-identifying data				
Analyzing data				
Publishing and sharing results				
Post-project treatment				

In Advance

- Read guides
- Call a privacy professional
- Consult a lawyer
- Connect the authorizers and the data people
- Do your homework

Toolkits and Guides

California Accountable Communities for Health Data-Sharing Toolkit

This toolkit is produced by the University of California Berkeley Center for Healthcare Organizational and Innovation Research and sponsored by the California Health and Human Services Agency and University of California Berkeley, School of Public Health. This report summarizes seven parameters for data sharing, Purpose/Aim, Relationship/Buy-in, Funding, Governance and Privacy, Data and Data-sharing, Technical Infrastructure, and Analytic Infrastructure while observing that parties will have varying levels of maturity and expertise across these categories.

CMS Administrative Simplification: Covered Entity Guidance

This clickable guide helps identify whether an organization or individual is a covered entity under the Administrative Simplification provisions of HIPAA. It is a good example of a straightforward tool that aids decision-makers to understand what laws apply to whom.

Department of Education Data Sharing Tool for Communities

This toolkit is designed to simplify the complex concepts of FERPA. It covers three primary focus areas: understanding the importance of data collection and sharing, understanding how to best protect student privacy when collectively using personally identifiable information from students' education records that are protected by FERPA, and understanding how to manage shared data using integrated data systems. It includes a sample MOU and sample consent form.

Health Care Systems Research Network DUA Toolkit

This toolkit includes a useful flowchart called "When do I need a DUA?" and a good glossary of terms, especially for health or healthcare projects.

National Association of County & City Health Officials (NACCHO) Data Sharing Framework

This report titled "Connecting the Dots: A Data Sharing Framework for the Local Public Health System" focuses on DUA content areas needed by local public health officials. It includes a case study involving data access in a Colorado community.

National Governors Association, Improving Human Services Programs and Outcomes Through Shared Data

More for policymakers than practitioners, this brief includes short examples of how data sharing helped states and their residents in Indiana, Kentucky, Maryland, Massachusetts, North Carolina, Pennsylvania, Rhode Island, South Carolina, Virginia, and Washington.

National League of Cities Sharing Data for Better Results Guide

Prepared with Stewards of Change, this guide was written for officials, agency leadership and managers. It highlights their incentives to share data, what information can be shared, and who can receive the information with specific examples across domains including education, health, mental health, substance abuse, human services, and criminal justice. They include sample MOUs from two counties, a city, and a state and have an appendix listing major federal laws and regulations.

Sharing Data for Social Impact: Guidebook to Establishing Responsible Governance Practices

Produced by Natalie Evans Harris, a program fellow with the Beeck Center for Social Impact and Innovation, this guide is for those who take action on the data and drive impact. The guide focuses on three phases: building the collective, defining the operations, and driving impact.

Develop the Agreement

Title

Data Use Agreement for [Data/System] Access between Party 1 and Party 2

Parties and Purpose

This Agreement is between Party 1 [Office, Agency, Department, Institution] and Party 2 [Office, Agency, Department, Institution]. Party 1 and Party 2 are entering into an Agreement that will allow the exchange of data and clarification of data access and use. Party 1 will provide data collected to Party 2 for the purposes of [specify].

Authority

Party 1 is a(n) [specify] organization whose mission is [specify]. The authority to enter into this Agreement is [xxx]. This authority permits the release of [data] [law/code] permits disclosure of [data] for [specify] functions. Party 2 is a [specify] organization whose mission is [specify].

Terms and Conditions

Description of planned data use by Party 2, consistent with Purpose above:

- *Treatment of data anomalies, including technical assistance from Party 1 as needed*
- *Terms for data storage, treatment of original data, handling of Personal Information, and data linkage protocols*
- *Conditions for storing modified data (including integrated, recorded, or derived data) during and after the project*
- *Terms for storage of researcher generated files (including retention, deletion, and the extent permitted by law, the original data received from Party 1 and Party 2 for [specify period].)*

Data Elements

*The following data will be provided under this Agreement:
[Specify list of data elements from named programs/systems, noting which populations, and/or geographies are sought.]*

Approved Research Uses

[Describe project objectives, intended data use, expected linkages.]

Limitations on Liability

In no event shall either party be liable to the other party under this Agreement or to any third party for special, consequential, incidental, punitive, or indirect damages, irrespective of whether such claims for damages are founded in contract, tort, warranty, operation of law, or otherwise or whether claims for such liability arise out of the performance or non-performance by such party hereunder.

Monitoring and Breach Notification

In the event of an actual or suspected security breach involving its information system(s), Party 2 will immediately notify Party 1 of the breach or suspected breach and will comply with all applicable breach notification laws. The parties agree to cooperate in any breach and remedy of any such breach, including, without limitation, complying with laws concerning unauthorized access or disclosure.

Remedies in Event of Breach

The parties recognize that irreparable harm may result in the event of a breach of this Agreement. In the event of such a breach, the non-breaching party may be enjoined to restrain the other from any continued violation. This section shall survive termination of this Agreement. In the event that a breach is identified and it is determined that the breaching party that (a) individual or public notification is required and (b) the requirement for notification is substantially caused by the other party, the breaching party shall be liable for the reasonable costs incurred by the non-breaching party to meet all federal and state legal and regulatory disclosure and notification requirements, including, but not limited to, costs for investigation, attorneys' fees, risk assessment, and required individual or public notification, fines, and mitigation activities.

Public Information

To promote organizational transparency, and in support of data discovery for current and future researchers, Party 2 may publish non-sensitive data documentation to public-facing websites. This documentation may include a project abstract, description, or summary of results.

Use of Name

Neither party will use the other party's name, logos, trademarks, or other marks without that party's written consent.

Community Stakeholders

The parties agree to engage community stakeholders in the course of this research project. No confidential data will be released or discussed with third parties, but the parties may agree to disclose de-identified aggregate reports to support their initiatives and engage community stakeholders.

Costs

This project shall not result in the transfer of funds from one party to another. Party 1 agrees to provide technical assistance to Party 2 to develop and deliver the initial data extract. If the parties determine that additional staff or supports are necessary at any stage of this research project, Party 2 agrees to seek funding to support those needs.

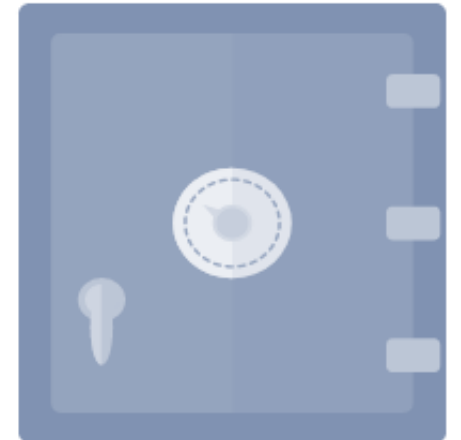
Identifiers

- Will user get direct identifiers
- Who can handle identifiers
- Protocols (e.g., honest broker, trusted third party)
- Maintenance/disposition
- Certifying de-identification



Security

- Requirements based on data, laws, and regulations
- Institutional requirements
- Monitoring and control
- Liability



Output Review

- Monitoring scope
- Pre-publication review
- Notification prior to release
- Capturing code, data, results, IP



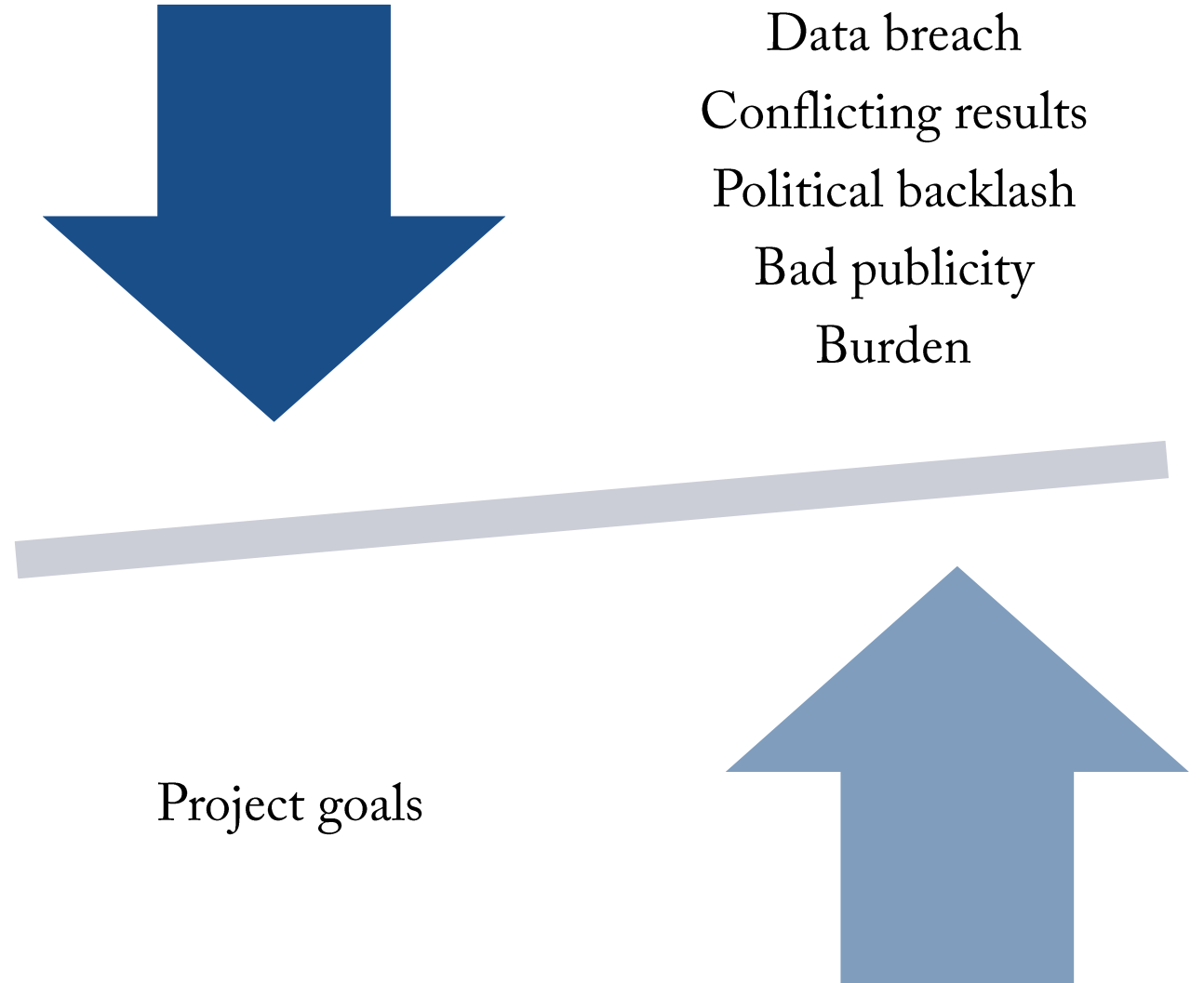
Publishing Results

- Notice or approval
- Branding
- Citation



If They Say “No”

- Legal
- Policy
- Cultural
- Financial



Getting to “Yes”

Agreement Collections

NNIP's Collection of Example Data-Sharing Agreements
This collection of agreements comes from multiple domains including labor and human services, department of motor vehicles, criminal justice, education, housing, and health and healthcare. It also includes some generic agreements and other materials, such as an information security incident protocol breach plan, and sample confidentiality pledge.

Data2Health Data Use Agreement Library
An analysis of DUA practices across 48 Clinical and Translational Science Award (CTSA) institutions, collection includes DUA templates, forms to request DUAs, and policies and guidance documents.

Drexel Data Sharing Agreement Repository (DataSAR)
This repository is a collection of DUAs, samples, contracts, use policies, and forms. It can be filtered by domain and discipline. This collection is aligned with Drexel's Licensing Model and Ecosystem for Data Sharing Initiative.

Contracts for Data Collaboration
This collection contains DUAs for domestic and international government administrative data and sector information. The site also includes a guide describing forms of collaboration and explanation of categorized DUAs based on Who, What, When, Where, Why, and How the data sharing was done.

Administrative Data Research Initiative Data Sharing Index
This index, a collection of standards, guides, and templates, is searchable by geographic category including city, county, state, or federal and domain categories such as education, health, justice, or workforce.

One of the most common reasons data providers say no does not relate to a legal or political issue, but to a practical one. Staff members are pressed with work for core agency operations and reluctant to prepare datasets and documentation for external users. Given fixed local government infrastructure, there is likely no way to eliminate the extra work for the staff, but you can articulate benefits to demonstrate the value of data sharing that justify the costs.

- **Offer additional analysis useful to the agency's work.** Agency staff might lack the time or expertise for analyzing own data for internal purposes. In return for data sharing, you can offer to fulfill simple agency requests or return enhanced files to the agency. For example, in exchange for a file of the locations of homeless prevention payments by the District of Columbia, [Greater-Urban DC](#) provided the local homeless coordination agency geocoded files and simple maps so they could explore the programs' impact on neighborhoods.
- **Offer access to relevant indicators derived from another office's data.** Agencies are often more willing to share data with an outside organization than with other agencies. For example, knowing the number of births or the number of new housing units planned by census tract helps school districts forecast enrollment, but planning and health departments might feel more comfortable sharing the data with a third party rather than directly, either for legal or political reasons. Even if the data sharing among agencies is possible, the school analysts could prefer to receive aggregate, clean data rather than doing the cleaning and analysis themselves.
- **Save the agency time by answering community inquiries.** Local agencies might already time fulfilling community data requests one by one. If you provide publicly available updated summary statistics in charts and maps, agency staff can refer data seekers to your website and spend less time answering inquiries. The Baltimore Neighborhood Indicators Alliance publishes its aggregate indicators on the [city's open data portal](#), making the data available for residents and city officials alike.
- **Reassure the data owners that you have the skills to use the data.** This includes letting them know that your qualified staff will not need assistance in basic data use perhaps through examples of other data analysis you have done.
- **Offer to share back documentation of the files.** Often local administrative data will not come with documentation of the contents or quality, so you can share back data dictionaries or diagnostics with the agencies. Agencies can use the documentation for sharing the data with other organizations in the future and might be interested in improving their data quality.

Following Through

- Getting it signed
- Agreement management
 - Compliance with the agreement
 - Modifying the agreement
- Do the work and explain results to stakeholder
- Build the trust