

By Deja Kemp and Amy Hawn Nelson



Strong Legal Frameworks for Data Integration: Four Questions for Moving Forward

Cross-sector data sharing and integration has become more routine and commonplace, and for good reason. When governments and their partners bring together data safely and responsibly, policymakers and practitioners are better equipped to:

- Understand the complex needs of individuals and families
- Allocate resources where they are needed most to improve services
- Measure impacts of policies and programs holistically
- Engage in transparent, shared decision making about how data should (and should not) be used
- Institutionalize regulatory compliance





Data sharing and integration is also not without risks, and clear legal frameworks are essential to mitigate those risks, protect privacy, and guide responsible data use. Designing the appropriate legal framework for your context can be a complex task and a test of endurance. In response, Actionable Intelligence for Social Policy (AISP) created *Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration*¹ to support the essential and challenging work of exchanging, linking, and using data across government agencies. This resource was developed in partnership with our national network of integrated data systems to

provide clear guidance on how to get started, including guiding questions to explore with partners, checklists to assist with drafting legal documents, memorandum of understanding templates, and site examples. We suggest starting with “the four questions” to identify relevant next steps for your jurisdiction.

The Four Questions

When working to establish data flow across public-sector organizations—specifically government agencies—the initial question partners ask is, “Is this legal?” While this is an essential question

Figure 1

|  1. IS IT LEGAL? |  2. IS IT ETHICAL? |  3. IS IT A GOOD IDEA? |
|---|--|--|
| <p>What legal authority is in place to use these data?</p> <p>Are there federal or state statutes that prevent or constrain this data access or use?</p> <p>What are the particular state and federal law requirements enabling data sharing?</p> | <p>Do the benefits outweigh the risks, particularly for groups historically marginalized by discriminatory systems?</p> | <p>What action can be taken as a result of this data use?</p> <p>What can reasonably be changed or improved based upon this analysis?</p> <p>Is this a priority among marginalized populations and/or individuals included in the data system?</p> |
|  4. HOW DO WE KNOW? WHO DECIDES? | | |
| <p>This is typically determined by agency-involved legal counsel.</p> | <p>This is typically determined by a data governance group, during the review process for data requests, that should include a variety of stakeholders, those “in” the data and users of the data.</p> | <p>This is typically determined by a data governance group, including data stewards who have deep expertise of the data, and data owners who will respond to insights that emerge from the analysis.</p> |

to answer, it is also the lowest bar. To ensure data use is both legal and ethical, we strongly encourage you to grapple with broader considerations to help you decide, together with your partners, whether and how to move forward with data sharing and integration.

Figure 1 outlines the four questions we recommend asking throughout all stages of this work.

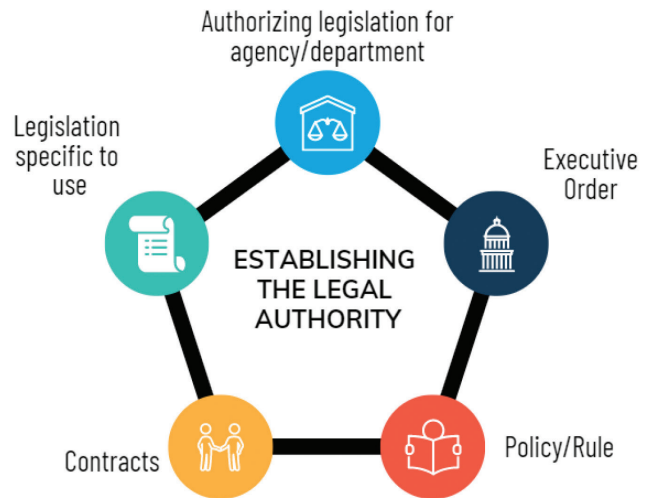
Determining Legal Authority and Drafting Agreements

After thinking through the four questions, you will need to consider your legal authority for sharing and integrating data. In many contexts, data can be shared, if shared for a purpose allowed under the law. Most often, legal authority relies upon contracts, or as they are commonly known—legal agreements. We recommend agreements that are: (a) tiered; (b) standardized but flexible; and (c)

transparent and comprehensible.

Tiered

We suggest a three-tiered approach for legal agreements to govern data access and use for an integrated data system: a Memorandum of Understanding (MOU), a Data Sharing Agreement (DSA), and a Data Use License (DUL). Depending on the specifics of your context and purpose, other agreements may also be needed, such as confidentiality or nondisclosure agreements for individual staff. Agencies may use different terms to refer to legal agreements. Examples include: data security agreement, information



sharing plan, memorandum of agreement, data sharing agreement, data exchange agreement, and data use agreement. We recommend learning the terms used by the agencies you hope to partner with and using them consistently.

See Legal Frameworks on page 34



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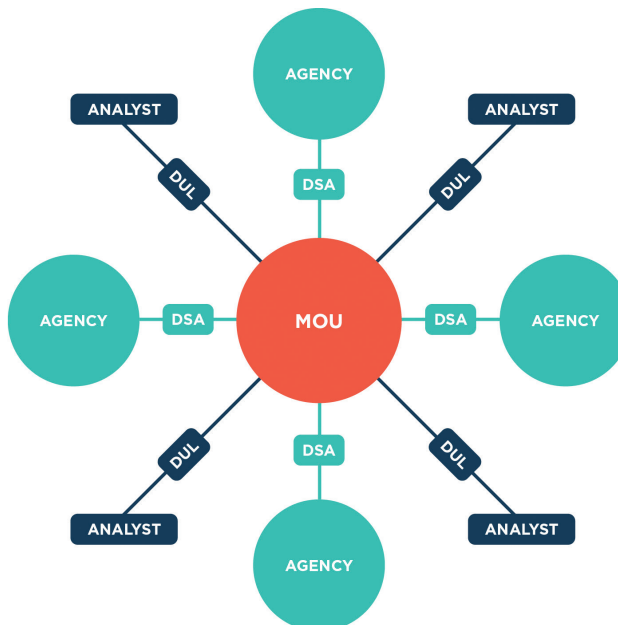


| FOUNDATIONAL LEGAL AGREEMENTS | | | |
|---|--|---|--|
| LEGAL AGREEMENT | PURPOSE | PROCESS | SIGNATORY |
| <p>Memorandum of Understanding MOU</p> <p><i>Overarching process document signed on by all data partners</i></p> | <p>The MOU documents the purpose and governance process. The MOU will be signed by all data partners as they enter the collaboration. The MOU references the DSA, DUL, and relevant policies, and procedures for data access and use.</p> | <p>Drafted in partnership with legal counsel from all participating data partners</p> | <p>Lead agency/ies + all data partners</p> |
| <p>Data Sharing Agreement DSA</p> <p><i>Agency-specific to how data will be used for integration</i></p> | <p>The DSA includes the specific terms and conditions that govern how data are transferred, stored, and managed when shared and integrated. The DSA references the MOU and the DUL. This document is specific to data held by a data partner.</p> | <p>Template is drafted in partnership with legal counsel from all participating data partners. Completed according to specific data assets of the data partner. Reviewed and updated annually, or as agreed upon.</p> | <p>Lead agency/ies + data partner</p> |
| <p>Data Use License DUL</p> <p><i>Data use-specific once data has been integrated</i></p> | <p>The DUL outlines the role and responsibilities of the data recipient. The DUL is often executed after the Data Request Form is approved. The Request Form and/or DUL should include: purpose, data fields, anonymization procedures, dissemination plan, and timeline of project completion. A DUL must be executed prior to data access.</p> | <p>Template is drafted in partnership with legal counsel from all participating data partners.</p> <p>Once data request is approved, a DUL is executed.</p> | <p>Lead agency/ies + data recipient</p> |

Standardized but Flexible

We recommend starting with a review of the agreements already used in your jurisdiction before selecting exemplars to template and use routinely across agencies. While this process requires an investment of time up front, it should make each subsequent negotiation faster and more predictable.

Using standard but modular documents allows users the confidence that agreements have been carefully considered and agreed upon by cross agency legal counsel, and, flexibility to modify for each use case as needed. Defining terms for standard agreements can be a complex exercise within one agency. Be sure to allot




adequate time to this important step, when doing so collaboratively across a range of government, nonprofit, and academic institutions, as recommended in the legal framework.

Transparent and Comprehensible

Legal agreements—in particular those operating at higher levels of the tiered structure, such as the MOU—should be written so that non-lawyers can follow along. We recommend the use of appendices to separate out things like security requirements and data elements from the main text of agreements. If legal agreements themselves, or at least the existence of the agreements, can be made public, this may also help

establish trust with the public and earn social license for data sharing.

Conclusion

There is no single “right” path to data sharing and use that is legal, ethical, and a good idea. Clear legal frameworks can help you discern what will work best in your context, and who should help decide. With the right team asking and considering the right questions, agencies and their partners can “find a way forward” to mitigate risks and responsibly share and integrate data. For more practical guidance and tools, check out the full report. 

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Reference Note

1. <https://aisp.upenn.edu/resource-article/finding-a-way-forward-how-to-create-a-strong-legal-framework-for-data-integration/>

DATA RELATIONSHIP continued from page 15

The invisible systems I have described have evolved in complexity to the point that we cannot serve the customer completely, immediately. Rather, each transaction takes on average three to five contacts. In one large county, 290,000 applications and renewals in one month led to 1.2 million contacts (i.e., calls, visits). This lost capacity was crippling in good times, but adding that to the end of the Public Health Emergency (PHE) workload and the massive labor shortage, there is simply no way an agency can sustain this level of work and even begin to meet demand.

While data are critical, the real value is the insights they offer, and, in turn, the informed decisions we make and actions we take. Data can be used to determine and monitor eligibility in real time, mitigating the need for workers to manually search for verifications, rely on old and incomplete data, or worse yet, wait days for customers to return information. Using up-to-date, actionable data available via commercial and public sources can also help increase program integrity and, at the same time, reduce churn and avoid an unnecessary break in coverage for eligible customers.

Human services is facing a capacity crisis that will only continue to get worse in the coming months as labor

The only way out of the capacity crisis is to serve our customers completely and immediately. And data can now help us do this, when used correctly and applied at the most opportune time. For instance, during each stage of the eligibility life cycle, we can allow data to do the heavy lifting, enabling us to serve clients with one touch and even no touch. Here is how:

Using real-time intelligence and verification throughout the entire eligibility life cycle:

- **INITIAL APPLICATION:** Validate real-time customer provided information at application against known and real-time data sources to speed verification and improve integrity.
- **ONGOING ELIGIBILITY:** Monitor active customers 365 days a year to identify life-changes that are relevant and actionable.
- **RENEWAL:** Enhance the renewal process by certifying customers without needing to mail out mid-certification reports when all authoritative data sources indicate ongoing eligibility for services. Also populate renewal forms with the latest known information about households before mailing packet to customers.

shortages continue and, in particular, when PHE ends and Medicaid agencies must redetermine eligibility for all applicants. To effectively navigate this next chapter, agencies must adopt a multipronged approach that focuses on process, technology, and people. Data—when used correctly, curated appropriately, and applied at the right time—is one of the most valuable tools agencies have that can help them manage all three of these critical areas. The key, however, is making

sure data is positioned in a way that will work for you and your agency rather than the other way around. Let it teach and show you what is important and what gaps may exist. Be ready to explore what it tells you and ask more questions, and then work with it to drive your decisions and take action. Only when we change our relationship with data and make it work for us in support of our purpose-driven mission can we unlock our agencies’ capacity to do more good. 