

## Data Privacy, Data Use, and Data Use Agreements (DUAs)

Data sharing is a critical component of many payment and delivery system reform efforts, particularly for those targeting Medicaid Beneficiaries with Complex Care Needs and High Costs (BCNs). However, leveraging data from many different sources and across agencies can be complex and extremely challenging, often requiring the creation of inter-agency Data Use Agreements (DUAs).

This brief highlights some of the challenges faced by states participating in the Centers for Medicare & Medicaid Services (CMS) Medicaid Innovation Accelerator Program (IAP) BCN program area as well as several resources these states found useful in developing DUAs. States embarking on inter-agency data use can leverage these tools as they pursue data sharing as part of their Medicaid delivery system reform efforts.

### Inter-Agency Data Use Agreements: Rationale and Mechanics

Medicaid BCNs are a diverse group of individuals with multiple physical and psycho-social needs. Because state health and human services agencies can serve many of the same individuals and populations across a spectrum of programs, data sharing is a critical factor for BCN initiative success, both in terms of identifying Medicaid BCNs and getting them linked to health care. In order to share data collected and maintained by different agencies, state agencies often enter into DUAs.

As a general rule, DUAs are formal agreements that address the following:

- **Outline the health goals of the data exchange partnership**
- **Specify the privacy, technical, and operational issues to be addressed** (e.g. data definitions, data elements, data uses and purposes.)
- **Detail each agency's responsibilities related to the use, disclosure, and storage of the data** (e.g. a list of authorized data users based on roles and responsibilities, rules and processes to safeguard sensitive or confidential information.)
- **Specify procedures for the information transfer**

### Helpful Tips in Developing DUAs

Ideally, DUAs not only enable data sharing between agencies, but also foster collaboration across agencies. Below are two key steps that participating IAP BCN states identified as essential to working through prior to developing and executing successful DUAs.

- **Understanding data privacy and consent requirements.** Privacy of different data elements is governed by different legal requirements, and agencies and programs may have vastly different cultures around privacy. Through joint work, inter-agency team members must reach a common understanding of the legal, programmatic and policy requirements of privacy and how they affect data sharing to improve health.
- **Determining the necessary data elements.** With this common understanding, inter-agency teams can then work together to determine what data elements are necessary, the rationale for using these data and how to effectively use said data in support of BCN initiative goals.

## Improving Care for Medicaid Beneficiaries with Complex Care Needs and High Costs (BCNs)

In July 2014, the Centers for Medicare & Medicaid Services (CMS) launched a collaborative between the Center for Medicaid and CHIP Services and the Center for Medicare & Medicaid Innovation called the Medicaid Innovation Accelerator Program (IAP). The goals of IAP are to improve the care and health care of Medicaid beneficiaries and to reduce costs by supporting states in their ongoing payment and delivery system reforms through targeted technical support. IAP represents CMS's unique commitment to support state Medicaid agency efforts toward system-wide payment reform and delivery system innovation. The Beneficiaries with Complex Care Needs and High Costs (BCN) program area began in October 2015. IAP is also working with states on other health care delivery system reform efforts in additional program areas: reducing substance use disorders, promoting community integration via long-term services and supports, and integrating physical and mental health.

## Data Use Agreement Resources

This section introduces several resources and examples that can serve as a starting point for states interested in developing a DUA with other state agencies.

### DUA Best Practices and Data Privacy Considerations

- **U.S. Department of Health and Human Services Data Use Agreement Practices Guide.** This Practices Guide is a brief document that provides an overview describing the best practices, activities, attributes, and related templates, tools, information, and key terminology of industry-leading project management practices and their accompanying project management templates.
  - [U.S. Department of Health and Human Services Data Use Agreement Practices Guide](#)
- **Office of the National Coordinator Permitted Uses and Disclosures Fact Sheets.** These fact sheets provide guidance related to the disclosure of Protected Health Information (PHI) by Covered Entities (CEs) under the Health Insurance Portability and Accountability Act (HIPAA). They explain the circumstances in which CEs are permitted, but not required, to use and disclose PHI to another CE or that CE's business associate for certain activities without first obtaining an individual's authorization, including for treatment and for health care operations of the disclosing CE or the recipient CE when the appropriate relationship exists.
  - [Permitted Uses and Disclosures: Exchange for Health Care Operation](#)
  - [Permitted Uses and Disclosures: Exchange for Treatment](#)

### State Examples of DUAs

Each of these agreements represent models of DUAs and its elements that can be used as examples to other states.

- **[Georgia DUA example \(Appendix 1\)](#).** This is an example of a short DUA between the two agencies and includes sections on data ownership, permitted use for purposes of health improvement and fraud prevention, and clearly defines roles and responsibilities of each agency. This type of agreement can stand alone or be supported by additional data sharing agreements. The Georgia agreement includes several additional addendums, attachments, and appendices that are good examples of additional support each implementing agency should consider prior to implementation such as Business Associate Agreement templates, a roster/list for completion of individuals permitted to receive, use and disclose any PHI contained in the data, data-use related policies and procedures, and Technology User Agreement templates.
- **[Louisiana DUA example \(Appendix 2\)](#).** This is an inter-agency agreement between four agencies and includes clauses for data custody, confidentiality, justification for access for each agency, benefits of use for each agency, and methods of access.



**CONTACT:** If your state is interested in learning more about the Medicaid's IAP BCN Program, email [MedicaidIAP@cms.hhs.gov](mailto:MedicaidIAP@cms.hhs.gov). Additional information on the IAP BCN program, including materials from national webinars, is available on the [Medicaid IAP BCN webpage](#).