Linking Health and Human Services Data Can Empower Patient Decisions and Increase Efficiency

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This brief describes how enhancing linked data infrastructure across health and human services programs can improve efficiency, increase transparency through strengthening outcomes research, and empower patients and families to make more informed choices.

KEY POINTS

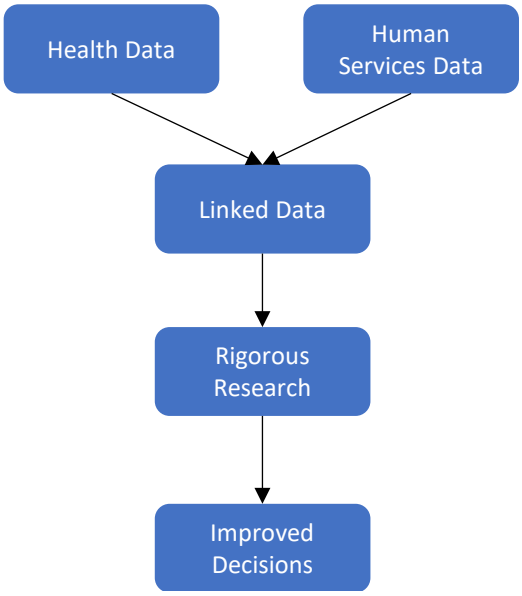
- Many families are involved in numerous health and human services programs, with data systems that do not always communicate effectively. This presents risks for duplication and overpayment, and makes it harder to know how participating in human services programs impacts health and well-being
- Linking data across health and human services programs can improve program efficiency, oversight of spending and services, and outcomes monitoring. For example, better data can address barriers faced by children in foster care with higher incidence of chronic disease and impediments to their well-being.
- Linking administrative records across health and human services programs can also lead to more rigorous research to better inform patients and families decision making.
- Human services agencies face barriers to linking data, but these barriers are surmountable. Ongoing efforts at the federal and state level have found success and offer lessons for future efforts.

INTRODUCTION

It is important for health and human services agencies to improve families' ability to take control of decisions related to their health and well-being and provide options based in rigorous outcomes research. Executive Order 14212 (Establishing the President's Make America Healthy Again Commission) recognizes the importance of research in supporting patients' ability to choose their best options, stating "all federally funded health research should empower Americans through transparency and open-source data…research funded by the Federal Government should prioritize gold-standard research on the root causes of why Americans are getting sick." One important tool to support this decision-making is improved data systems to provide rigorous and transparent data analysis and findings which can give patients and families get the information they need to choose what is best for them. Linked data can also reduce costs of programs, by increasing program integrity and by support more cost-effective decisions about services.

This brief discusses the value of linking administrative data across health and human services agencies, as well as some of the barriers to and opportunities from that linking. The federal government already collects a vast amount of data from agencies and offices as part of standard program operations. Utilizing these data increases government efficiency and empowers Americans to make their own choices based on transparent, open-source data. Figure 1 outlines the way that linking data across health and human services systems can lead to better choices for families and patients, first by supporting rigorous research and then from the results of that research, facilitating improved decisions that can be tailored to the needs of individuals.

Figure 1. Pathway for Linked Data to Empower Family Decision-Making Among Program Leaders, Providers, and Patients



Many families are involved in numerous health and human services programs—an estimated one in three children—each intended to meet needs in specific ways (Macartney and Ghertner 2023). Just as these programs often operate in silos, their data systems do not always communicate effectively. Among other complications, this presents risks for duplication and inefficiencies as well as a barrier to identifying how participating in human services programs impacts health and well-being. Too many families face complex choices about program participation without complete information about how it may impact their lives. Expanding linkages among traditionally siloed health and human services data sources, such as data related to nutritional assistance and health care claims data, facilitates research into understanding outcomes associated with health conditions while efficiently leveraging data that have already been collected. Without knowledge of how those choices interact with other indicators of health and well-being, patients and families cannot be empowered to make appropriate decisions.

LINKED DATA CAN IMPROVE PROGRAM EFFICIENCY

Linked data facilitate the federal government's decision-making by improving the delivery and oversight of services that involve participants in multiple agencies' programs, improving agencies' ability to monitor program spending and reduce costs by eliminating duplicated services or billing. Linked data allows more effective use of data already being collected by government agencies to determine if policies are having the intended or desired impact, while also allowing decision makers to properly address or eliminate programs and activities that are fragmented, overlapping, or duplicative. These data resources enable policy makers to identify patterns and insights that can optimize spending and achieve cost reductions.

Increasing government efficiency is dependent on having reliable information about what policies accomplish. By knowing if programs and policies are meeting identified needs, public officials can make smarter choices about how to allocate limited resources. Human services address key factors affecting health outcomes – for example, nutrition assistance can reduce food insecurity, which is tied to chronic disease (Weaver and Fasel, 2018; Seligman et al., 2010). Linked data between these systems can facilitate research to identify how realigning investments from one program area to another may reduce overall costs while increasing health and well-being.

Linked data also improves program efficiency by serving an important role in preventing fraud, waste, and abuse, such as preventing duplicate billing and enabling more aggressive program integrity efforts.. For

example, people involved in child welfare systems can receive behavioral health services paid for by both Medicaid and title IV-E foster care prevention services. Providers could inadvertently, or as bad actors, bill the same services to both systems for reimbursement. ASPE is currently working directly with Wyoming to enable the state to use linked data to eliminate duplicate billing by facility and community providers. Additionally, the state will be able to better identify costs from providers of similar services and identify fee schedule variance. By providing new levels of transparency around provider billing, these efforts are expected to result in meaningful cost savings for the state child welfare and Medicaid agency.

LINKED ADMINISTRATIVE DATA CAN FACILITATE RIGOROUS, HIGH-QUALITY RESEARCH, EMPOWERING AMERICANS WITH MORE INFORMATION AROUND HOW HEALTH CONDITIONS AND TREATMENT OPTIONS IMPACT THEIR LIVES

Administrative data typically contain the universe of all occurrences or individual recipients, rather than a sample, and these data can be more accurate and less biased than other sources because they are not self-reported, such as data from a survey (Bound et al. 2001). Linking multiple administrative datasets can promote high-quality, transparent research. In particular, linked data can be used in gold standard research using experimental designs. For example, researchers have used health claims data in a randomized control trial to study an intervention of how personalized prescription feedback can lower antibiotic prescription rates (Hemkens et al. 2017). ASPE's project, Child and Caregiver Outcomes Using Linked Data, is an example bridging health and human services systems (see sidebar). This project provided technical assistance to states to link child welfare records and Medicaid claims, bringing together information about child maltreatment and foster care with health diagnoses and services. These data have been used to uncover previously unknown relationships that can directly improve services, for example, the prevalence of untreated psychiatric and substance use disorders among caregivers with children in child welfare systems (Mark et al. 2024).

Child and Caregiver Outcomes Using Linked Data (CCOULD)

CCOULD provided technical assistance to two states – Florida and Kentucky – in linking the Medicaid claims of children and their caregivers with case-level data from child welfare systems. It combined state-specific datasets into a single, multi-state, deidentified dataset for data analysis. The data are currently publicly-available at no cost through the National Archive of Child Abuse and Neglect. Among other topics, researchers are currently using the CCOULD dataset to understand:

- Health Complexity, Utilization, and Cost and Initial Entry to Foster Care
- Building Bridges of Care: Opportunities for Supporting Families with Substance Use Disorder Involved in the Child Welfare System
- Service Trajectories of Children Entering Initial Residential Placement

Research results from linked data can be informative for patients and families. As an example, ASPE is facilitating data linking efforts in Iowa across child welfare and health systems. Iowa plans to use newly linked data to conduct analyses designed to ensure that psychotropic drugs are prescribed for children in foster care in an appropriate manner. Specifically, this data will aid the Medicaid and child welfare agencies in determining the volume at which such drugs are prescribed to children by age and other characteristics, the rate at which children in foster care are prescribed psychotropic drugs, and the number and rate of such children who have been prescribed multiple psychotropics. This information will not only encourage state agencies to identify and address facilities that have concerning prescription practices, but it can also be used so that families, caseworkers, and communities understand consequences of foster care and congregate care placement, and potentially direct community resources better and more efficiently.

HUMAN SERVICES AGENCIES FACE BARRIERS TO LINKING DATA, BUT THESE BARRIERS ARE SURMOUNTABLE

Despite the opportunities of linked administrative data, human services programs face substantial barriers to sustainable linked data infrastructure. Based on projects conducted by ASPE as well as others, some of the top barriers are:

Navigating data governance and complex privacy and data security rules

The institutional structures of agencies—including data ownership, location of agencies in the government organizational system, and historical relationships between agencies—influence the ability to establish agreements for linking data. These structures can be complex and are not uniform, even within the same agency. Organizations and agencies participating in data linking efforts may not have the capacity to navigate the complex process of successfully establishing data-sharing agreements and maintaining data-sharing partnerships necessary for linking data across different agencies. Navigating these relationships and interagency partnerships is foundational for the success of data linking projects. Project teams need to understand these structures and develop strategies to proactively break down agency silos and facilitate collaboration and communication across offices that might not have established processes for doing so.

Data quality and documentation issues

The success of linkage hinges on the quality of the linking variables. Administrative data systems often have poor documentation about variables, missing data, frequency of collection, and other important features. Typically, variables that are used for program operations are of high quality—such as those used for billing, program oversight, and specific decisions about participants—others that are less critical for operations may be of poor quality. Changes in data collection procedures, such as when programs make substantial changes or new data policies are put in place, are not always well-documented. As a consequence, analysis of linked data requires efforts to identify and plan for issues and gaps in data quality and documentation.

Limited and outdated IT systems

One primary challenge agencies face is the lack of IT infrastructure and human capital to perform data-linking work in a continuous or repeatable way. Many agencies work with legacy technology not intended to facilitate linking and must find modern technological solutions to meet privacy and security needs while also providing necessary capabilities. Data often reside in fragmented systems that exist at the point of collection—such as with a contracted service provider—rather than a single, centralized system. These individual systems do not always communicate with one another.

These and other barriers can be overcome with sustained, concerted effort through strategic partnerships. ASPE work has documented successful strategies, such as maintaining high quality documentation of data systems, ensure linking projects add value to various stakeholders involved, leveraging existing technical assistance resources for different aspects of projects, such as establishing data use agreements and identifying algorithms to conduct linkages. A number of federal data linking efforts have been funded by the Patient-Centered Outcomes Research Trust Fund (reauthorized by Further Consolidated Appropriations Act, 2020, P.L. 116-94), and states have spearheaded their own linking projects. For example, Washington state created the Integrated Client Database that brings together datasets from 10 different agencies to enable cost-benefit and cost-saving analyses, program evaluations, operational decision-making, and in-depth research. Indiana's initiative created the Management Performance Hub,

which initially focused on addressing the state's high infant mortality rate. The state linked 17 different datasets which allowed staff to better understand and map mortality rates and identify high risk populations. The success of this system was used to improve transportation safety, optimize Medicaid, and use naloxone treatment.

Among many strategies these efforts have in common, they all required strong collaboration and buy-in from all relevant agencies involved. In CCOULD, for example, state Medicaid and child welfare agencies, a university partner, and HHS offices, jointly recognized the value of the linked data and collaborated to navigate governance rules, identify IT solutions, provide staff support, and quickly address challenges as they arose. Another key piece is identifying beforehand the various legal, regulatory, and policy rules governing use and access to data. Each dataset has a unique governance framework, and mapping out how these frameworks align permit not only linking but access to the data by researchers and the general public, which is critical to success.

DISCUSSION

Agencies have typically focused on benefits to programs of linking administrative data across health and human services systems. These benefits include improved ability to conduct monitoring and oversight of services and spending, improved program integrity, and better policy and programmatic decision-making. Using linked administrative data can also be cost effective, as it leverages already existing data and avoids new costly data collections. In addition families and patients can directly apply findings to inform their decisions. Linked data contribute to more rigorous scientific research, which if disseminated in a transparent way to the public, can provide information to support decisions, as outlined in this brief.

Federal, state, and local agencies face barriers to linking human services data to health data. At times, these barriers can appear insurmountable—they are deeply entrenched in the siloes that programs operate within. However, numerous examples now exist of successful data linking projects, some at the federal level and some at the state level. As technology improves—including through greater adoption of artificial intelligence—and as data stakeholders see benefits and savings clearly demonstrated, it will become increasingly possible to successfully execute linked data projects. By improving the transparency of program spending and research and increasing patient choice, linked human services and health data can be a critical step towards health and well-being of Americans.

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SUGGESTED CITATION

Dost, Meredith, Robin Ghertner, and Emily Madden. "Linking Health and Human Services Data Can Help Empower Patient Decisions." Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, March 2025.

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