Multistate EMS and Medicaid Dataset (MEMD): A Linked Dataset for Patient-Centered Outcomes Research FINAL REPORT

The U.S. Department of Health and Human Services (HHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE) led the *Multistate EMS and Medicaid Dataset (MEMD): A Linked Dataset for Patient-Centered Outcomes Research* project which received funding in 2021 by the Office of the Secretary of HHS's Patient-Centered Outcomes Research Trust Fund. This final report includes background information about the project's focus area, an overview of the progress made on the project, and a discussion of several challenges the project team faced.

Background

Emergency medical services (EMS) are a major component of the acute care system and serve as the nation's safety net for people experiencing medical emergencies. The importance of EMS was greatly elevated during the COVID-19 pandemic, as EMS providers continued to serve millions of individuals regardless of their location and condition. EMS delivery was profoundly impacted by the pandemic, as efforts to reduce overcrowding in hospitals and minimize the risk of COVID-19 transmission led EMS personnel to deliver more care to individuals at the site of their emergency without transportation, as well as transporting patients to alternative destinations (e.g., hospital staging areas). Meanwhile, patients often delayed seeking medical care due to COVID-19 concerns, which resulted in higher rates of acute medical emergencies and therefore greater use of advanced EMS services.

Despite the major role of EMS in our healthcare system, few data sources enable research on the health outcomes of patients who engage with EMS. Many EMS agencies (especially in rural areas) rely on voluntary staffing and may not bill insurance for their services. Also, many EMS agencies receive funding directly from State and local governments, and therefore do not bill patient insurance. Thus, health insurance claims data generally exclude some EMS encounters. Additionally, many State Medicaid programs have historically limited reimbursement for EMS to situations where a patient is transported to a high acuity setting (e.g., emergency department), even though a substantial number of patients are not transported to these facilities.

In the absence of a robust data infrastructure to support research on the outcomes of patients after their EMS encounter, there is limited ability to assess healthcare services delivered by EMS providers and the policies that affect service provision. For instance, coverage policies that only reimburse EMS care that results in a transport of patients to high-acuity settings can result in unnecessary and inappropriate healthcare use, as many patients who receive EMS care are not experiencing conditions that require a hospital level of care. In these cases, patients may experience equivalent or superior care by receiving treatment in place or transportation to an alternative care setting (e.g., urgent care center, primary care office, behavioral health clinic).

The MEMD Project

The need for data infrastructure regarding the outcomes of EMS patients became apparent during the COVID-19 pandemic. During this time, EMS clinicians treated patients in place and/or transported the patients to alternative destinations at a greater rate than pre-pandemic, and some states waived transportation-related EMS coverage restrictions in Medicaid. ASPE believed that gaining insight into the outcomes of these patients would be helpful for states considering changes to their coverage policies and for EMS agencies to conduct modifications to clinical protocols.

To generate evidence, ASPE proposed the MEMD project, the creation of a publicly available dataset which links EMS electronic patient care reports (ePCRs) and Medicaid claims data from up to five states for the calendar years 2018 to 2020. Linking these datasets would enable longitudinal research to be conducted on the effectiveness of EMS clinical interventions and the outcomes of Medicaid beneficiaries who receive treatment in place and/or transportation to alternative care settings. MEMD was intended to satisfy unmet needs for a variety of end users, including:

- Federal and external emergency care and health services researchers, who have lacked data infrastructure to conduct patient-centered outcomes research on Medicaid beneficiaries who receive EMS care;
- Federal, State, and local policymakers, who lacked evidence on the outcomes of Medicaid beneficiaries who receive EMS care to inform coverage policies and scope of practice laws for EMS; and
- EMS agencies and clinicians who can use findings from research enabled by MEMD to inform clinical protocols and enhance patient care thereby improving patient outcomes.

ASPE partnered with the National Highway Traffic Safety Administration (NHTSA) on the MEMD project and incorporated the project activities into NHTSA's existing contract with the National EMS Information System Technical Assistance Center (NEMSIS TAC) at the University of Utah. The process to develop an Interagency Agreement with NHTSA and award funds to the NEMSIS TAC took several months to complete, which pushed the project start date to mid-2021.

After being awarded the funds, the NEMSIS TAC and the subcontractor Mathematica began the project by assessing the quality of states' Medicaid claims and ePCR data. Through this assessment, eleven states were identified whose data quality was sufficient for a probabilistic linkage. For each candidate State, the NEMSIS TAC contacted the respective state's Medicaid and EMS offices to solicit interest in participating in the project. When possible, the NEMSIS TAC leveraged existing connections with each state's EMS office and relied primarily on subcontractor connections in conjunction with internet searches to find contacts at State Medicaid agencies.

Initial conversations the project team conducted with State officials identified there was general interest in the focus of the project, but most were unable to commit to participation due to a variety of reasons (see *Challenges* section below for details) which resulted in what the project team believing that there were three states that would participate in this project. The process to secure data sharing agreements with states was originally projected to require 48 weeks with an anticipated completion date of July 11,

2022. However, states were slow to agree and process requests for project review and approval. In July of 2022, the project was reorganized to focus primarily on state approvals and a one-year no cost extension was requested and approved.

The project was discontinued in spring 2024 due to issues related to funding and challenges extending an interagency agreement between ASPE and NHTSA, which lapsed in September 2023. The NHTSA OEMS and ASPE determined the IAA could not be extended, and there was no other available avenue to have the project continue. The extended length of time needed to work with states facilitating data sharing agreements and data transfers resulted in all funds from the project being utilized.

State Participation

State by State breakdown

Among the eleven states initially selected for participation, only two states progressed to the point that the NEMSIS TAC personnel were approved to request data through a State Institutional Review Board process:

The State of Utah is viewed as a success insofar as both the Emergency Medical Services and the Medicaid departments within the State agreed to participate and assisted with the Institutional Review Board (IRB) process. EMS data were made available to NEMSIS TAC personnel within weeks of IRB approval. The process of obtaining the Medicaid data took several additional months.

Within the State of Washington, after many months, both the State EMS and Medicaid entities agreed to participate. While there was a single IRB process to obtain the data from both entities, coordination between the groups and support of the project proved difficult. Unfortunately, once the NEMSIS TAC successfully obtained the IRB approval and reached the stage to request data, funding (with an approved no cost extension) for the MEMD project expired.

Because only two of the initial eleven showed promise, The NEMSIS TAC and the subcontractor Mathematica identified a "next tier" of states based on "moderately sufficient" data availability and quality. In an effort to increase participation, an additional five states were assessed and contacted. The State of Kentucky was the sole State expressing an interest in participating during this solicitation. However, the State of Kentucky was unable to garner the necessary support among the EMS and Medicaid entities to receive approval to move to the IRB stage, as it was in the was process of restructuring how Medicaid data were housed and stored, and navigating the legal considerations involved in data sharing.

In general, State EMS offices had the ability and were eager to provide data via a secure file transfer protocol (SFTP) for the project. The Medicaid departments of each State expressed hesitation and are the primary source of the challenges to the MEMD project's success. However, as will be cited in the challenges section, a different approach may have improved access to Medicaid data.

Challenges

State selection for participation

Mathematica assessed the quality of the Medicaid data collected and the NEMSIS TAC assessed the quality of the EMS data collected. In total, sixteen states were identified based on the parameters established within the project plan. The parameters the NEMSIS TAC used to determine the quality of data collected were, by design, stringent and restrictive. This approach was taken due to the known issues associated with probabilistic linkage among divergent datasets. To maximize the potential success of a probabilistic linkage project, accurate and consistent data sets are a requirement. Nevertheless, data quality was the primary reason many states were not considered for participation. Selecting a larger pool of states initially may have resulted in more states being willing to approve and participate in the study, however, the potential success of the probabilistic linkage step in the project would have been diminished.

Barriers to State participation

Despite identifying sixteen candidate states, the project team was only able to obtain informal commitments from three states to participate in the MEMD project. For many states, after initial conversations, representatives cited State laws, statutes, or regulations that prohibited them from sharing data elements needed to conduct the required probabilistic linkage (e.g., personally identifiable information). Additionally, other states, particularly state Medicaid agencies, expressed added reasons that limited participation within the MEMD project. Several State Medicaid representatives expressed that they had inadequate staff capacity to compile and submit the data to the NEMSIS TAC for inclusion in MEMD, particularly due to the unravelling of the continuous enrollment requirement for Medicaid that was instituted during the COVID-19 pandemic. Similarly, these states reported being overwhelmed by the volume of work to reassess beneficiaries' Medicaid eligibility. States also indicated limited staff capacity, hampered by revised federal requirements that necessitated more frequent data audits. There were also mentions of competing priorities among State leadership as reasons to not participate. A few State Medicaid agencies also expressed confusion about whether federal rules permitted them to share Medicaid data with the project team, indicating that they wanted explicit approval from the Centers for Medicare & Medicaid Services (CMS) before agreeing to participate.

While the challenges states reported were at least partially attributable to challenges associated with the COVID-19 pandemic, the project team reflected on whether taking a different approach to engaging State Medicaid offices would have yielded more success. The project team connected primarily with State "data groups" or "data offices" that were staffed by personnel who lacked the necessary authority to agree to participate, and who, in many cases, very forthcoming that they were unable to participate due to a lack of capacity or competing priorities. The project team might have been more successful in recruiting states if they had initially engaged officials with roles that are better positioned to see the value of participating in MEMD. Those officials may have been able to act upon the findings of MEMD analyses and, most importantly, with the authority to set or manage State priorities, eliminate lack of capacity, drive priorities, or commit to the project's purpose. For example, in each of the partially successful examples above (UT, WA, KY), the State Medicaid agency's Medical Director helped champion the project within their agency.

Difficult processes for securing formal agreements

Among the three states with expressed interest in participating in the project (UT, WA, and KY), the process by which the subcontractor secured formal agreements was very difficult. The steps in the process varied in each State and often differed between the Medicaid and EMS entities. For example, in the State of Utah, the review and approval of the project by the State IRB was completed within three months, whereas in the State of Washington, over three months were required to schedule an initial meeting with a State official who was in a position to submit the project to an IRB on the project team's behalf.

There were several communication disruptions across states, leading to many month-long delays before progress could be made. In a few cases, staff turnover posed challenges, often one State official would begin working on the review of the project, only to have a successor restart the process. State officials were not always certain about their respective state's internal process to secure the agreements, which led to internal confusion within State agencies. This delay was compounded by the fact that within some State governments, Medicaid and EMS entities were housed in different departments that rarely, if ever, communicate.

Another approach to data collection undertaken by Mathematica was to obtain Medicaid data from the Transformed Medicaid Statistical Information System (T-MSIS), a federally standardized dataset compiled from State submissions containing various data types, including service utilization and costs. The ASPE had initially considered this as an option when developing the project proposal, but it was unclear whether the project team would be able to re-publish T-MSIS data for public use or, alternatively, whether CMS would be able to host MEMD. Additionally, the cost of acquiring T-MSIS data would have required a larger budget. If these impediments were overcome, the project team could have had easier access to Medicaid data through T-MSIS and, perhaps, the project would likely have initiated quickly and more smoothly.

Conclusion

The MEMD project received positive feedback from State officials and stakeholders for its potential to enable research on the outcomes of Medicaid beneficiaries who engage with EMS. Despite the project's discontinuation, a linkage of Medicaid and EMS data would provide helpful insights and be valuable to researchers, policymakers, and State officials. Future efforts should consider ways to streamline the acquisition of data, promote a mechanism to share data at a national level, including better means of recruiting and securing agreements with states, or leveraging other datasets.