Recent Comments from MHDO Data Users

"My experience working within the MHDO data structure has been a wholly positive experience. The Enclave system presents itself to a Data Analyst as a professional and secure workspace that allows me to focus on producing outcomes and removes some of the burden around understanding a new systems intricacies and architecture. The system has been laid out in a thoughtful manner and meets or exceeds industry standards/expectations in many capacities."

"The biggest value of the MHDO APCD comes with the ability to Benchmark. Without statewide data, it is difficult to know if the population you serve is unique or is similar to the broader population. This is particularly helpful when dealing with relatively small numbers. It is valuable to have a larger dataset to leverage."

"I think 2018 will bring great things for the MHDO and the APCD."

"The quality of the MHDO hospital data is the best it has ever been."

"MHDO’s APCD data is the only statewide data set that integrates medical claims and pharmacy claims data which opens up the possibility for various analysis. For example, understanding the patterns associated with prescribing antibiotics which may help inform future programs specific to Antimicrobial stewardship."

MHDO Board Retreat-June 7, 2018
MAINE HEALTH DATA ORGANIZATION
Board of Directors Retreat
June 7, 2018
9:00am-2:00pm
Meeting Location: FAME Board Room
5 Community Drive, Augusta

AGENDA

9:00 Board Retreat Opening
- Welcome – Meeting goals and introduce Craig - Neil Korsen, Board Chair
- About the Meeting - Agenda and ground rules - Craig Freshley, Facilitator
- Warm-up exercise - Craig

9:25 MHDO Baseline
Overview of MHDO, its statutory authority and new Legislation - Karynlee Harrington & Deanna White

9:50 National Landscape
Overview of activity at the National level- Karynlee

10:20 Break

10:30 MHDO Data Delivery Model
- Overview on the status of the MHDO data delivery model – Karynlee
- Board Reaction

11:15 CompareMaine
Level Set – Karynlee

12:00 Lunch

12:30 CompareMaine
- The future of CompareMaine - Karynlee
- Board Reaction

1:30 Key Work Items for Next 12-18 Months
A look ahead at MHDO's key deliverables - Karynlee

1:40 Closing Comments
Board Members

1:45 Public Comments

2:00 Adjourn Board Retreat and Begin MHDO Board Meeting
Content

1. MHDO Baseline
2. National Landscape
3. MHDO's Data Delivery Model Strategy
4. CompareMaine & 8712 Reporting Requirements
5. Key Work Items for Next 12-18 Months
MHDO Purpose – Title 22 Chapter 1683

The purposes of the organization are to create and maintain a useful, objective, reliable and comprehensive health information database that is used to improve the health of Maine citizens and to issue reports, as provided in section 8712.
§8712. Reports

The organization shall produce clearly labeled and easy-to-understand reports as follows. Unless otherwise specified, the organization shall distribute the reports on a publicly accessible site on the Internet or via mail or e-mail, through the creation of a list of interested parties. The organization shall make reports available to members of the public upon request. [2009, c. 613, §8 (AMD).]

1. Quality. The organization shall promote public transparency of the quality and cost of health care in the State in conjunction with the Maine Quality Forum established in Title 24-A, section 6951 and shall collect, synthesize and publish information and reports on an annual basis that are easily understandable by the average consumer and in a format that allows the user to compare the information listed in this section to the extent practicable. The organization’s publicly accessible websites and reports must, to the extent practicable, coordinate, link and compare information regarding health care services, their outcomes, the effectiveness of those services, the quality of those services by health care facility and by individual practitioner and the location of those services. The organization’s health care costs website must provide a link in a publicly accessible format to provider-specific information regarding quality of services required to be reported to the Maine Quality Forum.

[ RR 2009, c. 2, §63 (COR).]

2. Payments. The organization shall create a publicly accessible interactive website that presents reports related to payments for services rendered by health care facilities and practitioners to residents of the State. The services presented must include, but not be limited to, imaging, preventative health, radiology, surgical services, comparable health care services as defined in Title 24-A, section 4318-A, subsection 1, paragraph A and other services that are predominantly elective and may be provided to a large number of patients who do not have health insurance or are underinsured. The website must also be constructed to display prices paid by individual commercial health insurance companies, third-party administrators and, unless prohibited by federal law, governmental payors. Beginning October 1, 2012, price information posted on the website must be posted semiannually, must display the date of posting and, when posted, must be current to within 12 months of the date of submission of the information. Payment reports and price information posted on the website must include data submitted by payors with regard to all health care facilities and practitioners that provide comparable health care services as defined in Title 24-A, section 4318-A, subsection 1, paragraph A or services for which the organization reports data pertaining to the statewide average price pursuant to this subsection or Title 24-A, section 4318-B. Upon notice made by a health care facility
or practitioner that data posted by the organization pertaining to that facility or practitioner is inaccurate or incomplete, the organization shall remedy the inaccurate or incomplete data within the earlier of 30 days of receipt of the notice and the next semiannual posting date.

A. [2009, c. 613, §8 (RP).]

[ 2017, c. 232, §2 (AMD) .]

3. Comparison report. At a minimum, the organization shall develop and produce an annual report that compares the 15 most common diagnosis-related groups and the 15 most common outpatient procedures for all hospitals in the State and the 15 most common procedures for nonhospital health care facilities in the State to similar data for medical care rendered in other states, when such data are available.

[ 2003, c. 469, Pt. C, §29 (NEW) .]

4. Physician services. The organization shall provide an annual report of the 10 services and procedures most often provided by osteopathic and allopathic physicians in the private office setting in this State. The organization shall distribute this report to all physician practices in the State. The first report must be produced by July 1, 2004.

[ 2003, c. 469, Pt. C, §29 (NEW) .]

5. Prescription drug information. By December 1, 2018 and annually thereafter, the organization shall provide a report containing the following information about prescription drugs, both brand name and generic:

A. The 25 most frequently prescribed drugs in the State;

B. The 25 costliest drugs as determined by the total amount spent on those drugs in the State; and

C. The 25 drugs with the highest year-over-year cost increases as determined by the total amount spent on those drugs in the State.

Sec. 2. Further data collection by Maine Health Data Organization. The Maine Health Data Organization shall develop a plan to collect data from manufacturers related to the cost and pricing of prescription drugs in order to provide transparency in and accountability for prescription drug pricing. The organization shall consult with other state and national agencies and organizations to determine how to institute such data collection. The organization shall submit the plan, its findings and any recommendations for suggested legislation to the First Regular Session of the 129th Legislature no later than April 1, 2019. The joint standing committee of the Legislature having jurisdiction over judiciary matters may report out legislation related to prescription drug price transparency and the organization’s findings and recommendations to the First or Second Regular Session of the 129th Legislature.
Sec. 3. Appropriations and allocations. The following appropriations and allocations are made.

HEALTH DATA ORGANIZATION, MAINE

Maine Health Data Organization 0848

Initiative: Provides a one-time allocation to the Maine Health Data Organization to collect and present certain data to the Legislature and to develop a plan for further data collection.

<table>
<thead>
<tr>
<th>OTHER SPECIAL REVENUE FUNDS</th>
<th>2017-18</th>
<th>2018-19</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Other</td>
<td>$0</td>
<td>$25,000</td>
</tr>
</tbody>
</table>

OTHER SPECIAL REVENUE FUNDS TOTAL $0 $25,000

Effective 90 days following adjournment of the 128th Legislature, Second Regular Session, unless otherwise indicated.

[ 2018, c. 406, §1 (NEW.)]

SECTION HISTORY
MHDO’s Priorities

- Manage a high-quality, comprehensive health information data warehouse
- Promote the release of healthcare data and information
- Promote the transparency of healthcare cost and quality information
- Support ongoing stakeholder engagement with our data providers, data users and consumers
- Support a culture of change based on our stakeholders’ needs

Note: Priorities Established by MHDO Board at June 2016 Retreat
Continued-Baseline

Legislative Authorization to Spend Approx. $2.0 Million / Year

- Annual assessment generates approximately $1.5 Million
- $150,000 - $300,000 collected in fees associated with data access and analysis
- MOU between MQF & MHDO governs $300,000 transfers from MQF to help support CM
- In FY19 (July 1, 2018-June 30, 2019) MHDO will receive $25,000 from general fund/LD 1406
- Largest expense is contract with Human Services Research Institute (HSRI)/NORC
  - $1 million/year
  - 10 year contract based on competitive procurement process
  - November 30, 2022 contract with HSRI/NORC expires
  - MHDO is beginning to prepare for next competitive procurement process
  - Anticipate releasing RFP in fall of 2021
Continued-Baseline

**MHDO Data Sets Available for Release (over 1 billion healthcare records)**
- All Payer Claims Data (includes commercial & public payers)
- Maine Hospital Inpatient and Outpatient Encounter Data
- Hospital Physician Practice Data (primary and specialty care)
- Maine Hospital Quality Data
- Maine Hospital Financial Data
- Hospital Restructuring Data (currently collection of data is suspended based on action of board)

**Responsible for 10 different Agency Rules-primarily govern the collection of data, the release of data and data access fees.**
Continued-Baseline

Legislative Committee of Oversight: Committee of Health and Human Services

Other Legislative Committees with an interest in MHDO include: Insurance and Financial Services and Judiciary
Continued-Baseline

Legislative Reports MHDO Data Supports:

- Workers Comp: Title 39-A, section 209-A(3)(5)
- An Act To Prevent Opiate Abuse by Strengthening the Controlled Substances Prescription Monitoring Program - PL 488 Sec. 38
- Title 22 Chapter 1683, 8712, Reports (promoting the transparency of healthcare costs and quality)
- Maine Guaranteed Access Reinsurance Association Program - Title 24-A, Chapter 54-A
Continued-Baseline

The primary external use of the MHDO data as defined in Rule Chapter 120 is to produce meaningful analysis in pursuit of improved health and health care quality for Maine people.

Acceptable uses of MHDO data defined in Rule Ch.120 include, but are not limited to, study of health care costs, utilization, and outcomes; benchmarking; quality analysis; longitudinal research; other research; and administrative or planning purposes.
Continued-Baseline

Data Users and Partners Include:

- Private Sector; Government; Non-Profits; Hospitals; Payers; Universities

- MHDO data requests are posted on MHDO website for 30 day public comment (https://mhdo.maine.gov/datarequest.aspx)

- MHDO is a partner (47 States are partners) with the Healthcare Cost and Utilization Project (HCUP)-HCUP is a family of health care databases, software tools and reports developed through a Federal-State-Industry partnership and sponsored by the Agency for Healthcare Research and Quality (AHRQ)

- HCUP includes the largest collection of hospital encounter data in the United States
The Healthcare Cost and Utilization Project
Fact Sheet

What is the Healthcare Cost and Utilization Project (HCUP)?

HCUP is a family of health care databases, software tools, supplemental files, reports, and other related products developed through a Federal-State-Industry partnership and sponsored by the Agency for Healthcare Research and Quality (AHRQ). The project builds on the data collection efforts of State data organizations, hospital associations, and private data organizations (known as "HCUP Partners"). Without HCUP Partners' voluntary data contributions, this national resource supporting health services research and policy would not be possible.

Why is HCUP important?

HCUP includes the largest collection of all-payer, encounter-level hospital care data in the United States. HCUP provides reliable, comprehensive information that can be used to answer questions about health care use, access, outcomes, and costs related to hospital inpatient stays, ambulatory surgery and services, emergency department visits, and readmissions. HCUP databases, software tools, and reports enable research on a broad range of current health care issues and trends that are useful to policymakers, researchers, administrators, and consumers.

How are the HCUP databases developed?

HCUP Partners

- AHRQ transforms administrative health care data acquired from HCUP Partners into research-ready, uniform databases with a common set of data elements.
- Currently, 48 Partners (47 States and the District of Columbia) provide HCUP with statewide inpatient data, 35 Partners provide ambulatory surgery and services data, and 37 Partners provide emergency department data. The inpatient data represent 97 percent of inpatient discharges from community hospitals.

What databases are available from HCUP?

- The National (Nationwide) Inpatient Sample (NIS) is the largest publicly available all-payer inpatient database in the United States, yielding national estimates of hospital inpatient stays. The NIS approximates 20 percent of the discharges from all U.S. community hospitals and contains data from more than seven million hospital stays each year. Researchers and policymakers use the NIS to identify, track, and analyze national trends in health care utilization, access, charges, quality, and outcomes. The NIS is released yearly.
- The Kids' Inpatient Database (KID) is the largest publicly available, all-payer pediatric database in the United States, and was designed to facilitate study of hospital services, outcomes and charges for children and adolescents. It contains a sample of two to three million hospital pediatric discharges per year. The KID database is available every three years from 1997-2012. Because of the ICD-9-CM to ICD-10-CM/PCS coding transition during 2015, the 2015 KID was not produced. The 2016 KID will be the next data year, comprised of ICD-10-CM/PCS data only.
- The Nationwide Emergency Department Sample (NEDS) is a unique and powerful database that yields national estimates of emergency department (ED) visits. The NEDS database enables researchers to study a broad range of conditions and procedures related to ED use. It includes approximately 30 million records each year for patients who were either treated in the ED and released or treated in the ED and admitted to the same hospital. The NEDS is released yearly.
• The Nationwide Readmissions Database (NRD) supports analyses of repeat hospital visits in a year, addressing the need for nationally representative information on hospital readmissions for all ages and payers, including the uninsured. The NRD is released yearly.

• The State Inpatient Databases (SID) contain a powerful collection of hospital inpatient discharge information. The SID can be used to investigate questions that are unique to one State or to compare data from two or more States.

• The State Ambulatory Surgery and Services Databases (SASD) include encounter-level data for ambulatory surgery and other outpatient services from hospital-owned facilities. Some States provide data for ambulatory surgery and outpatient services from non-hospital-owned facilities.

• The State Emergency Department Databases (SEDD) contain discharge information on all ED visits that do not result in a hospital admission.

Additional information about these databases is available at www.hcup-us.ahrq.gov/databases.jsp.

How do researchers obtain HCUP databases?

Restricted-Access Public Release Nationwide Databases and Select State Databases (States permitted by HCUP Partners) may be purchased through the HCUP Central Distributor at www.hcup-us.ahrq.gov/tech_assist/centdist.jsp. The nationwide databases are delivered via secure digital download. The State-specific databases include data elements approved by each participating State while excluding data that might directly or indirectly identify a person. State-specific databases are delivered via hard copy media (DVD). All purchasers and users of HCUP data must complete a brief online Data Use Agreement (DUA) training course and sign a DUA.

What software tools and supplemental files are available from HCUP?

• Software Tools and Supplemental Files are developed and maintained by AHRQ to enhance the value of the HCUP databases. HCUP tools also can be used with HCUP data as well as with non-HCUP hospital administrative databases. HCUP tools include Clinical Classifications Software (CCS), the Chronic Condition Indicator (CCI), Elixhauser Comorbidity Software, Procedure Classes, Surgery Flags, and Utilization Flags. All tools are free of charge and available for download from the HCUP User Support (HCUP-US) Web site. HCUP also offers several supplemental files that are designed for use with and add value to HCUP databases, including the Revisit Analysis Variables, Cost-to-Charge Ratio Files (CCR Files), Hospital Market Structure Files (HMS Files), American Hospital Association (AHA) Linkage Files, NIS Hospital Ownership Files, and NIS and KID Trend Weight Files. Additional information is available at www.hcup-us.ahrq.gov/tools_software.jsp.

• HCUPnet is a free, online query system that uses HCUP data to provide quick access to statistical information about hospital inpatient and ED utilization. HCUPnet delivers statistics at the national level and, for States that have agreed to participate, at the State, region, and community levels. Users can generate tables and graphs with HCUPnet's easy-to-use, step-by-step query system. This interactive tool can be accessed at www.hcupnet.ahrq.gov.

• AHRQ Quality Indicators (QIs) are measures of health care quality associated with processes of care that occur in the inpatient setting. The AHRQ QIs consist of four modules measuring various aspects of quality: Prevention Quality Indicators (PQIs), Inpatient Quality Indicators (IQIs), Patient Safety Indicators (PSIs), and Pediatric Quality Indicators (PDIs). The QIs are analyzed with free software available from AHRQ that is designed to be used with HCUP and other administrative data. Additional information is available at www.qualityindicators.ahrq.gov.

• HCUP Fast Stats provides easy access to the latest HCUP-based statistics on health information topics. HCUP Fast Stats uses visual statistical displays in stand-alone graphs, trend figures, or simple tables to convey complex information at a glance. Information is updated quarterly or annually, as newer data become available. Additional information is available at www.hcup-us.ahrq.gov/faststats/landing.jsp.

What reports does HCUP produce?

• HCUP Statistical Briefs – short, focused reports with descriptive statistics on hospital use and cost topics
• HCUP Infographics – visual representations of Statistical Brief data
• HCUP Methods Series Reports – helpful reports addressing methodological issues for users of HCUP databases, tools, and supplemental files

Additional information is available at www.hcup-us.ahrq.gov/reports.jsp.

What support services are offered to HCUP users?

Technical Support is available to facilitate use of HCUP. The user-friendly HCUP-US Web site, www.hcup-us.ahrq.gov, contains extensive documentation about the project. Online FAQs answer many user questions. Self-directed HCUP online tutorials teach a range of HCUP use topics. HCUP presentations at professional conferences and HCUP training workshops educate users. User questions are responded to by experienced technical support staff by telephone at 866-290-HCUP and email at hcup@ahrq.gov. More information is available at www.hcup-us.ahrq.gov/techassist.jsp and www.hcup-us.ahrq.gov/news/events.jsp.
Continued-Baseline

Stakeholder Groups MHDO Supports:
Data User Group
Consumer Advisory Group
National Landscape

- Gobeille
- Common Data Layout (CDL)
- Bipartisan Request for Information-NAHDO's Response
- Agency for Healthcare Research and Quality (AHRQ) - APCD project
Impact of Gobelle v. Liberty Mutual Insurance Company and Voluntary Data Submissions

In 2016 the US Supreme Court held that the Employee Retirement Income Security Act (ERISA) invalidates state APCD reporting requirements for self-funded ERISA employee health plans.

- Depending on the cycle, self-funded ERISA claims data represents approximately 25-35% of APCD data.
- MHDO has maintained approximately **86-88%** of the volume of medical, pharmacy and eligibility records post Gobelle vs pre Gobelle (2015) data; primarily a result of the two largest self-funded ERISA employers directing their administrators to send their claims data to MHDO.
- No action to date from the US Department of Labor (DOL) regarding comments to proposed rule - The comments lay out a proposal that the DOL study the collection of additional health care claims and related data from self-funded ERISA plans under Schedule J through pilot programs in states with APCD capacities. To address administrative burdens, the states and payers have developed a Common Data Layout (CDL) that would replace the current state structures.
Continued-National Landscape

The National Association of Health Data Organizations (NAHDO) continues to raise awareness at the Federal level regarding the impact of both Gobeille and SAMHSA-Rule 42 CFR Part 2 on APCD’s and potential solutions.

March 2018, NAHDO responded to a bipartisan request for information about transparency in the health care market (copy of request and response included).

Note: Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (SAMHSA) -Rule 42 CFR Part 2 concerns the confidentiality of patient records that are maintained in connection with the performance of any federally assisted program or activity relating to substance abuse (now referred to as substance use disorder).
Dear Stakeholders:

We are launching a bipartisan effort to increase health care price and information transparency to empower patients, improve the quality of health care, and lower health care costs. To guide and inform this effort, we seek comments and further recommendations on the issue. Real world experience and evidence-based policies from health care stakeholders and experts will be important to craft a policy that most positively affects consumers and involves best practices from providers and states.

According to a survey from the Kaiser Family Foundation, Americans’ top health care priority is lowering costs. The United States spends almost twice as much on health care, as a percentage of its economy, as other industrialized countries. This is despite the fact that Americans usually use the same amount of health care as people do in other wealthy countries. We all agree that health care costs are too high and now is time to move towards a system that is more open, efficient, and accountable to the needs of the modern patient.

One policy area that is ripe for opportunity is greater price and information transparency. When asked more specifically about their concerns with health care, nearly two-thirds of Americans say it is too difficult to find out what medical care costs. In virtually every other industry, consumers are able to price shop, compare quality, and then decide what product best fits their needs. In health care, the lack of information and the inability to access it hurts patients and prevents normal market forces from driving competition, lowering prices, and improving quality.

Furthermore, the Catalyst for Payment Reform and the Health Care Incentives Improvement Initiative reviewed the strength and quality of every state’s health care price transparency laws and regulations and gave 43 states a failing grade. In one state, a report found that some consumers were spending thousands of dollars more on the same service received from different providers.

To best shape this effort, we are interested in your feedback on the following questions:

- What information is currently available to consumers on prices, out-of-pocket costs, and quality?
- What information is not currently available, but should be made available to empower consumers, reduce costs, increase quality, and improve the system?
- What role should the cash price play in greater price transparency? How should this be defined?
- Different states have used different methods to work towards price transparency:
  - Colorado - all providers publish paid amounts related to both in-patient and out-patient services.
- Kentucky - requires hospitals and ambulatory surgery centers to submit data on health care charges, quality, and outcomes that includes diagnosis-specific or procedure-specific comparisons.
- Virginia - performs an annual survey of carriers offering private group health insurance policies, to determine the reimbursement that is paid for a minimum of 25 most frequently reported health care services which may include inpatient and outpatient diagnostic services, surgical services or the treatment of certain conditions or diseases.
- Maryland - requires hospitals to provide and post the pricing information for the most common medical treatments in all hospitals, including the number of cases, the average charge per case and the average charge per day.

What are the pros and cons of these different state approaches? What is the best quality and price information to collect for consumers and businesses?

- Who should be responsible for providing pricing information and who should share the information with consumers?

- What role should all-payer claims databases play in increasing price and quality transparency? What barriers currently exist to utilizing these tools?

- How do we advance greater awareness and usage of quality information paired with appropriate pricing information?

- How do we ensure that in making information available we do not place unnecessary or additional burdens on health care stakeholders?

- What current regulatory barriers exist within the health care system that should be eliminated in order to make it less burdensome and more cost-efficient for stakeholders to provide high-quality care to patients?

- How can our health care system better utilize big data, including information from the Medicare, Medicaid, and other public health programs, to drive better quality outcomes at lower costs?

- What other common-sense policies should be considered in order to empower patients and lower health care costs?

We want to institute an iterative process that will incorporate feedback from a broad set of stakeholders. In addition to soliciting guidance and suggestions from stakeholders, we will host roundtable conversations with a variety of experts in the coming weeks and are also engaging the Administration, Members of Congress, and Governors. In order to ensure that your feedback is considered, we respectfully ask that you submit your comment letters to transparency@cassidy.senate.gov by March 23, 2017.
Thank you for taking the time to provide feedback on this important, bipartisan initiative. We look forward to reviewing your submissions.

Sincerely,

Bill Cassidy, M.D.  
Bill Cassidy, M.D.  
United States Senator

Chuck Grassley  
Chuck Grassley  
United States Senator

Todd Young  
Todd Young  
United States Senator

Michael F. Bennet  
Michael F. Bennet  
United States Senator

Tom Carper  
Tom Carper  
United States Senator

Claire McCaskill  
Claire McCaskill  
United States Senator

---

Continued-National Landscape

Report Title: Inventory and Prioritization of Measures to Support the Growing Effort in Transparency Using All-Payer Claims Databases (copy of report included)

Submitted to: Agency for Healthcare Research and Quality (AHRQ)

Prepared by: Stanford University (Prime Contractor); Truven Health Analytics; University of California, San Francisco and APCD Council

Purpose of the Report was to focus on three areas:

- Review of the overall landscape of APCDs
- Identification of measures of cost, utilization, and quality that can be defined using APCDs
- Evaluation of current APCD data for measurement use
Continued-National Landscape

Report Conclusions...a large number of measures are available for potential use with APCDs, covering a broad range of topics. Measures were grouped together to assess cost, quality, and utilization for specific topic areas for an assessment of population health management within or across diseases.

Although there are some limitations to both APCD data and the measures themselves, the measure inventory demonstrates that APCDs are potentially powerful tools for monitoring population health. They can be used to paint a more complete picture of health care delivery, across payers and across settings, in ways that have not previously been possible.

With continued development of both APCDs and measurement, stakeholders can look to use the APCDs to help fulfill the Triple Aim of better health, better quality, and lower costs.

With ongoing efforts, APCDs remain the most comprehensive source of data for monitoring population health and health care across the full system, assessing interventions aimed at improving population health, and assisting in assessing the value of health care.
Priorities of MHDO Data Delivery Model

Strategy

- Creating a clean raw data set for our approved data users that is closer to "analysis ready"
- Stakeholder Access to Data & Information
Data Cleansing (Scrubbing, Formatting) & Standardization

1. Data Cleansing: amending or editing codes in the database that are incorrect, incomplete, improperly formatted, or duplicated. Examples:
   a. “Codes” Data Fields
      ▪ Diagnose Codes DX1-DX4X (ICD-10)
      ▪ Procedure (CPT/HCPCS/ICD-CM) and Modifiers
      ▪ Drug Codes (NDC)
      ▪ Revenue Codes
      ▪ Provider Taxonomy Codes and Specialty Codes (NEEPS)
      ▪ Industry Classification codes (SIC)
   b. “Dates” Data Fields
      ▪ Service Dates (Claim & Claim Line level)
      ▪ Admission and Discharge Dates
      ▪ Prescription and Fill/Refill Dates

2. Data Standardization: harmonize data from different sources into standard formatting for Provider, Facility and Member geo data fields.
   ▪ Standardize Addresses USPS format
   ▪ Cities Standardization (Multiple Spellings)
   ▪ State Standardization (Multiple Spellings)
   ▪ Zip Codes Formatting and Correction
Basic Data Groupers

1. Diagnosis Grouper into Conditions and Diseases
   - Clinical Classification Software (CCS AHRQ)
   - Major Disease Categories (MDC)
2. Procedure Grouper into Procedure Categories and Subcategories:
   - BETOS from CMS,
   - Clinical Classification Software (CCS AHRQ)
3. NDC Grouper into Drug Classes:
   - FDA/NDC,
   - Therapeutical Class Grouper AHPS
4. Provider Code Grouper into Type, Specialties, Taxonomies
   - NPI database
   - NPEES taxonomy classification
5. Service Type Grouper (IP/OP/PROF categories)
6. Ancillary Enrichment (Zip-County-HSR-CBSB, Industry Codes SIC, etc.)
7. Inpatient Reimbursement (MS DRG / APR DRG – MDC)

Note: The software above are mostly open source or very cost effective options, industry standard lookups used by most researchers and private organizations to enrich the claims data; implementing this in MHDO data warehouse is an efficient and effective option, assuming the data cleaning phase is completed.
TBD: Apply Analytic Data Groupers

Episode of Care
Patient Risk Scores
Population Risk Stratification
Preventable and Population Health Grouping

Note: Most of the software packages for the analytic data groupers are proprietary and may incur significant cost and licensing considerations; implementation should be prioritized based on stakeholder and sustainability objectives.
Create Enhanced Data Releases

Examples:
Data Sets that are Cleansed and Pre-Joined
Summary Data Sets
# Access to MHDO Data & Information-Framework

<table>
<thead>
<tr>
<th>Public Facing Information</th>
<th>MHDO Produced Custom Reports</th>
<th>Self-Guided Access &amp; Reporting Services</th>
<th>Secure Remote Access to MHDO Data</th>
<th>Secure Access to MHDO Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Free information that is available on a MHDO website.</td>
<td>MHDO creates the query and static reports.</td>
<td>Access to rolled-up data in Tableau or other analytic tools.</td>
<td>Access to clean &amp; transformed data within the Enclave.</td>
<td>Access to clean and transformed data via secure download.</td>
</tr>
<tr>
<td>- CompareMaine</td>
<td>- Reports required per legislation</td>
<td>MHDO Data Users that are not equipped to work with the clean &amp; transformed data files but do have the capacity to work with a claims based analytic tool.</td>
<td>- Metadata</td>
<td>- Access to clean and transformed data via secure download</td>
</tr>
<tr>
<td>- Quality Measures/Chapter 270</td>
<td>- Reports requested by Stakeholders</td>
<td></td>
<td>- Statistical and Programming Applications</td>
<td>- Metadata</td>
</tr>
</tbody>
</table>
| - MONAHRQ | | | - National Code Sets | | Note: MHDO Metadata includes:
| - HCUP | | | - Access to data updates in real time | - Business Rules; Entity Relationship Diagrams (ERD); Data Dictionaries, Release Notes; Release Reports including sum of record counts by submitter; Validation Report by submitter |
| - 8712 Reports | | | - Secure computing environment | |
MHDO Delivery Model (slide from 2017 MHDO board retreat)

Pricing Framework:
- Subscription model that allows a customer to purchase a level of service in the Enclave for a specific period of time for a set price
- Maintain current pricing structure defined in Chapter 50 for accessing MHDO data as structured today with the exception of increasing our hourly rate of $80/hour to $150/hour
MHDO Delivery Model

NORC Data Enclave:

The insight received from MHDO data users piloting the NORC data enclave has highlighted the diverse needs of our data users specific to the structure and services provided by the NORC Data Enclave.

Because of the feedback received, NORC has created two levels of access to the NORC Data Enclave: **Basic and Customized***
## NORC Data Enclave

<table>
<thead>
<tr>
<th>Data Access &amp; Formats</th>
<th>Data Access into NORC Data Enclave Basic Level</th>
<th>Data Access into NORC Data Enclave Customized Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Storage for data files, reports, spreadsheets, documents</td>
<td>Access DB tables/views in Vertica HP (read only)</td>
<td>On request, requiring Feasibility Assessment and Estimating by NORC *</td>
</tr>
<tr>
<td>Database Software</td>
<td>50 GB personal H Drive;</td>
<td>Custom DB Storage + Custom File Storage as agreed with NORC</td>
</tr>
<tr>
<td></td>
<td>200 GB shared storage available for the research team</td>
<td>Vertica HP database with Dbeaver SQL Client Tool + Other Data Management Tools if supported by DE</td>
</tr>
<tr>
<td></td>
<td>Vertica HP database with Dbeaver SQL Client Tool</td>
<td>SAS or STATA, R Studio, Python,</td>
</tr>
<tr>
<td></td>
<td>SAS or STATA, R Studio, Python.</td>
<td>Additional Software, customer needs to provide license; software should be Citrix compatible</td>
</tr>
<tr>
<td>Data Analysis Software</td>
<td>Access to Tableau Desktop with provision of external license</td>
<td>Microsoft Office Productivity Suite - Excel, PPT, Word, etc.</td>
</tr>
<tr>
<td>Presentation Software</td>
<td>Microsoft Office Productivity Suite - Excel, PPT, Word, etc.</td>
<td>Custom Number of Downloads and Size, as agreed with NORC</td>
</tr>
<tr>
<td>Download Files / Reports</td>
<td>5 SDC-reviewed export requests per month (Aggregated Data Files, Reports)</td>
<td>Custom Number of Uploads, as agreed with NORC</td>
</tr>
<tr>
<td>Upload 3rd party Data</td>
<td>50 GB for Ancillary Data Files</td>
<td>1 day response SLA for technical issues, defined as: account management, application launch failure, and database connectivity errors. Guaranteed issue resolution.</td>
</tr>
<tr>
<td>Support Tier Description</td>
<td>2 day response SLA for technical issues, defined as: account management, application launch failure, and database connectivity errors. Guaranteed issue resolution.</td>
<td>Self-guided onboarding to Data Enclave / NHDD Data via FAQs and short web-based video. 1 hour initial environment and data access training.</td>
</tr>
<tr>
<td>Training</td>
<td>Self-guided onboarding to Data Enclave / NHDD Data via FAQs and short web-based video. 1 hour initial environment and data access training.</td>
<td>Creation of Temporary tables in Vertica is allowed. Table/Views can be migrated to PROD (persistent) by NORCIT only</td>
</tr>
<tr>
<td>Data Objects Permissions</td>
<td>Read only access to data views for all available years in Vertica (low memory and temp table limits)</td>
<td>Creation of Temporary tables in Vertica is allowed,</td>
</tr>
<tr>
<td>Database New Objects development (Tables/Views/Summary Tables)</td>
<td>Creation of Temporary tables in Vertica is allowed</td>
<td>MHDH APCD and Hospital Encounters Data (Levels I and II)</td>
</tr>
<tr>
<td>Data Availability</td>
<td>MHDH APCD and Hospital Encounters Data (Levels I and II)</td>
<td>Hosting Fee Per User/Per Year = $5200</td>
</tr>
<tr>
<td>NORC Fee Structure</td>
<td>Hosting Fee Per User/Per Year = $5200</td>
<td>2TBs Vertical Storage = $20K / 2 TB</td>
</tr>
<tr>
<td></td>
<td>Additional File Storage = $ 400 / 100GB</td>
<td>3TBs File Storage = $ 1,000 / 3TB</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VM server 2012 R2 ~ $10,000 / 12 month</td>
</tr>
<tr>
<td></td>
<td></td>
<td>VM server 2012 R2 ~ $5,000 / 12 month</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Managed Services Fee (OS patches, Vulner PT Monitoring, Backups, etc.) ~ $150/machine / month</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total Fees TBD based on final design</td>
</tr>
</tbody>
</table>

**NOTE:** MHDH Data access fees apply as described in MHDH Rule Chapter 50.

MHDH Data access fees apply as described in MHDH Rule Chapter 50.

Page 25
CompareMaine (CM)

Level Set
Website Stats
Release 5.0 and Upcoming 6.0
The Future of CompareMaine
Reporting Quality Data On CompareMaine
CompareMaine-Website Stats

October 1, 2015-April 30, 2018: Approx. 52,000 Sessions and 313,000 pageviews

Top 10 Procedures Searched on CM since launch:

1. Colonoscopy with Biopsy for Noncancerous Growth
2. Vaginal Delivery
3. Knee Replacement
4. Colonoscopy Without Biopsy for Encounter for Preventative Health Services
5. Hip Replacement
6. Gallbladder Removal
7. MRI Scan of Lower Spinal Canal
8. New Patient Preventive Care Visit for Adult, Ages 18 to 39
9. MRI Scan of Leg Joint
10. MRI Scan of Brain
Overview of CompareMaine 5.0

Launched in March 2018 with the following enhancements:

1. Updated Quality Data
   - HCAHPS Patient Experience Summary Star (1/1/16-12/31/16)
   - Serious Complications (7/1/14-9/30/15)
   - Healthcare-Associated Infections C.diff and MRSA SIRs (1/1/16-12/31/16)

2. Updated Cost Data (7/1/16-6/30/17)

3. Reduced the Data Threshold from 10 to 5

4. Improved Mapping Functionality
CompareMaine 6.0

Scheduled to launch in September 2018 with the following enhancements:

1. Update Quality Data and Refine the Display
   - HCAHPS Patient Experience Summary Star
   - Serious Complications
   - Healthcare-Associated Infections C.diff and MRSA SIRs
   - Recommend removing the CG-CAHPS data b/c of declining use of the tool

2. Update Cost Data (CY2017)
   - Recommend holding on surgical procedure estimates from MEG while we transition to New Episode Grouping Tool for Surgical Procedures
   - Add Chiropractic Data (separate display will show data by county)
   - Add Low Dose CT Scanning for Lung Cancer Screening
   - Add Volume to the Data Display

3. Streamline the Facility/Payer Data Review Period

4. Develop Historical/Trending Data Dashboards
Facility/Payer Data Review Period

Goal: Streamline resources and the review process

External Review Statistics
- 49% of facilities and 80% of payers logged into the demo site (153 unique contacts)

Annual Registration Period
- Facilities and payers will review, update and sign-off on how contact information and affiliations will be displayed on CompareMaine that year.
- Will occur separate from a CompareMaine update.

Data Review Period During CompareMaine Updates
- Facilities and payers receive login information to review the demo site prior to launch.
- Payers will be asked to focus on reviewing the data, including any flagged outliers, and sign-off on the information.
- Facilities will have opportunity to review the data and ask questions; however, they will not be required to sign off on the cost data.
LD445: An Act To Encourage Maine Consumers To Comparison-shop for Certain Health Care Procedures and To Lower Health Care Costs

Sec. 6. 24-A MRSA §4303, sub-§21 is enacted to read:

21. Health care price transparency tools. Beginning January 1, 2018, a carrier offering a health plan in this State shall comply with the following requirements.

A. A carrier shall develop and make available a website accessible to enrollees and a toll-free telephone number that enable enrollees to obtain information on the estimated costs for obtaining a comparable health care service, as defined in Title 24-A, section 4318-A, subsection 1, paragraph A, from network providers, as well as quality data for those providers, to the extent available. A carrier may comply with the requirements of this paragraph by directing enrollees to the publicly accessible health care costs website of the Maine Health Data Organization.
Continued-LD 455

Sec. 2. 22 MRSA §8712, sub-§2, as amended by PL 2011, c. 525, §1, is further amended to read:

2. Payments. The organization shall create a publicly accessible interactive website that presents reports related to payments for services rendered by health care facilities and practitioners to residents of the State. The services presented must include, but not be limited to, imaging, preventative health, radiology and, surgical services, comparable health care services as defined in Title 24-A, section 4318-A, subsection 1, paragraph A and other services that are predominantly elective and may be provided to a large number of patients who do not have health insurance or are underinsured. The website must also be constructed to display prices paid by individual commercial health insurance companies, 3rd-party administrators and, unless prohibited by federal law, governmental payors. Beginning October 1, 2012, price information posted on the website must be posted semiannually, must display the date of posting and, when posted, must be current to within 12 months of the date of submission of the information. Payment reports and price information posted on the website must include data submitted by payors with regard to all health care facilities and practitioners that provide comparable health care services as defined in Title 24-A, section 4318-A, subsection 1, paragraph A or services for which the organization reports data pertaining to the statewide average price pursuant to this subsection or Title 24-A, section 4318-B. Upon notice made by a health care facility or practitioner that data posted by the organization pertaining to that facility or practitioner is inaccurate or incomplete, the organization shall remedy the inaccurate or incomplete data within the earlier of 30 days of receipt of the notice and the next semiannual posting date.
Continued-LD 445

A. "Comparable health care service" means nonemergency, outpatient health care services in the following categories:

(1) Physical and occupational therapy services;
(2) Radiology and imaging services;
(3) Laboratory services; and
(4) Infusion therapy services
Total Payments

• The total payments on CompareMaine represent 80% of the total payments for those same specific sub-categories of procedures (ex. all hip replacements) in APCD (commercial claims only).

• The total payments on CompareMaine represent 51% of the total payments for those same general categories of procedures (ex. all surgeries).
  • The CPT codes on CompareMaine account for 3% of CPT codes in the APCD for the same general categories (278/8,609).

• The total payments on CompareMaine represent approx. 45% of the total payments for all procedures.

*Data are APCD commercial claims from 7/1/16 through 6/30/17.
<table>
<thead>
<tr>
<th>Category</th>
<th>Calculation</th>
<th>Unique Claim Count</th>
<th>Total Paid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrative Medicine</td>
<td>CompareMaine</td>
<td>51,075</td>
<td>$4,489,101.06</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>446,662</td>
<td>$20,200,012.69</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>11.43%</td>
<td>22.22%</td>
</tr>
<tr>
<td>Laboratory</td>
<td>CompareMaine</td>
<td>1,291,221</td>
<td>$47,360,789.66</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>1,989,261</td>
<td>$97,621,931.12</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>64.91%</td>
<td>48.51%</td>
</tr>
<tr>
<td>Mental &amp; Behavioral Health</td>
<td>CompareMaine</td>
<td>281,201</td>
<td>$26,666,977.56</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>295,752</td>
<td>$27,509,075.81</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>95.08%</td>
<td>96.94%</td>
</tr>
<tr>
<td>Deliveries</td>
<td>CompareMaine</td>
<td>2,650</td>
<td>$6,958,222.43</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>2,650</td>
<td>$6,958,222.43</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>100.00%</td>
<td>100.00%</td>
</tr>
<tr>
<td>Ob/Gyn</td>
<td>CompareMaine</td>
<td>184,763</td>
<td>$21,081,668.11</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>270,040</td>
<td>$48,633,152.29</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>68.42%</td>
<td>43.35%</td>
</tr>
<tr>
<td>Outpatient Procedures</td>
<td>CompareMaine</td>
<td>41,964</td>
<td>$29,837,563.31</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>937,514</td>
<td>$131,068,921.28</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>4.48%</td>
<td>22.76%</td>
</tr>
<tr>
<td>Office Visits</td>
<td>CompareMaine</td>
<td>1,487,933</td>
<td>$167,145,492.74</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>1,529,202</td>
<td>$172,059,265.79</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>97.30%</td>
<td>97.14%</td>
</tr>
<tr>
<td>PT &amp; OT</td>
<td>CompareMaine</td>
<td>775,603</td>
<td>$42,485,098.66</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>802,462</td>
<td>$45,163,868.62</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>96.65%</td>
<td>94.07%</td>
</tr>
<tr>
<td>Radiology and Imaging</td>
<td>CompareMaine</td>
<td>316,710</td>
<td>$75,872,965.35</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>606,636</td>
<td>$130,530,515.80</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>52.21%</td>
<td>58.13%</td>
</tr>
<tr>
<td>Surgical Procedures</td>
<td>CompareMaine</td>
<td>39,100</td>
<td>$20,129,563.05</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>353,768</td>
<td>$191,421,462.35</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>11.05%</td>
<td>10.52%</td>
</tr>
<tr>
<td>Totals</td>
<td>CompareMaine</td>
<td>4,472,220</td>
<td>$442,027,441.93</td>
</tr>
<tr>
<td></td>
<td>APCD</td>
<td>7,233,947</td>
<td>$871,166,428.18</td>
</tr>
<tr>
<td></td>
<td>Percent</td>
<td>61.82%</td>
<td>50.74%</td>
</tr>
</tbody>
</table>
Total Number of Providers

The total number of healthcare providers on CompareMaine represents 59% of the number of healthcare providers in the same specialties in the APCD.

The total number of healthcare providers on CompareMaine represents 51% of all healthcare providers claims in the APCD.

*Data are from 7/1/2016 through 6/30/2017
# Procedure Categories on CompareMaine (CM)

<table>
<thead>
<tr>
<th>Category</th>
<th>% of Payments on CM Out of All Commercial APCD Payments</th>
<th># CPT Codes on CM vs. AMA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deliveries</td>
<td>100%</td>
<td>12 / 12</td>
</tr>
<tr>
<td>Office Visits</td>
<td>97%</td>
<td>27 / 73</td>
</tr>
<tr>
<td>PT &amp; OT</td>
<td>94%</td>
<td>24 / 33</td>
</tr>
<tr>
<td>Mental &amp; Behavioral Health</td>
<td>97%</td>
<td>12 / 36</td>
</tr>
<tr>
<td>OB/GYN</td>
<td>43%</td>
<td>12 / 265</td>
</tr>
<tr>
<td>Laboratory</td>
<td>49%</td>
<td>94 / 1,433</td>
</tr>
<tr>
<td>Radiology &amp; Imaging</td>
<td>58%</td>
<td>35 / 576</td>
</tr>
<tr>
<td>Integrative Medicine</td>
<td>22%</td>
<td>8 / 16</td>
</tr>
<tr>
<td>Surgical Procedures</td>
<td>11%</td>
<td>45 / 5,392</td>
</tr>
<tr>
<td>Outpatient Procedures</td>
<td>23%</td>
<td>9 / 773</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>51%</strong></td>
<td><strong>278 / 3,609</strong></td>
</tr>
</tbody>
</table>
## Infusion Therapy-New Category

Understanding infusion therapy claims in MHDO’s commercial claims data

<table>
<thead>
<tr>
<th>Three Purposes:</th>
<th>Three settings:</th>
<th>Three Code Types Per Episode:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Chemotherapy</td>
<td>- Hospital</td>
<td>- Medication</td>
</tr>
<tr>
<td>- Therapy/Prevention/Diagnosis</td>
<td>- Clinic</td>
<td>- Supplies</td>
</tr>
<tr>
<td>- Hydration</td>
<td>- Home</td>
<td>- Administration</td>
</tr>
<tr>
<td>Drug</td>
<td>Uses</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Rituximab injection (100 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Trastuzumab injection (10 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Natalizumab injection (1 mg)</td>
<td>Treat autoimmune disorders</td>
<td></td>
</tr>
<tr>
<td>Bevacizumab injection (10 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Gammagard liquid injection (500 mg)</td>
<td>Protect against infection in immune system disorders</td>
<td></td>
</tr>
<tr>
<td>Privigen liquid injection (500 mg)</td>
<td>Protect against infection in immune system disorders</td>
<td></td>
</tr>
<tr>
<td>Nivolumab injection (1 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Pertuzumab injection (1 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Pemetrexed injection (10 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Oxaliplatin injection (0.5 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Abatacept injection (10 mg)</td>
<td>Treat autoimmune disorder</td>
<td></td>
</tr>
<tr>
<td>Ringers lactate infusion (up to 1000 cc)</td>
<td>Restore fluids and electrolytes</td>
<td></td>
</tr>
<tr>
<td>Bortezomib injection (0.1 mg)</td>
<td>Treat cancer</td>
<td></td>
</tr>
<tr>
<td>Propofol injection (10 mg)</td>
<td>Reduce anxiety, relax patient and induce anesthesia</td>
<td></td>
</tr>
<tr>
<td>Octagam liquid injection (500 mg)</td>
<td>Protect against infection in immune system disorders</td>
<td></td>
</tr>
</tbody>
</table>
Continued-Infusion Therapy

- Total Cost for Top 15 Infusion Drugs is approx. $30,000,000 in 7/1/16-6/30/17
- Total Cost for all Infusion Drugs is approx. $47,000,000 in 7/1/16-6/30/17
- Top 15 represent approx. 64% of total

Note: Stats above represent commercial claims data only
Strategy for Reporting Infusion Therapy on CompareMaine (CM)

Incremental Approach:
Start with reporting the costs for the top 3-5 high cost infusion drugs (costs on CM would include the costs associated with the drug and its administration listed separately) by setting (clinic, home and hospital).

Timeline: June 2019 Release

Issues to work through over next 8-12 months:
- Create infusion therapy “bundles” that combine each medication with its most common administration code(s)
- Analyze APCD data for home infusion providers
- CM relies on all providers of the same service billing the same code. Facilitate like-to-like comparison between different provider types in CM’s framework:
  - Home infusion providers bill HCPCs and hospitals and clinics bill CPT codes.
  - Home infusion providers typically bill per diem where as hospitals and clinics bill per code per unit
CompareMaine-Costs

Proposed Goal:

➢ Target 80% of costs reported in the commercial claims data

➢ Don’t limit the addition of procedures to “shoppable”; review the commercial claims data and look for most costly procedures and most common (at least 5 providers performing the service and there is variation in costs)
Quality Data on CompareMaine

Current Quality Measures on CM
Proposal for Adding New Quality Measures on CM
Request from Legislature, Employers and Consumers for Procedure Specific Quality Data
Technical Challenges with adding quality measures that are procedure specific
§8712. REPORTS

1. Quality. The organization shall promote public transparency of the quality and cost of health care in the State in conjunction with the Maine Quality Forum established in Title 24-A, section 6951 and shall collect, synthesize and publish information and reports on an annual basis that are easily understandable by the average consumer and in a format that allows the user to compare the information listed in this section to the extent practicable. **The organization's publicly accessible websites and reports must, to the extent practicable, coordinate, link and compare information regarding health care services, their outcomes, the effectiveness of those services, the quality of those services by health care facility and by individual practitioner and the location of those services. The organization's health care costs website must provide a link in a publicly accessible format to provider-specific information regarding quality of services required to be reported to the Maine Quality Forum.**
§6951. Maine Quality Forum

4. Reporting. The forum shall work collaboratively with the Maine Health Data Organization, health care providers, health insurance carriers and others to report in useable formats comparative health care quality information to consumers, purchasers, providers, insurers and policy makers. The forum shall produce annual quality reports in conjunction with the Maine Health Data Organization pursuant to Title 22, section 8712. No later than September 1, 2010, the forum shall make provider-specific information regarding quality of services available on its publicly accessible website.
<table>
<thead>
<tr>
<th>Quality Measure</th>
<th>Facility Type</th>
<th>About the Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Experience</td>
<td>Hospital</td>
<td>- Hospital CAHPS data from Hospital Compare/ Medicare sample - 2016.</td>
</tr>
<tr>
<td></td>
<td>Physician Office</td>
<td>- Clinician &amp; Group CG-CAHPS data from MQF Maine Experience Matters Initiative.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Physician offices affiliated with hospitals on CompareMaine show Hospital CAHPS not CG-CAHPS.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- <strong>Retire measure due to declining use of CG-CAHPS data/need to replace with other ambulatory care measure</strong></td>
</tr>
<tr>
<td>Preventing Serious Complications</td>
<td>Hospital</td>
<td>- Data from Federal Agency for Health Research &amp; Quality’s Patient Safety Indicators collected during July 1, 2014 - September 30, 2015</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Fee-for-service Medicare only</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Facility’s rating is the rate per 1,000 eligible hospital discharges. A lower number is better.</td>
</tr>
<tr>
<td>Preventing Healthcare-Associated Infections (C. diff.)</td>
<td>Hospital</td>
<td>- Data from Federal CDC’s National Healthcare Safety Network (NHSN) for the January 1, 2016 - December 31, 2016 reporting period</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Based on inpatient days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Facility’s rating is the ratio of the number of infections in a facility over the expected number of infections. A lower number is better.</td>
</tr>
<tr>
<td>Preventing MRSA</td>
<td>Hospital</td>
<td>- Data from Federal CDC’s National Healthcare Safety Network (NHSN) for the January 1, 2016 - December 31, 2016 reporting period</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Based on inpatient days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Facility’s rating is the ratio of the number of infections in a facility over the expected number of infections. A lower number is better.</td>
</tr>
</tbody>
</table>
## Chapter 270 and Other Publicly Reported Quality Data

<table>
<thead>
<tr>
<th>Proposed Quality Measure</th>
<th>Publicly Reported/Data Source</th>
<th>What's currently publicly reported</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls with Injury</td>
<td>Chapter 270 (NSPC-3)</td>
<td>• 7/1/15 - 6/30/16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 35 hospitals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• All payers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Rate per 1,000 patient days</td>
</tr>
<tr>
<td></td>
<td>Leapfrog</td>
<td>• 1/1/16 - 12/31/16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 29 hospitals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Rate of patient falls or other types of trauma per 1,000 patient discharges</td>
</tr>
<tr>
<td>Pressure ulcers</td>
<td>Chapter 270 (NSPC-1)</td>
<td>• 7/1/15-6/30/16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• All hospitals (except psych.)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• All payers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Percentage of patients with a Stage II-or-greater pressure ulcer in a quarterly, one-day prevalence study</td>
</tr>
<tr>
<td></td>
<td>Leapfrog</td>
<td>• 1/1/16 - 12/31/16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 29 hospitals</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• PSI-03 Rate of Stage III or Stage IV pressure ulcers per 1,000 patient discharges</td>
</tr>
<tr>
<td></td>
<td>Hospital Compare (AHRQ PSI-03)</td>
<td>• 7/1/14 - 9/30/15</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 17 hospitals (PPS only)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Medicare only</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Better, same or worse</td>
</tr>
</tbody>
</table>
## Continued

<table>
<thead>
<tr>
<th>Proposed Quality Measure</th>
<th>Publicly Reported/ Data Source</th>
<th>What’s currently publicly reported</th>
</tr>
</thead>
</table>
| Hospital-Wide All-Cause Unplanned Readmission Measure (READM-30-HOSP-WIDE) | Hospital Compare              | • 7/1/15 - 6/30/16  
• 33 hospitals  
• Score compares to national rate (better, same, & worse)  
• Medicare only*                                                                 |

* Testing using APCD
# Procedure-Specific Hospital Quality Measures

<table>
<thead>
<tr>
<th>Proposed Quality Measure</th>
<th>Publicly Reported Data Source</th>
<th>What's currently publicly reported</th>
</tr>
</thead>
</table>
| Birth trauma - Injury to neonate (PSI-17) | MONAHRQ | • 2012 data  
• 16 of 33 hospitals with a rating (48%)  
• Score compares to nat’l avg. (better, avg., below avg.)  
• All-payer based on hospital discharge* |
| Complication rate following elective primary total hip arthroplasty and total knee arthroplasty | Hospital Compare | • 4/1/13 - 6/30/16  
• 26 of 33 hospitals have a rating (79%)  
• Score compares to national rate (better, same or worse)  
• Medicare-specific* |
| Hip and knee replacement Surgical Site Infection (SSI) | Not currently, but could begin in 2021 based on anticipated Chapter 270 rule changes | • Not currently available |
| Colonoscopy - Facility 7-Day Risk-Standardized Hospital Visit Rate after Outpatient Colonoscopy (OP-32, NQF #2539) | Hospital Compare | • 1/1/16 - 12/31/16  
• 23 of 33 hospitals reporting  
• Medicare-specific  
• Score compares to national rate (better, same or worse) |

* Testing using APCD
# Ambulatory Care Settings

## Procedure-Specific Quality Measures

<table>
<thead>
<tr>
<th>Proposed Quality Measure</th>
<th>Publicly Reported Data Source</th>
<th>What’s currently publicly reported</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AMBULATORY CARE/ PHYSICIAN OFFICES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comprehensive Diabetes Care (NQF #0731)</td>
<td>MONAHRQ</td>
<td>MONAHRQ reports the diabetes composite measure and its constituent parts: HbA1C, retinal exams, blood pressure control, nephropathy tests</td>
</tr>
<tr>
<td>Preventive Screening Measures (PQI #90)</td>
<td>MONAHRQ</td>
<td>Preventative Quality Indicator Overall Composite</td>
</tr>
</tbody>
</table>
# Procedure-Specific Quality Measures

<table>
<thead>
<tr>
<th>Proposed Quality Measure</th>
<th>Publicly Reported Data Source</th>
<th>What's currently publicly reported</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IMAGING CENTERS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MRI Scan Lower Spine - MRI Lumbar Spine for Low Back Pain (OP-8, NQF #0514)</td>
<td>MONAHRQ</td>
<td>Only hospital-based imaging included</td>
</tr>
<tr>
<td></td>
<td>Hospital Compare</td>
<td>Medicare data only</td>
</tr>
</tbody>
</table>
Guidelines for Prioritizing Quality Measure Selection on CM

**Nationally endorsed measure:** Measure is endorsed by the National Quality Forum or required by a federal agency for public reporting

**National benchmark:** A national benchmark is available so performance can be compared to a national standard

**Data availability:**
- The data is available nationally (HospitalCompare, MONAHRQ)
- The measure can be calculated from available MHDO data (i.e. claims, hospital discharge, Chapter 270 data)

**Recommendation:** Flexibility with the above guidelines
RFP for Data Analytic Platform

- MQF Board approved the release of an RFP for the acquisition of a data analytic platform to assist in reporting healthcare quality as described in MQF Statute.

- There are data analytic platforms available that use claims data and or hospital data to produce comparable information specific to costs and provider performance and outcomes.

Examples include: MedInsight, SurgeonCheck; Prometheus, etc.
Continued-Cost & Quality

High Level Next Steps:

- Continue Market Research (availability and what other states are doing)
- Meet with Key Stakeholders
- Develop RFP for acquisition of an analytic platform for both Episode Grouping and Quality Analysis
- Release RFP (Q4 2018)
- Identify Selection Committee
- Execute a contract (Q2 2019)
- Develop a plan in 2019 to begin to report quality at the provider level beginning in 2020

Note: working timeline-subject to change
Strategic Focus for the Next 12-18 Months

Data Delivery Model/Data Quality Enhancements
CompareMaine Enhancements (content & functionality)
8712 Reporting Requirements
Re-Design of MHDO Website
Data Analytic Platform (cost and quality)
Stakeholder Engagement
HCUP ONLINE RESOURCES

HCUP USER SUPPORT WEB SITE

The Public Access HCUP-US Web Site

The Healthcare Cost and Utilization Project (HCUP) User Support (HCUP-US) Web site – www.hcup-us.ahrq.gov – provides detailed information on HCUP databases, including the online purchase of HCUP databases; free tools and software; database documentation; HCUP publications; and access to technical support.

- **Home page** – Introduces HCUP, its databases, products, and support services, including a link for joining the Agency for Healthcare Research and Quality's (AHRQ) HCUP mailing list.
- **Databases** – Includes descriptions of the HCUP databases, with detailed technical documentation, related reports, and Data Use Agreement (DUA) requirements.
- **Tools and Software** – Provides links to HCUPnet, the AHRQ Quality Indicators (QIs), HCUP Fast Stats, and other HCUP analytic tools. HCUP tools and software have been developed by AHRQ to enhance the value of administrative health care data. These analytic tools utilize clinical measures and include the Clinical Classifications Software (CCS), Chronic Condition Indicator (CCI), Elixhauser Comorbidity Software, Procedure Classes, Surgery Flags, and Utilization Flags. Many of HCUP’s tools have also been converted to beta versions for use with ICD-10-CM/PCS data. HCUP also offers supplemental files designed to augment and enhance the HCUP databases. These include Cost-to-Charge Ratio (CCR) Files, Hospital Market Structure (HMS) Files, Supplemental Variables for Revisit Analyses, American Hospital Association (AHA) Linkage Files, Nationwide Inpatient Sample (NIS) and Kids' Inpatient Database (KID) Trend Weight Files (NIS and KID Trend Weight Files), and NIS Hospital Ownership Files.
- **Reports** – Includes links to HCUP publications, including HCUP Statistical Briefs, HCUP Methods Series, HCUP Infographics, Topical Reports on priority populations, Nationwide and State Database Reports, and Mental Health and Substance Use Disorders. The page also includes Research Spotlights and a search feature for peer-reviewed journal articles and other publications that use HCUP data. An ICD-10-CM/PCS Resources page summarizes issues for researchers using HCUP and other administrative databases that include ICD-10-CM/PCS coding. This recently updated page documents key differences in the structure of HCUP databases, provides general guidance and forewarning to users analyzing outcomes that may be impacted by the transition to the ICD-10-CM/PCS coding system, and lists other related Web resources.
- **HCUP Fast Stats** – HCUP Fast Stats provides easy access to the latest HCUP-based statistics on health information topics at State and national levels. HCUP Fast Stats uses visual statistical displays in stand-alone graphs, trend figures, or simple tables to convey complex information at a glance. Information is updated regularly (quarterly or annually, as newer data become available). Fast Stats currently includes three topics: State Trends in Hospital use by Payer, National Hospital Utilization and Costs, and Opioid-Related Hospital Use, National and State.
• **News and Events** – Contains the collection of quarterly HCUP e-News issues, HCUP Announcements, a calendar of events, databases, and product releases, HCUP Outstanding Article of the Year Awards, and the HCUP Virtual Exhibit Booth.

• **Purchase HCUP Data** – Applications for Nationwide and State Databases, as well as requests for complimentary supplemental files that augment information contained in these HCUP databases, may be submitted through the online HCUP Central Distributor. All users interested in purchasing HCUP databases are required to execute an online DUA as well as complete the required HCUP DUA training course. HCUP Nationwide Databases are delivered via secure download from the HCUP-US Web site. Purchased State Databases are delivered on hard copy media (DVD).

• **Technical Assistance** – Provides information for users, including detailed database overviews, access to the Central Distributor Web page for ordering HCUP databases, HCUP Frequently Asked Questions (FAQs), HCUP publishing requirements, an interactive HCUP Overview Course, the HCUP Online Tutorial Series, the HCUP DUA Training Course, and contact information for technical support and for purchasing HCUP databases.

• **Data Innovations** – Provides information about activities as well as products and tools sponsored by AHRQ to improve and enhance clinical content, race/ethnicity data, laboratory data, and collection of “Present On Admission (POA)” indicators in administrative databases. Resources are also available for researchers using HCUP and other administrative databases that include ICD-10-CM/PCS coding.

**The Secure HCUP-US Partners Section**

A username and password are required to access the secure Partners section of the HCUP-US Web site. To gain access, Partners should log in to [www.hcup-us.ahrq.gov/login.jsp](http://www.hcup-us.ahrq.gov/login.jsp). This section of the HCUP-US Web site contains information and documents of specific interest to data organizations participating in HCUP.

The Partners section provides easy navigation to Partnership information and Partner topics from HCUP, including:

• **Map of HCUP Partner Organizations** – Includes hyperlinks to Partner data organization Web sites.

• **Partner Events and Activities**
  o **What’s New – Partner Updates** – Features items from the Partner Calendar that may be of particular interest to Partners.
  o **Partner Calendar** – Provides Partners with information about upcoming and past HCUP events. An archive of all events is also available.
  o **Partner Meetings** – Provides agendas, slides, minutes, and other meeting materials from the HCUP Partner Webinar series.
  o **Partner Workgroups** – Includes slides, minutes and materials from workgroup meetings on POA Data Quality; ICD-10-CM/PCS Implementation Considerations, and Payer Typology.
  o **Partner Contacts** – Contains public-access Partner contact information and Web sites.
- MOA Partnership Information – Includes documents used to formalize the HCUP Partnership (sample HCUP Memorandum of Agreement (MOA), Data Security Plan, and other references), Central Distributor overview for Partners, information related to the redesign of the 2012 NIS, and AHRQ uses of HCUP data including links to the National Healthcare Quality and Disparities Report (QDR), and other resources. Partners may request a copy of the "My HCUP Data Elements" State-specific report for all data elements supplied to HCUP by their Organization and released on HCUP databases.

- HCUP Partner Resources
  - Exclusive Tools and Reports for Partners – Includes analytic tools and reports designed in response to Partner requests for more statistical feedback on data quality and editing, and to improve data collection. Available tools include ICD-10-CM/PCS Resources and Code Edits; Border Crossing Report (including overview tables and graphs); and Race Data Quality Tables. Previously issued reports and resources are available in the archives section.
  - National Data Standards – Provides information on issues related to national data standards including summaries of the National Uniform Billing Committee (NUBC) and the National Uniform Claims Committee (NUCC) meetings and other important data standards topics such as status of the National Health Plan Identifier. Previous data standards information is available in the archive section which offers links to useful Health Information Technology (HIT) and national data standard Web sites.
  - Clostridium difficile Infection (CDI) Toolkit – Includes a comprehensive set of materials for data organizations and stakeholders ranging from links to national initiatives, educational materials, and national and State reports.
  - Community-Level Statistics – Includes presentation slides from the November 2015 HCUP Partners Webinar, which discussed the new features added to the Community-Level Statistics pathway on HCUPnet in 2014. The features included AHRQ Prevention Quality Indicators (PQIs) and Pediatric Quality Indicators (PDIs), as well as sub-State regions (groups of counties) and displays of statistics by county-level maps.
  - Readmissions Activities – Includes methods on the development of the Supplemental Variables for Revisit Analyses from workgroup sessions held in 2009 and slides from the HCUP Readmissions Methods Webinar held in 2012. Contains methods used to identify patient revisits and readmissions across time and hospital settings.
  - Race and Ethnicity Activities – Includes useful information on racial and ethnic disparities in health care and related data measurement issues as well as notes and reports from workgroup sessions held through 2010.
  - Archives – The archives section provides Partners with a variety of materials related to data collection and coding of inpatient and outpatient data. It includes resources for improving race-ethnicity data collection, resources related to outpatient data, reports on external cause of injury codes (E codes), observation status, encrypted patient identifiers, post hospitalization mortality activities, and data standards listed above.

- HCUP Information
  - HCUP Summary Fact Sheet – Provides a succinct overview of HCUP.
- **HCUP Description** – Provides a detailed description of the HCUP project.
- **HCUP Project Overview** – Contains copies of HCUP Annual Activities Reports, as well as an electronic version of the current HCUP Project Overview Binder.

For more information on the password-protected HCUP-US Partners section or to receive a username and password, please contact Kathy Hickey at Truven Health Analytics, An IBM Company (Kathy.Hickey@us.ibm.com).

**HCUPnet**

HCUPnet – available at [www.hcupnet.ahrq.gov](http://www.hcupnet.ahrq.gov) – is a free, online query system that provides instant access to statistics from HCUP data. Using HCUPnet's easy, step-by-step query system, users can generate tables and graphs on national statistics and trends for community hospitals in the United States. In addition, State, region, and county-level statistics are available for those States that have agreed to participate. HCUPnet provides statistics on 30-day readmissions to the hospital based on the Nationwide Readmissions Database (NRD). It also has information on measures of healthcare quality based on the National (Nationwide) Inpatient Sample (NIS) from the AHRQ QDR.

HCUPnet has query paths that allow users to generate national, regional, and State estimates on visits for children, mental health and substance abuse, and emergency department visits. HCUPnet also provides community-level statistics for participating States, which includes the number of hospital discharges, length of stay, costs by diagnostics categories and procedures, and AHRQ Prevention Quality Indicators (PQIs) and Pediatric Quality Indicators (PDIs).

HCUPnet generates statistics using data from HCUP's NIS, KID, Nationwide Emergency Department Sample (NEDS), Nationwide Readmissions Database (NRD), State Inpatient Databases (SID), State Emergency Department Databases (SEDD), and State Ambulatory Surgery and Services Databases (SASD).

**AHRQ Quality Indicators (QIs)**

AHRQ QIs – available at [www.qualityindicators.ahrq.gov](http://www.qualityindicators.ahrq.gov) – are measures of healthcare quality that make use of readily available hospital inpatient administrative data. The AHRQ QIs may be used with HCUP data to highlight potential quality concerns, identify areas that need further study and investigation, and track changes over time. Beta version 7.0 of QI software is currently available for all four QI modules for use with ICD-10-CM/PCS data (SAS and WinQI) and includes numerators, denominators, and observed rates; however, it does not include risk-adjustment, smoothed rates, and calculations of provider-level composites. Risk-adjusted rates cannot be added to the software until a full-year reference population is available for testing. The full release of the all-payer ICD-10-CM/PCS software with risk-adjustment and smoothing is set to occur in 2018.

The AHRQ QIs consist of four modules measuring various aspects of quality:

- **Prevention Quality Indicators (PQIs)** identify hospital admissions that evidence suggests could have been avoided, at least in part, through high-quality outpatient care.
- **Inpatient Quality Indicators (IQIs)** reflect quality of care inside hospitals including inpatient mortality for medical conditions and surgical procedures; possible overuse, underuse, or misuse of procedures; and volume of procedures for which there is evidence that a higher volume may be associated with lower mortality.
- **Patient Safety Indicators (PSIs)** also reflect quality of care inside hospitals, but focus on potentially avoidable complications and iatrogenic events.

- **Pediatric Quality Indicators (PDIs)** reflect both quality of care inside hospitals and identify potentially avoidable hospitalizations among children.

Software and user guides for all four modules are available for download to assist users in applying the AHRQ QIs to their own data.
March 23, 2018

Dear Senators Bill Cassidy, M.D. (R-LA), Michael Bennet (D-CO), Chuck Grassley (R-IA), Tom Carper (D-DE), Todd Young (R-IN), and Claire McCaskill (D-MO),

Thank you for the opportunity to provide responses to the questions posed in the February 28, 2018, Health Care Price Transparency Initiative letter. On behalf of the APCD Council, we commend your goal “to empower patients, improve the quality of health care, lower health care costs” and your support of transparency as key to being able to successfully achieve those goals.

The All-Payer Claims Database (APCD) Council, is a learning collaborative of government, private, non-profit, and academic organizations focused on improving the development and deployment of state-based all payer claims databases (APCDs). The APCD Council is convened and coordinated by the Institute for Health Policy and Practice (IHPP) at the University of New Hampshire (UNH) and the National Association of Health Data Organizations (NAHDO).

The leadership team for the APCD Council respectfully submits the following feedback, in response to your specific questions. We have focused on states’ efforts to drive transparency, understanding that there is a broader universe of stakeholders who will likely comment with their own unique lens.

We also welcome the opportunity for more discussion with you and your teams, about any of our comments, or about additional questions you may have. We would also be very interested in participating in the roundtable conversations you are planning or in other venues, as you deem helpful.

1. **What information is currently available to consumers on prices, out-of-pocket costs, and quality?**

As articulated in the letter requesting comments, the health care industry, is unique in how consumers make decisions about how and where to purchase services. Relative to other services for which consumers pay, there is relatively little comparison shopping for health care services. Health care has not historically been an industry where the consumer evaluates various providers in making a decision about where to receive care. Research released in April 2017 found that over half of Americans were not aware that doctor or hospital prices vary. This study also found that consumers are increasingly seeking out price information. The study
reported that 50 percent of Americans have tried to find health care price information before getting care, including 20 percent who have tried to compare prices across multiple providers.\(^1\)

Health care, as an industry, is unique in the way prices are established. The price for the same service can vary widely. Determining the price for a service is not a simple exercise, yet many states are making strides to provide price information to consumers. The example below, from the NH HealthCost website from the New Hampshire Insurance Department,\(^2\), shows that an X-ray of the knee (using the same procedure code) can vary three-fold in cost, for a person covered by group health insurance from a single insurer, depending on location of the service.

This example from New Hampshire highlights the utility of developing data systems to collect data to support health care system transparency. States have over 30 years’ experience developing Hospital Discharge Data Systems (HDDS; see www.nahdo.org for a list of states with HDDS) and using those data to support transparency in health care. States have been developing All-Payer Claims Databases (APCD) for over 10 years (see www.apcdcouncil.org for a

---


\(^2\) www.nhhealthcost.com
list of states with APCDs). The two statewide health care data systems are discussed in more
detail in the sections below.

All-Payer Claims Databases (APCDs)

APCD data have been used to support transparency efforts related not only to consumer tools
that focus on price and costs of services, but also a range of analyses to support health policy
and clarity to support consumer-focused public policy, more generally. This includes:

- **Assessing geographic variations in price and utilization.** The Oregon Health Authority
  publishes quarterly reports that compare per-member per-month costs and utilization,
  by service category, for commercially insured, public employees, and public payers
to study price variation for common procedures among facilities
  Maryland uses APCD data to compare the unit-costs, utilization, per-member per-month
costs, out-of-pocket and insurance payments, geographic variations, and physician
access data across geographic regions

- **Tracking health care spending drivers and trends.** Massachusetts uses its APCD data to
  produce an annual report analyzing trends in health care spending for commercial
  payers by category of service, type of episode, and geographic area
  (http://www.mass.gov/anf/docs/hpc/apcd-almanac-chartbook.pdf). Minnesota has
  used its APCD data to analyze prescription drug spending by therapeutic category and
  setting (office-administered vs. pharmacy benefit)(
  Island released a report analyzing the top 15 clinical complaints and associated costs of
  potentially avoidable emergency room visits broken down by payer type
  (http://health.ri.gov/data/potentiallypreventableemergencyroomvisits/)

- **Promoting public health.** Organizations in Virginia
  (http://www.vhha.com/research/2016/01/29/data-show-southwest-virginia-hard-hit-
  by-opioid-crisis/) and Utah
  (http://healthinsight.org/files/Utah%20Partnership%20for%20Value-
  Driven%20Healthcare/Transparency%20Advisory%20Group/In-
  Person%20Events/TAG%20Slides%204-19-16%20final.pdf) have used APCD data to track
  opioid prescription claims across geographic areas and patient characteristics to
  understand and address trends in opioid use as have the Agency for Healthcare
  Research and Quality (https://www.hcup-
  APCD data to measure access to and utilization of preventive services, such as cancer
screening or diabetic testing and treatment, among its adult Medicaid population (https://www.dhhs.nh.gov/ombp/documents/adultpreventivebrief.pdf) 

- States are using their data systems to improve outcomes and reduce costs associated with avoidable inpatient and Emergency Department visits and hospital readmissions (https://profiles.health.ny.gov/measures/all_state/16284)

More specifically related to the question about price and cost information for consumers, states have developed many exemplary tools using APCD data. The example above demonstrates NH's consumer tool. Additional state tool examples include:

Maine's CompareMaine site: http://www.comparemaine.org/
Maryland’s WearTheCost site: http://healthcarecost.mhcc.maryland.gov/

These tools provide comparative information about the cost for selected services, typically focusing on services for which people have time and ability to choose where to receive care. The full functionality of these tools is beyond the scope of these comments, and we encourage you to spend time using the tools to understand how they can be used to assist consumers.

In terms of information related to quality of care, several of the above tools also incorporate aspects of health care quality into the consumer tools. The tools incorporate such quality dimensions as complications, health care associated infections, and patient experience.

Hospital Discharge Data Sets (HDDS)

Another source of rich quality information stems from statewide hospital discharge data sets. These data sets capture all discharges from all acute care facilities in a state for all patients (regardless of payer, including uninsured and self-pay), providing key information on the sickest, costliest populations in a state. Beginning with the landmark Coronary Artery Bypass Graft outcomes reports in New York and Pennsylvania in the early 1990’s, other states have followed with their own provider quality reports.
Almost every state has some form of statewide hospital reporting system, with many releasing public reports or maintaining websites with quality comparisons. Research indicates the “making performance data public results in improvements in the clinical area reported upon and that consumer surveys suggest that inclusion did affect hospitals’ reputations”.3 “Widespread reporting of hospital performance has been shown to drive improvements.” “Making performance information public appears to stimulate quality improvement activities in areas where performance is reported to be low”4 with availability of statewide hospitalization data as underpinnings of quality studies.

Many states use the Agency for Healthcare Quality and Research (AHRO) Quality Indicators—standardized measures and benchmarks of health system and hospital performance with open-source software capabilities. (http://www.qualityindicators.ahrq.gov/). It is important to note that while measures and analytic tools are important to public reporting, the underlying data source must be available—collected, audited/validated, and standardized in order to produce these measures of quality.

States publish their hospital quality data in reports and websites (too numerous to list here). Examples include:

- **Virginia Health Information (VHI):** VHI’s hospital quality website published four types of quality ratings on the site: recommended care, results of care, patterns of how care is delivered, and patient experience. This site shows hospitals’ quality ratings on several different topics, including patient safety and specific health conditions. The following depicts ratings on hospital deaths and readmissions for heart attack and chest pain patients: http://www.vhi.org/monahrq2014/index.html#/professional/quality-ratings/condition?topic=8&subtopic=22

---

3 Health Affairs, July/August 2005: https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.24.4.1150
4 Health Affairs, March/April 2003: https://pdfs.semanticscholar.org/3c46/1fcc32f7e817a71efc171995c24695b3d9ce.pdf
## Deaths or returns to the hospital

### Heart attack and chest pain

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Performance</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. Vincent's Health Center</td>
<td>Better</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Better</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
<tr>
<td>hospital</td>
<td>Average</td>
</tr>
</tbody>
</table>

- **Pennsylvania Health Care Cost Containment Council (PHC4):** PHC4 publishes hospital performance reports and makes downloadable data sets available to the public (www.PHC4.org). An example, below, reports the volume of admissions for colorectal procedures (volume of patients treated can be a proxy measure predicting outcome, with higher volume associated with better outcomes), the mortality rate for those treated, and the average hospital charge, which does not reflect costs but which is a benchmark or reference list price to negotiate payment rates with insurers.
As valuable as hospital discharge data systems have been for driving industry quality improvement, consumers have not been the direct users of hospital quality data. In addition to lack of awareness of its availability or how these data can be used, many consumers do not “shop” for hospital services because of network restrictions and hospital data do not include actual costs and estimates of patient liability. APCDs supplement HDDS to fill this information gap.

2. What information is not currently available, but should be made available to empower consumers, reduce costs, increase quality, and improve the system?

There continue to be important gaps in publicly-available comparative information, including:

Provider and provider-group level data: Consumers seek reliable and independently-validated information at the provider or provider-group level. States expend considerable resources on provider identification and mapping providers into practice groups, due to limits on physician identifiers. Further, attributing individual patients to specific physicians is a difficult process due to limitations in the claims reimbursement process in which the billing provider may not be the service provider.
Data related to behavioral health or substance use disorder treatment: Some data submitters, particularly to state APCDs, have interpreted rules from the Substance Abuse and Mental Health Services Administration (SAMHSA) related to data sharing (42 CFR Part 2 Confidentiality of Substance Use Disorder Patient Records\(^5\)), very broadly to remove data that are critical to understanding availability and costs of services related to behavioral health and substance use disorder treatment. The missing data hinders a state’s ability to assess and shape opioid intervention policies and activities.

Given certain policy barriers, there are some consumers who may not be included in data collection efforts at the state APCD. This includes:

**Some consumers covered by self-funded insurance plans:** The United States Supreme Court Decision in Gobeille vs. Liberty Mutual ruled that self-funded employers covered by ERISA cannot be legally obligated to have their data submitted to a state APCD. Employers can opt in to data collection efforts, but cannot be mandated to do so. This issue is discussed further in question 9, below.

**Federal Employee Health Benefits Program (FEHBP) and Tricare Data:** Not all data from plans that are administered for Federal employees or Military personnel submit data to state APCDs.

3. What role should the cash price play in greater price transparency? How should this be defined?

Given the variation in costs and the fact that negotiations are tied to insurance contracts, cash prices may not be terribly meaningful for consumers. Few (if any) people pay a set “price” that is standard at a facility, for a service. Instead, the price paid will depend on a set of negotiations, either by the payer or the individual. It is unclear if this metric can provide real transparency or decision-making support.

Best practice transparency information includes cost data that represents the total amount paid for a service by both consumer and insurers, an allowed amount that indicates the amount that has been negotiated as what is “allowed” to be paid for that service.

\(^5\) https://www.samhsa.gov/health-information-technology/laws-regulations-guidelines
Although not the same as cash price, one lesson learned from state-level analysis is that variable and potentially expensive out-of-pocket costs, such as deductibles and coinsurance, is important information for consumers. As cost-sharing increases for consumers, this information can be useful for decision-making and planning for health care expenses. Research has shown that insured Americans with high deductibles are more likely to have tried to find price information before getting care. Sixty-nine percent of insured Americans with deductibles above $3,000 have tried to find price information while only 50 percent of those with deductibles less than $500 have done so.\(^6\)

4. Different states have used different methods to work towards price transparency. What are the pros and cons of these different state approaches? What is the best quality and price information to collect for consumers and businesses?

Public reporting initiatives navigate a delicate balance between concerns about sharing information considered proprietary with the need to inform the public and provide comparative performance information. While both private and public organizations play roles in transparency, states play a significant role. Responsible for health care oversight and protection of their citizens, state agencies have been collecting and using health care system data for over 30 years and have established ample evidence that a community data system has a positive influence on the market and can support informed policy decisions.

While states have adapted approaches to statewide data collection to reflect their local market and political environments, there are remarkable similarities in the statewide reporting programs, especially in the data elements they capture. For example, most states collect hospital and claims data under legislative authority; some states without such legislation rely on voluntary submission by providers and payers. The governance approach may influence the comprehensiveness of the data collected and its access to the general public. State hospital and APCD reporting legislation typically authorizes the state agency or health data authority to collect and manage data, either internally or through contracts with external vendors. Legislation grants legal authority to enforce penalties for noncompliance and other violations, while separate regulations define reporting requirements. State legislation typically establishes the authority for, and scope of, data collection. The table below indicates how approaches may differ and how these approaches influence key aspects of data practices.

Summary of State Approaches to Data Governance

<table>
<thead>
<tr>
<th>Mandatory/required by law</th>
<th>Data Collection</th>
<th>Data Oversight</th>
<th>Transparency at provider level</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Compliance to reporting requirements with penalties for non-compliance</td>
<td>Data release governed by law/oversight committee policies</td>
<td>Reporting policies defined by law and regulation and more likely to result in release of provider-level reporting</td>
<td>The majority of states adopt a mandated reporting approach for hospital and APCD systems</td>
<td></td>
</tr>
</tbody>
</table>

| Voluntary reporting | Reliance on voluntary submission | Varies | Varies according to submitter support | Voluntary initiatives rely on submitter support |

State approaches to using data to support transparency vary, because there is no “one size fits all” approach. Some states have requirements for how data are to be used in their legislation or in other regulation. For example:

The legislation that established the APCD in Colorado states: “The All-Payer Health Claims Database shall: (a) Be available to the public when disclosed in a form and manner that ensures the privacy and security of personal health information as required by state and federal law, as a resource to insurers, consumers, employers, providers, purchasers of health care, and state agencies to allow for continuous review of health care utilization, expenditures, and quality and safety performance in Colorado.” (italics added)7

Massachusetts’ Chapter 224 of the Acts of 2012, “An Act Improving the Quality of Health Care and Reducing Costs Through Increased Transparency, Efficiency and Innovation,” created the Center for Health Information and Analysis (CHIA), which develops an annual report of health care system performance across Massachusetts.8

---

8 http://www.chiamass.gov/ma-apcd/
As the health care system evolves, what is and becomes "the best quality and price information to collect for consumers and businesses" may need to change to match the changing landscape. What is critical is to create the ongoing collection of detailed data that can be configured to meet a variety of needs, including granular or detailed data to support local-level decisions by purchasers, consumers, as well as policy makers. Data systems that are available to authorized parties and developed with broad stakeholder input and with open and transparent methods and policies are necessary to achieve real transparency.

5. Who should be responsible for providing pricing information and who should share the information with consumers?

A broad array of partners should play a role in providing pricing information and sharing this information with consumers. However, the competitive nature of the health care market is one of the greatest barriers to data sharing and reporting, as some information (e.g., contracted rates) may be considered proprietary. Thus, states have a key role because of their legislative authority and ability to compel reporting across players as well as incorporating all local stakeholders in designing the data system and policies governing the data. Although difficult, states have demonstrated it is possible to establish a data commons with useful information for both industry and the public.

But states alone cannot bear the entire burden of supporting people to be effective health care consumers. Such an effort will require a multi-faceted approach. Employers, providers, payers, advocacy organizations, policy makers, and others all play a role. While there are many important players efforts to support transparency, states will continue to have a crucial and central role. Research has shown that the vast majority (80%) "think it is important for their state governments to provide people with comparative price information."  

6. What role should all-payer claims databases play in increasing price and quality transparency? What barriers currently exist to utilizing these tools?

APCDs are the only statewide data source for a state that captures the utilization and costs across payers and providers in a state, including pharmacy, physician, and dental data. APCD data systems are robust enough to allow granular data analysis to support local-level information. Our comments to the previous questions demonstrate several of the roles that APCDs can play in the efforts to improve transparency for consumers, as well as to the larger

---

health care stakeholder community. As discussed, APCDs have been used in many ways to improve health care system, from tools directed to consumers to broader views into the health care system to inform policy to support health improvement. APCDs have a key role in regulation, consumer support, population health improvement, and planning for system change. The APCD Use Case Showcase (www.apcdshowcase.org) demonstrates a much broader set of examples than can be described in this response.

The greatest barrier to state APCD development is the lack of funding to establish and sustain reporting programs. Federal engagement in partnership with states is needed to fill critical gaps in data collection, to assure that the data can include as many people as possible, and to support the widest range of needs possible.

7. How do we advance greater awareness and usage of quality information paired with appropriate pricing information?

States are poised and interested in being active partners with other organizations to assure the public availability and effective use of the data being collected. The tools and information being made available by the states can be coupled with education and awareness efforts from other stakeholders.

In addition, maximizing the potential of the data relies on robust data sources. It is critical to invest in the data systems to ensure that adequate funding and resources are available to establish and sustain a viable ongoing system of data collection and reporting. We suggest that federal agencies have an opportunity to more fully support development of best practices in data management and quality assurance/validation of the data and assist in the promulgation of these practices and tools across state initiatives. There are also opportunities to support commonality and relevancy in development of consumer-oriented information, such as shared investments in website and mobile application development geared to consumer use.

8. How do we ensure that in making information available we do not place unnecessary or additional burdens on health care stakeholders?

A critical aspect to minimizing burden is to leverage the claims payment transaction infrastructure, which is the foundational premise of the APCDs. APCDs rely on relatively standardized data feeds, reducing the burden on individual payers to report, and provide wide-angle views of the health care delivery system’s performance. Also, strategic linkage of state claims-based data with clinical information will enhance the value of the data without imposing additional abstraction burden on clinicians. States are demonstrating the feasibility of such
linkage, but states alone cannot develop a policy and technical infrastructure to support ongoing and effective linkage across data sources without federal support.

9. What current regulatory barriers exist within the health care system that should be eliminated in order to make it less burdensome and more cost-efficient for stakeholders to provide high-quality care to patients?

**Self-funded data collection:** As previously mentioned, the SCOTUS ruling in *Gobeille vs. Liberty Mutual* held that ERISA pre-empts certain self-funded insurers from submitting data to the state mandated APCDs. That ruling discussed the ability of DOL to use its authority to create a mechanism for data collection. Justice Breyer commented: "I see no reason why the Secretary of Labor could not develop reporting requirements that satisfy the States' needs including some state-specific requirements, as appropriate."10 In response, the APCD Council leaders, NAHDO and UNH, as well as NASHP submitted comments to a DOL rule that provides a path for these data to be collected.11 There are also modifications that can be made to ERISA as a solution to the issue.

**FEHBP data submission:** There are allowances that can be made by the Office of Management and Budget to streamline data submission from plans for Federal Employees.

**42 CFR Part 2:** There are clarifications that can be made by SAMHSA to provide assurances of the allowance of the submission of behavioral health and substance use disorder claims to state entities.

10. How can our health care system better utilize big data, including information from the Medicare, Medicaid, and other public health programs, to drive better quality outcomes at lower costs?

No one data set or data system will serve all of the needs of every user or supply information for every use. As information needs grow through value-based purchasing, population health management, and consumer transparency uses, policy makers and industry need to move beyond siloed and fragmented data sets to strategic approaches that include data sharing and data partnerships that leverage existing data assets more effectively. For example, states capture important information for their own policy and market uses (population health,

transparency, policy evaluation), yet these data sets capture important information such as Medicare Advantage encounters that should be of interest to CMS (which CMS does not routinely obtain). Strategic data exchange and data linkage will enhance the information that is already available without duplicating expensive data collection initiatives. For example, some states are linking claims with clinical information to develop robust risk assessment and performance evaluation reimbursement practices. Our comments have illustrated a range of data reports, information, tools, and data uses that inform can inform cost containment and quality improvement projects. These uses can be coupled with efforts around dissemination and education to maximize the use of the data.

11. What other common-sense policies should be considered in order to empower patients and lower health care costs?

A coalition of state and national payers, coordinated by the APCD team, have harmonized APCD reporting data elements and formats across states, known as the Common Data Layout (CDL). Policy efforts that focus on implementing the CDL in order to fill data gaps, as well as maintain and update and implement the common reporting formats, will reduce reporting burden and improve comparability of claims-based data across states. This effort has not been implemented due to a combination of factors: 1) Department of Labor delay in enacting a final reporting rule and 2) lack of funding to support the finalization and maintenance of the APCD reporting standard.

State and private reporting initiatives will benefit from shared solutions to common technical issues, where possible. Seeking common solutions to cross-cutting issues will benefit all. This includes:

a. Physician identifiers and attribution
b. Common approaches to data quality/claims data edit logic
c. Open-source measures and tools, such as episodes of care, consumer transparency tools, and quality measures

Resolutions to these barriers to enhanced health care transparency are not insurmountable, but states alone cannot solve them without federal collaboration. We recommend that federal-state partnership is needed to support continued development and commonality in claims-based data collection and use.

12 https://www.apcdn council.org/standards
We respectfully submit this feedback for your consideration as you move forward with your Health Care Price Transparency Initiative. We are available for further discussion.

Sincerely,

Denise Love, BSN, MBA
dlove@nahdo.org
Executive Director
National Association of Health Data Organizations
801-532-2262

Josephine Porter, MPH
Jo.Porter@unh.edu
Director
Institute of Health Policy and Practice, UNH
603-862-2964
List of Resources Cited in this Response:

www.nahdo.org
www.apcdcouncil.org
www.apcdshowcase.org
http://mhcc.maryland.gov/transparency/Default.html
http://www.health.state.mn.us/healthreform/olpayer/20160229_rxtrends.pdf
http://health.r.i.gov/data/potentiallypreventableemergencyroomvisits/
https://profiles.health.ny.gov/measures/all_state/16284
http://www.comparemaine.org/
http://healthcarecost.mhcc.maryland.gov/
www.nhhealthcost.com
http://www.chiamass.gov/mo-apcd/
http://www.scotusblog.com/case-files/cases/gobeille-v-liberty-mutual-insurance-company/
https://www.apcdcouncil.org/standards
Final Contract Report

Inventory and Prioritization of Measures To Support the Growing Effort in Transparency Using All-Payer Claims Databases

Prepared for:

Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857
www.ahrq.gov

Contract No. HHSA2902001200003I, Task Order 5

Prepared by:

Stanford University (Prime Contractor)
Sheryl M. Davies, M.A.
Kathryn McDonald, M.M.

Truven Health Analytics
Erica Danielson, Ph.D.
Manju Gokhale, M.A.
Stella Chang, M.P.H.

University of California, San Francisco
Naomi S. Bardach, M.D., M.A.S.
Grace A. Lin, M.D., M.A.S.
Mitzie Dean, M.S., M.H.A.
R. Adams Dudley, M.D., M.B.A.

APCD Council
Denise Love
Ashley Peters
Josephine Porter
Emily Sullivan

Stanford University
Center for Primary Care & Outcomes Research, School of Medicine
Center for Health Policy, Freeman Spogli Institute for International Studies

AHRQ Publication No. 17-0022-1-EF
March 2017
The findings and conclusions in this document are those of the author(s), who are responsible for its content, and do not necessarily represent the views of AHRQ. No statement in this report should be construed as an official position of AHRQ or of the U.S. Department of Health and Human Services.

**Disclaimer of Conflict of Interest**

None of the investigators has any affiliations or financial involvement that conflicts with the material presented in this report.

**Funding Statement**

This project was funded under contract number HHSA2902001200003I from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services. The opinions expressed in this document are those of the authors and do not reflect the official position of AHRQ or the U.S. Department of Health and Human Services.

**Public Domain Notice**

This document is in the public domain and may be used and reprinted without special permission. Citation of the source is appreciated.

Table of Contents

Introduction ......................................................................................................................... 1
  Overview of All-Payer Claims Databases ................................................................. 1
  Uses of All-Payer Claims Databases .................................................................... 1
  Purpose of Project ..................................................................................................... 2
Reviewing the Landscape of All-Payer Claims Databases ........................................ 3
  Technical Expert Panel ......................................................................................... 3
  Environmental Scan ............................................................................................... 6
Measure Inventory ....................................................................................................... 11
Data Evaluation of All-Payer Claims Databases ....................................................... 12
  Methods .................................................................................................................. 13
  Results of Data Evaluation .................................................................................... 13
Discussion .................................................................................................................... 21
  Limitations of APCD Data for Measurement ....................................................... 22
  Ongoing Efforts To Improve APCD Data ............................................................ 24
Conclusion and Future Directions ........................................................................... 25
References .................................................................................................................... 27
Appendix A: Technical Expert Panel and Learning Network Members .................. 29
Appendix B: Prioritization of Conditions for Measure Inventory ............................ 30
Introduction

Overview of All-Payer Claims Databases

For the past three decades, measures of health care quality have been embraced as tools for quality improvement, transparency, and accountability. As health care costs continue to rise, more stakeholders are calling for such measures to be used as part of value assessments, to understand how high health care expenditures, high out-of-pocket costs, and high local and Federal spending on health care can be shifted toward better care at better prices.

Price transparency, or readily available access to information on variations in cost across health care providers, alongside access to quality metrics, may help shape innovative policies, improve health care efficiency, and promote value in the health care system. Comprehensive datasets that support the development of quality and cost measures across large populations are well suited to reach these goals.

All-payer claims databases (APCDs) incorporate utilization and cost across the health care system and may fill critical data needs for State agencies and other stakeholders. The hope is that these databases can serve to inform policy and provide transparency for decisionmakers, including consumers, purchasers, and policymakers. APCDs are large datasets that aggregate medical, facility, pharmacy, and sometimes dental claims, as well as eligibility and provider data from private and public payers.¹

Currently, 18 States have legislation mandating the creation and use of APCDs or are actively establishing APCDs. More than 30 States are maintaining or developing an APCD, or have a strong interest in developing an APCD. Seven States have public reporting Web sites with cost and quality information either wholly or in part coming from APCD data.²

Uses of All-Payer Claims Databases

APCDs represent a new approach to providing information about care. Before the advent of APCDs, datasets tended to be limited to certain groups (e.g., Medicare and Medicaid claims, which omit a large portion of the overall population) or to particular components of care (e.g., hospital discharge abstract databases, which cover only inpatient care) and posed challenges making it difficult or expensive to follow patients longitudinally.

The promise of APCDs is that they allow creation of a more comprehensive picture of care than is otherwise available in most States.² By collecting data from all payers, State APCDs capture encounters for all but a small minority of patients (e.g., patients who are uninsured or are covered by a Federal health care plan such as Veterans Affairs benefits) and across settings.

This expanded database has several advantages, including that patients in a well-implemented APCD can be followed over time and across settings, to capture full episodes of care and account for variations in the type of care received. APCDs are not limited by turnover in patients among providers or payers because the records are captured for each patient regardless of provider or payer. This unique aspect of an APCD can facilitate measures of continuity of care, coordination of care, and other traditionally difficult constructs to measure.³ Compared with single-payer
databases, APCDs may have larger sample sizes, potentially facilitating measures for rarer events and among smaller entities (e.g., individual providers, small areas).

APCDs have a variety of other potential uses as tools for improving quality of care and population health. As mentioned at the outset, they create a more comprehensive picture of outpatient and pharmacy care than is otherwise available in most States as they include a large percentage of insured individuals, which allows APCDs to reflect the health of the population.  

APCDs also facilitate price transparency and highlight significant price variation in the system. Such transparency may allow purchasers to negotiate with providers more effectively. In addition, it can help providers assess their own quality and value in shared risk and accountability payment models and allows consumers to weigh value in health care decisions as they assume greater financial responsibility.  

Local data aggregated into APCDs can be used to understand local market functioning and assess whether spending variations reflect pricing, utilization, or both. APCDs also can provide data to help States develop strategic plans for public health legislation or to determine the impact of policy changes at the State level.  

In addition, APCDs can support research that may be of interest to State policymakers, such as comparative effectiveness studies or the development and evaluation of targeted interventions to improve chronic disease care.

The comprehensive nature of APCD data allows:

- Estimations of disease prevalence across a population,
- Identification of patterns of utilization and potential areas for targeted interventions, and
- Planning and evaluation of health reform programs and legislation on cost, quality, and access to care.

While APCDs offer many advantages over other databases, they do have known limitations. These include lack of data for uninsured patients, questions about the feasibility of gathering and maintaining datasets, variation in data quality among submitters, and lack of clinical detail (e.g., laboratory values, biometric details). It is unknown how these limitations affect the ability to use APCD data for quality and value measures locally, within States, and nationally.

**Purpose of Project**

The Agency for Healthcare Research and Quality (AHRQ) funded the APCD project, which focused on three areas:

- Review of the overall landscape of APCDs;
- Identification of measures of cost, utilization, and quality that can be defined using APCDs; and
- Evaluation of current APCD data for measurement use.

In addition, the project team convened a Technical Expert Panel (TEP) to provide input on the overall direction of the project and provide check-in opportunities on key project milestones. The TEP provided input for the environmental scan and literature review that was conducted for the
measure inventory. The TEP also provided critical feedback on priorities for the measure inventory.

The project focused on measures that address aspects of the health care system not covered well by other datasets, such as ambulatory care, pharmacy, and cost. Multiple use cases were considered for APCD-based measures:

- Supporting States in achieving overall high-value care for their population.
- Assisting physicians and physician groups in understanding quality and cost in managing their own patient populations.
- Supporting consumer choice when choosing providers or health plans, although currently this application is limited by the lag in price and quality information, and in some cases lack of relevant measures to support the decision.

After internal deliberations and TEP consultations, the team agreed to focus on measures that supported population health management.

This APCD project resulted in three specific work products:

1. **A report on the current APCD measurement landscape**: The goal of the environmental scan was to assess potential use cases for APCD measures and to understand and summarize the current evidence for and limitations of APCD measures. The environmental scan informed both the measure inventory and data analytics.

2. **An inventory of measures that could be constructed using APCD data**: The overall goal of the measure inventory was to provide a useful and usable inventory of measures that could be derived from APCDs, to provide a framework and basic measure specifications for assessing existing measures for use with APCDs, and to inform future measure assessment for other APCD users and use cases.

3. **A preliminary analytic assessment of three existing APCDs**: The goal of the data assessment was to acquire three APCDs and assess data availability, documentation, and data completeness. The analysis focused on aspects that were relevant to measures and provided a preliminary assessment of the completeness and face validity of critical data elements.

**Reviewing the Landscape of All-Payer Claims Databases**

**Technical Expert Panel**

**Panel composition and role.** A Technical Expert Panel (TEP) was formed based on suggestions from the project team and the AHRQ project officer. The TEP consisted of State APCD representatives, researchers, and consumer advocates, as well as a learning network (Appendix A lists TEP and Learning Network members). TEP members provided input on overall project direction and check-in on key project milestones during three focused TEP calls and occasional email-based discussions.

Goals for the first TEP call were to garner feedback on the approach to the APCD measure inventory. TEP feedback was desired on the framework for organizing and prioritizing measures.
The second TEP call used a thought experiment to help increase the usability and relevance of the measure inventory. The third TEP call focused on high-priority clinical areas to focus a more intensive evaluation of select potential measures ("the deep dive").

Over the three TEP calls and emailed feedback, the TEP provided key information on the APCD uses and users, organization and prioritization of measures, ideal application of APCDs to improve population health, and limitations of APCDs. They also ranked APCD use cases from various condition-specific areas.

**APCD measure audiences and potential uses.** TEP panelists noted that APCD measures have a variety of potential audiences, ranging from policymakers to consumers. Potential audiences included State health and data agencies, policymakers, payers, providers, third-party service providers, data or business analytic companies, consumers, and researchers.

Panelists maintained that policymakers were the primary target audience for initial reporting of measures using APCD data. These policymakers can affect further development of APCDs, as they need population-based measures that use readily available data, and are less affected by limitations such as data delays, which can severely limit the use of measures in consumer choice and negotiation.

Panelists noted that among the uses discussed, including choice, negotiation, accountability, and policymaking, one of the biggest potential targets for APCD measures is the market at large. Price transparency can be a powerful tool to help even out variations and constrain health care costs.

To further prioritize potential measures for inclusion in the measure inventory, panelists discussed the usefulness of the National Quality Forum (NQF) list of 20 high-priority Medicare conditions as one potential resource. Panelists noted that it may not adequately capture the interests of diverse audiences and recommended that consideration be given to three distinct payer audiences: Medicare, Medicaid, and payers. Consumers, for instance, would need measures that are "shoppable," meaning they cover conditions for which consumers have time to investigate the value of provider options.

The consumer use case was repeatedly discussed because consumer audiences have increasingly become a focus in reporting and use of APCDs. Panelists felt that while it would be useful to provide consumers with information on out-of-pocket costs, this use case presented certain challenges. A weakness of APCDs is the lag between claims and what is currently happening in the market. Given this delay, using the APCD for current pricing may not be effective or appropriate. Furthermore, informing the consumer was noted to be difficult and it would be hard to reach large numbers of consumers to change their behaviors in meaningful ways. Ultimately, an informed decision was made to not integrate consumer choice into the measure inventory.

Finally, usefulness and use cases are affected by data consistency and the ability to apply the measures across different APCDs and for across-State comparison. An illustration of this issue is that not all APCDs use the same clinical groupers (level of major diagnostic categories, diagnosis-related groups [DRGs]), and some do not use groupers at all. Thus, measures based on these groupings cannot be applied across APCDs.
Framework for organizing measures. Panelists expressed support for a framework presented by the project team, which organized measures by three functions of measures: choice, negotiation, and accountability. However, they noted that this might not be the most effective way to organize measures within the inventory. Panelists expressed the need for a framework that was flexible and could encompass the many possible current and future uses of APCD data.

Ideas for improving the framework included:

- Adding uses or functions such as feedback to providers and transparency.
- Considering which audience or stakeholder a use case applies to.
- Considering who the individual users are and their unique needs.
- Integrating use (such as the Choice, Negotiation, Accountability framework) and audience.

Ideal application of the measure inventory. To guide the presentation of the measure inventory to maximize its usefulness for the target audience of States, TEP members were asked to engage in the following thought experiment: “Imagine you are a state developing and/or maintaining an APCD. What would be the ideal application of that APCD to improve population health?” In response, TEP members provided the following feedback:

- TEP members noted the power of an APCD dataset lies in its ability to look at a broad cross-section of patients from multiple different payer types for any given provider. It was suggested that there is great interest in using such data to spot variation (e.g., in utilization, spending, rates of preventive screenings) and determining why that variation exists.
- Panel members expressed interest in looking at children across commercial versus Medicaid and the Children’s Health Insurance Program to analyze access and utilization rates to study disparities.
- TEP members found it valuable to make data available to researchers and to have a dataset that allows people to investigate a broad range of topics.
- Topics of great interest included high-cost populations and the opioid addiction problem.
- Finally, panel members suggested that it might be more manageable to classify different stakeholder groups, develop an understanding of how each contributes to population health, and determine what information might allow each to make more meaningful contributions to population health.

High-priority clinical areas for measurement. To assist with selecting measures that would be assessed indepth, TEP members discussed and ranked the importance of use cases from a predetermined set of clinical priority topics: Diabetes, Mental Health and Substance Abuse, Childbirth and Reproductive Health, Imaging, and Medications. These topics met the criteria of being common clinical concerns and having multiple identified potential measures.

- **Diabetes**: Some members ranked this condition as high priority due to the large proportion of health care spending and it being a broad public health problem. Diabetes also offers an opportunity for improvement by better understanding differences in patterns of care across geographic regions.
• **Mental Health and Substance Abuse:** Members had widely differing opinions on Mental Health and Substance Abuse. One member ranked it as high priority because the topic was of interest in his/her State, while others ranked it as middle or lower priority. There was also uncertainty among the panel about the collection of mental health and substance abuse data, especially, privacy laws and concerns or noncoverage of care. Although some saw this condition as a high priority, others raised concerns that measures identified in the measure inventory were not sufficient to understand the cost/quality paradigm, specifically due to the limited number of quality measures. Also, utilization and cost measures in the absence of quality measures could be misleading and thereby discourage people from seeking services altogether in areas with limited choice or alternatives.

• **Childbirth and Reproductive Health:** Some members felt this area was high priority, because from the consumer perspective, there is time to plan; from the provider perspective, there is an opportunity to inform and educate. It was noted that the frequency of the ongoing prenatal care measure would be a challenge and APCDs may not be able to support this measure, but the area crosses payers, thereby providing consumers the ability to take action.

• **Imaging:** This use case ranked low among TEP members. They noted a limited breadth of measures, along with issues such as sizable price variation in imaging; and different technologies used for the same procedure, which leads to unproductive conversations and disagreement on costs.

• **Medications:** One of the advantages of an APCD is the ability to highlight differences in amounts paid for common medications. There are opportunities to focus the measures around medication to inform public policy that could result in better care and lower costs.

More TEP members prioritized diabetes than other categories, stating that the topic has the prospect of improving care dramatically for a significant portion of the population. In addition to diabetes, members suggested expanding the topic to focus on high-cost, manageable, chronic conditions in general (e.g., asthma, mental health, substance abuse). Mental health was the second most commonly prioritized topic area; TEP members hoped that the focus would promote development of better measures.

**Environmental Scan**

**Objective.** The objective of the literature review and environmental scan was to map an approach to creating an inventory of measures of quality, cost, and utilization of care across settings for potential use with APCDs, noting gaps or current barriers to APCD measurement. The literature review and environmental scan provided a foundation for the work, describing the breadth of available measures and generating a framework for choosing measures and organizing them in the final inventory.

A large number of measures are based on administrative health data, in particular, hospital discharge abstract databases. For the purpose of the environmental scan, the focus was on measures that leveraged the unique aspects of APCD data. These included longitudinal data from multiple sources that allow patients to be tracked across time and settings, pharmacy data, and data on dollar amounts paid by insurers and patients. These key characteristics of APCDs enable measurement not possible with hospital discharge claims data alone, in particular, measures of...
ambulatory care (including measures that require data from multiple settings), episode-of-care measures, and cost measures.

**Guiding questions.** Several guiding questions were used to focus the search strategy and data collection efforts. The guiding questions resonated with the objectives of the report:

1. What measures or outcomes (quality, utilization, safety, price, etc.) that leverage the unique data in APCDs have been reported in the scholarly literature or in online public reports using APCD data?
2. What measures or outcomes have been proposed for use with APCD data or claims data that are episode based or longitudinal in nature?
3. What important measure gaps have been noted in relation to transparency initiatives? Have APCD-specific measure concepts been proposed to fill these gaps (even if no fully specified measures yet exist)?
4. What potential barriers to using and reporting measures with APCD data have been identified in the peer-reviewed or grey literature, including issues around availability and access to data elements? What strategies for overcoming these barriers have been proposed in the literature?
5. What are some of the methodological considerations and issues pertaining to using APCD data for measurement that have been discussed in the peer-reviewed or grey literature?

**Summary of key findings from literature review and environmental scan.** The peer-reviewed literature search yielded two basic types of articles: overview papers presenting concepts related to measurement in the areas of focus and those presenting particular measures used in addressing the authors’ specific research question. The team screened a total of 189 articles; of those, 98 articles were included in a full review, of which 17 were overview articles and 81 were research articles.

Overview articles presented concepts related to measurement using APCDs or other large claims databases. The research articles focused on measurement of cost, quality, or utilization using APCDs, multipayer claims databases, or other claims databases (Medicare or Medicaid). The measures found most often focused on a specific research question or discussed the application of specific measures for public reporting or price transparency initiatives.

The environmental scan yielded information on existing APCDs and the potential of using APCDs to measure quality, cost, and utilization of care across populations and settings. Of the 236 different sources of information identified using the initial search criteria, 127 sources were included that met the inclusion criteria for this report. Sources found in the environmental scan came from AHRQ expert materials, the APCD Council, reports, task force papers, policy briefs, trade papers, business journals, white papers, books, APCD public reporting Web sites, measure inventories such as the National Quality Forum (NQF), and other sources.

National and State-specific general resources most often described the basis for the national trend to develop APCDs, as well as State-specific issues related to building or implementing APCDs. State resources, in particular, focused on building the case for and the barriers to establishing APCDs and using them for measurement. Many States with active APCDs have also issued reports of statewide quality, utilization, and cost.
Finally, resources related to price transparency were also included, as this is a major application of APCDs. The resources included high-level summaries of current efforts and barriers from governmental and nongovernmental sources, as well as State-level price transparency reports.

**Major organizations and key contributors to APCDs and measurement.** Several national organizations have developed expertise with APCDs and measurement using APCDs and have created resources and provided support for States creating APCDs. Such organizations include AHRQ, which has supported several initiatives, including:

- The United States Health Information Knowledge (USHIK) database (available at [https://ushik.ahrq.gov/mdc/portals](https://ushik.ahrq.gov/mdc/portals)), a repository for State APCD file submission specifications and data elements;

Nongovernmental organizations have also played a key role in advancing the science and implementation of APCDs:

- The APCD Council and the National Association of Health Data Organizations have taken the lead in supporting and documenting current State efforts and legislative work around APCDs. Efforts include working to harmonize data collection and release across States and providing technical and policy support to States that have or are developing APCDs.
- Catalyst for Payment Reform is a nonprofit organization that brings the perspective of purchasers to APCD efforts. They also provide tools such as report cards on States' efforts on price transparency to help purchasers and other stakeholders understand issues related to payment reform and transparency.
- The Health Care Cost Institute is a nonprofit organization whose goal is to provide access to health care cost and utilization data to researchers and policymakers trying to understand the factors influencing health care costs. They create twice-yearly cost reports based on claims from four major insurers.
- The Robert Wood Johnson Foundation has also been instrumental in bringing together multiple stakeholders to improve the quality of health care. For example, their Aligning Forces for Quality initiative has resulted in public report cards about quality in some States.
- In terms of measurement science, NQF is a leader in endorsing and encouraging implementation of evidence-based, valid, reliable measures that are meaningful to stakeholders, including consumers.

Other major sources of measures for this report included the literature review, public reporting Web sites from APCDs, and other online reports of cost and quality. Individual organizations, such as the National Committee for Quality Assurance (NCQA), the Quality Alliance Steering Committee (QASC), and Bridges to Excellence, also had useful measures.
**Major sources of measures.** The table below gives a high-level overview of the key sources of measures identified through the environmental scan and literature review. The focus was on measures that leverage the strengths of APCDs, namely ambulatory measures, episode-of-care measures, and cost measures. This review formed the basis of the measure inventory for use with APCDs. Because numerous measures were identified, the first step of the measure inventory was to prioritize the measures.

| Table 1. Number of measures or number of public reports for potential use with APCDs |
| Source                                                                 | Number                                      |
| Literature review                                                     | 65 papers\(^1\)                              |
| NQF Administrative Claims measures                                    |                                             |
| Ambulatory quality                                                    | 143 measures                                 |
| Resource                                                               | 9 measures                                   |
| National Quality Measures Clearinghouse                                |                                             |
| Episode measures                                                      | 141 measures                                 |
| Cost measures for physicians                                          | 74 measures                                  |
| APCD public reports                                                   | 7 Public Reporting Websites                   |
| Other public reports with cost or resource measures\(^1\)              | 7 Public Reporting Websites or Reports        |
| Other measure stewards or resources                                   |                                             |
| NCQA Relative Resource Use Measures                                   | 5 measures                                   |
| Quality Alliance Steering Committee                                   | 22 measures                                  |
| APCD Showcase                                                         | 41 reports                                   |
| Bridges to Excellence                                                 | 2 NQF-endorsed measures                       |


\(^1\) These papers provide measures or potential measures by describing one measure that is specific to the study question, using claims data, or describing the use of a group of measures that are already in use and are described elsewhere (e.g., NQF-endorsed measures, CMS measures).


The literature provides studies using individual measures, some with well-described technical specifications. NQF and NQMC are measure aggregators and provide access to structured technical specifications. Public reporting Web sites either explicitly use State APCD data or use a combination of several data sources and measures. Some of these can be adapted for use with APCD data, although technical specifications are not always easily available through the online resource. Lastly, several organizations contribute discrete groups of claims-based measures. For example, NCQA, QASC, and Bridges to Excellence have made the technical specifications publicly available or available on request.

**Key categories and domains for measures that leverage APCD data.** The team identified key concepts and measure categories described in the literature review and environmental scan. These key categories and domains were used to organize the measure inventory, as well as in prioritizing certain categories of measures.

For instance, the purpose of performance reporting (e.g., for choice, negotiation, or accountability) can help guide measurement choice in the following way: if the purpose of a public report is to support consumer choice of providers, then a cost measure that only shows the average insurance
reimbursement rate without including the patient out-of-pocket cost for each provider will not be helpful. However, if the purpose of the measure is to assist in negotiations between insurers and providers, average insurance reimbursement would be potentially more useful.

In addition, measures may be used for population health and policy purposes. For example, population-level measures of utilization and cost are important to strategic planning to help eliminate health care disparities at the State, regional, and local levels. APCD data may also be used in State operations such as budgeting and rate review.

**Barriers to using APCDs for measurement and potential solutions to overcome them.** Although APCDs are meant to contain comprehensive claims data across settings and time, there are still many barriers to using APCDs for measurement. Issues with data completeness, quality, standardization, and access hamper such efforts. Identifying and resolving these barriers is critical to using APCDs to improve health care value. The table below summarizes key barriers to APCD data collection and use and potential solutions for overcoming them.

<table>
<thead>
<tr>
<th>Table 2. Key barriers and potential solutions related to data availability, quality, and access</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barrier</strong></td>
</tr>
<tr>
<td>Missing data elements</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Low data quality</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Lack of data standardization</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Difficulty with data linkage and aggregation</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Lack of data access and availability</td>
</tr>
<tr>
<td>Policy barriers and resource limitations</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

**Methodological issues or barriers pertaining to using APCD data for measurement.** As more States develop APCDs and public reporting Web sites based on APCD data, it is critical to find valid measures that are relevant to stakeholders and feasible to implement on a large scale. Multiple methodological issues have arisen in pursuit of this goal. Key issues include:

- Inadequate measurement science that may threaten the validity and reliability of measures.
- Lack of standardization of measure concepts and specifications.
- Difficulties in implementing measures due to privacy concerns, denominator deficiency, difficult or inaccurate provider attribution, inadequate risk adjustment, or provider reluctance to participate in public reporting initiatives.
- Measure gaps, including methodological gaps and gaps in existing measures.
These methodological issues and measure gaps will need to be addressed for States and others to fully realize the potential of APCDs in increasing health care value. Some States are using their APCDs initially for public reports of State-level performance and substate (e.g., county or ZIP Code level) variations before the release of more granular analysis (e.g., by provider or payer). This allows early public reporting of policy-relevant data from APCDs for State decisionmakers, while the barriers described above are being addressed.

**Conclusion.** While it is clear that there is much to be learned to maximize the potential of APCDs and to reduce the difficulty and cost of using them, there is also national momentum building behind developing measures to be used with APCDs and defining the business cases for maintaining APCDs. This environmental scan provides an overview of both the potential for APCDs to generate the information needed to improve care, as well as caveats to keep in mind while doing so.

**Measure Inventory**

The overall goal of the measure inventory was to provide a useful and usable inventory of measures that can be derived from APCDs. The inventory is based on a literature review and environmental scan completed in January 2015. It consists of measures identified in spring 2015 from the environmental scan, in consultation with a multi-stakeholder TEP, and with AHRQ program officer input.

Collected measures related to cost, utilization, and quality focused on measures relevant to ambulatory care or measures across settings (inpatient and outpatient), because APCDs are distinguished from other widely available datasets (e.g., hospital discharge data) by the inclusion of claims across multiple settings. The measures also focused on high-priority conditions, chosen based on a brief environmental scan (spring 2015) of priority conditions identified by the Institute of Medicine, the National Quality Strategy, the Centers for Medicare & Medicaid Services, Healthy People 2020, and others (noted in Appendix B).

The high-priority areas included:

- Measures that are not condition specific, such as imaging and medication management, and
- Measures that address specific high-priority conditions, (i.e., cardiac disease, preventive services, kidney or bladder conditions, mental health and substance abuse diagnoses, diabetes, and gastrointestinal disorders).

Several use cases for APCD-based measures have been proposed, including:

1. Choice, defined as measures that inform consumer or purchaser decisions;
2. Negotiation, such as use of measures in price or contract negotiation;
3. Accountability, or measuring provider or plan quality and efficiency of care; and
4. Population health and policy, to assess population health and inform and assist in policy decisions for States (e.g., efforts to assess health reform efforts or decrease cost).
In the literature review, environmental scan, and discussions with the TEP, the team assessed the use case that might best support the development and use of APCDs and be most useful to the States sponsoring them. The TEP found that the State-based use case focused on population health management was likely the most immediately useful and feasible one.

The inventory includes 302 measures. Provided with each measure is a brief description of the measure, measure steward, NQF endorsement status, type of measure (cost, quality, or utilization), risk adjustment, and Web site or reference (if measure is from the literature) where the measure was found.

In addition, for a smaller subset of measures, the team conducted a “deep dive.” The team chose deep dive measures from high-priority topics with measures for cost, quality, and utilization. These measures contain more detailed measure specifications, information on whether validity and reliability testing were conducted, and information on use in Federal programs, among other details.

In summary, a large number of measures are available for potential use with APCDs, covering a broad range of topics. Measures were grouped together to assess cost, quality, and utilization for specific topic areas for an assessment of population health management within or across diseases.

Although there are some limitations to both APCD data and the measures themselves, the measure inventory demonstrates that APCDs are potentially powerful new tools for monitoring population health. They can be used to paint a more complete picture of health care delivery, across payers and across settings, in ways that have not previously been possible. With continued development of both APCDs and measurement, stakeholders such as States, payers, providers, and consumers can look to use the APCDs to help fulfill the Triple Aim of better health, better quality, and lower costs.

**Data Evaluation of All-Payer Claims Databases**

To further assess the potential and current limitations of APCDs to support health care measures, the team acquired APCD data from three States, along with accompanying documentation and online documentation. These data were used to conduct preliminary analyses. The focus of the assessment was on tables and fields particularly relevant to the calculation of health care measures, such as those identified in the measure inventory.

Specifically, each APCD was reviewed to:

- Determine whether the fields received were correct (e.g., fields provided matched the documentation, values fell within expected ranges);
- Document any anomalies;

---

1 In agreement with the States providing the data, the States are not named in this report. Resource limitations allowed limited analyses, focused primarily on descriptive statistics and missingness of data across the full, unmanipulated datasets. The results are presented in qualitative form in accordance with the project-specific Data Use Agreement for each APCD.
• Note any differences over quarters, across States, or both;
• Provide a preliminary assessment of whether the data could be used to construct reliable and valid health care measures; and
• Provide insight into future analyses that will further validate these data for use in measure construction.

Methods

The team analyzed data for each State separately and did not link the data across States. The APCDs evaluated were limited or restricted datasets to provide a fuller range of variables that could be used for measure construction and to provide information on potentially useful variables for validating APCD data elements in future projects. When feasible, the datasets include the majority of non-patient-identifying fields (except for unique, encrypted patient identifier) from medical claims, enrollment records, and provider records.

This initial evaluation focused only on medical and pharmacy claims. While some States include dental claims, these were not evaluated. Also, due to limitations in data availability and time available to obtain data, APCDs varied with regard to the inclusion of Medicare and Medicaid records, which limited the ability to compare analyses across States.

The analyses were conducted and are reported in accordance with each State's Data Use Agreement. Detailed data analyses were available to AHRQ and researchers to construct recommendations for future work.

The analyses were intended as a high-level overview of the existing, unmanipulated APCDs. The overall data assessment sought to assess:

1. Accessibility of data.
2. Basic usability of data and documentation received.
3. Availability of data elements needed to construct health care measures in the utilization, quality, and cost domains, such as unique identifiers, provider or facility identifiers, service dates, sociodemographic fields, payment fields, revenue codes, clinical diagnosis and procedure codes, payer, and claim status.
4. Consistency of the distribution of key data elements with the documented data standards and face validity of the values.

For all key fields, the percentage missing/populated, distribution of values for continuous fields, and frequencies for categorical variables (up to 50 most frequent values) were calculated. The team also assessed the number of unique patients, unique claims, and number of transactions by month. These numbers were compared with State populations obtained from the U.S. Census Web site for qualitative assessment only.

Results of Data Evaluation

Availability of APCD data. This report provides a brief summary of the availability of datasets. Because the project required a large number of potential variables to conduct the global assessment, the experience of obtaining data for this project may not reflect the experience of
obtaining data for other measurement efforts. Although up to 14 States had APCDs in 2014, only 7 had made those data available for extramural analyses. Four State APCDs were pursued with the intention of obtaining three for analysis.

The applications for data varied somewhat but were all reasonable in length and detail and were consistent with other data request applications. One application for a Limited Data Set version was denied due to the lack of consistency of this project’s goals with the data release guidelines for that APCD. In some cases, the process for obtaining data required iterative submissions and communication with the APCD organizations.

Overall, the application process required more time than anticipated, but all remaining applications were approved, except for Medicaid data for one State. The data were provided at a cost consistent with other public datasets, and educational or government rates were frequently available. Some States provide data without charge to government or educational institutions.

**Data usability assessment.** The first step was to confirm that the expected data files were received with documentation and to assess the ability to convert the flat data files into SAS files. The analysts completing these tasks were experienced in taking in raw data of this type, such that the usability assessment here may have limited application to users with less data experience.

All data dictionaries, control totals, and user guides were received as they were available with the data. Few issues were experienced in loading the data. Upon data intake, the team learned some files were missing from one State dataset as specified in the documentation and some documentation did not match the data layout provided. One file could not be imported into SAS for unclear reasons. The APCD team worked with the project team to provide a file that could be read. When available, the record numbers reported in the control tables were observed in all resulting SAS files.

In general, States provided reasonable assistance with all issues identified. However, because APCDs are often run with limited staff, adequate time allocations were required to be made to overcome the limited staffing of these organizations.

Examination of the reference tables (e.g., lookup tables providing labels for market, diagnosis codes, etc.) for all three States did not show any problems with the values in these tables with regard to duplicates or values/contents in the files. One can use the lookup tables with confidence.

**Evaluation of data elements and completeness.** The team checked the databases for unique members, data elements used to construct health care measures, and other criteria such as data elements used to identify unique encounters.

*Unique members in database.* The team assessed the total number of unique members by month to observe any large fluctuations that may suggest concerns about the unique patient
identifier or completeness of the claims provided. In some cases, modest variability over time was found, which appeared from Web site documentation to be due to incomplete claim submission.\(^\text{ii}\)

It was observed in one case that the total number of unique individuals could exceed the population within a State, suggesting incomplete matching of claims to individuals. This situation can occur due to carve-outs, multiple coverage for one individual, duplicate claims, or failures in the patient identifier encryption methods. Despite these two issues, which were addressed in subsequent data releases or clarifications, these analyses showed reasonable numbers of unique patients relative to State populations and consistency over time.

**Data elements used to construct health care measures.** APCDs are typically organized into eligibility, claim, and provider files. However, data elements across these files are important to construct health care measures of utilization, quality, and cost. This section discusses several groups of measures that serve unique functions in health care measures. For any given measure, a subset of these elements would be used.

This section aims to describe the completeness of the data in qualitative terms, consistent with the project-specific Data Use Agreements and to provide context for the findings of the limited analytic review. In many cases, further analyses would better evaluate the validity and reliability of these data elements. This section also notes similarities and differences between the definition and coding of the data elements, as such consistency across States provides additional measurement opportunities.

**Data elements used to identify unique encounters and link encounters.** Most measures derived using APCD data will at minimum require the distinction between the type of health care encounters represented by the claim, such as isolating outpatient visits or prescriptions. Here, the team made the assessment on the following:

- Unique patient identifiers,
- Service dates,
- Variables that provide clues to movement through the health care system (e.g., discharge status or admission source),
- Variables used to identify the type of encounter (e.g., hospital, pharmacy, outpatient), and
- Claim status, used to determine whether a claim is the final paid claim.

The analyses show the percentage missing on all claims for variables used to isolate or link encounters. Some variables are not expected to be 100 percent populated, because they are only used for specific claim types, such as inpatient claims. Other variables, while being fully populated, have important caveats.

Identifying unique encounters requires that data elements facilitate removal of any duplicate claims. Unlike administrative data, such as hospital discharge data, a single encounter often results in multiple claims from providers, facilities, and pharmacy and may also have multiple claims representing different claim processing statuses. Variables such as service dates and

\(^{\text{ii}}\) Missing claims are frequently added in subsequent releases of the data.
bill/service types are essential to build a dataset with only unique encounters, but additional variables such as clinical variables or provider variables are also important. These variables are described later, because they also serve other functions in health care measurement.

Some measures count encounters of a certain type without concern for multiple unique encounters for a single patient, such as the total number of prescriptions of a class of medication per population. In this case, whether 50 or 500 people obtained the observed prescriptions is not relevant to the measure. These measures would require information about (1) the service or bill type, to isolate the encounter type of interest; (2) the service provider and date, to ensure unique claims; and (3) the status of the claim, to ascertain whether the claim is the final adjudicated claim. In this case, encrypted member or patient identifiers will also assist in identifying unique encounters, even if the measure does not require linking across encounters.

Measures designed to track care across the health care system, to track encounters for the same individual over time, or to construct “episodes of care” all must have robust patient identifying information. For this purpose, a unique encrypted patient identifier is necessary. Additional information about the patient, such as age, gender, date of birth, or clinical information about the encounter (e.g., diagnosis or procedure codes), can be used to ensure proper linkages across claims and to clean data.

Although the analyses did not specifically examine the quality of the patient identifying variable, some modest fluctuation over time was observed (i.e., more unique individuals were identified within a database than anticipated). This suggests that single individuals may have more than one unique identifier, complicating linkage of claims.

Because some variables are unique to inpatient encounters, the analyses were inconclusive but suggest further investigation to understand these variables. The completeness of inpatient-specific variables varied even within APCDs by 5 to 15 percent on the low end; in some cases, one or two variables appeared to be populated at a much higher rate. This variation suggests that the variables may contain either invalid or placeholder entries or may be used for claims of different service or facility types. Overall, the data completeness was robust.

Although users should always analyze for and potentially remove duplicate claims for the same encounter, many APCDs intake data from payers and prepare the data to assess quality and remove certain duplicate claims. For instance, in Maine, the State data steward applies an algorithm to remove duplicate pharmacy claims so that the same prescription will not be double counted.6

Some data cleaning undertaken by the APCD or the user will remove real multiple encounters that occur on the same day, such as multiple emergency department visits or the same drug administered twice on the same day. As of yet, however, few variables are available to assist with such targeted data cleaning. Further, the issue of duplicate claims likely far outweighs the claims lost.
Table 3. Select variables useful for identifying and linking encounters

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Range of Nonmissing Across APCDs and Quarters</th>
<th>Notes on Expectations and Validity*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unique patient identifier</td>
<td>100% consistent across quarters and years</td>
<td>Unique patient identifier is typically created and fully populated. Usefulness of the identifier may be affected by methods used to create identifier. Observed higher numbers than anticipated given known covered lives, suggesting multiple identifiers per patient.</td>
</tr>
<tr>
<td>Service date</td>
<td>100% consistent across quarters and years</td>
<td>Typically includes day, month, and year.</td>
</tr>
<tr>
<td>Admission date</td>
<td>Highly variable, 10%-100%</td>
<td>Required only for inpatient claims, so lower rates would be expected. Unclear whether quarters with 100% of claims with nonmissing admission dates represent valid dates or whether dates match the service date. In general, inpatient claim variables are not reported at the same rate in data, suggesting use of fields for non-inpatient claims or missing values.</td>
</tr>
<tr>
<td>Admission type</td>
<td>Highly variable, 16%-75%</td>
<td>Required only for inpatient claims, so lower rates would be expected. Unclear whether quarters with 75% of claims with nonmissing admission type represent valid data. In general, inpatient claim variables are not reported at the same rate in data, suggesting use of fields for non-inpatient claims or missing values.</td>
</tr>
<tr>
<td>Discharge date</td>
<td>Highly variable, 21%-93%</td>
<td>Required only for inpatient claims, so lower rates would be expected. Unclear whether quarters with 93% of claims with non-missing dates represent valid dates or whether dates match the service date. In general, inpatient admission date and discharge date are reported at different rates, suggesting use of fields for non-inpatient claims or missing values.</td>
</tr>
<tr>
<td>Discharge status</td>
<td>14%-37%</td>
<td>Required only for inpatient claims, so lower rates would be expected. In general, APCDs were less variable in reporting but reported frequently on more claims than anticipated (typically, 30% of claims are not inpatient).</td>
</tr>
<tr>
<td>Admission source</td>
<td>13%-41%</td>
<td>Required only for inpatient claims, so lower rates would be expected. In general, APCDs were less variable in reporting but reported frequently on more claims than anticipated (typically, 30% of claims are not inpatient).</td>
</tr>
<tr>
<td>Bill type, service type, billing provider type</td>
<td>95%-100%</td>
<td>APCDs have different ways of populating this key variable. National billing standards break out facility type from provider services. While all APCDs evaluated had the standard fields populated at similar rates, each had unique fields that were fully populated with the type of service or facility.</td>
</tr>
<tr>
<td>Claim status</td>
<td>100% consistent across quarters and years</td>
<td>Variable is reported consistently, but the available categories vary by APCD.</td>
</tr>
</tbody>
</table>

*Additional information on validity can be found in Discussion section of this report.
Data elements that describe the clinical aspects of an encounter. Because claims data focus on payment, the clinical information provided is limited. However, to provide context for and to justify a claim, certain useful clinical elements are included:

- International Classification of Diseases, Ninth Revision (ICD-9, and now, the Tenth Revision, ICD-10) codes for diagnoses and associated present on admission (POA) flags
- Current Procedure Terminology (CPT) or ICD-9/10 codes for procedures
- Drug codes for pharmacy claims and details about the prescription, such as whether it is a new prescription or refill, the quantity dispensed, and the anticipated day supply.

These fields were found to be nearly always populated as appropriate.

First listed or principal diagnosis codes were usually listed, while secondary diagnosis codes were listed in just over half of claims and further diagnoses dropped further. Although secondary diagnoses can be used across different types of claims, it is known that outpatient claims contain fewer diagnosis codes. Secondary diagnosis codes often do not affect reimbursement. But for inpatient claims, where these codes do affect reimbursement, the number of available diagnosis code fields can affect measures.

Even in the inpatient setting, the APCDs evaluated did not adequately support POA coding, which should be available for all secondary diagnoses (and can be assigned to principal diagnoses). The lack of secondary diagnosis codes and POA coding affects the usefulness of these data for adequate risk adjustment without linking across multiple encounter and pharmacy records to establish comorbidities for a patient.

Procedure or service codes could be assigned to office visits as well as inpatient visits, but high variability in the inclusion of these codes was observed. This finding is consistent with other similar data.

DRG data are of limited usefulness in all-payer data unless derived after data are received, as providers are often not required to report DRGs to payers that do not use DRG-based reimbursement.

Table 4. Variables that describe the clinical aspects of the encounter

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Claims Populated Range in Quarter and State*</th>
<th>Notes on Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principal or first listed diagnosis</td>
<td>99%-100%</td>
<td>ICD-9 or ICD-10-CM codes</td>
</tr>
<tr>
<td>Secondary diagnoses</td>
<td>The secondary diagnosis codes range from 53%-66% for the second position, then appropriately drop in frequency after about 5 diagnosis codes.</td>
<td>Secondary diagnosis codes can be included in records of different types but typically are more frequent in inpatient records where secondary codes can affect reimbursement. Outpatient records often include a limited number of diagnosis codes.</td>
</tr>
<tr>
<td>POA</td>
<td>0%-33%</td>
<td>Typically accompany inpatient diagnoses only but variable not populated or reported for majority of States/quarters.</td>
</tr>
<tr>
<td>Variable Type</td>
<td>Claims Populated Range in Quarter and State*</td>
<td>Notes on Expectations</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>---------------------------------------------</td>
<td>---------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Admitting diagnosis</td>
<td>4%-31%</td>
<td>Most State-quarter combinations have high missing rates (more than 90% missing). Admitting diagnosis differs from principal diagnosis, which is assigned at discharge. Low rates of admitting diagnosis are consistent with other data.</td>
</tr>
<tr>
<td>ICD-9 Principal Procedure</td>
<td>3%-22%</td>
<td>ICD-9/10 procedure codes are used most frequently in inpatient or high-intensity outpatient settings (some emergency departments, ambulatory surgery). Expected percentage is low, because not all receive procedures. Some APCDs combine procedure classifications into one variable (CPT, ICD-9).</td>
</tr>
<tr>
<td>CPT #1</td>
<td>20%-94%</td>
<td>Some APCDs combine procedure classifications into one variable (CPT, ICD-9). Outpatient encounters can almost always receive a CPT service code for an office visit.</td>
</tr>
<tr>
<td>Secondary procedure codes</td>
<td>&lt;10%</td>
<td>APCDs vary on number of procedure fields available.</td>
</tr>
<tr>
<td>DRG</td>
<td>3%-17%</td>
<td>Typically only for inpatient claims. Not all payers use a DRG system. This will be populated at a low rate and for younger patients, lower than the inpatient rate. The DRG version is reported for a quarter of cases but may be auto-populated.</td>
</tr>
<tr>
<td>National Drug Code</td>
<td>100%</td>
<td>Included in the pharmacy claims, but reliability was not assessed.7</td>
</tr>
<tr>
<td>Prescription details such as refills, day supply, quantity</td>
<td>100%</td>
<td>Included in the pharmacy claims, but reliability was not assessed.</td>
</tr>
</tbody>
</table>

* Unless specific to a pharmacy claim as noted, all missing values are based on the medical claim records only.

Data elements used in attribution to a provider or payer. APCD data can be used to calculate measures at different levels, including geographic (e.g., State), payer, facility, or provider. Because of the nested nature of the data, it is possible to build measures, but attribution remains a complex problem in most data sources.

Providers may use multiple Medicaid numbers or National Provider Identification numbers or provide care across different locations based on administrative and logistic features of their practice. Therefore, it can be difficult to attribute all encounters to the provider. The team observed a large number of providers in some quarter-State combinations, suggesting single providers using multiple provider IDs. The team did not evaluate whether the location of service was populated for most provider claims or if the population was consistent with the data submission guidelines. In addition, prescribers were not consistently identified in pharmacy records.

It is important to evaluate the provider data across the data tables. For instance, the master provider table may have limited information on specialty, while the claims table has this field populated as expected. Provider address and name variables can be used to further validate providers but can also vary by table.
The data also do not provide definitive markers for either assigned or utilized primary care providers, medical homes, or other constructs. This information may be estimated based on plurality of visits, payment arrangements suggesting medical homes, or other methods. A current NQF committee has developed a report on the attribution of care to providers and facilities.

Table 5. Variables used for measure attribution

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Missing Range in Quarter and State</th>
<th>Notes on Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Submitter</td>
<td>100%</td>
<td>Some records have submitters that differ from the payer.</td>
</tr>
<tr>
<td>Payer</td>
<td>100%</td>
<td>In some record types, payer may be reported less frequently.</td>
</tr>
<tr>
<td>Pharmacy location</td>
<td>74%-99%</td>
<td>ZIP Code</td>
</tr>
<tr>
<td>Billing provider (any unique</td>
<td>100%</td>
<td>The best variable for identifying billing providers is not clear. APCDs may populate</td>
</tr>
<tr>
<td>identifier)</td>
<td></td>
<td>Medicaid or Medicare numbers, National Provider Identifier, or unique provider codes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some have multiple fields populated. Observed high numbers of providers in some cases,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>suggesting multiple identifiers for one provider.</td>
</tr>
<tr>
<td>Service provider city/ZIP Code</td>
<td>0%-100%</td>
<td>State is always provided, but more granular data varies depending on data request.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Must justify more granular data when available.</td>
</tr>
<tr>
<td>Location of service</td>
<td>58%-100%</td>
<td>Location of service varies for State-quarter combinations.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Applies to provider records.</td>
</tr>
<tr>
<td>Primary insurance indicator</td>
<td>96%-100%</td>
<td>Flag or identification of primary insurance.</td>
</tr>
</tbody>
</table>

Variables used to calculate cost. The variables associated with payment for services, which allow tracking and measuring of expenditure trends, were nearly always populated. These included payer/submitter, diagnosis, procedure, and all payment fields (copay, deductible, coinsurance, prepaid, and insurance payment). This finding is not surprising given that these data files are built from claims submitted to payers for reimbursement.

In relation to out-of-pocket health care costs, although all records have information on co-insurance and deductible, few records contain any information on the premium patients paid. Another source of missed costs is the exclusion of denied claims, which may, if not paid by a secondary insurer, result in out-of-pocket payment.

Other cost information related to secondary or other payers varied, such as co-insurance days or Medicare payments. However, because the total number of records where these fields would be relevant is not known, an assessment cannot be made regarding the observed variation in the completeness of these variables. Not all APCDs contain information on secondary payers.

Table 6. Variables used to calculate cost

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Nonmissing Range in Quarter and State</th>
<th>Notes on Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copay amount</td>
<td>100%</td>
<td>In claims file</td>
</tr>
<tr>
<td>Deductible amount</td>
<td>100%</td>
<td>In claims file</td>
</tr>
<tr>
<td>Amount prepaid</td>
<td>100%</td>
<td>In claims file</td>
</tr>
<tr>
<td>Amount paid</td>
<td>100%</td>
<td>In claims file</td>
</tr>
<tr>
<td>Variable Type</td>
<td>Nonmissing Range in Quarter and State</td>
<td>Notes on Expectations</td>
</tr>
<tr>
<td>-------------------------</td>
<td>---------------------------------------</td>
<td>-----------------------</td>
</tr>
<tr>
<td>Coinsurance</td>
<td>100%</td>
<td>In claims file</td>
</tr>
<tr>
<td>Allowed amount</td>
<td>100%</td>
<td>Key variable for cost measures</td>
</tr>
<tr>
<td>Insurance type</td>
<td>100%</td>
<td>In eligibility file</td>
</tr>
<tr>
<td>Year and month of enrollment</td>
<td>100%</td>
<td>In eligibility file</td>
</tr>
<tr>
<td>Coverage flags (medical, pharmacy)</td>
<td>100%</td>
<td>In eligibility file</td>
</tr>
</tbody>
</table>

**Demographic variables.** While demographic variables beyond age and gender are rarely used to construct measures, they do have roles in assessing disparities and in some cases, where the application indicates, risk adjustment. The demographic variables in APCDs are limited. Age and gender are well populated while race and ethnicity are more variable. The validity of the race variable was not assessed, but this should be assessed further since it is unlikely that race is accurately reported on all records and not all individuals report a second race.

Other variables, such as insurance type or the member’s residence, can be used as a proxy for other demographic variables, although imperfect. The member address and ZIP Code on file may not always match the actual residence of the member.

**Table 7. Demographic variables**

<table>
<thead>
<tr>
<th>Variable Type</th>
<th>Missing Range in Quarter and State</th>
<th>Notes on Expectations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race, primary</td>
<td>19%-100%</td>
<td>Potentially over- and underreported. Most datasets do not contain 100% quality race data.</td>
</tr>
<tr>
<td>Race, secondary</td>
<td>17%-100%</td>
<td>Potentially over- and underreported. Most datasets do not contain 100% quality race data.</td>
</tr>
<tr>
<td>Ethnicity or Hispanic flag</td>
<td>74%-100%</td>
<td>Potentially over- and underreported. Most datasets do not contain 100% quality race data.</td>
</tr>
<tr>
<td>Insurance type</td>
<td>100%</td>
<td>Used as a proxy, but primary insurance type may not capture dual-covered or dual-eligible individuals.</td>
</tr>
<tr>
<td>Member city/county</td>
<td>98%-100%</td>
<td>Counties and cities can be heterogeneous, but data are available for socioeconomic status of county communities.</td>
</tr>
<tr>
<td>Member ZIP Code</td>
<td>99%-100%</td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td>100%(nonmissing)</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>100%(nonmissing)</td>
<td></td>
</tr>
</tbody>
</table>

**Discussion**

With nearly 18 States that have or are readying legislation for APCDs and with more than 30 States showing increasing interest in setting up APCDs, they are potentially a rich data source that captures unique data points and presents unique measurement opportunities. Unlike other data sources derived from a sliver of the health care system, APCDs allow more comprehensive evaluations of care across the health care system and the integration of cost of processes of care.

These data include a wider range of individuals than other data sources; namely, they include a large proportion of covered encounters for commercially insured individuals and in some cases...
Medicare and Medicaid populations. Theoretically, information on individuals is not lost when switching providers or insurance coverage.

Because of these unique attributes, APCDs offer several unique opportunities for measurement:

1. Ambulatory care. Although Medicare fee-for-service utilization is widely studied across the inpatient and outpatient setting, data on all-payer ambulatory care are limited. APCDs can capture process measures occurring in the outpatient setting, such as appropriate ordering of laboratory testing or imaging, outpatient visits for chronic disease, and ambulatory care for adverse events following ambulatory surgery or hospitalization.

2. Pediatric care. This area has been particularly difficult to measure, because most children receive all of their care in outpatient settings. Pediatric measures such as immunizations, filling of prescriptions for asthma, and appropriate antibiotic prescriptions already are defined in other data sources.

3. Cross-cutting, episodic care. Measures that capture the spectrum of care can help us learn more about our health care system and effective care transitions. In addition, measures that capture care over an episode of several encounters are less susceptible to variation in the locations where patients seek or receive care. APCDs can capture followup care and care coordination and identify more entities involved in a patient’s care.

4. Population health. Because APCD data capture large portions of the population and are relatively inexpensive to collect, they are prime candidates for use in population health measures. Utilization measures are already used as proxies for population health, and APCDs can aid in expanding that view to different types of care, capturing routine care utilization and acute care that does not result in hospitalization. Some processes can also be captured in APCD data that are relevant to population health or the measures can be used to assess policy changes or disparities. From a resource use perspective, APCD-based measures can provide a window into the health care system, understanding the value of care and how health care costs are tied to the local practice patterns and population.

5. Value measure suites. Although claims data have been tagged a source of health care price transparency, when cost data are paired with quality data, value measure suites can provide more nuanced information to both consumers and payers. These measure sets can be used to learn about more efficient ways to achieve better outcomes.

Limitations of APCD Data for Measurement

Missing populations. Although APCDs do include a large number of health care claims, some populations are omitted. If the data from these populations differ systematically from the data included in the APCD, the omission will result in biased measures. APCDs typically do not include:

- Uninsured patients;
- Some substance use, mental health, and HIV populations, depending on State regulations;
- Worker’s compensation patients;
- Tricare or Veterans Affairs data;
- Federal Employee Health Benefit Plan patients; or
- Indian Health Service patients.
A recent Supreme Court case (*Gobetle v. Liberty Mutual*) emphasized that certain plans are exempt from data submission requirements, although some will choose to submit anyway. In this case, the Court found that the Federal Employee Retirement Income Security Act statute that preempts State legislation pertains primarily to self-insured health plans. Because many employer-sponsored plans across the Nation are self-insured, this potential gap is being watched closely.

APCDs also have different rules regarding which patients should be included in the dataset. Some States require all care for patients residing in the State, while others require those employed within a State or those employed by a company within the State. Because these are all slightly different definitions, users must be clear about the desired population for their use and clean the data appropriately.

**Data quality.** APCDs are prone to several data quality concerns. Claims data do not have details included in electronic health record data, including laboratory and biometric values. Most importantly, they typically do not contain patient outcomes. In this case, linking when possible to hospital administrative data records, electronic health records, or State mortality data add data. The data also may not capture bundled payments.

Many of the critical data elements were well populated and were defined using uniform billing standards or other standardized data collection methods. However, some data elements for the validity or reliability of the populated values were not assessed. Two critical data elements in particular create data quality challenges.

First, the patient identifier is often based on a combination of static patient numbers (e.g., Social Security number, date of birth) and contract plan number. If patients switch from one plan to another, even if not switching providers, the unique identifier may change. In addition, if patients switch providers, employers, or claims from carve-out coverage, it may result in additional identifiers for the same individual. This can create difficulty linking encounters over months when plan changes are likely to take place (e.g., open enrollment, first of the fiscal or calendar year).

In a similar manner, there is evidence that payers and providers are not fully consolidated. In this case, administrative features may lead to a provider using different identifiers.

**Delay in data versus data completeness.** In the evaluation and on State APCD data Web sites, the struggle between data timeliness and completeness is highlighted. Some submitters fail to provide complete or cleaned data to the APCD in a timely manner, leading to claims being omitted. Therefore, one sees drops in utilization or data completeness until those data are received.

Although late data are eventually folded into the data, the delay in receipt of the full complement of claims can limit the usability of APCDs. In particular, cost is a factor that can change quickly. If APCDs are to provide cost transparency to consumers, the data must be available quickly. Because of this limitation, consumer use cases may be the most challenging use case for APCD measures.
Measure development gaps. Although hundreds of potential measures were identified that might be applied to APCDs, a few major measurement gaps exist. Specifically, measures of behavioral health, potentially due to data limitations, are not well developed or cannot be applied to the data. Pediatric measures focus primarily on a few clinical topics and could capture additional care.

Measure sets are likely to provide the best picture of health care value. Often, however, for the same population, few measures are available for cost, quality, and utilization. In particular, our review showed that quality measures were lacking. Again, data limitations may hamper the development of quality measures that assess outcomes using only APCD data, but linking to other datasets may allow stronger measures.

Finally, many measures were not rigorously tested for validity and reliability. Others may have been tested for reliability and validity for a specific level of analysis (e.g., health plan) but not another (e.g., physician group). Testing is required before a measure can be fully implemented.

Ongoing Efforts To Improve APCD Data

In speaking with States and reviewing State Web sites, the team identified a large number of ongoing activities related to improving data. These included:

- Ongoing evaluation of documentation and the release of validation reports by States,
- Work with researchers or other interested parties to assess the data against other data sources (e.g., mortality vital records) and
- Creation of reports based on APCD data.

Some States are isolating different methods for categorizing cost data that will best accommodate and present resource use information. Finally, some States have active user communities that provide an effective feedback loop on both usability and data quality issues to State organizations.

APCD core set of data elements. In 2009, the APCD Council and AHRQ began to develop a common core set of data elements that most of the APCD States were capturing. The result of that work was the APCD Core, a set of data elements common to most APCDs, which would provide a foundation for new States to grow their APCDs. Since then, the APCD Council has worked with two data standards maintenance organizations to develop standards based on electronic transactions used for claims adjudication. States have varied in their uptake of the APCD Core, with some adopting a unique format or, more commonly, using the core as a starting place for submission requirements.

In light of the 2015 Gobeille v. Liberty Mutual ruling, the APCD Council and the National Academy of State Health Policy have convened States to consider options for working with the U.S. Department of Labor (DOL), including development of a uniform dataset standard referred to as the common data layout (CDL). Although it remains in draft form, once finalized, the CDL can be referred to in work with DOL to identify a process for submitting self-funded plan data to State APCDs.
Federal interest in standards. Recognizing the emerging need for national standards, the National Committee on Vital and Health Statistics (NCVHS) convened a day-long public meeting, "Hearing on Claims-based Databases for Policy Development and Evaluation: Overview and Emerging Issues," in Washington, DC, on June 17, 2016. The purpose of this meeting was to highlight the current state of development, challenges, issues, and opportunities faced by claim-based databases, including State-based APCD initiatives and private-sector multipayer claim-based database efforts.

The meeting had the following priorities:

- Engage stakeholders on key issues related to claims-based databases.
- Identify priority areas and opportunities for recommendations to the Secretary of Health and Human Services and the health care industry.

Of particular interest to the Committee was to identify benefits, efficiencies, and barriers to the adoption of a common claim-based database and APCD reporting standard, to outline a roadmap for achieving standardization, and to determine how NCVHS could provide support.

NCVHS is currently reviewing the results of the meeting and formulating recommendations to the Secretary that are within the scope of the Committee’s statutory role and priorities identified at the June meeting.

Conclusion and Future Directions

APCDs hold promise as a way for policymakers, payers, providers, and consumers to gain information about health care quality, cost, and utilization and use it to help achieve higher quality, lower cost care. In addition, APCD measures can help us:

- Understand utilization patterns in national and local health care systems,
- Understand how patients move through the system, and
- Assess the variety of providers touching a patient during an episode of care to inform studies on the attribution of measures to providers.

Measurement using APCDs is still a developing field. However, across multiple phases we identified:

1. Increasing interest and activities aimed at improving and using APCD data;
2. Varied measures in high-priority clinical areas theoretically feasible using APCD data;
3. Well-populated key data elements, many of which were systematically coded between States; and
4. Ongoing national activities that aim to address some of the limitations of APCD data for measurement.

Future efforts can provide useful information and tools for using APCD in health care measurement. Specifically, mental health and pediatric care are areas where APCD data can uniquely contribute to population health. Measures that cut across the health care system and value-based measure suites should also be considered for future measure development.
This study was a preliminary assessment of APCDs as a source of measurement data. Additional and detailed data analyses are required before the full assessment of APCD-based measures can be completed. These analyses should first focus on key data elements stratified by claim type. This will require building a dataset by removing potential duplicates or claims that have been replaced by a final paid claim, if necessary.

Next, the consistency of data elements across measured entities, such as payers or providers, should be assessed to determine whether any consistent bias exists. This review is particularly important for diagnosis and procedure information, where the data are variable and differences between the claim data submitted may result in biased measures.

Finally, some select measures should be applied to the data to assess trends across measured entities and time, reliability of key data elements, and validity of measure scores. Aside from measure analyses, the continued efforts to improve documentation will provide a record of changes and improvements in the data. Benchmarking efforts will provide more context for data users and valuable public data.

With ongoing efforts, APCDs remain the most comprehensive source of data for monitoring population health and health care across the full system, assessing interventions aimed at improving population health, and assisting in assessing the value of health care.
References


Appendix A: Technical Expert Panel and Learning Network Members

Technical Expert Panel

Marilyn Schlein Kramer, M.B.A.
Vice President/General Manager
Provider and Health Plan Markets, Health Data & Management Solutions, Inc.
Former Deputy Executive Director
Commonwealth of Massachusetts Center for Health Information and Analysis
Boston, Massachusetts

Jonathan Mathieu, Ph.D.
Vice President for Research & Compliance and Chief Economist
Center for Improving Value in Health Care
Denver, Colorado

David Newman, J.D., Ph.D.
Executive Director
Health Care Cost Institute
Washington, DC

Kenneth Park, M.D.
Vice President
Real World Evidence Solutions
IMS Health
Former Vice President
Payer and Provider Solutions
Anthem, HealthCore
Plymouth Meeting, Pennsylvania

Doris Peter, Ph.D.
Director

Health Ratings Center
Consumer Reports
New York, New York

Norman Thurston, M.A.
Director
Office of Health Care Statistics
Utah Department of Health
Salt Lake City, Utah

Rachel Werner, M.D., Ph.D.
Associate Professor of Medicine
University of Pennsylvania
Senior Fellow, Leonard Davis Institute of Health Economics
Core Faculty
Center for Health Equity Research and Promotion
Veterans Affairs Medical Center
Philadelphia, Pennsylvania

Learning Network Members

APCD Council
National Association of Health Data Organizations
## Appendix B: Prioritization of Conditions for Measure Inventory

Organizations from which high-priority condition lists were reviewed:

<table>
<thead>
<tr>
<th>Source</th>
<th>Full Title</th>
<th>Link to Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Academy of Pediatrics</td>
<td>Priority Topics</td>
<td>No link available</td>
</tr>
<tr>
<td>Center for Medicare &amp; Medicaid Innovation</td>
<td>Priority Measures for Monitoring and Evaluation</td>
<td>No link available</td>
</tr>
<tr>
<td>NQF</td>
<td>NQF 2012 Multiple Chronic Conditions Measurement Framework, Appendices B and C</td>
<td><a href="http://www.qualityforum.org/Projects/Multiple_Chronic_Conditions_Measurement_Framework.aspx">http://www.qualityforum.org/Projects/Multiple_Chronic_Conditions_Measurement_Framework.aspx</a></td>
</tr>
<tr>
<td>Office of the Assistant Secretary for Health (OASH)</td>
<td>OASH List of Chronic Conditions</td>
<td><a href="https://www.cdc.gov/pd/issues/2013/12_0239.html#table3_down">https://www.cdc.gov/pd/issues/2013/12_0239.html#table3_down</a></td>
</tr>
<tr>
<td>Patients Like Me</td>
<td>Patients Like Me: Conditions</td>
<td><a href="https://www.patientslikeme.com/conditions">https://www.patientslikeme.com/conditions</a></td>
</tr>
<tr>
<td>Quality Alliance Steering Committee</td>
<td>High-Value Health Care Project program results report, Appendix 7</td>
<td><a href="http://www.ahrq.gov/content/dam/ahrq/reports/program_results_reports/2011/nwi71110">http://www.ahrq.gov/content/dam/ahrq/reports/program_results_reports/2011/nwi71110</a></td>
</tr>
</tbody>
</table>