

COMBINING CLAIMS AND REGISTRY DATA FOR PATIENT-FOCUSED OUTCOME MEASUREMENT

Performance measurement is fundamental to improving quality, engaging consumers through transparency, and supporting payment reform. One of the challenges of effective performance measurement is capturing robust and accurate data. This brief describes innovative and technically feasible steps that could be taken today to measure patient-centered outcomes along the continuum of care.

Many of today's wide-scale performance measurement efforts rely on accessing administrative data sources (i.e., medical, laboratory, and pharmacy claims). These electronic databases provide a comprehensive view of a patients' and populations' health care utilization over time. While claims data can be useful for performance measurement, these data also have shortcomings. Specifically, claims data lack clinical detail needed to measure many aspects of health care quality or appropriately risk-adjust certain patient outcomes.¹

Alternatively, clinical data, such as lab results and data from patient registries, can provide detailed information about aspects of care, but it is often not readily electronically accessible to allow for efficient collection of performance results.² Procedure-based registry data – including data maintained by the American College of Cardiology (ACC) and the Society for Thoracic Surgery (STS) – are available for many patients undergoing cardiac procedures and contain detailed information on patient risk factors, co-morbid conditions, care processes, short-term outcomes of a particular event or procedure, and certain demographic information

such as race/ethnicity. While registries make up for some of the deficits of administrative data, they have their own shortcomings – including no information on long-term medication usage, prior services, follow-up care, or long-term clinical outcomes, such as death, readmissions, or repeat procedures.³ Claims data are often described as “a mile wide and an inch deep” (information over time and across care settings, but without rich clinical detail) while registry data are “an inch wide and a mile deep” (rich clinical detail about a brief encounter).⁴ Combining these two sources of information could overcome some of the respective shortcomings of data from each source, significantly inform care improvement and decision-making, and support performance measurement.

As part of the High-Value Health Care (HVHC) Project, the Engelberg Center for Health Care Reform – in conjunction with the ACC and UnitedHealthcare (UHC), as well as STS and Wellpoint – engaged in efforts to combine administrative medical, laboratory, and pharmacy claims data with registry data, apply performance measures to the linked datasets, and engage stakeholders to determine the utility of this approach for quality improvement, payment reform, and public transparency. Stakeholder representatives examined the technical feasibility of replicating this approach in markets across the country, and studied the business case for sustaining these data aggregation and performance measurement efforts. For additional project details, see Appendix 1 and 2.

GENERAL FINDINGS

During proof-of-concept discussions for both projects, stakeholders provided perspectives on issues such as feasibility/replicability, utility, and financial viability of producing performance measures from linked claims and registry data.

Data Linkage. The ACC/UHC, ACC/Medicare, and STS/WellPoint linkages illustrated that – even in the absence of direct identifiers such as name, address, and social security number – it is technically feasible to link clinical and claims data for targeted patients and providers to support performance measurement (over 84 percent of records were linked with high confidence). Several challenges presented themselves while establishing the data linkage. Although the STS/WellPoint data linkage involved the use of a limited data set, many eligible institutions had perceived concerns about the HIPAA Privacy Rule. Even though the STS/WellPoint legal review showed the project to be HIPAA-compliant, some hospitals remained concerned about any potential breach of their responsibility with respect to protecting PHI, and chose not to participate. California Senate Bill 541 and Assembly Bill 211 impose penalties upon California institutions that fail to protect the privacy of medical records, with penalties varying as high as \$250,000.⁵ As a result, California could be a more difficult state to launch projects that require the release of even a limited data set for linkage purposes. This challenge did not arise in the ACC/UHC activity, as contracts between ACC and participating providers did not require ACC to obtain permission from each provider to link clinical data with claims data.

Applying New Measures to Assess Longitudinal Quality of Care. Both projects illustrated the feasibility of applying new useful measures to linked data to assess longitudinal quality of care received by patients undergoing cardiovascular procedures. The ACC registry linkages with both UHC and Medicare claims produced sufficient sample sizes to calculate performance

measures and analyze aggregate results at the hospital level. While the patient sample size for the STS/WellPoint linkage was too small (n=329) to allow for meaningful interpretation of hospitals' performance results, the linkage was successful, as 95 percent of records were linked with high confidence. The STS/WellPoint effort focused on examining the utility of selected measures, as well as performance and utilization patterns. For example, the data showed that approximately 62 percent of all patients visited two or more hospitals during this period for both inpatient and outpatient care. These hospital visits include the index CABG event and were not limited to ischemic heart disease-related reasons. These findings may highlight challenges associated with continuity of care, as well as a potential difficulty in with attributing patient care to specific providers.

Stakeholder Views on Performance Measures.

Stakeholders offered different perspectives on the use of performance measures that rely on linked registry and administrative data. Key themes raised by various stakeholders are listed below:

Provider Perspectives

- Providers noted challenges in aligning performance measurement with physician and hospital incentives. For example, measures of complications, outcomes, and process/utilization that rely on linked claims and registry data provide a longitudinal view of patient care that often is not reflected in current physician or hospital reimbursement or incentive arrangements. Incentivizing quality of care along the care continuum as measured by these performance measures may require new accountability structures that similarly span care sectors.
- Provider resource constraints make data collection and measurement activities challenging. Providers are more apt to pursue measurement activities that are closely tied to financial incentives.

- Various payers require hospitals to report different measures or assess the same measure differently. Physicians and hospitals encourage payers to agree on a common measure set, as there are currently considerable inefficiencies with different payers using different measures. Similarly, payers that do business in multiple states also have an interest in establishing consistent measurement requirements across the country.
- Providers have concerns about the accuracy and validity of methods used for provider attribution. Provider involvement in the development of attribution methods, education about employed methods, as well as continuous efforts to integrate provider feedback prior to public reporting, may alleviate concerns about attribution methods.
- While the linkage of clinical and claims data may have resulted in large enough samples to calculate results at the facility level, sample size were not large enough to allow for the calculation of reliable performance results at the individual physician level. Multi-payer or all-payer data would allow for more comprehensively capturing care rendered to all patients.
- Measures that rely on linked clinical and claims data may have more credibility in the eyes of both physicians and hospitals. This increases the likelihood that providers will use the data, for example, to develop a better understanding of readmissions and where patients are seeking care prior to and after procedures. Providers may also use these data to better assess and improve continuity of care and long-term outcomes.
- Measures identified and calculated for this project that rely on linked data allow physicians to examine care processes they previously had been unable to analyze.

However, more testing is needed to ensure the reliability and validity of performance results based on these measures. After such testing is completed and broader consensus around these measures has been achieved, they could be appropriate for public reporting or pay-for-performance.

Payer Perspectives

- Performance measures must be easy to interpret and suitable for initiatives that seek to align quality with reimbursement. With measures that use both clinical and claims data, payers can develop reward programs based on a robust longitudinal picture of care.
- Payers see potential value in using information from linked or merged data sets to enhance care/disease management programs run by health plans.
- Payers can use measure results from linked data to help providers promote greater care coordination and management, which could lead to reductions in readmission rates and reduced health care costs.

Purchaser Perspectives

- It is important to find ways to engage consumers so that they take more responsibility for their own health. Generally, employers struggle to identify incentives and necessary information to encourage consumer engagement in health care decision-making.
- Measures should indicate a clear object of accountability (entity that is responsible for the outcome being measured). In addition, best practices for improvement should be available and, where appropriate, the role that purchasers, patients, and providers might play in improving outcomes should be described.

Consumer Perspectives

- Many challenges exist in providing information that will influence consumer health care decision-making. Evidence suggests that consumers would like more information about the quality and experience of care received by “patients like me” from various health care providers.
- In many cases, limited consumer health literacy affects understanding of health care performance measures. However, even when performance results are understood, they are not the only factor consumers consider when choosing a provider.⁶ For example, while performance measures may indicate which physicians provide high-quality care, consumers may not select these physicians if they are not easily accessible.

Financial Viability of Linking Clinical and Claims Data. To encourage continuing use of measures from linked clinical and claims data, data linkage activities must be financially sustainable. Continuation of similar projects depends on the value proposition to the various stakeholders involved. Multiple organizations – such as payers, providers, purchasers, policy makers, and consumer groups – might need to be involved in developing appropriate business models and will need to see direct and indirect benefits from using these data. The business model would have to demonstrate cost savings associated with improved care, as well as improvement in quality and patient outcomes.

During stakeholder meetings, the following suggestions for viable business models were discussed:

- **Charge data use fees.** It was suggested that a data use fee to interested stakeholders could be a feasible business model. The fee could vary across the different stakeholders depending on the costs associated with collecting and aggregating the data, as well as the value of the data to a particular user.

- **Align quality with payment reform strategies.** Enhanced, risk-adjusted quality measures that can be derived from the linked data set could be used to more closely align performance measures with payment and incentives. The linked data set could be particularly useful in reform strategies that target care coordination, such as accountable care organizations and/or bundled payments.

RECOMMENDATIONS AND POLICY CONSIDERATIONS

While clinical and claims data each have shortcomings, linking these data produces extensive new and clinically-detailed information. The results of the ACC/UHC/Medicare and STS/WellPoint activities demonstrate that linked clinical and claims data can be used to generate more valid and comprehensive performance measurement in order to assess and improve quality care. As the linkage of clinical and claims data increases, the following recommendations and policy considerations could improve such efforts:

- **Involve multiple payers and registries in future projects.** To date, linkages have typically included one procedure-based registry program, one commercial payer, and Medicare. Involving multiple payers – including all relevant commercial health plans in a market, plus Medicare and Medicaid – in activities involving data linkage and subsequent application of performance measures, will allow for the calculation of more meaningful, population-based results. Linkage of registry data to Medicaid could serve as a third data set for assessing the variation attributable to age in the different populations, assessing the outcomes associated with indigent care, and examining the implications for probabilistic matching of dual-eligible patients.

Registry-owning organizations in related clinical areas – such as the ACC, STS, and American Heart Association – collaborating

on registry development could reap significant benefits. Working together, these organizations could increase the number of patients whose clinical data can be linked with claims data, allow for analyses of continuity of care – such as long-term care, readmission rates, and utilization – and facilitate use of linked registry and claims data for assessment of comparative effectiveness of technologies and treatments. Some strides have been made in this direction. For example, STS and ACC have harmonized many of the common data elements in their registries to facilitate data linkage.

- **Build transparent relationships with all stakeholders.** Crucial to the success of linking data across different data owners and uses is the involvement of all stakeholders – including payers, providers, purchasers, policy makers, and consumers. The early involvement of key stakeholders can increase participation and project transparency, facilitate selection of consensus-based performance measures that fully utilize linked data and that are useful to various audiences, and help determine the best use of the results. Furthermore, involvement of all stakeholders in these data linkage and performance measurement projects may encourage consensus around different policy perspectives and the best use of performance measures.
- **Increase adoption of electronic health records (EHRs) to allow for the creation of registries supported through clinical and administrative data.** The broader adoption of EHRs, as facilitated by the American Recovery and Reinvestment Act, can play an important role in the use of both clinical and administrative data to improve care. EHRs provide real-time, in-house, electronic repositories for patient-specific data and provide an accessible data source for hospitals and physician groups to

develop internal registries. Several physician groups, integrated delivery systems, and health information exchanges have reported adopting or creating their own internal registries that contain both clinical and administrative data elements. Such internal registries can generally process and analyze data more quickly for real-time application to care management.

As organizations transition to EHRs and meaningful use criteria and guidelines for EHRs are developed further over the next five years, effective exchange of information between EHRs and other data sources including national registries is desirable. National registries play a key role in this process. By continuing to standardize data elements across registries and creating interoperability between EHRs and registries, national registries can automatically link their data with claims data to enhance performance measurement, facilitate quality improvement efforts, and support patient centered care. For example, ACC is working to link claims data to their ambulatory care registry connected with EHRs to provide real time linkage and data use. Sustained efforts like these align with meaningful use requirements and goals, as they promote EHR technology for electronic exchange of health information to improve the improve quality, safety, and efficiency of care.⁷

In the future, the role of national registries might evolve to focus increasingly on setting uniform national data standards, developing performance measures, producing national or regional performance benchmarks, and developing test beds for applications – including guideline-based decision support tools – that can be implemented at the point of care. The large databases of national registry programs are likely to continue to play a role in research that links care processes to patient outcomes across large patient populations. As EHRs become more

common, however, providers might turn to internal registries for continuous quality improvement programs to support the process of care in real time.

- **Use linked clinical and claims data to support performance measurement.**

Linking clinical and claims data can support clinicians in improving care and allow for the calculation of patient-centered performance results across care settings. Currently, efforts are underway to better understand health care quality by making consistent and meaningful performance measures widely available. Routinizing the linkage of clinical and claims data, identifying standard measures requiring the linked data, and implementing these processes consistently across private and public sectors could generate additional information about the performance of health care.

- **Use linked clinical and claims data to enhance the comprehensiveness of information available for public reporting.**

Public reporting has the ability to influence quality improvement, inform consumer choice, and influence purchaser-based health care decisions. Using linked clinical and claims data could enhance public reporting efforts by providing more

valid and comprehensive performance measurement information. Linked data offers the opportunity to rely on clinical data elements to risk adjust measures relying on administrative data (e.g., cost of care), as well as allow for the evaluation of long-term outcomes (e.g., post-discharge mortality, severe complications). Public reporting using linked clinical and claims data could lead to more accurate evaluation of hospital and physician performance, greater acceptance of resulting information among health care providers, and more useful results that can support payment reform programs.⁸

- **Provide additional guidance on interpreting HIPAA.** There is a significant amount of confusion and misinformation on how HIPAA, or the Privacy Rule,⁹ affects how health care organizations and other entities may use and share PHI for quality improvement purposes.¹⁰ Federal and state agencies should issue necessary clarifications of existing laws and identify illustrative examples of what is and is not permitted under current law with respect to data linkage involving claims and registries.

1. Dokholyan RS, Muhlbaier LH, Falletta JM, Jacobs JP, Shahian D, Haan CK, Peterson ED. Regulatory and ethical considerations for linking clinical and administrative databases. *Am Heart J.* 2009 Jun;157(6):971-82.

2. Hammill BG, Hernandez AF, Peterson ED, Fonarow GC, Schulman KA, Curtis LH. Linking inpatient clinical registry data to Medicare claims data using indirect identifiers. *Am Heart J.* 2009 Jun;157(6):995-1000.

3. Dokholyan RS, Muhlbaier LH, Falletta JM, Jacobs JP, Shahian D, Haan CK, Peterson ED. Regulatory and ethical considerations for linking clinical and administrative databases. *Am Heart J.* 2009 Jun;157(6):971-82.

4. Engelberg Center for Health Care Reform. "How Registries Can Help Performance Measurement Improve Care." June 2010. [http://www.healthqualityalliance.org/userfiles/Final%20Registries%20paper%20062110\(1\).pdf](http://www.healthqualityalliance.org/userfiles/Final%20Registries%20paper%20062110(1).pdf)

5. California Laws AB211 and SB541

6. Marshall MN, Shekelle PG et. al. The Public Release of Performance Data: What Do We Expect to Gain? A Review of the Evidence. *JAMA.* 2000;283:1866-1874.

7. http://www.cms.gov/EHRIncentivePrograms/35_Meaningful_Use.asp#TopOfPage

8. Engelberg Center for Health Care Reform. "Enhancing Hospital Performance Measurement Through Greater Data Integration: Linking Clinical Data to All Payer Administrative Data." July 2010. <http://www.healthqualityalliance.org/userfiles/VHI%20technical%20brief%2072810.pdf>

9. 67 Fed. Reg. 53182 (Aug. 14, 2002) codified at 45 C.F.R. Parts 160 and 164

10. 45 C.F.R. § 160.103

Appendix 1: American College of Cardiology and UnitedHealthcare

Data Sources

- **CathPCI Registry®.** The CathPCI Registry® measures the outcomes of diagnostic catheterizations and percutaneous coronary interventions (PCIs) to support institutional quality improvement programs. It contains detailed clinical data on comorbidities, acute outcomes, discharge care, and demographics, such as race/ethnicity data.
- **Medicare Claims Data.** The Medicare Part A claims files contain information on all hospitalizations of patients enrolled in fee-for-service Medicare. These datasets also include demographics, date of death, and eligibility information.
- **UHC Claims Data.** The UHC data contain all inpatient, outpatient hospital and physician claims, as well as demographic data (with the exception of race/ethnicity) for coronary artery disease patients defined on the basis of pre-specified diagnosis and procedure codes.

Linkage Timeframe, Accuracy & Total Sample Sizeⁱ

- **CathPCI and UHC Linkage.** The linkage timeframe was July 1, 2006 to June 30, 2008. Eighty-four percent of all matched patients linked on five variables of interest. The linkage resulted in a total of 16,485 matched patients.
- **CathPCI and Medicare Linkage.** The linkage timeframe was July 1, 2006 to December 31, 2006. Ninety-two percent of all matched patients linked on five variables of interest. The linkage resulted in a total of 886,648 matched records for 751,456 distinct patients.

Selection of Measuresⁱⁱ

The project's Steering Committee and the ACC's Internal Workgroup identified 10 new, non-endorsed measures that require both claims and registry data and are associated with clinical outcomes, variance by race/ethnicity, and resource utilization. Examples include:

- Proportion of patients who have more than one urgent interventional procedure during the same admission (process/utilization measure).
- Proportion of patients who have a normal catheterization with coronary angiography after non-invasive imaging testing within 30 days of the procedure (outcome measure).

Stakeholder Involvement

The Steering Committee, representing payers and registry-owning organizations as well as an ACC Internal Workgroup comprised of physician volunteers, convened at the beginning of the project to advise on measures of interest and a pilot site. In January 2010, the committee added additional stakeholders – including representatives from employer groups, health plans, hospitals, physicians, state agencies, and consumer groups – from Florida, the pilot location, to review project findings and provide recommendations on the project's utility, feasibility/replicability, and financial viability. Florida was chosen as the pilot location based on several factors, including UHC market share, market penetration of CathPCI Registry®, and average PCIs per 1,000 Medicare enrollees in 2003.

i. For documentation regarding the linkage methodology, accuracy, and total sample size, see: http://www.healthqualityalliance.org/userfiles/ACC%20Data%20Linkage%20Report%2012_11_09.pdf

ii. For a full list of measures, see: <http://www.healthqualityalliance.org/userfiles/ACC%20Metrics%20Analytic%20Table.pdf>

Appendix 2: Society of Thoracic Surgeons and WellPoint

Data Sources

- **STS Adult Cardiac Surgery Registry.** STS maintains an Adult Cardiac Surgery Registry with detailed information on the processes and outcomes of care associated with most types of cardiothoracic surgery, including coronary artery bypass graft (CABG). This registry also collects information on the clinical characteristics of the patients undergoing these procedures and thus allows for case-mix adjustment when comparing rates for processes of care and outcomes.
- **WellPoint Claims Data.** The full administrative data for patients from WellPoint's California plan, Anthem Blue Cross, were captured in the database, including utilization and cost for professional services, institutional inpatient services, institutional outpatient services, and prescription drugs.

Linkage Timeframe, Accuracy & Total Sample Sizeⁱⁱⁱ

The linkage timeframe was January 1, 2006 to March 31, 2008. Ninety-five percent of records linked with high confidence. Fifteen out of 85 eligible California hospitals participated in this effort, resulting in 329 matched patients.

Selection of Measures^{iv}

Measures developed in both the United States and the United Kingdom were evaluated to inform the quality of care for a patient during the 12-month interval pre- and post-CABG. Of particular interest were measures that assessed the quality of care during the transition period from hospital to outpatient settings. Thirty-nine measures – 11 requiring STS registry data only, eight based only on claims data, and 19 requiring data from both the registry and claims – were identified. The measures focus on post-operative complications, drug therapies, screening and post-discharge care that extends beyond the usual 30-day window post-surgery. Examples of measures requiring the linked database include:

- Deep sternal wound infections or renal insufficiency within or beyond 30 days post-discharge;
- Discharge on a statin or other pharmacologic lipid-lowering regimen (filled within seven days and remained on medication for six months); and
- Follow-up care within 30 days post-discharge.

Stakeholder Involvement

California was the selected site for the pilot, as there was a large number of participants in the STS Adult Cardiac Surgery Database who were also insured by WellPoint. A stakeholder meeting with representatives from California employer groups, health plans, hospitals, physicians, state agencies, and consumer groups took place in April 2010 to garner recommendations on the project measures' utility, the project's feasibility/replicability, and financial viability.

iii. For documentation regarding the linkage methodology, accuracy, and total sample size, see: <http://www.healthqualityalliance.org/userfiles/STS%20Linkage%20Methodology.pdf>

iv. For a full list of measures, see: http://www.sts.org/documents/pdf/ndb2010/LQOCS_Measures_for_Hospitals_%282%29.pdf