The breadth and burden of data collection in clinical practice

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Abstract
The clinical practice of neurology generates an enormous amount of data. Current data entry tools and reporting requirements are inefficient and frustrating. This comprehensive review of data collection in multiple domains of clinical practice includes billing and payment requirements, electronic health record documentation requirements, quality measurements, public reporting, and the evolution of clinical decision support. Quality measurements are increasingly affecting patient care and physician reimbursement. By understanding current data collection and by using appropriate tools, neurologists can begin to reduce the burden of data collection and ensure maximum reimbursement. The American Academy of Neurology’s Axon registry is the next step in the evolution of clinical data collection and will begin to empower every neurologist to succeed in the shifting landscape of health care and physician payment reform. Neurol Clin Pract 2016;6:81–86

This is the first of 2 proposed articles reviewing the breadth and burden of data collection in the clinical practice of neurology. This article provides a comprehensive review of current data collection and measurement in several domains and its effect on clinicians. The second article will review the concept of clinical registries and introduce the American Academy of Neurology’s new Axon Registry, the goal of which is to enhance patient care and improve physician performance while maximizing revenue. Participation in the registry will assist neurologists in meeting the data-gathering requirements from multiple entities.

Proponents of data collection tout the benefit of improved patient care. The Hawthorne effect notes the improvement in a behavior simply by observation. Data collection begins with observation but also requires proper recording and must result in meaningful measurement. Clinicians are skilled at observation and medical decision-making but have struggled with accurately recording and measuring our activities. The electronic health record (EHR) has allowed the health care industry to focus on the clinical encounter as a robust source of data. The EHR requires detailed data entry in a manner that it is not well-matched to clinical workflow. Despite clinicians’ frustrations and objections, the EHR has become a repository of information that is examined and parsed by multiple entities and often shared with patients in
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real time. Sharing EHR data through clinical summaries generated at the time of the visit or through patient portals may improve documentation accuracy.\(^2\) A well-devised, fully utilized, and accurate clinical dataset of large patient populations has the potential to be much more robust and powerful than information collected in superbly designed studies of several hundred patients.\(^3\)

We are in the midst of an evolution from rigorous data collection performed solely at research centers to data collection from clinical encounters performed at physicians’ offices. The clinical practice of medicine generates an enormous amount of data. Each touchpoint in health care results in information recorded by different operators at different locations and in different formats. Receptionists, medical assistants, trainees, and physicians all enter information. Recording occurs at various locations in the office, hospital, and at remote locations. Entry occurs in different formats such as text, numbers, and pictures. Information may be highly structured when entered through predetermined checklists or unstructured when entered as free text.

With all of this information, it is difficult to determine the most meaningful data to collect. Decisions on data metrics are often made without input from practicing clinicians. This results in additional frustration and reluctance to participate in the data collection process. It is this reluctance that has resulted in multiple financial incentive programs that present increasingly major financial repercussions. A shift in understanding and embracing health care data will improve not only physicians’ use of the EHR but also their financial stability.

**Data collection in clinical practice**

The process of data collection is well-established in the submission of claims data. Specifically, physicians report both the service rendered and the diagnosis through well-established datasets.

Current Procedural Technology (CPT) is the dataset used by payers to allow physicians to bill for services rendered. The American Medical Association (AMA) developed CPT in 1966 as a shorthand mechanism for documentation independent of billing. In 1983, CPT codes were first used and mandated for Medicare billing. The codes are maintained and adjusted annually by the AMA’s CPT editorial panel. Queries for changes may come from any interested health care service provider.\(^4\) Clinical practices must understand this uniform language to communicate effectively with payers and maximize revenue.

The ICD was created in 1948 and is managed by the WHO. The 10th version was endorsed in 1990 and is used worldwide, although it has only recently been implemented in the United States. The ICD is an attempt to define and categorize all disease states. Its set of codes has increased from the original 13,000 to the current 68,000. The ICD can be used to define patient volume, determine case mix, define expected mortality, and adjudicate claims. The burden on practitioners of learning and adopting the new code set has resulted in delayed implementation.

The Meaningful Use (MU) program was developed by the Center for Medicare and Medicaid Services (CMS) to improve efficiency and coordination of care while engaging patients in a secure and compliant manner.\(^5\) By incentivizing EHR participation, health care providers’ data collection has increased. The 3-stage program has many reporting requirements. The first stage focuses on data capture and information sharing. The second stage focuses on advanced clinical processes and includes more rigorous requirements for the exchange of health care information between providers. The third stage will focus on improved outcomes. Each stage contains a set of core objectives that must be met by meeting a specific threshold of success. There are
additional menu set objectives of which clinicians must select a subset for reporting. These include items such as medication reconciliation and patient education. Electronic prescriptions, which began as an independent program, are now recorded through the MU program.

The Physician Quality Reporting System (PQRS) is designed to pay practitioners to report quality data for patients cared for under the Medicare program. Data collection now involves over 250 measures that focus on areas including patient safety, care coordination, clinical processes, and population health. The types of measures reported vary from year to year. Reporting of data is available through several methods. Clinicians may contract with a specific PQRS registry, submit information through their EHR, select a data submission vendor, or join a qualified clinical data registry such as the AAN’s Axon Registry.

The overall financial effect of the data collection incentive programs described is considerable. Full participation in all current incentive programs will result in bonus payments while nonparticipation will result in a payment penalty of up to 9% by 2018. If a neurologist selects participation, he or she must become aware of all of the methods for measuring quality and begin incorporating them into his or her practice.

In managed care, data-driven quality metrics have been in place for some time. The Health Effectiveness and Data Information Set (HEDIS) is made up of performance measures used by managed care companies. The National Committee for Quality Assurance maintains 75 measures in 6 domains. Examples include effectiveness of care, access and availability of care, experience of care, and utilization of services. HEDIS measures currently affect physician reimbursement in managed care and Medicare Advantage (MA) plans and will likely become more widely utilized in the setting of value-based care. The 5-star quality rating system (STARS) was developed by CMS to compare MA health plans. Plans are compared over 5 domains including staying healthy, managing chronic disease, member experience, member complaints, and customer service. STARS ratings, from 1 to 5 stars, are partially dependent on the number of HEDIS measures met. Although originally designed to help patients choose a health plan, CMS currently uses STARS to determine payments to plans that will affect physician reimbursement.

Private health insurers have been collecting robust data on physician utilization and spending. Physicians are ranked based on the cost of care they provide. Many insurers have developed tiered health plans using this information. By lowering patient copays to specific groups of physicians, they incentivize referrals to those who spend less money on care. Performance and quality measures may or may not be considered. The insurers’ stated goal is to reduce rising health care costs though the ultimate effect may be to increase insurers’ profit.

As insurance companies collect data unavailable to physicians and patients, the demand for transparency has increased. The public reporting of health care data is expanding. Examples of publicly available data include mortality, hospital admissions, and epidemiologic information.

The impetus for public reporting is the premise that transparency is a powerful driver of health care reform. Medicare’s public reporting of hospital quality data began in 2005. The objective effect of this program on patient morbidity and mortality appears to be minimal.

With public reporting of health care data comes public debate on the meaning of the information presented. Physician Board certification status is publicly available and easily retrieved. Although there may be some discussion on the meaning of Board certification, the general public has enough basic knowledge to interpret these data. A more complex example of public reporting is Medicare’s Provider Utilization and Payment Report. The suggestion that a physician with high reported Medicare revenue is somehow behaving badly has become a common conclusion but may be incorrect. A physician whose name is attached to billing services for a large group of physicians may be publicly reported as an outlier or excessive utilizer. The data selected for presentation and the manner of presentation will clearly influence public interpretation.

Transparency and data sharing may benefit other areas of medicine. Clinical research often operates independently from clinical practice. Screening patients for randomized clinical trials
(RCT) has been hampered by incomplete and inaccurate medical information. Verbal history and copies of medical records may be supplemented by improved integration and sharing of data between the EHR and the clinical research site. This may result in improved efficiency and increased trial enrollment.

Clinical data collection may also play an important role in validating RCT results in broader and more diverse populations. Currently RCTs are conducted in rigorous controlled settings and conclusions based on the study population are then extrapolated to the general population. Many of the patients neurologists care for would not meet eligibility criteria for the RCTs that are being used as the basis for clinical decisions.\textsuperscript{16} Therefore, population data may provide additional guidance for clinical decision-making. In addition, adverse events are more likely to be reported and tracked through large clinical databases.

Value-based payment entities also rely on large clinical databases. Accountable care organizations (ACOs) allow groups of physicians to come together to coordinate high-quality care as established by the Affordable Care Act. Quality metrics are currently recorded in 33 domains and are likely to expand.\textsuperscript{17} At present, none is specific to neurology. The quality metrics have no influence over payment, but it is only a matter of time before quality measures are reflected in the compensation model. There are several ACO models, each of which uses shared savings as the financial goal. Detailed data analytics determine if the ACO physician group meets a savings threshold and is eligible to receive a percentage of the amount of money saved.

Management service organizations (MSOs) have many similarities to the ACO model. The MSO operates under the MA program where private companies contract directly with Medicare to cover all Medicare services. The MSO model can operate in shared savings plans like the ACO model. The MSO model can also operate in the full-risk model. Detailed data collection in many of the domains outlined above is critical to the MSO goals of providing quality care in a cost-efficient manner.

A key value-based concept is to identify high-risk patients who are frequent utilizers. By extracting data points from the EHR and performing predictive modeling, early intervention can occur. Predictive modeling has been used in many settings, most commonly to predict the risk of inpatient hospitalization\textsuperscript{18} and 30-day readmission risk.\textsuperscript{19} The ability to predict an adverse health care event results in the ability to intervene and prevent that outcome, improve patient health, and reduce cost.

Clinicians can also use data at the point of care to assist with health care decisions. Clinical decision support can be presented in several forms, such as clinical alerts, evidence-based guidelines, and problem-specific order sets. The goal is to enhance efficiency, avoid errors, and improve quality of care. Access to point of care decision support has been shown to have a positive effect on drug ordering and health maintenance reminders.\textsuperscript{20} There is growing evidence that this tool can improve outcomes in specific disease states.\textsuperscript{21}

CONCLUSION

The evolution of the data collection in health care is largely due to replacing paper medical records by data entry into the EHR. Many clinicians believe that the EHR is inefficient. Physician participation has been made challenging by the considerable variability in the specific data requirements of the programs reviewed. It is critical to begin to harmonize data collection and quality metrics across all stakeholders, payers, and health systems.\textsuperscript{22}
The public and other groups have increasingly demanded transparency in health care data. Physicians should also demand transparency for the information we generate. Physicians need to participate in the design of data collection tools and help select the method of presentation to our patients and the public. Data collection should not be a burdensome obligation imposed by outside authorities but a new opportunity to improve the practice of neurology and the health of our patients.

The tools to accomplish these goals will occur with the power, advocacy, and support of large numbers of neurologists working together. A neurologic registry sponsored by the AAN is the next step in the evolution of data collection in the clinical practice of neurology. Axon will empower neurologists in the shifting landscape of health care and physician payment reform.

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