Validation of Audiological Care: Data Registries and Your Role

By Therese Walden

What Is a Data Registry and Why Should I Care?

According to the Agency for Healthcare Research and Quality (AHRQ), a service under the U.S. Department of Health and Human Services, registries are ongoing studies, “that focus on understanding how the treatments, tests, and services that are used in routine clinical care and by specialists affect patient-health outcomes.” The article goes on to say that the scientific information obtained about effectiveness, safety, and quality of the services performed is used by various entities, such as regulators and other decision-makers, who are looking for objective information or data to support claims about the benefits (or harms) of specific procedures and/or treatments. In other words, data registries are actually repositories into which we add some type of uniform (de-identified) information each time we see a patient and then share in the collective outcomes from all that data.
Imagine the power behind such “big data!” Imagine data collected from each vestibular patient with a diagnosis of BPPV (benign paroxysmal positional vertigo), each pediatric patient with single-sided deafness, each geriatric patient with co-morbid conditions of hearing loss and cognitive decline, for just a few examples. Then, imagine all of us contributing to a data set that can capture, store, and analyze that data so we can turn around and use it effectively for the next patient with the same condition who walks into the office!

A data registry can do that, and allow us to share data and search on data strings. From that, we can develop clinical best practices, prove our cost-effectiveness in the provision of care, and demonstrate the benefit of autonomous care delivery by audiologists. I am talking about real, live, evidence-based practice, not anecdote.

Data registries have benefits beyond reports from individual-clinical trials or individual-research studies and projects. Registries allow us to collect data on broad populations and evaluate outcomes in real time. As you might imagine, analysis of a single, large set of related data allows for easier correlations and trend spotting as compared to separate smaller sets.

“Big data” and data registries are already a part of your life, even outside of the health-care arena. Each time you use your smartphone, tablet, or GPS device, you are sharing in data mining. Data sets are developed due to ever-present information-gathering from mobile devices, cameras, microphones, radio frequency identification (RFID) readers, and more. Data registries are used in business and financial arenas, to combat crime, to power real estate searches, for online shopping, and to determine real-time traffic conditions—just a smattering of examples of how “big data” is used every day. In addition, as you might guess, many data management/technology suppliers have developed tools (for sale) that allow data to be collected, verified, stored, analyzed, and shared.

**What’s In It for Me (WIIFM)?**

Development of a registry/data repository specific to audiology would serve to provide information regarding current clinical-practice patterns and patient outcomes, and the data would result in consensus measures that would be used to improve patient care and (ultimately) reimbursement. Further, uniform data reporting would align the Academy and its members with current and future requirements within the national health-care arena for improved health-care utilization and outcomes, in terms of access to safe and cost-effective care under the changing health-care landscape.

In her March/April 2014 *Audiology Today* article, “Shaping the Future of Audiology in a Post-Affordable Care Act (ACA) Landscape,” Dr. Debra Abel describes how the sweeping changes in health-care provision and reimbursement may affect the profession of audiology, and what we as individuals and as a group can do to maximize our position in this new health-care reality. Dr. Abel goes on to say audiologists will need to understand the factors that will determine professional viability for audiologists under the ACA. She lists several important opportunities; chief among those is that we need to define our (patient) outcomes. How we contribute to them is based on collective, uniform data reporting.

We cannot simply say what we are worth to the health-care system, to the patient, to other providers, to third-party payers; we have to prove what we are worth (Abel, 2014). Data registries provide us the vehicle to demonstrate our cost-effectiveness and, by contributing individually to the registries, we benefit from the power of large data sets based on the work that is accomplished every day by each audiologist with each patient seen.

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An example of how audiology has already used “big data” is demonstrated in the Dobson/Davanzo report on Medicare savings through direct access to audiologists for Medicare beneficiaries. The report summarized the methodology used to mine large (de-identified) data sets for beneficiaries who received audiological care (hearing and balance) from various health-care providers over a specific timeframe. The quantitative analyses based on a sampling of actual Medicare data resulted in a projected nearly quarter of a billion dollars in savings “from avoided duplicative and unnecessary services and from decreased hospital and other (health-care) utilization…” (Dobson et al, 2012). If you haven’t read this executive summary, I encourage you to do so. It is the perfect illustration of the impact of the use of big data to prove benefit.
Next Steps

Pay for performance under the Affordable Care Act and within CMS (Centers for Medicare and Medicaid) will require audiologists to participate in data registries to develop national consensus quality reporting measures with a focus on continuous quality improvement. Further, commercial payers (to include federal third-party payers) have been including and will continue to include performance incentives in reimbursement strategies. A national audiology data registry will ready the Academy, its members, and all audiologists as health care moves to a quality reporting system that incentivizes the individual practitioner. Reporting into a national data registry will eventually become a requirement as opposed to a voluntary task.

Audiologists are uniquely positioned to illustrate our cost-effective care provision to regulators, third-party payers, and consumers, but we have to use data registries to demonstrate this claim. Setting up a data registry is a huge undertaking. However, many health-care professions are already using registries and the Academy is exploring these tools/suppliers to determine what would work best for the profession.

Some registries use electronic health records (EHR) to extract de-identified data. However not all practices are engaged in the use of EHRs currently, so another form of data extraction would need to be employed. The “how” of setting up a registry is laborious and time-consuming, but it is not a choice; we are going to have to expend the resources to accomplish this or some other entity beyond the profession will do it for us.

Think of it this way—data registries are the perfect illustration of “research to reality.” Registries allow us to document and define what we do every day for every patient using current best practices. We then report that information, in a systematic and well-defined manner that enables us to answer clinical and research questions simultaneously, based on real-time care for thousands of real-life patients who come to us and depend on us to enable them to live a more robust, healthy, and connected lifestyle. That’s the patients’ reality; that will be our reality.

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References

