

EDITOR'S PAGE

Harmonizing for Health

When musicians harmonize, whether they are a barbershop quartet, the Beach Boys, or a symphony orchestra, the effectiveness is clear. We are now in an era in which effectiveness is a major goal of medical care delivery. You might say, "No, it is cost effectiveness," and I am sure cost applies to music as well. The cost of medical research can be staggering, so in order to measure medical effectiveness, the emphasis is shifting from randomized controlled trials (which are still essential to answer many questions) to databases reflecting the practice of medicine.

The cardiology discipline has been a leader in using databases to inform our guidelines and best practices. The major payer, the U.S. government, and others want to know which diagnostic and therapeutic measures are most effective for which patients. Databases are broadly based and are more generalizable than focused randomized controlled trials. They can have massive numbers of subjects and, therefore, look very impressive. However, their value in reflecting the truth depends on the quality of the data. All databases are not alike. They vary from prospective registries with clear research plans, to population registries collecting mandated clinical information, to voluntary registries with entry of clinical data, and to administrative databases designed for billing purposes with limited clinical information. Some registry data is audited, and some is not. Some measure acute outcomes, and others are designed to collect long-term results. Much data collection is duplicative of the medical record, requiring trained personnel at significant costs.

I have just returned from Albany, New York, where I chair the New York State Cardiac Advisory Board. Among the responsibilities of that board is to advise and support the New York State percutaneous coronary intervention and cardiac surgical registries. The registries were made possible by the mandated prospective collection of data, and the long-term outcomes by linking the data to the New York State vital statistics data. All hospitals offering these services must participate in the data collection. At the same time, there is a concerted effort to enroll all hospitals in the National Cardiovascular Data Registry (NCDR) and the Society of Thoracic Surgery (STS) data registry. This effort is laudable; however, a significant number of the New York hospitals do not participate because of the added costs. The NCDR and New York State have moved beyond procedural data to the diagnostic level, and now New York State has an access registry of diagnostic catheterization patients. In addition, the American College of Cardiology's PINNACLE registry has begun collecting data in the ambulatory practice environment.

Collection of data is not a trivial effort for the participating hospitals, and the costs are not supported by any extra revenue. In an effort to reduce the burden on hospitals in New York, the Cardiac Advisory Committee is evaluating databases in an attempt to harmonize the fields, ensuring that duplication is kept to a minimum and that broad participation in the NCDR and STS can be achieved. Other states, such as Massachusetts, New Jersey, and California, face the same problem. Some would say, "Why not collapse all the states' databases into the NCDR and STS without maintaining separate state databases?" The answer is that these state databases can produce results that are valuable in comparing programs, auditing entry, and measuring long-term outcomes that are not yet achievable on the national level. The reluctance to use unique patient identifiers has impeded the ability to perform nationwide long-term follow-up.

So, if states are to maintain registries to ensure quality of care while supporting national efforts to participate in NCDR and STS registries, there needs to be harmonization of the



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data elements to reduce the burden of duplicate data collection. This has been done in Massachusetts and in California for coronary artery bypass surgery and in Massachusetts for percutaneous coronary intervention. The NCDR and STS registries are more extensive than some of the state-mandated registries, but because of the mandates, the state registries are more complete. State registries, such as New York's, ensure accuracy of 30-day mortality by linking to the statewide vital statistics file and limiting the registry to state residents. A recent report showed that 22% of 30-day deaths occurred after hospital discharge. Completeness of enrollment is ensured by comparing registry data to the state's administrative data system. Long-term survival is similarly ensured using the vital statistics file. Routine audits, which ensure appropriate selection as well as outcomes and provide an even playing field, can be performed best in a statewide system.

I am certainly no expert in the field of data management, but it seems time for a harmonization of

the effort. Who pays for this? The beneficiaries of improved quality and cost-effectiveness are the patients, the providers, and the payers. Currently the providers are footing the bill. It is time for the payers to realize the value of supporting the efficient and accurate collection and analysis of clinical information. As a New Yorker, Goffredo Gensini, told me in the mid-1970s as we were starting the Emory cardiac database, "You need one version of the truth." Someday, comprehensive electronic medical records may enable that, but in the meantime, we can at least strive for harmony.

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