EDITORIAL

WILEY · Congenital Heart Disease

Consolidate or constipate: What are we going to do with all our registries?

At the last count, the Heart Institute at Cincinnati Children's Hospital participated in well over 20 regional, national, and international registries, learning networks, research consortia, and databases. Some of you will be participating in more, some less, but no matter how many, they have become a necessary part of the activity of all of our programs. Each one is an outstanding example of how we should be assessing practice and driving improvement in congenital heart disease. For example, who can deny the value and impact of the National Pediatric Cardiology Quality Improvement Collaborative (NPC-QIC). Initially formed by a small number of centers working with parents dedicated to improving interstage outcomes in hypoplastic left heart syndrome, in less than a decade NPC-QIC has grown into a truly national network of 64 centers submitting data from all patients with functionally single ventricles from diagnosis to 1 year of age. It is a shining example of how we should be working together to share emerging knowledge and best practices, and truly integrate, and respond to, the wishes of the parents that we share the management of our patients with. But this is but one example of the increasing number of, and increasingly comprehensive, datasets that we as a specialty have committed to providing. STS, PC4, PAC3, IMPACT, C3PO, CNOC, ACTION are all worthy and important registries that no doubt have and will continue to contribute to improved care of our patients, but each requires us to commit our ever dwindling time and resources to the extraction, processing, and submission of the data that supports them.

Some of the data, and many of our patients, are common to all of the registries. Much of the information we need is in our electronic medical records, but how many of us have truly harnessed our EMR's to auto-populate the many overlapping fields for the many overlapping registries? Instead, we employ individuals to laboriously scan patient charts, collect real-time data, transcribe, and send our data to the various repositories. We are at risk of spending more time collecting data than analyzing it, and the sheer volume of data that we are collecting, and the resources that are required to sustain it are themselves getting close to becoming unsustainable.

Perhaps it is time for a rethink. Shouldn't our registries be working together to unify the data that they manage? While not entirely inclusive, all of our patients who undergo surgery are included in STS submissions, their ICU progress is documented in PC4, and now their ongoing recovery is being recorded in PAC3 data submissions. Could

not each patient episode be unified into a single submission to a single database? The dataset for each of the registries would become broader, and its analysis potentially richer for it. The good news is that the "owners" of these registries are moving toward consolidation, but it is not as simple as it sounds. Politics and ego will no doubt play a part, but there are important practical hurdles to overcome when trying to combine different datasets, stored using different platforms, the data from which is processed using different softwares. However, at the recent Learning Sessions of the NPC-QIC held in Cincinnati in mid-May, Jeff Anderson hosted a dinner for registry leaders, and organized a session specifically to address the ways in which the larger networks and registries might consolidate some of their activities. There was, I think, consensus that the groups need to work together to work together. A great first step.

An even loftier goal might be to attack this issue at the backend. I am sure we can all agree that neither Epic nor Cerna are appropriate solutions to the need for a truly comprehensive database for all of the data from all of our patients. Many of us have our own local partial solutions, but comprehensive patient databases that consolidate most if not all of the anthropometric, hemodynamic, and imaging data into a single, searchable database are emerging. Once we all have access to such a system, exporting some of that data to registries, or all of it into a singular "congenital heart disease registry" that could ultimately be a national, international, or worldwide resource, would be easy. Easy, that is, if the trillions of datapoints could be housed somewhere, and we had the analytic capability to integrate and interrogate data of "biblical" rather than "big" proportions. But if Google and Amazon can do it, then surely so can we—all we need is a corporate partner that sees congenital heart disease as the emotive pathway into healthcare dominance such that they will support us for free! A few months ago I had the pleasure of visiting Children's Hospital in Kansas City, and was truly impressed by the system that they have developed, locally, to manage essentially all of their data. They also have a burgeoning relationship with Microsoft. Could this be the system and partner that we might all support to make a truly transformational impact on our field, for our patients? Maybe there are others? If we as a specialty were to be able to get behind a single system and corporate partner, a unified data collection protocol, and a shared model of data access, think how potent that would be. Once again, congenital heart care (just as we did with

congenital heart surgery, catheter intervention, integrated multidisciplinary heart teams, etc) would lead the way for our adult colleagues to follow. I am ready to sign up!

CONFLICT OF INTEREST

None.

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