



Health Data Quality Questioned



Most US clinical registries that collect data on patient outcomes are substandard and do not really track in a systematic way how well physicians and hospitals perform. The findings are from a Johns Hopkins study that examined 153 US registries containing health service and disease outcomes data. On average, a registry contained information on more than 160,000 patients treated across more than 1,600 hospitals.

Clinical registries are databases of patient outcomes developed and maintained by medical organisations and medical specialty groups. To evaluate the quality of these registries, the researchers created "a registry of registries" to study the way the healthcare industry measures its performance.

"We found it's the Wild West," says senior author Marty Makary, MD, MPH, professor of surgery at the Johns Hopkins University School of Medicine. "With a few notable exceptions, most registries are underdeveloped, underfunded and often are not based on sound scientific methodology." Results of the study are reported in the *Journal for Healthcare Quality*.

Of the 153 US clinical registries evaluated by researchers:

- Less than 25 percent of registries adjusted their results for differences in disease complexity — information statistically reflective of disparities in illness severity and socio-economic status among patients treated across hospitals.
- Less than 20 percent of registries contained independently entered data — information entered by clinicians other than the ones involved in care (ie, this helps to mitigate the well-established bias of self-reported data).
- 40 registries were funded by taxpayers, but only three shared their data publicly.

In addition, 84 percent (98 of 117) of US recognised medical specialties had no national clinical registries — a significant gap in the efforts to compare the efficacy of treatments and evaluate the quality of care on a large scale.

Such failure to capture and measure patient outcomes is troubling because the insights gleaned from such information could have a direct and profound impact on scientific research and human lives, the researchers note.

"A robust clinical registry can tell doctors in real time what medications work well and which are harming patients, yet the infrastructure to achieve that is vastly under-supported," explains study co-author Michol

Cooper, MD, PhD, a surgical resident at the Johns Hopkins University School of Medicine. "The same rigorous standards we use to evaluate how well a drug does ought to apply to the way we report patient outcomes data."

Dr. Makary's team cites several organisations that maintain exemplary registries with rich, carefully analysed data, audited and reported in a meaningful way, including:

- National Surgical Quality Improvement Program (maintained by the American College of Surgeons) - Its data have generated valuable insights about surgical infections, transformed practice and improved patient outcomes.
- National Cardiovascular Data Registry of the American College of Cardiology - This has also led to improvement in the rates of inpatient mortality among participating hospitals.

Dr. Makary is currently working with colleagues at the Johns Hopkins University Bloomberg School of Public Health and the Brookings Institution to develop formal guidelines for establishing and maintaining useful clinical registries.

Source: [Johns Hopkins Medicine](#)

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