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Comprehensive Data Management System for National Patient-Centered Outcomes Research for Comparative Effectiveness in Total Joint Replacement

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Introduction

The Agency for Healthcare Research and Quality (AHRQ) funded research program, Function and Outcomes Research for Comparative Effectiveness in Total Joint Replacement (FORCE-TJR), is a national patient-centered outcomes research registry. To serve such multi-center longitudinal patient-reported outcomes research, we designed an innovative system to support systematic data collection, management and quality monitoring for long-term outcome evaluation of care.

Methods

The system structure design explicitly considered the continuum of study procedures, including patient enrollment, patient-reported baseline and follow-up surveys, joint implant components, and ambulatory record review for future potential adverse events. Patient enrollment process is recorded through a web-based data capture system. Patient-reported outcomes are completed by patients via scannable paper or web-based standardized surveys before and after surgery. Patient risk factors and implant components are collected from community-based orthopedic practices and hospital operating rooms. All data from the different sources are combined into a centralized database. Quality checks and monitoring processes are routinely conducted for each source of data. De-identified data are cleaned and scored for research analysis and surgeon quality reporting.

Results

This system for the registry program was initiated in 2011. As of Feburary 2014, over 16,000 patients have been enrolled from more than 130 surgeons in 22 states. The centralized database integrating data from patients, surgeons and hospitals is updated weekly. Cleaned, scored data are provided quaterly for all surgeons to review their site- and individual-surgeon-specific outcomes through web reports.

Discussion

This comprehensive data management system is expected to enhance future uses of multisource data to guide surgeon decisions and drive quality improvement. We anticipate that this system will facilitate translation of data integration to broad clinical research to inform best practices in TJR.