

REDCap and clinical registries as a platform to promote clinical translational research

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Patient registries provide a powerful tool to observe the course of the disease; to understand variations in treatments and outcomes; to examine factors that influence prognosis and quality of life; to describe standard of care patterns; to assess effectiveness; to monitor safety; and to change behavior through feedback from data. Clinical outcome studies consistently demonstrate that implementing patient registries improves outcomes and reduces hospital and in-patient costs. An institutional neonatal surgical registry was created that includes patients less than 30 days old with congenital diaphragmatic hernia, hirschprung's disease, necrotizing enterocolitis, gastroschisis and omphalocele. Data are collected on prenatal history, demographics, birth history, surgical data, clinic follow-up visits, complications and functional status. Patients are consented for long term follow-up to assess quality of life and functional status over time and agree to be contacted for participation in future research studies. The registry was developed using REDCap™; a secure, HIPAA compliant, data collection web application. Advantages to REDCap include consolidation and tracking of projects, open source software, secure access from anywhere with an Internet connection, multi-site access, a library of standardized data collection tools and safeguarding protected health information. Data collection for the surgical basic science research projects are now being built in REDCap. Storing data in a common platform enables researchers to track common interests between basic science and clinical outcomes research. Existing registry, outcomes and basic science data are available to launch collaborative studies. The registry provides an important resource to access patient populations and conduct translational research.

Biography

Laura D. Cassidy has a MS in Biostatistics and a Ph.D. in Epidemiology from the University of Pittsburgh, Graduate School of Public Health. She is an Associate Professor at the Medical College of Wisconsin in the Institute for Health and Society, Director of Epidemiology, Director of the Ph.D. Program in Public and Community Health and is also the Director of Clinical Research in the Division of Pediatric Surgery. She has published over 70 peer-reviewed journals.

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