# Prospective Registry

Only 100 years ago, traumatic spinal cord injury (SCI) was commonly lethal. Today, most people who sustain SCI survive with continual efforts to improve their quality of life and neurological outcomes. Spinal cord injury epidemiology is changing as preventative interventions reduce injuries in younger individuals, and there is an increased incidence of incomplete injuries in aging populations. With decompressive surgery and proactive interventions to improve spinal cord perfusion, early treatment has become more intensive. Accurate data, including specialized outcome measures, are crucial to understanding the impact of epidemiological and treatment trends. Dedicated SCI clinical research and data networks and registries have been established in the United States, Canada, Europe, and several other countries.

Kelly-Hedrick reviewed four registry networks, the North American Clinical Trials Network (NACTN) SCI Registry, the National Spinal Cord Injury Model Systems (SCIMS) Database, the Rick Hansen SCI Registry (RHSCIR), and the European Multi-Center Study about Spinal Cord Injury Study (EMSCI). They compared the registries' focuses, data platforms, advanced analytics use, and impacts. They also describe how registries' data can be combined with EHR or shared using federated analysis to protect registrants' identities. These registries have identified changes in epidemiology, recovery patterns, complication incidence, and the impact of practice changes like early decompression. They've also revealed latent disease-modifying factors, helped develop clinical trial stratification models, and served as matched control groups in clinical trials. Advancing SCI clinical science for personalized medicine requires advanced analytical techniques, including machine learning, counterfactual analysis, and the creation of digital twins. Registries and other data sources help drive innovation in SCI clinical science [1)].

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Kelly-Hedrick M, Abd-El-Barr M, Aarabi B, Curt A, Howley SP, Harrop JS, Kirshblum S, Neal CJ, Noonan VK, Park C, Ugiliweneza B, Tator C, Toups EG, Fehlings MG, Williamson T, Guest J. The Importance of Prospective Registries and Clinical Research Networks in the Evolution of Spinal Cord Injury Care. J Neurotrauma. 2022 Dec 28. doi: 10.1089/neu.2022.0450. Epub ahead of print. PMID: 36576020.