Kelly-Hedrick et al. reviewed four registry networks, The NACTN Spinal Cord Injury Registry, The Spinal Cord Injury Model Systems (SCIMS) Database, The Rick Hansen Spinal Cord Injury 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 Spinal Cord Injury 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)].

1)
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.