



The 2nd International Neurotrauma Congress & the 4th International Roads Safety Congress

Shefa Neuroscience Research Center, Tehran, Iran, 18-20 February, 2015

The Neuroscience Journal of Shefaye Khatam

Volume 2, No. 4, Suppl. 3

Poster Presentation

Iranian Quality Registry of Spinal Cord Injury, Key Considerations for Implementation

Zahra Azadmanjir^{1, 3}, Vafa Rahimi-Movaghar^{2*}, Seyed Behzad Jazayeri², Seyed Mohammad Ghodsi³, Seyed Mehdi Sharif-Alhoseini², Mohammad-Reza Zarei², Abbas Norouzi Javidan³, Seyed Hassan Emami Razavi³

¹Health Information Management Department, School of Allied Medical Sciences, Tehran University of Medical Sciences, Tehran, Iran.

²Sina Trauma and Surgery Research Center, Sina Hospital, Tehran University of Medical Sciences, Tehran, Iran.

³Brain and Spinal Injuries Research Center, Tehran University of Medical Sciences, Tehran, Iran.

Published: 18 February, 2015

Abstract

Prevalence of spinal cord injury (SCI) in Iran is considerable and developing a national registry is substantial. Registry can be a foundation of efforts for patient care improvement, clinical research facilitation, preventative strategy formulation and policymaking for better support of patients. With respect to long-term and multiple consequents of the lesions that will have a negative impact on patient quality of life, implementation of quality registry would be more appropriate. There are some considerations for this due to the special nature of medical condition, which is SCI, and development objectives. This paper will be discussed on the key considerations. The study has been performed by discussion groups and brainstorming sessions as well as literature review on international experiences about develop and implement spinal cord registry. Key considerations for implementing the quality registry of SCI are related to defining detailed objectives, inclusion criteria for both traumatic and non-traumatic, methods for case finding according to distribution and movement of individuals across the country, identifying data sources, data registration and clinical assessments standards, processes, controls and auditing, confidentiality and administrative and technical infrastructures. Given the complexities that are available in the nature of injury, care and follow up processes and budget limitations, successful implementation depends on the appropriateness of the defined administrative structure, processes and quality control and registry auditing instructions with regard to key considerations that implied. In addition, the spirit of cooperation related originations and authorities, commitment to the principles of the program, comply with the ethical framework such as confidentiality and using the loop of feedback in the development process of registry are critical success factors for implement it.

Keywords: Spinal Cord Injury, Registry, Implementation Considerations.

***Corresponding Author:** Vafa Rahimi-Movaghar

E-mail: v_rahimi@tums.ac.ir