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Oral Presentation

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

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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. In 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.

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