

**KHORASAN TERRITORY DATA BANK FOR RHEUMATIC DISEASES: A MULTI-REGISTRY
RHEUMATIC DISEASE DATA BANK IN MASHHAD UNIVERSITY OF MEDICAL SCIENCES**

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TYPE OF ARTICLE: CONFERENCE ABSTRACT**ABSTRACT**

Introduction: Registry data are critical in order to develop an understanding of the various features of rheumatic diseases, disease-specific outcomes and also the burden of diseases. The Khorasan territory registry for rheumatic diseases will be used to describe diseases and co-morbid illness, assesses disease outcomes and the consequences of the therapeutic interventions, and has potential for measuring the costs and its cost-effectiveness. Khorasan territory registry for rheumatic diseases was founded by the Rheumatic Diseases Research Center (RDRC) in 2015. The Khorasan Data Bank for rheumatic diseases is designed for various rheumatic diseases. It will be used principally to study individuals with Systemic Lupus Erythematosus, Antiphospholipid Syndrome, Rheumatoid Arthritis, Poly-Dermatomyositis and other diseases. The main purpose of the rheumatic diseases registry is to design a system for systematic gathering, saving, analyzing and interpretation of data of patients with rheumatic diseases, and to further develop for prevention and treatment strategies in regards to planning the patients' care.

Methods: Rheumatologist-written questionnaires have been developed to gather demographics, medical history, pregnancy history and outcomes, physical examinations as well as the patient's specific characteristics in accordance with their diagnosis of various rheumatic diseases and the treatment that each patient has received with regards to new biologics. It enrolls patients from the community who refer to rheumatology clinics at MUMS university hospitals, follows up with a validated key patient data set founded by the informatics center of MUMS. Rheumatologist-written data core make this longitudinal and ongoing registry available to statisticians for detailed analysis. Bio-banking will be our future mission.

Results: So far, we have prepared the foundations and physical spaces and also, well organized questionnaires have been provided.

Conclusion: Implementation of a well organized and funded registry are mandatory in our region in the north east of Iran for the prevention of the chaotic nature of the healthcare system and to provide well designed resources not simply for estimating the incidence of rheumatic diseases, but because it will also be a rich source of valid data for further studies. These data should be helpful in planning the delivery of rheumatology services not only in Mashhad-Khorasan, but also in the north east of Iran.

KEYWORDS: Registry, Rheumatic diseases, Data bank, Khorasan-Mashhad

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