



**MEMORANDUM OF UNDERSTANDING**

**Systemic Sclerosis Registry Agreement**

**Rheumatology Research Center (RRC), Tehran University of Medical  
Sciences (TUMS) and Ilam University of Medical Sciences (IUMS)**

**October 2018**



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## Introduction

Rheumatology Research Centre (RRC), Tehran University of Medical Sciences (TUMS) is mainly based in the Shariati Hospital in Tehran. A registry software is established for different rheumatic diseases, including Systemic Sclerosis or Scleroderma in RRC.

RHEUMATRY program is conducted by Rheumatology Research Center (RRC). Prof. Ahmadreza Jamshidi is the manager of RRC and RRC representative.

RHEUMATRY (<http://rheumatry.com>) is a web software of registry for all rheumatic diseases including Rheumatoid Arthritis, Ankylosing Spondylitis, Systemic Sclerosis, Systemic Lupus Erythematosus, Behcet's Disease, and etc. founded by Ministry of Health and Medical Education and executed by Rheumatology Research Centre (RRC), Tehran University of Medical Sciences (TUMS). RHEUMATRY is established to improve care for rheumatic patients worldwide by monitoring their disease activity. The database can be used as a benchmark by participating rheumatologists and collated data can be a source for scientific research.



### **Timing**

IUMS will enter the data online to RHEUMATRY online database.

### **Intellectual property**

IUMS owns its data and the administrator of IUMS can download and use these data for research purposes at any time. All intellectual and industrial property rights of the data in the RHEUMATRY database vest in RRC. Therefore, it is necessary that IUMS administrator transfer any intellectual property or other rights in the database to RRC. The IUMS administrator will not have any license to use the data in the database, other than its own data. All collaborators can use the database in research and publications by permission of RRC and others.

### **Executive Scientific Committee**

RHEUMATRY Executive and Scientific Committee acts as the Board's forum for discussion on strategic and feasibility aspects of RHEUMATRY. They are a platform for judging scientific questions raised by researchers who wish to use the database, while safeguarding the ethical and scientific aspects of RHEUMATRY. RRC is pleased to welcome Dr. Nasrin Bazgir as the head of Systemic Sclerosis Registry of Ilam University of Medical Sciences (IUMS). She is also a member of the Executive Scientific Committee of RHEUMATRY, with the possibility to submit research proposals and discuss submitted requests.

### **Research Projects**

Rheumatologists, who upload the data into the RHEUMATRY database, can submit proposals for research projects, according to a predefined research proposal template (the template is downloadable on [rheumatry.com](http://rheumatry.com)). Research proposals are assessed on ethical, scientific and feasibility aspects by the Executive and Scientific Committee of RHEUMATRY. Research proposals without a request for funding can be submitted at any time. Research proposals with a request for funding can be submitted once a year. The deadline to submit these proposals, along with the maximum financial support and project duration, will be announced by email.



## Activities

Responsible for IUMS export:

Dr. Nasrin Bazgir will supervise and coordinate all the activities.

Responsible for RHEUMATRY upload:

Dr. Mahdi Mahmoudi will supervise and coordinate all the activities.

Activity	Responsible
Providing online access and questionnaires + support	RHEUMATRY
Testing the Plan	RHEUMATRY and IUMS
Testing Execution	RHEUMATRY and IUMS



## Term and termination

This agreement enters into force on October 1, 2018 and will be expired by October 1, 2019.

RHEUMATRY is interested in a long-term collaboration. This agreement can be continued for 5 years, after successful evaluation of the first year.

## Executives on behalf of:

### Rheumatology Research Center

**Name:** Ahmadrza Jamshidi

**Place:** Tehran

**Date:**

**Signature:**

### Ilam University of Medical Sciences

**Name:** Nasrin Bazgir

**Place:** Ilam

**Date:**

**Signature:**