

**Abstract**

**Original Article**

**Designing an Electronic Registry for Patients with Beta  
Thalassemia Major for Mazandaran Province, IR Iran 2016**

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**Background:** Beta thalassemia major is the most prevalent genetic disease in Mazandaran province. The national prevention program is successful, however our patients grow older and their managements get more complicated. Paper based clinical notes are being used and there are some electronic data banks mainly for financial matters. This registry (ETR Mazandaran) is designed to be a reliable data bank for epidemiologic and clinical data for beta thalassemia major patients living in the province. This registry will be a source for health system decision makers.

**Methods:** Thalassemia Research Center (TRC) with collaboration of informatics Technology Department of Mazandaran University of Medical Sciences (MUMS) designed an Electronic Thalassemia Registry (ETR, [Http://thr.mazums.ac.ir](http://thr.mazums.ac.ir)) in Persian language, in 2015-2016. There are 16 dedicated clinics and wards under MUMS in the province taking care of about 2700 patients. In each thalassemia clinic a nurse has been elected and educated. Questionnaires were designed by an experienced clinician with collaboration of a software developer. Each patient was registered by the national identification number and by his (her) name. Epidemiologic, clinical data, complications and medication have been registered. Confidentiality has been considered and no reports include patient's name. All research proposals were ethically evaluated in TRC research committee and university ethical committee if involves intervention in patients management. A biologic bank for blood or DNA samples has been anticipated.

**Results:** A Web-based Thalassemia Registry system was designed to serve as an electronic medical file for patients retrieving data from medical files by trained registrars. Data was audited and cleaned before it was archived in the electronic filing system. The registry is consisted of

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epidemiologic data, clinical history and important physical examination points, laboratory results, a list of classic complications, list of medication. Each record should be up dated at least one time in each season. There are also a separate form for special checkup such as echocardiogram, MRI T2\* and bone mineral densitometry which should be updated annually for patients 16 years old or older. There is a form for migration to other provinces and death. This registry is designed to run for at least 10 years. Thalassemia registry is easily adaptable for usage in other provinces.

**Conclusion:** Electronic Thalassemia Registry is an online data bank for patients, physicians and policy makers for better research and development in the field.

**Key words:** Beta Thalassemia Major, Electronic Registry, Mazandaran, IR Iran