Epidemiological information for rare diseases is crucial for many reasons – study the natural history of diseases, research, optimization of treatment protocols, health planning, etc.

Materials and methods
There are seven centers in Bulgaria that cater the patients with Thalassemia. With the help of the physicians working there all the patients will be enrolled onto a database and their medical records will be stored in a central computer at the Information Center for Rare Diseases and Orphan Drugs, situated in Plovdiv.

Participation in the registry is voluntary. Each patient is entitled to receive a copy of the consent form that has to sign as an approval for wishing to be registered. Everyone may discontinue his participation in the registry at any time. This project is being approved through a local Ethics Committee and the Commission for personal data collection in order to protect the confidentiality of each patient who is enrolled.

Benefits of the registry
The registry will help doctors, scientists and health authorities to determine the quality of life and long-term outcome of Bulgarian patients with Thalassemia. They will also be able to compare overall management of Thalassemia patients in Bulgaria with other countries. Moreover, this experience could be used as a model for starting registries for other rare diseases in the country.