



ISLAMIC REPUBLIC OF IRAN



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Research Affairs  
Disease Registry Unit

## In the Name of GOD

### **REGISTRY PROPOSAL: (1-2 PAGES excluding references)**

#### A. Title of Registry

Parkinson's Disease Registry in Patients Referred to Neurology Clinics of Shahid Beheshti University of Medical Sciences in Tehran (SBMU-PDR)

#### B. Brief Intro to Registry –Literature Review (1-2 paragraphs)

Among degenerative neurological disease, Parkinson Disease (PD) is the second most common disorder. Although a wide range of incidence and prevalence rate exist in reviewed literatures due to a consequence of variation in study methodologies, the crude prevalence rate above 60-year-old is 1%. increase in aging population will lead to an increase in PD patients.

The symptoms usually emerge slowly. Early in the disease, the most obvious symptoms are shaking, rigidity, slowness of movement, and difficulty with walking. Thinking and behavioral problems may also occur. Dementia becomes common in the advanced stages of the disease. Depression and anxiety are also common, occurring in more than a third of people with PD. Other symptoms include sensory, sleep, and emotional problems.

#### C. Registry Objectives (what is it you are specifically looking at, trying to reach?)

The PD registry will be used to facilitate the understanding of basic epidemiological features of the disease, genetic and non-genetic risk factors, co-morbidity, the up-to-date treatment strategies and the related economic burden from medical and surgical treatment (deep brain stimulation), to develop new therapeutic protocols as well as healthcare policies, and ultimately, to improve the quality of life of PD patients. PD registry will also be served as data bank for investigators in the field of PD to quickly identify and notify research subjects about other research studies for which they are eligible.

#### D. Registry Design (participants, data collection, statistical analysis plan, etc.)

The 3 main university hospitals including: Shohada-e-Tajrish, Loghman, and Imam Hossein will serve as representative of pilot study for PD registry. This will be a record-based,

multi-center, nation-wide, cohort study. A user-friendly, yet, encrypted registration platform will be provided through internet for authorized personnel. The contents of PD registry will be as follow: demographic features, risk factors, clinical profiles of diagnostic criteria, co-morbidity, images profiles, and treatment regimens in details.

E. Timeline for your Registry project (project deadlines set by you and your mentor)  
The estimated deadline would be around 5 years.

F. Who will provide support and feedback and how often will this occur?  
Clinical neurologist, every 6 months.