



ISLAMIC REPUBLIC OF IRAN



Shahid Beheshti
University of Medical Sciences

Research Affairs
Disease Registry Unit

In the Name of GOD

REGISTRY PROPOSAL: (1-2 PAGES excluding references)

A. Title of Registry

Iranian pulmonary arterial hypertension registry: A development and update project of PH website

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

Pulmonary hypertension has been defined as an increase in the mean pulmonary arterial pressure (PAP) ≥ 25 mmHg at rest as assessed by right heart catheterization (1, 2). This value has been used for selecting patients in all randomized clinical trials and registries of pulmonary arterial hypertension (3, 4). Pulmonary artery hypertension (PAH) is a fatal disease with a prevalence of 15.5 per million. The prevalence of PAH is about 8.6 per million. The incidence of PAH is 1.2 per million (5) Registry systems are organized not only to acquire a definite and standard approach to the diagnosis of the disease and creation of a database, but also updating the knowledge of managing physicians. Prompt diagnosis and patient identification in the preliminary stages of the disease can result in a more effective treatment. Considering the aforementioned facts, it would be justifiable to present a national data registry system for PAH to prevent inappropriate prescribing in order to ensure that the best possible care is delivered to those with this disease.

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

1-Acquire a definite and standard approach to the diagnosis of pulmonary hypertension and creation of a database for collection of patients' information

2-updating the knowledge of managing physicians.

3- Prompt diagnosis and patient identification in the preliminary stages of the disease and as a result, in a more effective treatment.

4.Preventing inappropriate drug prescription in order to ensure that the best possible care is delivered.

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

A website (<http://www.IPAH.ir>) was developed for IPAH and PAH registration in which the information of the patients collected was updated by using the latest guidelines such as European Respiratory Society (ERS), European Society of Cardiology (ESC), International Society of Heart and Lung Transplantation (ISHLT). In the first step, IPAH and PAH patient information is added to the registry. Data entry was allowed for physicians and other healthcare organizations that were qualified to log-in to the registry via Internet with a personalized username and password. Physicians could access patient data entered by them. The most important stage of adding the information was entering the average pulmonary artery wedge pressure, which was obtained by right heart catheterization.

E. Timeline for your Registry project (project deadlines set by you and your mentor)

The registry was opened in Iran since November 2009 and is being updated and developed and updated to a more comprehensive and sophisticated platform in the next three months via renewal of the aforementioned website and addition of updated information for both patients and different health care personnel, in the future.

F. Who will provide support and feedback and how often will this occur?

Our main educational support will be through our related colleagues in Shahid Beheshti university and also throughout the country. At the present time we have an integrated scientific team from different universities in Tehran, Isfahan, Mashad, and also Tabriz. More over there are scientific committees which are expert in Pulmonary hypertension in this network and provide support and feedback to this project, mostly every season.

References

1. D'Alonzo GE, Barst RJ, Ayres SM, Bergofsky EH, Brundage BH, Detre KM, et al. Survival in patients with primary pulmonary hypertension. Results from a national prospective registry. *Ann Intern Med* 1991; 115 (5): 343- 9.

2. Hatano, S. (Ed.). Primary Pulmonary Hypertension: Report on a WHO Meeting, October, 1973. World Health Organization; 1975.

3. Humbert M, Sitbon O, Chaouat A, Bertocchi M, Habib G, Gressin V, et al. Pulmonary arterial hypertension in France: results from a national registry. *Am J Respir Crit Care Med* 2006; 173 (9): 1023- 30.

4. Peacock AJ, Murphy NF, McMurray JJ, Caballero L, Stewart S. An epidemiological study of pulmonary arterial hypertension. *Eur Respir J* 2007; 30 (1): 104- 9.

5. Tueller C, Stricker H, Socal P, Tamm M, Aubert JD, Maggiorini M, et al. Epidemiology of pulmonary hypertension: new data from the Swiss registry. *Swiss Med Wkly* 2008; 138 (25- 26): 379-84.