



ISLAMIC REPUBLIC OF IRAN



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Research Affairs
Disease Registry Unit

In the Name of GOD

**Brief Proposal of Iranian registry of pediatric endoscopy
databases system clinical outcomes research initiative
procedures and liver biopsy**

A. Brief Intro to Registry –Literature Review:

In pediatric medicine, we confront a range of common or uncommon familial, sporadic or secondary gastrointestinal and liver diseases with various gastrointestinal manifestations including abdominal pain, chronic diarrhea, weight losing, absorption disorder, malnutrition, developmental delay, recurrent vomiting, upper or lower gastrointestinal bleeding, inflammatory bowel or pseudo-IBD disease, recurrent gastrointestinal reflux, food allergy, and ingestion of foreign bodies, swallowing chemicals and burns materials, liver manifestations, neonatal or infantile cholestasis, acute or chronic hepatitis, acute or chronic cirrhosis. Differential assessment is not possible by conventional diagnostic methods just. Diagnosis delayed can be causes complication and reduce complications is dependent on early diagnosis. Therefore our study aimed to facilitate early diagnosis.

B. Registry Objectives:

- Determining the incidence of procedures;
- Conducting full care of patients during treatment;
- Conducting unification of treatment process in similar cases;
- Assessing clinical disease progress;
- Evaluating health care and medical intervention;
- Identifying the complication of the disease;

Reducing complications of procedures;
 Conducting studies and using evidence-based medicine;
 Conducting a caring system for the prevention and control of diseases and their complications;
 Determining the benefit and cost-effective index of procedures and their complications;
 Conducting clinical trials for determining benefit and cost effect index of different treatment;
 Identifying the correlation between different treatment and severity of the procedures;
 Conducting epidemiological studies to determine the associated factor related to recurrence and death.

C. Registry Design:

The data of children ≤ 18 years old referred to Mofid children medical center that underwent endoscopic procedures will be collected by the trained assistant according to the specific checklists. Also, outpatient's data will be collected by trained staff. At the same time, other focal points will be collecting data. All of the data will be registered in the system. Some of the patients' information will be carried out by telephone calls weekly and monthly. We will be entering data in a designed application system (<https://pedgiregistry.ir>).

During data gathering, data analysis will be carried out in the period of 3 months by an epidemiologist of the project and under the supervision of the strategic committee. Also, in the same session, the quality of registration and registration procedures will be evaluated.

The program will be supervised by the steering committee. The committee tasks are to determine the requirements needed to meet the predetermined goals. The coordination center of the data, which is under the supervision of the strategic committee, is responsible for controlling the quality of information, how to access them as well as how the database outputs to perform the analysis.

D. Timeline for your Registry project:

| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|--|---|---|---|---|---|---|---|---|---|----|
| Proposal submission | * | * | * | | | | | | | |
| Designing Registration system | | | | * | * | | | | | |
| Coordination with other focal point for registration | | | | | | * | * | * | * | * |
| Registry duration set 5 years | | | | | | | | | | |
| Each 5 years data will be evaluated and results use in researchers and articles to improve patient's conditions. | | | | | | | | | | |

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

Shahid Beheshti University of medical science provides financial support for the registry of Iranian registry of pediatric endoscopy databases system clinical outcomes research initiative procedures and liver biopsy.

Also, some experts plan to collect information or other items in the program, all of which are in the committee's decisions through the coordinating center strategic committee formation, preparing the internet system for patient registration. To inform all the pediatricians and gastrointestinal pediatricians. Also, other experts will be invited to participate.