Registry of Congenital Gastrointestinal Anomalies

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

Congenital gastrointestinal anomalies are one of the most important congenital diseases. Symptoms of congenital anomalies are different in terms of the severity and location of the defect, and in the different ages with different manifestations(1).

One of the most common congenital anomalies in the esophagus are esophageal atresia. It causes the esophagus to end in a blind-ended pouch rather than connecting normally to the stomach. In the most common type of esophageal atresia esophageal atresia is associated with fistula (in over 90 % of the cases). Esophageal Atresia with distal TEF (tracheoesophageal fistula) that the lower esophageal pouch connects abnormally to the trachea. The upper esophageal pouch ends blindly. Treatment includes suctioning out any fluid that is trapped in the stomach, providing fluids intravenously, and surgical repair of the esophageal closure(2).

Duodenal atresia is another common congenital gastrointestinal anomalies with absence or complete closure of a portion of the lumen of the duodenum. It causes increased levels of amniotic fluid during pregnancy (polyhydramnios) and intestinal obstruction in newborn babies(3).

Other common congenital gastrointestinal anomalies are Hypertrophic pyloric stenosis. Hypertrophic pyloric stenosis is blockage of the passage out of the stomach due to thickening (hypertrophy) of the muscle at the junction between the stomach and the intestines(4).

In medicine, we face a series of congenital gastrointestinal anomalies that have similar manifestation and it is impossible to separate them based on common diagnostic methods. So their treatment is based on causes of disease, and in most cases, they don't respond appropriately to conventional treatments.

Therefore, we need to use new diagnostic methods. Also, the clinical disease progress and the evaluation of health services provided and interventions in this group of rare diseases are possible only in the form of registry formation. So, by performing fundamental studies, it is possible to utilize the cause-based treatment methods and also with monitoring of patients - can be valuable information about the clinical disease progress and the effectiveness of the treatment.

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

Assessing clinical disease progress;

Evaluating health care and medical intervention;

Identifying the complication of the disease;

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 diseases 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 disease;

Conducting epidemiological studies to determine the associated factor related to recurrence and death.

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

The data of neonates and children with congenital gastrointestinal anomalies including signs and symptoms of disease, the consultations report, the results of diagnosis imaging and etc will prepare by the trained nurse according to the checklist. Also, outpatient's data will collect by trained staff. At the same time, designing an application system for the registration system.

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. During data gathering, data analysis will be carried out in the period of 3 months by 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 (project deadlines set by you and your mentor)

	1	2	3	4	5	6	7	8	9	10
Proposal submission	*	*	*							
Designing Registration system				*	*					
Coordination with other focal point for registration						*	*	*	*	*

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 congenital gastrointestinal anomalies project.

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, neonatologists, pediatric surgeons and gastrointestinal pediatricians. Also, other experts will be invited to participate.

Reference:

1. Guandalini S. Essential Pediatric Gastroenterology, Hepatology, and Nutrition: McGraw Hill Professional; 2005.
2. Parthasarathy A. IAP Textbook of pediatrics: Jaypee Brothers, Medical Publishers Pvt. Limited; 2019.
3. Sinha IP, editor Nelson textbook of pediatrics. Seminars in Fetal and Neonatal Medicine; 2012: Elsevier.
4. McInerny TK, Adam HM, Campbell DE, Foy JM, Kamat DM. AAP textbook of pediatric care: Am Acad Pediatrics; 2016.