Review Article:

Information Registry System on Congenital Hypothyroidism: A Systematic Review

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ABSTRACT

Background: Congenital hypothyroidism is the most common congenital disorder of the endocrine system, leading to preventable mental retardation.

Objectives: We aimed to evaluate the current status of congenital hypothyroidism information registry systems.

Methods: In this systematic review 290 papers identified. A total of 254 articles were screened, of which 17 qualified articles were selected through the databases of Scopus, science direct ProQuest, PubMed, as well as the search engine Google scholar (no restriction on date of publication) up to 2020, were searched. Inclusion criteria were the Articles with the English language that examining information registry systems on congenital hypothyroidism. Articles whose full texts were not accessible, case reports, and letters to the editor had to be excluded.

Results: This study showed that the primary goal of nearly half (50%) of the information registry systems for congenital hypothyroidism is to evaluate the efficiency and effectiveness of the screening program. Other information registry systems for congenital hypothyroidism have examined the epidemiology of the disease in 4 studies (23.6%), monitoring iodine deficiency in 3 studies (18%), surveillance disease in 1 study (6%), and describing the clinical and familial features of the patient in 1 study (6%).

Conclusions: Few studies have been done on developing information registry systems, and most studies have focused on the use of information systems in this field. Further comprehensive reviews are recommended to investigate the infrastructure of the commission national registry and world network to record information units on congenital hypothyroidism.

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1. Context

Thyroid hormones play a vital role in developing the brain, nervous system, and most body organs. Undetected congenital hypothyroidism is the leading cause of mental retardation around the world [1]. Using clinical signs for the diagnosis of the disease is rarely possible [2]. A definite diagnosis is possible only with a screening program and measurement of T4 and TSH in the baby's blood sample [3]. Then in case of timely treatment, the side effects of the disease can be prevented [4]. The prevalence of congenital hypothyroidism is approximately 1 per 2000-3000 live births [5]. Also, the prevalence of congenital anomalies, such as cardiac anomalies, in these patients is almost several times higher than in healthy infants [6]. In recent years, the incidence of congenital hypothyroidism disease is twice the original number. This increase is due to various factors such as population changes, infant survival preterm, and more comprehensive diagnostic criteria (with the possibility of finding intermediate cases of congenital hypothyroidism) [1]. The American Academy of Pediatrics emphasizes the need to follow up, provide care, and measure T4 and TSH periodically (from once per two weeks at the time of diagnosis to once per six months until completion of growth) [7].

According to the above results, health managers should pay more attention to solve the problems. These problems can be solved by providing the most effective solutions. One of the solutions is the use of the disease information registry system. It serves as the best solution for organizing and recording information correctly in disease control and follow-up. However, because of the chronic nature of this disease and its continuous monitoring, accurate and timely data recording, together with the use of information registry systems, plays an essential role in improving the quality of screening programs (diagnosis and treatment) of patients promptly.

Moreover, the use of disease information registry systems as an essential tool for disease surveillance has also expanded in developed countries. The disease registry provides standardized and organized methods of systematically collecting clinical data based on predefined objectives [8]. In the end, using the disease information registry system is inevitable due to the accessibility, accuracy, and reliability of the information, its low cost, and ease of use for physicians, managers, and health care providers [9]. The natural history of the disease, disease etiology, epidemiology, disease boundaries, location of treatment, regional or national variations in treatment can be described by using the registry data, and the results also help improve the safety, quality, and value of patient care [10].

Disease information registry systems are a rich source of information for health decision-making and policy-making. The development of the registry and the use of the data stored in its database significantly impact identifying potential risk factors, disease-associated anomalies, diagnostic methods, and standardize screening methods. Moreover, it helps in selecting the best treatment, as well as performing epidemiological studies. Also, it is essential in disease surveillance. Lastly, it establishes a framework for randomized clinical trials [11-14].

2. Objective

Several studies have focused on the creation or use of data from congenital hypothyroidism registry information systems. Still, no review articles have ever been published to investigate the goals and application of congenital hypothyroidism information registry systems. We aimed to review the current status of congenital hypothyroidism information registry systems in the world.

Search strategy

In this study, the databases of Scopus, ScienceDirect, ProQuest, PubMed, and Google Scholar search engine (no restriction on date of publication) were searched. A manual search was also conducted to ensure the comprehensiveness of the study. There was no time limit for searching to retrieve all relevant research. Therefore, all published articles up to 2019 were reviewed. The keywords of "registries", "surveillance", "information system", "registry system", "congenital hypothyroidism" were used to access the articles.

Criteria for eligibility

The inclusion criteria of articles in this structured review were the original articles published in English, focused on the information registry system of congenital hypothyroidism. The exclusion criteria included thesis, book chapters, letters to the editor, reports, review articles, and lack of access to full-text of related articles.

Study selection

Initially, based on the search strategy and keywords, a list of all the things contained in the databases was prepared. The titles of the obtained articles were reviewed by two researchers, leading to excluding the duplicates.

The titles and abstracts of the remaining items were then carefully studied, and the unrelated articles were removed (Figure 1). Finally, the analysis and evaluation of the full text of possible related articles were done, and these reviews prompted the selection of relevant materials. All the steps of extraction and examination of resources were performed by two researchers and independent of each other to prevent biases. EndNote (X9) software was employed for resource management.

Quality assessment

The quality of the articles was evaluated by two experts independently. In cases of disagreement between the two researchers, the article was reviewed by a third party.

Data extraction

After extracting the full text of the articles, two authors used the data extraction form to extract relevant data from the included studies independently. To enhance the validity and reliability of the information, the data extraction process was repeated (not divided amongst the two authors). Discrepancies amongst authors were solved through discussion and reaching a consensus. The extracted data from each study were general information and particular category (Figure 1).

Data synthesis and analysis

Evaluating and analyzing the articles was done based on the specified categories. The summary of the results and the classification of the items are shown in (Table 1). The reviewed items were categorized into five groups based on goals. These five groups include articles aimed at evaluating the effectiveness and efficiency of screening programs, epidemiological research, iodine deficiency monitoring, disease surveillance, and the description of clinical features of the disease.

3. Results

Description of included studies

We present the first systematic review on congenital hypothyroidism information registry systems in the world. In this review, 290 relevant articles were identified through an electronic database search. After reviewing the full text of the articles, a total of 17 articles met the inclusion criteria.

However, after extracting the full text of the articles, evaluating and analyzing the articles was done based on the specified categories (Figure 2). The summary of the results and the classification of the items are presented in Table 1. The reviewed items were categorized based on goals into five groups. These five groups include articles aimed at evaluating the effectiveness and efficiency of screening programs, epidemiological research, iodine deficiency monitoring, disease surveillance, and the description of clinical features of the disease.

Distribution of articles based on the main objectives of the information registry system

Evaluate the Effectiveness and Efficiency of the Screening Program Admitting the patient to the screening program is the initial step in diagnosing and identifying congenital hypothyroidism. The disease must be diagnosed and treated promptly to prevent its further complications. Hence, the ongoing evaluation of the efficiency and effectiveness, and quality improvement of the screening program was inevitable. Among the included studies, eight articles were associated with the objectives of the screening program. Olivier et al. examined the Italian information registry system of congenital hypothyroidism. The Ministry of Health has established this system at the national level to monitor the efficiency of the screening program.

All centers for screening, diagnosis, and follow-up, as components of an integrated approach, contribute to the national registry for congenital hypothyroidism. Active and continuous collaboration between screening and follow-up centers with the information registry system standardizes the screening methods and considerable improvement in the initiation and treatment of patients [14]. By developing the disease information registry system, Shahmoradi et al. collected and recorded the screening program, treatment, and follow-up of congenital hypothyroidism to evaluate the efficiency and effectiveness of the screening program in Iran. The study results showed that by identifying the problems of the screening program, this system has a positive effect on improving the quality of the program and improving the accuracy and correctness of the input information [15]. By creating a comprehensive database on all Scottish infants (with high TSH), M-Ray et al. assessed the effectiveness of the screening program. Data such as (positive time notification, the start of treatment, late detected or undiagnosed cases, and the uncertain status of children with possible definitive diagnosis) were collected and then analyzed. Determining the average time (collection of samples, laboratory response, and starting treatment) and helping reduce possible delays are the study results [16].

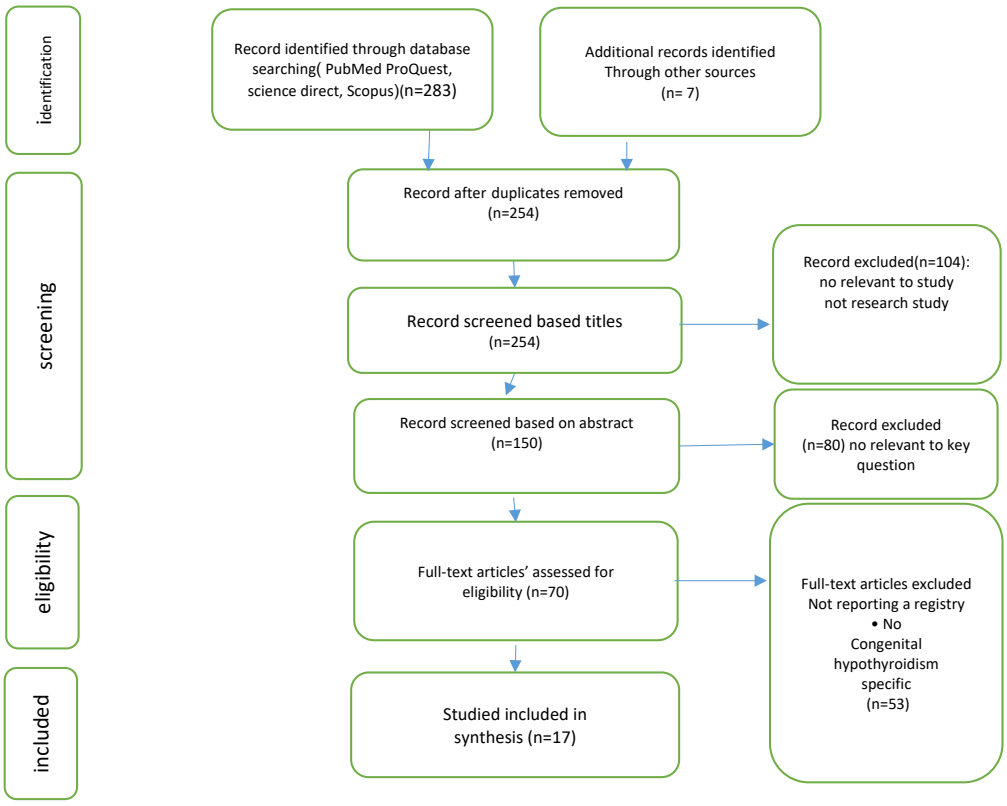

Figure 1. Flowchart illustration search results

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The information registry system has many advantages, such as managing congenital hypothyroidism screening programs. Nano et al. conducted a study to identify the benefits of the National Congenital Hypothyroidism Information Registry System in Romania. The results of their study indicate the possibility of loading and statistical analysis of infant TSH results by connecting the computer system to laboratory equipment. Other advantages of the information registry system include screening coverage at the national level (national, gynecology, and obstetrics hospitals and regional) and the step-by-step monitoring of the federal screening program. Also, other results of this study were accurate determination of disease progression, epidemiological research, and iodine deficiency monitoring in the country [17]. National Guidelines recommend a screening threshold (TSH level of 10 µg/L) in the UK screening program. To this end, Rachel Knowles et al., in a one-year prospective follow-up, estimated the performance of the congenital hypothyroidism screening program on different thresholds. This study aims to calculate and compare the national standards to achieve a possible positive test threshold result (6 and 8 µg/L). The study results assessed the performance of the screening program thoroughly. Still, the use of new thresholds compared to the limits recommended by guidelines has higher sensitivity, accuracy,

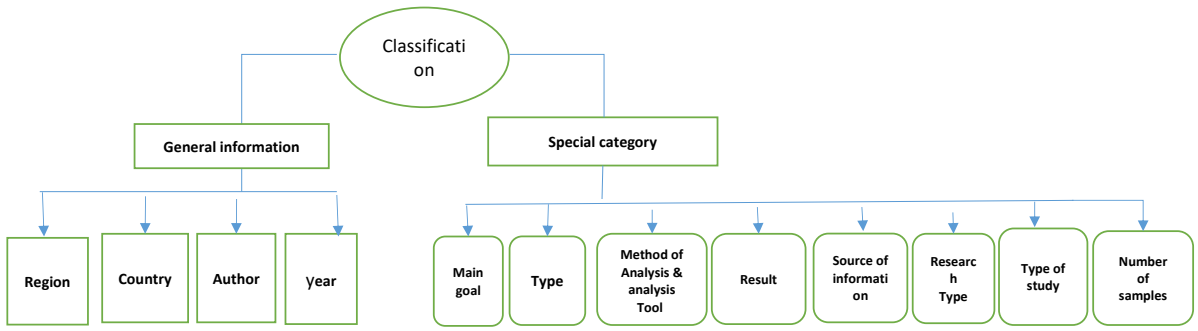

Figure 2. Classification of reviewed articles

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and reporting value. They suggested that the current limit required further evaluation and research to explore the consequences of transient congenital hypothyroidism concerning the screening policy [18].

The importance of information systems in facilitating management and improving the quality of health care is significant. For this purpose, Taheri et al. in Isfahan Province (Iran) have developed web-based software that is effective in improving the quality of screening programs, providing services, better performance, effectiveness, and cost reduction. The goal of this software was to improve trends in congenital hypothyroidism screening and neonatal phenyl ketone urea with the help of electronic resources. Another study result was reducing human errors, improving the quality of services provided to patients, and increasing the accuracy and competency of input information [19]. Jonathan et al. conducted a descriptive retrospective study to analyze and describe the flow of information in the screening program and determining the general trend for achieving the golden age of treatment in Albert, Canada. Complete information on the various stages of the screening program was collected and analyzed in a database designed for this purpose. Evaluations indicate the need for work to improve quality and reduce potential delays and keep the program efficient [20]. Hetarichi et al. evaluated the congenital hypothyroidism screening program regarding coverage, effectiveness, diagnosis, and management of cases in southern Sri Lanka. For this purpose, the data of the screening program database were analyzed from January 2011 to December 2012, and the researchers proposed a system of direct communication between the screening program and the family unit to improve the tracking time and facilitate the sharing of information [21].

Epidemiological research

It is possible to perform epidemiological studies to determine the prevalence, incidence, and disease risk using the data collected from the disease information recording systems. These four reviews show the study of related articles on the epidemiological logistics of congenital hypothyroidism. These systems focus on collecting demographic information, geographic area, and risk factors for the disease. Korinzuk et al. tried to use a population-based information system to examine the epidemiological screening program for congenital hypothyroidism in Australia. In this study, by comparing the prevalence rate in two 10-year periods, the course of the disease was determined over time. The study results include the prevalence of congenital anomalies and the determination of disease risk factors. They concluded that by linking the population-based information system with the screening program database, valuable information about disease epidemiology, screening program evaluation, and disease knowledge promotion could be obtained [22].

The prevalence of congenital anomalies in neonatal hypothyroidism in infants is higher than in healthy infants. For this purpose, Robert et al. studied the link between the two necessary population information recording systems (congenital anomaly information recording system and screening program database) in Atlanta, USA. They determined the epidemiology of the disease and the pattern of associated anomalies. The study results identified 97 infants with congenital hypothyroidism and congenital anomalies in these infants. The researchers concluded that the epidemiological pattern of congenital hypothyroidism is very similar to congenital disabilities [23]. In a retrospective study, Elnazi et al. employed data from the Central Hospital's Neonatal Registry Office in the Saudi city of Arar and determined the prevalence of congenital hypothyroidism among girls and boys in general. Analysis of screening data showed that the prevalence in this state is similar to that reported in other Saudi provinces [24]. Cama Tamara et al. conducted a retrospective study at Morgan Hospital in New York City using existing databases from 2007 to 2011. The primary purpose of this study was to investigate the genetic epidemiology of congenital thyroid disease (thyroid disorders). The study has identified different types of thyroid disorders and compare the prevalence for 5 years in Morgan Hospital with New York City [25].

Disease surveillance

Monitoring of the disease is essential to ensure continued treatment, quality control, and disease management. Only one study monitored the condition, hence, making it to be the only available publication. Elbrook et al. developed an application called Hypo Doc to record the longitudinal documentation of patients with congenital hypothyroidism in Germany. The ultimate objective of this study was to analyze the usefulness of the software in the follow-up medical care and treatment of patients in the endocrine centers. The results indicated the benefit of using the software to assess quality control and cumulative research tools from the database. However, in this study, more emphasis is placed on data quality and the long-term display of output parameters. Another result of this study is the number of calls and determination of the number of possible positive and

Table 1. Characteristics of included studies

Results and Findings	Epidemiological studies, sound knowledge of the disease, identification of risk factors for the disease, disease surveillance, improving and upgrading screening programs	Access to screening results with an average of 7.3 days. Test confirmation 8.4 days and the start of treatment 11 days. The average TSH is 180.0 mIU/L, and the results were compared with national guidelines	The confirmed prevalence of CH 1/3576 - 1/4746 and the average birth result of the INSMC test is 19 days.	Family clustering of the disease indicates the role of genetic factors.	The prevalence of congenital hypothyroidism is 5.3 per 10000 live births. Using the native TSH threshold, sensitivity, accuracy, and predictability are positive results of 96.76%, 99.97%, and 66.88%, respectively.	A total of 344 positive samples were categorized. The prevalence of the disease is 1 in 4400 live births. The average treatment start is between 11 to 15 days.
Method of Analysis and Analysis Tools	Statistical analysis	Statistically analyzed. performed by using SAS Version 9.4	Statistical analysis	Poisson distribution and statistical analysis	Statistical analyses were performed by using Stata Se13	Descriptive statistics
Number of Samples	Total infants with CH in Italy	Anonymized data of 1 080 patients	Infant diagnosis with CH	A total of 2472 CH patients	A total of 629 newborns	Presumptive positive screening
Type of Study and Time	Registry base study (1987)	Registry base study 2000–2014	Registry base (2011-18) study	Registry base study 2010	Prospective surveillance from June 2011 to June 2012	Comprehensive Database 1979–93
Sources of Information	Screening program, diagnosis, and follow-up data	Forty-five pediatric endocrine centers in Germany and one center in Austria	Maternity hospitals, screening laboratories, endocrinology network of treating physicians	Neonates screened for CH and the questionnaire	Sixteen UK newborn screening laboratories	All Scottish infants with high TSH was detected on Guthrie screening.
Type	National	Regional	National	National	National	National
Research Type	Prospective	Retrospective	Prospective	Retrospective	Prospective	Prospective
Main Goal	Monitoring newborn screening for congenital hypothyroidism (CH), surveillance, epidemiology research, monitoring iodine deficiency, research	Analyze the long-term follow-up of a patient with CH and compare treatment with guidelines, surveillance	Newborns monitoring screening for CH, surveillance, epidemiology research	Describe the clinical characteristics of these familial cases and to compare them with sporadic cases	Monitoring newborns screening for CH, epidemiology research, surveillance	Evaluate the efficiency of the screening program for congenital hypothyroidism in Scotland
Year of Publication	2009	2015	2019	2001	2018	1997
Author(s)	Olivieri [14]	Ellerbroke [26]	Nanu [17]	Castan et al. [28]	Knowles [18]	Ray [16]
Country	Italy	Germany	Romania	France	The UK	Scotland
#	1	2	3	4	5	6
Region	Europe					

Results and Findings	The national prevalence of elevated TSH is 7.2% and%. Seasonal changes are essential, and the prevalence of the disease is higher in winter	The prevalence of transient congenital hypothyroidism is 1: 1682. The false-positive rate among screened infants is less than 0.70%. The Mean (SD) age of serum approval is 23.8 [8].	The results show that all states of Thailand suffer from some degree of iodine deficiency from mild to severe, increasing year by year.	The prevalence of hypothyroidism among infants between 2008 and 2014 was 3.1% for boys and 2.1 per 10000 births, and the overall prevalence was 2.6 per 10000.	Disease information registry system is effective in recording and storing information, disease surveillance, epidemiological research, and standardization screening	Monitoring and tracking of samples, online approval, daily schedule creation, receiving, and analysis results
Method of Analysis and Analysis Tools	Statistical analyses were performed by using SPSS, Excel	Statistical analyses	-	Descriptive statistics	-	-
Number of Samples	Original specimens obtained were 550927	18989 screened newborns	543121 639583 and 766392	n=654	Infant diagnosis with CH, 2019	Infant screening program in Isfahan Province, 2017
Type of Study and Time	Database study in 2014	Retrospective study (Registry base) from January 2011 to December 2012	Geographic Information System technique 2003-2006	Registry base study2019	Registry base study 2019	Web-based software was designed, 2017
Sources of Information	Newborns were registered in the National Newborn Screening Program	Newborns registry in Central hospital.	Newborn Screening System Database	Newborn screening system	Newborn Screening Program data	Screening program, Pediatricians office
Type	National	Regional	National	Hospital	Regional	Regional
Research Type	Retrospective	Retrospective	Retrospective	Retrospective	Prospective	Not determined
Main Goal	Analyze neonatal TSH levels to predict the current status of iodine nutrition in Turkey	Evaluating the CH screening program in the southern region of Sri Lanka in terms of coverage, the effectiveness of detecting and managing the cases.	Assessment of Iodine Deficiency Monitoring (TSH) with the use of a Geographic Information System technique, the degree of severity of iodine deficiency	Assess the prevalence of CH among children born in Arar City	Monitoring newborn screening for CH, surveillance, epidemiology research,	Monitoring and managing newborn screening for CH, web-based software was designed.
Year of Publication	2016	2014	2008	2017	2019	2017
Author(s)	Çaylan [29]	Hettiarachchi [21]	Charoensiriwatana [30]	Alenazi [24]	Shahmoradi [15]	Taheri [19]
Country	Turkey	Srilanka	Thailand	Saudi	Iran	Iran
#	7	8	9	10	11	12
Region			Asia			

Ghasempour M, et al. Information Registry System on Congenital Hypothyroidism. J Pediatr Rev. 2021; 9(3):197-208.

Results and Findings	The prevalence of CH is 1.74 in every 10000 births alive. The prevalence of the disease was compared between 1981-1987 and 1988-1998, and CH children were significantly exposed to congenital anomalies.	It provides stability and is effective in collecting, analyzing, and reporting screening results to the primary care physician with an average of 8 days; the next step is from birth to 11 days of treatment.	Ninety-seven infants were diagnosed with CH through screening program and MACDP program. The prevalence among whites is higher. A comparison of prevalence between male and female infants was performed.	Hypothyroidism does not change much with relocation. Hypothyroidism is associated with the birth of premature infants.	The 5-year prevalence of CH at Morgan Hospital is significantly higher than in New York City.
Method of Analysis and Analysis Tools	Poisson regression Using the Stata 6.0 program	Statistical analysis was done using Microsoft Excel and SPSS 14.0 Software.	Statistical analysis, Poisson distributions (one-sided) and observed to expected ratio (O/E) analysis	Logistic regression computer analyses were performed using SAS version9.1	All statistical analyses were performed using SAS software
Number of Samples	(n = 126), a random sample of controls (n = 1260)	The data of 47 babies who tested positive for hypothyroidism were analyzed.	A total of 97 infants identified	A total of 1482 cases ofCH	(n = 126)
Type of Study and Time	Registry base study 1981–1998	Database study 2008-14	Registry base study, 1979-1992	Registry base and Cohort study2000-04	Retrospective review of a preexisting database 2007 to 2011
Sources of Information	Population-based registers and databases were used to identify cases of congenital hypothyroidism	Cases were identified from the Newborn Metabolic Screening database, physician offices	The Metropolitan Atlanta Congenital Defects newborn and screening records program	Birth and infant health registry	Morgan Stanley Children's Hospital's internal Newborn Screen log
Type	Regional	Eparchy	Eparchy	Department of defense	Hospital
Research Type	Retrospective	Retrospective	Retrospective	Retrospective	Not determined
Main Goal	describe the epidemiology, including trends over time	Analyze and describe the informatics of the newborn screening program.	By linking data from two population-based registries, we describe the epidemiology of CH and associated defects in Atlanta from 1979 to 1992.	This study was designed to compare hypothyroidism among infants born to US military families in countries of varied iodine nutrition status	To study the frequency of congenital hypothyroidism (CH)/ thyroid disorders at a major, urban medical center
Year of Publication	2002	2011	1997	2010	2013
Author(s)	Kurinczuk [22]	Dawrant [20]	Roberts [23]	Cranston [27]	Cameo [25]
Country	Australia	Alberta, Canada	America (Atlanta)	America (military infants)	New York (America)
#	13	14	15	16	17
Region	Australia	North America			

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false negative cases, which are in line with national guidelines at the end [26].

Iodine deficiency monitoring

Most babies with a diagnosis of congenital hypothyroidism suffer from some degree of iodine deficiency. Blood TSH levels are directly related to iodine deficiency. By analyzing the data collected in the monitoring system, it is possible to screen iodine deficiency at different geographical scales—three of the studies aimed at monitoring iodine deficiency. Kaylan et al. conducted an analysis based on data collected from the National Disease Screening Database to monitor iodine deficiency in Turkey. TSH levels above 5 mIU/L were processed and classified according to the geographical area, birth season, and sampling time. The study results indicate mild degrees of iodine deficiency in Turkey. Researchers suggest a more comprehensive analysis and evaluation of the vulnerable population.

Using GIS software and based on data from the screening program database, Bacharonsuantina et al. conducted a cross-sectional study in 2003-2006 and the World Health Organization guidelines to assess iodine deficiency in different states of Thailand. The results indicate iodine deficiency from mild to advanced levels in different country states, which is increasing every year. The study results show the program's positive effects in identifying states with severe iodine deficiency and the significant contribution of this software to policymakers in the country's health sector regarding the plan to eradicate iodine deficiency [20]. Marcus et al. conducted a cohort study based on data from the Department of Defense's Neonatal Information recording system to monitor iodine deficiency in the study countries with different iodine nutrition statuses. The results of this study showed that hypothyroidism has little to do with geographical location. Other findings include identifying risk factors such as the sex of the baby, the race of the parents, and the mother's age [27].

Description of clinical features

One study described patients' clinical and familial characteristics and compared them with diffuse cases. Castent et al. compared the 19-year-old data from a screening program collected at the Congenital Thyroid Dysfunction Information System in France. In this study, in addition to the available data, a questionnaire was sent to physicians to complete the information. The study results strongly emphasize that atherosclerosis and the ectopic gland are genetic. They found that the genetic factors influencing thyroid formation were also associated with developing other organs in the body [28].

4. Discussion

Different countries have different systems for storing and sharing data at the national level. Congenital hypothyroidism is a tool for collecting, storing, processing, sharing disease information and knowledge [14, 17, 31]. These results are almost consistent with the primary purpose of creating the disease information registration system, expressed in various studies [32, 33]. The present study aims at examining the current state of the information system concerning congenital hypothyroid in the world. Since there is no structured review study, this research is the first step to strengthen our knowledge and understanding of the congenital hypothyroidism information registry system. It is necessary to have clear objectives for determining the framework and processes of data collection to ensure that the output of the information recording system answers important questions [34]. The study results showed that the goal of most thyroid congenital malformations is to evaluate the efficiency and effectiveness of the screening program.

Other goals of information recording systems include epidemiological research, iodine deficiency monitoring, disease monitoring, and description of the clinical features of the disease [18, 23, 26, 28, 29]. However, other results from this study suggest that some congenital hypothyroidism registries cover more than one goal. For example, the Italian birth control system is besides evaluating the effectiveness of screening programs, has other objectives, such as disease monitoring, epidemiology research, identification, and disease risk factors.

Screening programs are one of the greatest achievements of preventive medicine and an essential public health plan. With the correct implementation of this program, it is possible to diagnose and treat the disease and thus prevent its complications [25, 35, 36]. Given the importance of this disease at the national level, continuous assessment of the efficiency and effectiveness of the iodine screening program is essential in the program [18, 28]. An examination of the articles showed that the average time (sampling, response, diagnosis, treatment initiation, etc.), cost reduction, program quality, and program compliance with national guidelines are essential factors in evaluating the efficiency and effectiveness of screening programs. Data related to these factors should be continuously collected, analyzed, and finally reported. So it is best to use a disease information registration system for this purpose [19, 20].

The study results show better management of screening programs, improvement of program quality, reduction of costs, reduction of delays, standardization of screening methods, compliance of the program with guidelines, and in some cases, the need for change in the recommended thresholds using the disease information registration system [32, 33].

In a systematic review, Dolk et al. reported that information recording systems provide a good source for research and various studies [37]. This study emphasizes the epidemiological research in the disease: the incidence and prevalence of the disease, the course of the disease over time, the risk of the disease, and the prevalence of associated anomalies.

In line with the current study, Dolk et al. [37] determined the epidemiology of congenital anomalies in Europe using data obtained from the network of basic population information recording systems. In another similar study, Dastgerdi et al. developed a system for recording the information of congenital anomalies in western Iran to determine the epidemiology of congenital disabilities and plan to prevent these anomalies [38]. Also, the study result showed that by communicating and matching the data of the screening program database, the system provides the population information of the primary congenital anomalies, valuable information about the prevalence of the disease and congenital disabilities that screening program data alone cannot provide [23].

The World Health Organization (WHO) emphasizes the role of clinical guidelines in helping improve the quality and sustainability of care. There is a significant improvement in the quality of diagnosis, treatment, and follow-up of patients with congenital hypothyroidism. The development is due to the invention of the Hypo Dock software, the use of clinical guidelines, and compliance with the German information system for congenital hypothyroidism. Regarding the monitoring of Rachel Knowles et al.'s disease, it was concluded that studies aimed at monitoring the condition could lead to a change in screening threshold from its current level and a change in screening policy to increase the detection of intermediate cases of the disease.

According to the guidelines, different levels of TSH are an indicator of iodine deficiency. In the current study, iodine deficiency monitoring was performed using information from the database of the information registry systems in three studies [27, 29].

The study results indicate using a disease information registration system to monitor iodine deficiency at the regional or national level. Iodine deficiency monitoring using data from registration systems has many positive effects on health policymakers' awareness and efforts to eradicate this problem.

Study Limitations

Despite significant advances in the development of congenital hypothyroidism registries, there are limitations in this area:

1. Developing a system for recording congenital hypothyroidism is a new field of research in many countries.

2. Significant heterogeneity in goals or overlapping of several goals makes it difficult to compare the information registry systems at the international level and cannot consider a specific category for them.

3. The minimum standard data set for congenital hypothyroidism has not been determined internationally.

4. It is impossible to share information between data collection systems (for example, interoperability).

5. There is no data on operating costs and profit costs of the information registry systems, despite studies on the value of the screening program.

5. Conclusions

The study results showed that not much research had been conducted in creating a system for recording the information on congenital hypothyroidism, and most studies have used information systems in this field. They determine the incidence and prevalence of the disease, its epidemiology, surveillance, condition, research, etiology, etc. Future proposals could include examining the infrastructure for establishing a national system for registering congenital hypothyroidism in Iran and establishing a global network to coordinate and compare globally.

Ethical Considerations

Compliance with ethical guidelines

There were no ethical considerations to be considered in this research.

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Authors' contributions

All authors equally contributed to designing, running, and writing all parts of the research.

Conflicts of interest

The authors declared no conflict of interest.

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