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International Comparison of Thalassemia Registries: Challenges and Opportunities

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ABSTRACT

Background: Patient registries use standardized methods to systematically gather uniform data for specific groups of patients managed in clinical practice to evaluate specified outcomes. **Aim:** The objective of this study was to identify and describe structures of the identified thalassemia registries in worldwide and summarize their key characteristics. **Methods:** We reviewed the literature on thalassemia registries. A search of PubMed, Scopus, ProQuest, and Science Direct databases was conducted in September 2018. We also reviewed the existing thalassemia registry websites in different countries. The keywords used to our search were as follows: Thalassemia, Hemoglobinopathy, Registry, Database, and Registration System. Some features such as the name of registry, funding source, objectives of the registry, minimum data set, and methods of data collection were determined. **Results:** We identified 16 thalassemia registries operating on a multinational, national, or regional level between1984 and 2016. Most of these aimed to improve the diagnosis and management of control programs. Government funding was the most common funding source for registries. Furthermore, the most common method of data submission was Web-based data entry. The data were entered by a member of the clinical team or a nominated data manager. **Conclusion:** Registries provide a positive return on investment; their establishment and maintenance require ongoing support by government, policy makers, research funding bodies, clinicians, thalassemia patients and their caregivers. However, the results of research suggest the establishment of an international network for coordination and collaboration between thalassemia registries.

Keywords: Thalassemia, Hemoglobinopathy, Surveillance, Registry, Database.

1. INTRODUCTION

Thalassemia is a blood related genetic condition which characterized by decreased synthesis of one of the two types of polypeptide chains (α or β) (1). This disorder encompasses the lack of or errors in genes accountable for the construction of hemoglobin, a protein present in the red blood cells (2). The World Health Organization (WHO) announced that the frequency of thalassemia and abnormal hemoglobin carriers is 5.1% with nearly 226 million carriers worldwide (2, 3). Nearly 80% of thalassemia cases worldwide are detected in the area extending from sub-Saharan Africa to the Mediterranean Basin, the Middle East, and South and Southeast Asia (4).

Currently, as a result of important clinical and scientific improvements, thalassemia and other hemoglobin disorders are considered as remediable and preventable in cases where effective national programmers are in place and where there is free access to quality healthcare for people living with these conditions (5). The management of thalassemia patients is compound and requires a multidisciplinary strategy that integrates clinically and the laboratory features (6). As with other chronic disease management, the healthcare procedure is long-lasting and continuous of consisting multiple different parts of the process (7). Therefore, having IT tools such as healthcare systems to assist the progression can improve the healthcare services quality (8). Besides providing more accurate and timely information regarding patient care, it has been found to improve the efficiency of healthcare organization services especially in terms of

patient data management (9).

Several approaches are being applied across different healthcare systems around the world, including the use of patient registries, which have been identified as a method of improving quality and cost efficiency in health and healthcare (10, 11). High quality patient registries provide valuable contributions to designate demographics, clinical features and to determine baseline prevalence and variation in practices 'in the real world' (12-14). They let surveillance of important health conditions, a better understanding of patient health status and requirements, evaluate changing practice and trends over time, and allow predictions for resource requirements (15, 16).

A thalassemia registry encompasses comprehensive information related to thalassemia patients, over many years (17, 18). Moreover, the thalassemia registry provides data on access to and quality of care, and patient outcomes such as survival and Quality of life (19, 20). It has successfully followed changing dynamics and healthcare requirements and allowed detection of health system faults to aids, not only disease research but also the development and evaluation of a prevention program and the creation of clinical strategies (18, 21). In recent years, the thalassemia registry has been considered as an important tool for monitoring and improving the quality of patient care (1, 22). European Medicines Agency (EMA) recognizes the need for common approaches to foster the optimal use of national and multinational registries (23).

2. AIM

The objective of this study was to identify existing thalassemia registries in worldwide and describe their main characteristics including objectives, data sources, responsible institutions, core data set and the process of registration in different countries.

3. METHODS

We reviewed the literature reporting on thalassemia registries. The databases PubMed, Scopus, ProQuest, and Science Direct were searched up until September 2018. In addition, Google and Google Scholar were searched for thalassemia registry websites, unpublished studies and grey literature. There was no restriction on date of publication. The keywords used for the search were the following; Thalassemia, Hemoglobinopathy, Surveillance, Registry and Database. All documents and reports on thalassemia registries were included if they provided details about the program characteristics. We did not apply language constraints and provided a translation service if needed for non-English documents. The references of found articles were used to identify other related articles. In addition, we contacted the authors of the included studies to ask if they were aware of any further registries.

In this study we did not set any language restrictions, we used only English search words. After a complete search, all search results were reviewed separately based on studies title or running title and relevant documents were selected. The duplicated documents were excluded. Afterward agreement on the final included studies was reached, one author independently extracted

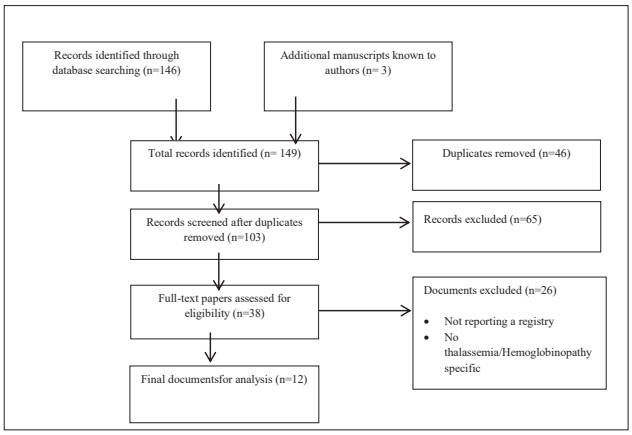

Figure 1. Preferred reporting items for reviews flow diagram

data using a standard data extraction form, which was then cross-checked by the second reviewer. If the contact details were provided in retrieved sources, an email was sent to a registry manager asking for additional peer-reviewed publications and other resources, such as conference presentations and annual reports. In case of no response, two follow-up reminders were sent. The unknown field for incomplete/not response was entered into the data extraction table.

Based on retrieved peer-reviewed publications and gray literature, the selected thalassemia registries were further analyzed to obtain the following information: (a) region, (b) country, (c) registry name, (d) responsible institutes, (e) Internet home page, (f) type of registry, (g) institution year, (h) funding sources, (i) objectives, (j) diseases coverage, (k) language of collected data, (l) participation type, (m) core data set, (n) data sources, and (o) methods of data collection.

4. RESULTS

Using the search strategies, 149 references were identified and 12 papers (13, 14, 16-20, 22, 24-27) met the inclusion criteria (Figure 1). We identified 16 thalassemia registries (set up from 1984 and 2016). Out of total amount, 13 registries were national, 1 multinational and 2 regional. The identified registries were established in 14 countries distributed in Asia (n=4), Europe (n=9), North America (n=2), and Oceania (n=1). No thalassemia registry was identified in Africa and South America (Table 1). Six registries were specifically designed to collect data on thalassemia patients and 10 were hemoglobinopathies registries including also thalassemia patients.

Moreover, Government funding was the most common funding source for registries. Only the National Hemoglobinopathies Registry in Greece was private funded. The time length of funding was not reported. The objectives of most thalassemia registries were improving diagnosis and management of control programs. Other purposes of thalassemia registries include healthcare planning, epidemiological and clinical research, education, policy making, prevention, and follow up (Table 2). The most common method of data submission was web-based data entry. The data were entered by a member of the clinical team or a nominated data manager (Table 3).

Region	Country	Name of registry	Responsible institute	Internet home page
Asia	Iran	Electronic Thalassemia Registry (ETR Mazandaran)	Thalassemia Research Center and Mazandaran University of Medical Sciences	http://thr.mazums.ac.ir/
	Singapore	National Thalassemia Registry (NTR)	KK Women's and Children's Hospital	https://www.kkh.com.sg
	Oman	National Register of Symptomatic Hemoglobinopathies	Genetic Blood Disorders Unit and Ministry of Health	Unknown
	Saudi Arabia	Pediatric Non-Malignant Blood DisordersRegistry	King Faisal Specialist Hospital	Unknown
Europe	Bulgaria	National Registry of Patients with Thalassemia in Bulgaria (NRPTB)	Bulgarian Association for Promotion of Education and Science and Information Centre for Rare Diseases	https://www.raredis.org
	United Kingdom	National Haemoglobinopathy Registry (NHR)	National Health Service	http://nhr.nhs.uk
		European Haemoglobinopathy Registry(EHR)	National Health Service	https://www.sicklecellsociety.org/resource/european-haemoglobinopathy-registry/
	France	Register of Thalassemic Patients in France	National Institute of Health and Medical Research and National Institute of Health Surveillance	https://www.ap-hm.fr
	Italy	Italian Multiregional Thalassemia Registry (HTA-Thal)	Consorzio per Valutazioni Biologichee Farmacologiche and Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus	http://www.cvbf.net/tag/hta-thal-registry
		Sicilian Registry Thalassemia and Hemoglobinopathies (ReSTE)	Epidemiological Observatory of the Regional Councillorship	http://pti.regione.sicilia.it
	Greece	National Registry for Haemoglobinopathies in Greece (NRHG)	Greek Society of Hematology	http://www.enerca.org/members-centers/center/22/national-center-for-thalassaemia-and-haemoglobinopathies-of-laikon-general-hospital-of-athens-greece
	Spain	National Registry of Hemoglobinopathies in Spain (REPHem)	Spanish Society of Pediatric Hematology and Oncology	https://www.e-clinical.org/rephem/index.aspx
	Turkey	Turkish Hemoglobinopathy Registry	Turkish Society of Pediatric Hematology	http://www.tphd.org.tr/
North America	United States	Registry and Surveillance System for Hemoglobinopathies (RuSH)	Centers for Disease Control and National Heart, Lung, and Blood Institute	https://www.cdc.gov
	Canada	Data Information System for Hemoglobinopathies(DISH)	Children's Hospital of Eastern Ontario	https://www.project-redcap.org/
Oceania	Australia	Haemoglobinopathy Registry (HbR)	Monash University	http://www.torc.org.au/hbr

Table 1. General overview of the identified registries

5. DISCUSSION

Thalassemia registries are essential tools and an important resource for planning and evaluating of disease prevention program based on facts (26, 28). In particular they will enhance surveillance of important health conditions, awareness of the prevalence of the disease, better understanding of patient health status, treatment options and detection of shortcomings in the healthcare system (20, 25, 29). This was the first review of its kind to compare existing thalassemia registries in worldwide. We identified 16 thalassemia registries, which consisted of 13 national, one multinational and two regional registries.

An important element in determining the feasibility of developing a new registry relates to funding (21). Registries with good coverage and accuracy will most likely require significant and sustainable funding sources (30, 31). The registries were received funding from various sources, including government agencies, scientific organizations, research collaborators, pharmaceutical manufacturers, accreditation bodies, philanthropic organizations and non-profit organization (32, 33). Based on our study most of the thalassemia registries were funded by the government agencies. This tendency might be explained by the superiority of government funding in terms of continuity and predictability, which is required to sustain a thalassemia registry. Clear objectives are essential to define the structure and process of data collection and to ensure that the registry effectively addresses the important questions through the appropriate outcomes analyses (34, 35). The purposes of the registry have to be obviously defined and approved upon by the registry sponsors (36). Results of this study showed that objectives of most thalassemia registries were improving diagnosis and management of control programs. However, other purposes of thalassemia registries include healthcare planning, epidemiological and clinical research, education, policy making, prevention, and follow-up. Moreover, objectives often overlap, for example, improving diagnosis and prevention can provide improve quality of care. The time and resources needed to collect and process data from a registry can be substantial (36, 37).

Registries should define a core data set of essential data elements and patient outcomes that will address the critical questions anticipated by the purpose and objectives for which it was created (35). Elements of data to be included must have potential value in the context of the cur-

Registry	Type	Year	Funding	Objectives of registry	Disease Coverage	Language	Participation
ETR Mazandaran	Regional	2016	Thalassemia Research Center, Uni	Improving diagnosis, Research, Decision making	Thalassemia major	Persian	Voluntary
NTR	National	1992	Gov	Management of control programs,follow- up, Prevention, Counseling and Screening	Thalassemia major	Unknown	Voluntary
National Register of Symptomatic Hemoglobinopathies	National	2000	Gov	Improving diagnosis, Control of blood disorders, Research	Thalassemia major, Sickle cell	English	Voluntary
Pediatric Non-Malignant Blood DisordersRegistry	National	2008	Gov	Management of control programs, Follow-up, Improving diagnosis	Thalassemia major, Sickle cell	Arabic	Voluntary
NRPTB	National	2009	Gov	Improving diagnosis, Follow-up, Prevention, Policy making, Research, Compare management practices	Thalassemia major,Intermedia	Bulgarian	Voluntary
NHR	National	2009	Gov	Improving care, Management of control programs, Prevention, Research	Thalassemia major, Sickle cell	English	Voluntary
EHR	Multi national	2004	Public	Improving diagnosis, Follow-up, Prevention, Research, Planning	Thalassemia major, Otherhemoglobinopathy	English	Voluntary
Register of Thalassemic Patients in France	National	2005	Gov	Improving care, Compare conventional treatment, Research	Thalassemia major, Intermedia	French	Voluntary
HTA-Thal	National	2008	Gov,Fondazione Giambrone	Improving diagnosis, Management of control programs, Healthcare planning,Research	Thalassemia major	Italian	Voluntary
ReSTE	Regional	1984	Gov	Management of control programs, Care Planning, Research	Thalassemia major, Intermedia, Sickle cell, Other hemoglobinopathy	Italian	Voluntary
NRHG	National	2009	Private	Improving care, Monitor treatment, Prevention, Research	Thalassemia, Sickle cell, Hemoglobin lepore	Greek	Voluntary
REPHem	National	2014	Industrial Association	Improving diagnosis, Improve Treatment, Prevention, Research,Comparison with other registries	Thalassemia major, Intermedia, Sickle cell	Spanish	Voluntary
Turkish Hemoglobinopathy Registry	National	2012	Gov. Uni	Improving diagnosis, Management of control programs, Research	Thalassemia major, Intermedia, Sickle cell	Turkish	Voluntary
RuSH	National	2010	Gov	Improving care, Monitoring health care utilization and clinical outcomes, Planning, Research, education	Thalassemia, Sickle cell	English	Voluntary
DISH	National	2014	Gov	Management of control programs, Research, Improving care	Thalassemia ,Sickle cell, Other Hemoglobinopathies	English	Voluntary
HbR	National	2014	Industry partners	Improving diagnosis, Follow-up, Research, Monitoring outcomes	Thalassemia major, Sickle cell, Other haemoglobinopathies	English	Voluntary

Table 2. Structures of the identified thalassemia registries

rent scientific and clinical climate and must be chosen by a team of experts (38). Registries within this review most commonly collected data on: (a) demographics; (b) clinical; (c) complications of disease and therapy; and (d) outcomes. Although, the core minimum data set for thalassemia registries was almost similar in different registries and covered all aspects of quality of care, the number and details of data elements various in different countries.

Accuracy, integrity and completeness of data are the most important elements in the quality and value of any registry (39). Low data quality can be due to inadequate collection of data at reporting sites, inattentive abstracting of information from clinical data sources, poor definition and specificity of data, inadequate understanding of complex data elements by those providing the data and lack of incentive and collaboration among reporting centers (39-41). Comparability of data is essential for interpretation and this in turn, depends on standardization of the methodology and the diagnostic criteria applied (40). Effective quality control using regular internal and external audits and monitoring site visits can help to achieve these foremost goals (33). Data collection of thalassemia registries from diverse and dispersed sites, including general practice, thalassemia clinics, hematopoietic stem cell transplants, and pediatric hematology centers, is a significant challenge. Procedures and policies to ensure completeness and validity of data should be developed before the data collection commence and reviewed at regular intervals. In addition, good quality information systems are needed for effective data collection to support the registry. Integration of the registry infrastructure with the information and communications technology systems already in place within the national health care systems enables automatic data capture, which significantly reduces the burden of data entry. The web-based data entry was a core feature of the majority of registries within this review. In recent years, the web-based registries have become popular because they are user friendly and can be managed from different locations (42, 43).

Additionally, the web-based systems offer the best access to the registry's data, increase the accuracy of data and facilitates real time data entry, updates, reporting and mapping functionalities (42, 44, 45). The initial cost to develop a web-based registry can be expensive; however web-based data collection was found to yield a shorter case registration time, lower cost per case to maintain

Registry	Core minimum data set	Data sources	Data submission
ETR Mazandaran	Demographics, Clinical, Complications, Medication	Haemoglobinopathy centers	Web-based
NTR	Demographics, Clinical	Hospitals	On-line data transfer
National Register of Symptomatic Hemoglobinopathies	Administrative, Clinical	Hospitals, Tertiary care centers	Paper, On-line data transfer
Pediatric Non-Malignant Blood DisordersRegistry	Demographic, Consanguinity, Diagnostic, Laboratory	Hospitals, Haemoglobinopathy centers	Web-based
NRPTB	Demographic, Diagnostic, Mortality	Hospitals, Thalassemia centers	Web-based
NHR	Patient, Adverse Events, Annual Review	Treatment centers, other bodies such as blood and transplant centers	Web-based
EHR	Demographics, Clinical, Treatment, Laboratory	Hospitals, Haemoglobinopathy Centers	On-line data transfer
Register of Thalassemic Patients in France	Epidemiological, Clinical, Biological	Hospitals, Pediatric centers, stem cell transplants database	Web-based
HTA-Thal	Demographic,Clinical, Complications, Quality of life,Cost	Hospitals, Haemoglobinopathy centers	Web-based
ReSTE	Demographics,Clinical	Hospital, Haemoglobinopathy centers	Paper, fax
NRHG	Demographic, Disease	Hospitals, Haemoglobinopathy centers	Web-based
REPHem	Demographic, Clinical	Hospitals, Haemoglobinopathy centers	Web-based
Turkish Hemoglobinopathy Registry	Demographic, Disease	Hemoglobinopathy centers	Web-based
RuSH	Administrative, Clinical, Health care utilization	Haemoglobinopathy centers ,Public health records, Clinical records, registries	Paper, On-line data transfer
DISH	Demographic, Diagnostic, Hospitalizations, transfusions, Tests, Medication, Bone marrow transplant	Hospitals	Web-based
HbR	Demographics, Diagnosis, Laboratory , Complications, Clinical outcomes	Hospitals, Haemoglobinopathy centers, registries, Medical databases	On-line data transfer

Table 3. Data collection onthe identified thalassemia registries

the system and lower rate of error occurrence than the paper-based data collection (46). This review had several limitations. The development of thalassemia registries is a new field of research; therefore, the number of included studies is restricted and there was no standard recommendation for reporting the results. We identified a number of gaps in thalassemia registry coverage. Few registries were identified in areas with emerging economies; the majority being based in high income countries, that creating geographic gaps in coverage. In much of the Asia Pacific region, South America and Africa, registries were either absent entirely or had limited data or poor accessibility for outside research. Unfortunately, 2 registries of Cyprus and Malaysia were excluded from the study due to lack of available information.

The use of English only search words might have resulted in the failure to identify registries in some countries. Therefore, we tried to obtain our necessary information from various peer reviewed articles, reports and web sites. In addition, Contact with authors of the included papers provided valuable detail on registries.

6. CONCLUSIONS

This analysis confirms the utility of thalassemia registries for the collection of large set of data. In particular, the considerations derived from this data set highlight how the use of large, well monitored patients' registries can guide health authorities and health providers to plan cost efficient services and to meet patients' needs and expectations. We suggest the establishment of an international network for collaboration between thalassemia registries. Global harmonization of data submission methods and minimum data set would facilitate international comparisons. Registries provide a positive return on investment; their establishment and maintenance require ongoing support by government, policy makers, research funding bodies, clinicians and patient with thalassemia.

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