12. THALASSAEMIA REGISTRIES: A CALL FOR ACTION
A REPORT OF THE THALASSAEMIA INTERNATIONAL FEDERATION

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EXECUTIVE SUMMARY

Registries are organised systems that use observational study methods to collect uniform data on individuals of a specific population defined by a disease, condition, or exposure, in order to serve a predefined clinical, scientific, administrative or other purpose. They can be extremely powerful evidence to generate tools while providing a central meeting point for all implicated stakeholders, facilitating their networking and interaction.

Registries can play a major role in addressing the challenges of caring for thalassaemia patients. By collecting updated and representative data on disease burden, features, management and outcomes at local, national, regional and global levels, thalassaemia registries may allow the evaluation and benchmarking of provided healthcare services, the detection of unmet clinical needs and the identification of inequalities in healthcare delivery.

A total of 16 thalassaemia registries have been in place since 1984, being characterised by heterogeneity and incomplete geographic coverage. Representativeness, interoperability, harmonisation, quality assurance and sustainability are important features that thalassaemia registries should pursue.

The Thalassaemia International Federation aims at playing a key role in promoting the coordination and collaboration among existing thalassaemia registries and the establishment of new ones, with particular focus on areas of emerging economies. In this regard, TIF has undertaken the design, development and implementation of a web-based platform to host a global thalassaemia registry.

Introduction

In 2014, the Agency for Healthcare Research and Quality (AHRQ) defined registries as organised systems that use observational study methods to collect uniform data on individuals of a specific population defined by a disease, condition, or exposure, in order to serve a predefined clinical, scientific, administrative or other purpose [1].

Registries can be classified by various criteria, including their primary objective (public health, clinical, administrative or product registries), geographical coverage (population or non-population-based and local, national, regional or international), drivers (physician or patient-driven), data collection methods (paper or electronic-based), administration schemes and many others [2].

Registries can be extremely powerful evidence generating tools. They collect real-world data on the epidemiology, clinical characteristics, physical history, management and outcomes of specific diseases and conditions. These pieces of evidence are valuable for the evaluation and benchmarking of provided healthcare services, the identification of unmet clinical needs and the detection of inequalities in healthcare. These information sources may in turn inform all implicated stakeholders to better plan their goals and activities, including governments and healthcare authorities, regulatory bodies, physicians, basic and clinical researchers, industry stakeholders and patient organisations and advocacy groups. Registries can further provide a central meeting point for all the aforementioned stakeholders, facilitating their networking and interaction [3].

In this context, the European Medicines Agency (EMA) has stressed the important role that registries may play in pharmacovigilance, regulatory decision-making and post-authorisation monitoring. For this reason, the EMA launched in 2015 an initiative to make better use of existing registries and facilitate improving the quality of new ones, promoting more systematic and standardised approaches that enhance the contribution of registries to the safety of medicines [4].

To serve the aforementioned purposes, registries should be populated by accurate, representative, prospective and usable data. The introduction and widespread distribution of electronic databases and digital healthcare records has considerably facilitated the development and maintenance of quality clinical registries through the use of integrated software solutions [5].

Registries are particularly important for rare diseases (RD). RD are defined as medical conditions with a prevalence of 1/2000 or less; almost 80% of these disorders have a genetic origin [6]. Although RD are collectively not rare, as they affect 1 out of every 17 people [6], the low prevalence of each individual disorder poses an important barrier for the collection of a critical bulk of evidence, which may in turn adversely affect the quality of healthcare provided to these patients [3]. Registries are the ideal tool to overcome this barrier by ensuring pooling of data from different populations to create the necessary bulk of evidence. The European Organisation for Rare Diseases, the National Organization for Rare Disorders and the Canadian Organization for Rare Disorders (EURORDIS, NORD, CORD respectively) defined in 2012 a list of 10 principles for the development of RD registries [7]. These principles are summarized in Table 1.

Table 1. European Organisation for Rare Diseases, the National Organization for Rare Disorders and the Canadian Organization for Rare Disorders (EURORDIS-NORD-CORD) principles for rare disease (RD) registries [7].

1	RD registries should be recognised as a global priority.
2	RD registries should encompass the widest geographic scope possible.
3	RD registries should be centred on a disease or group of diseases rather than a therapeutic intervention.
4	Interoperability and harmonization between RD registries should be consistently pursued.
5	A minimum set of Common Data Elements should be consistently used in all RD registries.
6	RD registries data should be linked with corresponding biobank data.
7	RD registries should include data directly reported by patients along with data reported by healthcare professionals
8	Public-Private Partnerships should be encouraged to ensure sustainability of RD registries.
9	Patients should be equally involved with other stakeholders in the governance of RD registries.
10	RD registries should serve as key instruments for building and empowering patient communities.

THE NEED FOR REGISTRIES IN THALASSAEMIA

DISEASE BURDEN

Haeglobinopathies, including thalassaemias and sickle cell disease, are inherited haemoglobin disorders, caused by genetically determined, quantitative or qualitative impairment of the synthesis of globin chains, resulting in chronic haemolytic anaemia and other complications [8, 9]. Haemoglobinopathies constitute the most common monogenic disorders in humans. It is estimated that 5.2% of the world population carries a clinically significant haemoglobinopathy gene variant, while 1.1% of couples worldwide are at risk of having children with a haemoglobinopathy [10]. Although highly prevalent and once confined to certain geographical areas, including sub-Saharan Africa for sickle cell disease and the Mediterranean Basin, Middle East, South and Southeast Asia for thalassaemia, migration of populations has render them globally distributed (for more information see Chapter on Epidemiology).

Thalassaemias are caused by the reduced or depleted synthesis of the alpha (α) or beta (β) globin chain that results in chronic anaemia [8]. In many cases, as in thalassaemia major, anaemia is severe and requires repetitive blood transfusions for survival. Over time, complications arise in vital organs, which require regular monitoring and multi-disciplinary care.

Thalassaemia was once a fatal disease of childhood or adolescence, but has now become a chronic manageable condition due to the therapeutic advances of the past decades and the systematisation of patient care. As a result, the survival of patients, with access to modern therapy and monitoring, tends to reach that of the normal population [11]. In parallel, prevention programmes have limited the number of affected births [12]. Still, β-thalassaemia remains a very demanding medical condition, requiring intensive, multidisciplinary and lifelong care [8]. (For more information see Chapters on Prevention, Iron Overload, MRI and Multidisciplinary Care).

Thalassaemia patients and their families, along with the many different healthcare professionals involved in their management, currently face a number of important challenges. These challenges are described briefly below.

CURRENT CHALLENGES

The complexity of thalassaemia clinical outcomes and care makes for complex clinical records, for which an electronic recording system is ideal. The ageing of patients also requires data collection over long periods of time, which again requires an electronic system for storing and processing.

Equal access to modern systematic therapy and monitoring for all thalassaemia patients across the world remains the primary unmet need. Despite the global distribution of the disorder, the majority of thalassaemia patients are born and live in areas of emerging or developing economies [10], where disease management programmes are often absent or suboptimal. As a result, patients living in these areas are deprived of at least some, if not all, of the important pillars of current thalassaemia management including regular blood transfusions, chelation therapy, iron overload monitoring, multidisciplinary care and others, which impacts adversely their prognosis and survival. (For more information, see Chapter on Unmet Needs).

The global epidemiology of thalassaemias is a rapidly changing one due to the current refugee crisis. Many patients originating from high-prevalence areas of the Middle East, South East Asia and Africa have migrated or are in a process of migrating to European countries. As a result, the number of patients with haemoglobin disorders in Europe is significantly increasing. However, haemoglobinopathies in Europe fall within the official EU definition for RD and thus thalassaemias' prioritisation in national health agendas remains low. In this context, TIF has launched the THALassaemia In Action (THALIA) project, funded by the EU Commission, to promote the prioritisation of thalassaemia in national healthcare plans and policies in Europe [13].

The absence of adequate disease management programmes in several high-prevalence regions is coupled with the lack of systematic patient recording. This leads to insufficient epidemiological data on disease prevalence, clinical features, incidence of complications, management and outcomes. The existing evidence on the current global and regional burden of the disease remains suboptimal. This in turn precludes the accurate description of unmet needs, which

further prevents proper adaptation of healthcare policies, research and advocacy to address these needs.

As previously stated, advances in therapeutic and monitoring modalities and the systematisation of care accomplished over the past decades have considerably improved the prognosis and survival of thalassaemia patients. As a result, patients having access to organised disease management programmes have entered a new era of prolonged survival. This accomplishment, however, comes at the cost of a changing clinical spectrum with increasing incidence of age-related disorders that were once unknown to thalassaemia populations [11]. The evolving clinical spectrum of the disease requires proper adaptations to management programmes that need to take into account the risk of conditions related to ageing.

Despite the therapeutic advances of the past decades that have dramatically changed patients' prognoses, thalassaemias remain a field of rigorous research. Novel drugs that improve patient outcomes have lately been approved or are under investigation. Luspatercept, recently authorised by the FDA and EMA, has been shown to improve ineffective erythropoiesis, the hallmark of thalassaemia's pathophysiology, thus leading to improved haemoglobin levels and significantly reduced transfusion needs in a phase III clinical trial [14]. Other new therapies such as the minihepcidins are in an earlier stage of development [15]. Besides new drugs for disease management, a fascinating new era of cure may emerge by virtue of the recent advances in gene therapy [16]. However, even if they are cost-effective in the long term, new therapies significantly increase the immediate costs of disease-related healthcare. Given the recent global financial crisis and the unstable economical environment created by the COVID-19 pandemic, coverage of new therapies by healthcare systems is not secured, even in high-income countries.

The ongoing COVID-19 pandemic has stressed the importance of rapid and efficient response of healthcare systems in public health emergencies. Although data on COVID-19 and thalassaemia remain scarce, these patients may be a population with increased propensity for severe COVID-19, thus requiring efficient protection measures [17]. On the other hand, the provision of regular care that is vital for patients' survival and wellbeing, such as blood transfusions, should not be interrupted or jeopardised as a result of distancing measures or reallocation of healthcare resources. Therefore, the proper adaptation of care during the current and potential future public health emergencies is crucial [17].

Expected benefits from registries

Registries can play a major role in addressing the aforementioned challenges. They constitute the ideal tool for the generation of accurate and updated data on disease burden, features, management and outcomes at local, national, regional and global levels. Collected data may concern the prevalence of the disease, the demographics and clinical characteristics of patients, the natural history of the disease (including the incidence of complications and the prevalence of comorbidities), the applied therapeutic and monitoring modalities, the organisation of care and the outcomes of patients (including both hard clinical endpoints but also patient reported outcomes). These pieces of evidence allow the evaluation and benchmarking of quality and appropriateness of provided healthcare services; the detection of insufficiently covered clinical

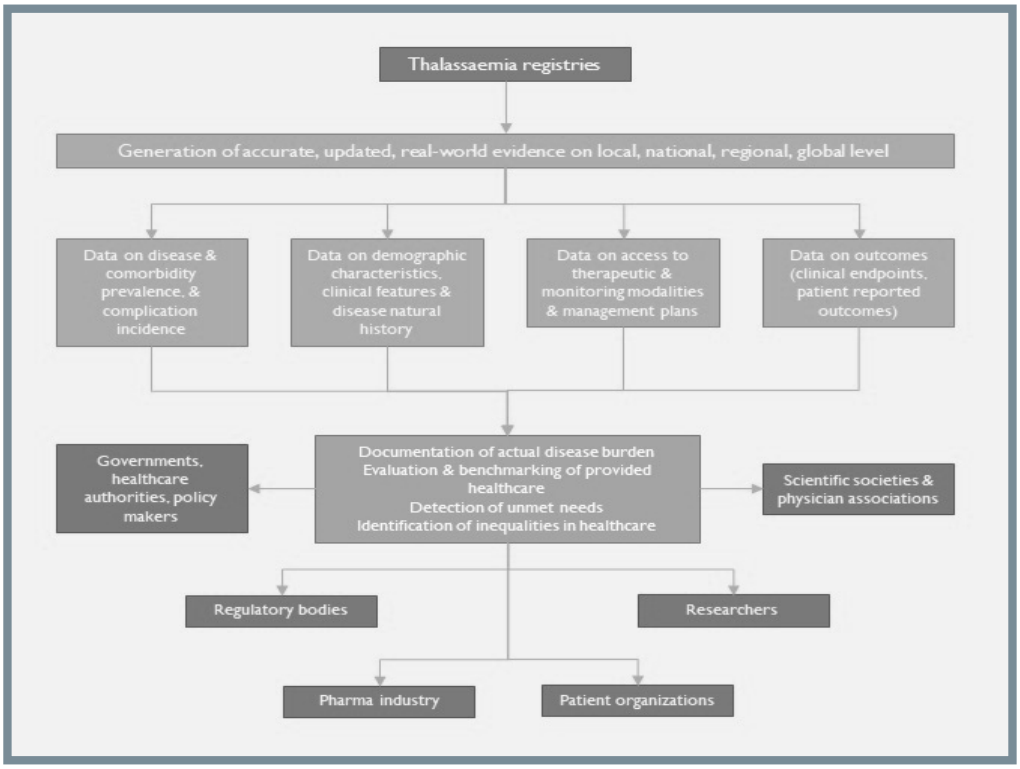
needs, including unaddressed comorbidities or complications, but also the degree of adherence to recommendations; and the identification of inequalities in healthcare delivery.

Evidence would provide valuable feedback to all implicated stakeholders. More specifically, governments, healthcare authorities and policymakers will be able to understand the need for prioritising thalassaemia care, to gauge the performance of thalassaemia care, to plan improvements to provided services and to balance the allocation of resources. Physician associations and scientific bodies would be facilitated in developing clinical practice guidelines and planning training programmes for physicians but also in issuing proper recommendations addressed to healthcare authorities, researchers and the pharma industry [3]. Regulatory authorities would be able to prioritise drug approval in the field of thalassaemia and organise more efficient post-approval pharmacovigilance programmes. The pharma industry will be able to prioritise investments in the demanding field of thalassaemia. Researchers will be provided updated epidemiological evidence and large sample sizes to analyse, while they will further be facilitated in the generation of clinical hypotheses for new therapeutic targets, drugs and interventions, be supported in the conduct of clinical trials by the low cost, rapid enrolment, efficient follow-up and enhanced generalisability of results that registry-based trials provide [2,3,18]. Last but not least, patient organisations and advocacy groups will have the necessary evidence at hand to better advocate patient needs, but also to promote the education of patients and families. Well-informed patients and families are empowered to better handle the disease, help other patients, and claim the improvement of their care. The final outcome is the improvement of patient outcomes through the enhancement of healthcare quality. Table 2 summarises the expected benefits from thalassaemia registries, and Figure 1 depicts the central role of registries in the interactions among all stakeholders implicated in the healthcare of thalassaemia patients.

Table 2. Main areas and issues related to thalassaemia healthcare where registries are expected to contributed

EPIDEMIOLOGY	- Current disease burden at local, national, regional and global levels - Changing epidemiology due to current refugee crisis and migration flows
ORGANISATION AND PROVISION OF CARE	- Evaluation and benchmarking of provided healthcare services - Update of healthcare services, reprogramming of resource allocation - Changing clinical spectrum due to ageing - Unmet needs in developing/low-income countries (e.g., prevention programmes, access to regular transfusions and iron chelation, established multidisciplinary care, and social support) - Unmet needs in medium/high-income countries (e.g., access to latest developments, access of refugees and migrants to care)
RESEARCH	- Research collaboration, large sample sizes - Generation of research hypotheses, identification of treatment targets - Randomised trials with low cost, rapid enrollment, efficient follow-up & increased generalisability
ADVOCACY	- Unmet needs in developing/low-income countries - Unmet needs in high-income countries
PUBLIC HEALTH EMERGENCIES & CRISES	- Implications for thalassaemia patients - Proper & timely response of healthcare providers and authorities

Figure 1. Central role of thalassaemia registries in the interactions among all stakeholders implicated in the healthcare of thalassaemia patients



EXISTING THALASSAEMIA REGISTRIES

In a study of thalassaemia registries across the world, published in 2019, Noori and colleagues were able to identify 16 different thalassaemia registries, developed between 1984 and 2016 [19]. The majority of these registries are national, while only one is multinational and two are regional. Most of the identified registries rely on government funding, while a small number receive funding from the industry. Six of 16 registries are focused on thalassaemia, while the rest also include patients with sickle cell disease and other haemoglobinopathies. In contrast to the geographical distribution of thalassaemia, the majority of these registries are based in European countries, while the authors were not able to identify any thalassaemia registry in Africa. Recently, the Sickle Pan Africa Research Consortium (SPARCO) reported results from the first African registry on sickle cell disease from three countries, Nigeria, Ghana and Tanzania [20]; however, this registry does not include thalassaemia patients, in accordance with the epidemiology of haemoglobinopathies in Sub-Saharan Africa. In addition to the above registries, we were able to identify another one in Malaysia [21].

The authors of the aforementioned report identified a considerable heterogeneity among the existing thalassaemia registries[19]. They serve diverse objectives and goals, they use various data sources and types, they rely on different information, standardisation and management systems, they are governed by diverse models, and they have been developed in different languages. Table 3 summarises the features of the existing thalassaemia registries.

Table 3. Existing thalassaemia registries (Modified from Noori T. et al., Acta Inform Med 2019;27:58–63.19)

Registry	Country or Region	Geographical coverage	Disease coverage	Launch year
Europe				
Sicilian Registry Thalassemia & Haemoglobinopathies (ReSTE)	Sicily, Italy	Local	Thalassemia, SCD, Other	1984
European Haemoglobinopathy Registry (EHR)	UK/Europe	Regional	Thalassemia, Other	2004
National Registry for Thalassemia	France	National	Thalassemia	2005
Italian Multiregional Thalassemia Registry (HTA-THAL Registry)	Italy	National	Thalassaemia	2008
National Haemoglobinopathy Registry (NHR)	UK	National	Thalassemia, SCD	2009
National Registry for Haemoglobinopathies in Greece (NRHG)	Greece	National	Thalassemia, SCD, Other	2009
National Registry of Patients with Thalassemia in Bulgaria (NRPTB)	Bulgaria	National	Thalassemia	2009
Turkish Society of Pediatric Hematology National Hemoglobinopathy Registry	Turkey	National	Thalassemia, SCD	2012
Spanish registry of haemoglobinopathies (REHem)	Spain	National	Thalassemia, SCD	2014
Asia				
National Thalassaemia Registry (NTR)	Singapore	National	Thalassemia	1992
National Registry of Symptomatic Haemoglobinopathies	Oman	National	Thalassemia, SCD	2000
Malaysian Thalassaemia Registry	Malaysia	National	Thalassemia	2007
Pediatric Non-Malignant Blood Disorders Registry	Saudi Arabia	National	Thalassemia, SCD	2008
Electronic Thalassemia Registry Mazandaran (ETR Mazandaran)	Mazandaran Province, Northern Iran	Local	Thalassemia	2016
Punjab Thalassaemia Prevention Programme (PTPP), Ministry of Health of Punjab	Punjab, Pakistan	Regional	Thalassaemia	2022
North America				
Registry and Surveillance System for Hemoglobinopathies (RuSH)	USA	National	Thalassemia, SCD	2010
Data Information System for Hemoglobinopathies (DISH)	Canada	National	Thalassemia, SCD	2014
Oceania				
Haemoglobinopathy Registry (HbR)	Australia	National	Thalassemia, SCD, Other	2014

SCD: Sickle cell disease

Comments

The paediatric non-malignant blood disorders registry is not at this time fucnctioning as a national registry according to a virtual meeting with hematology experts from Saudi Arabia in Novernber 2022.

Thalassaemia support associations have, in some countries, developed their own registries. In Indonesia the Yayasan Foundation has attempted to cover the whole country. In Bangladesh the Thalassemia Foundation Hospital has an internal registry, which in 2021 included 4373 patients (most have Hb E beta thalassemia 3042 and beta thalassemia 890). These may evolve to national registries with governmental support.

One approach suggested by a team from the National Center on Birth Defects and Developmental Disabilities, CDC, USA, is to extract useful information from administrative healthcare data sets as a unique means to study healthcare use among people with SCD or thalassemia because of the ability to examine large sample sizes at fairly low cost, resulting in greater generalizability than is the case with clinic-based data. Such datasets include:

- Hospital Data Sets which inclue data on hospitalisations, emergency department and ambulatory clinic data, as well as inpatient records.
- Health Insurance Claims Databases since both public and private health insurance plans maintain detailed records on healthcare use and expenditures.

Administrative data have both strengths and limitations for health services research on haemoglobinopathies and other blood disorders. The main advantages are the large numbers of observations and the low cost of data acquisition. However, the inability to validate information in diagnoses by reference to medical records. The diagnostic codes used for administrative purposes might not meet the diagnostic criteria used for surveillance case definitions, codes for underlying conditions might not be reported, or codes might be applied incorrectly by those recording data. These datasets provide a source for better understanding of the magnitude of the public health and economic effects of these conditions [Grosse SD, Boulet SL, Amendah DD, Oyeku SO. Administrative data sets and health services research on hemoglobinopathies: a review of the literature. Am J Prev Med. 2010 Apr;38(4 Suppl):S557-67. doi: 10.1016/j.amepre.2009.12.015. PMID: 20331958]

THALASSAEMIA REGISTRIES: A CALL FOR ACTION

CHALLENGES OF THALASSAEMIA REGISTRIES

The amount and complexity of data that are collected for each thalassaemia patient and the length of time that records are kept render the definition of the exact use of each registry and the type and amount of data to be included quite challenging. The existing thalassaemia registries are characterised by considerable heterogeneity. These inconsistencies may pose significant barriers to the interoperability of registries, the sharing and pooling of data and the overall coordination of similar concurrent initiatives, as well as the future re-use of data for different purposes, including administration, planning, research and advocacy. In addition, the provided geographic coverage is incomplete, as most registries are based in European countries.

It is important that registries provide longitudinal data in a continuous manner, which allows the provision of updated evidence and the identification of trends in disease epidemiology, management and outcomes. An additional challenge that thalassaemia registries may face in this regard is their long-term sustainability, which is directly related to the sources of funding.

Hitherto, thalassaemia registries are funded mostly by governments, with the considerable workload being covered by volunteers and often by clinic staff [19]. Therefore, continuation of public funding and voluntary work is crucial, while complementary sources of financial support should be attracted in parallel by contacting other public or private bodies, humanitarian organisations or the pharmaceutical industry. The particularly active thalassaemia patient organisations and advocacy groups have to play an important role in this regard.

Technical challenges are also important. Pooling data from different registries is necessary to reach large numbers of patients and allow comparisons among different populations. This is particularly relevant for thalassaemia registries, since several are already in place in different parts of the world. At the same time, linking registries with existing electronic medical records and administrative healthcare databases would ensure the ability to exploit large amounts of representative data at a low cost and workload while avoiding inaccuracies in data entry. However, linking data from different databases with diverse language, structure and software protocols requires proper technical support and collaboration [22]. As previously stressed, the existing thalassaemia registries are quite heterogeneous.

Ethical issues are also involved and should be taken under consideration during the design and implementation of a registry. All patients enrolled in a registry should give their consent for the collection, recording, storage and future processing, and potential sharing of their data, after being fully informed about the aims of the registry. At the same time, confidentiality and safety of data should be ensured by applying the proper protocols in compliance with national and international regulations for the protection of personal data. For example, the recent European Union Data Protection Regulation has set clear principles that apply to all use of patients' data and to all data controllers (article 5 of the regulation) [23].

HARMONIZATION AND QUALITY ASSURANCE

In an effort to address the heterogeneities of existing registries and ensure the overall quality of registries, the Italian National Center for Rare Diseases has recently issued a list of recommendations [2]. These recommendations constitute a quality assurance framework and concern ten sequential areas of activities including (i) governance, (ii) data sources, (iii) data elements, (iv) information technology (v) infrastructure, (vi) data quality, (vii) information, (viii) documentation, (ix) staff training, and (x) audit [2].These recommendations are particularly relevant for thalassaemia registries and provide a solid ground for their harmonisation and quality assurance. Table 4 provides an overview of these recommendations.

Table 4. Recommendations of the Italian National Centre of Rare Diseases for quality assurance and management of registries [2]

	MAIN AREAS	ACTIVITIES
1	**GOVERNANCE**	• Define registry objectives • Determine database structure • Involve all relevant stakeholders • Build a registry team • Ensure compliance with relevant ethical & legal rules • Ensure start-up budget and complementary sources
2	**DATA SOURCE**	• Select primary & secondary data sources • Define inclusion/exclusion criteria • Ensure representativeness
3	**DATA ELEMENTS**	• Define data types according to objectives • Determine what data from each source • Build proper case report forms • Ensure use of standardization systems (e.g. disease classification, phenotype descriptions etc)
4	**IT INFRASTRUCTURE**	• Ensure compliance with FAIR principles: o Findable o Accessible o Interoperable o Reusable
5	**DATA QUALITY**	• Establish regular central and local monitoring • Programme regular quality reporting
6	**QUALITY INFORMATION**	• Define statistical analysis plan • Ensure dissemination to all stakeholders
7	**DOCUMENTATION**	• Determine documentation to ensure transparency
8	**TRAINING**	• Ensure systematic training of: o Registry staff o Data providers
9	**AUDIT**	• Develop an audit system • Define red flags and audit triggers

New Registries: Pakistan (Punjab) the first electronic medical registry of thalassaemia of patients living in the Punjab is now established. This was created in collaboration with the Specialized HealthCare & Medical Education Department of the Ministry of Health of Punjab and with the help of the Punjab Information Technology Board (PITB). It includes data from 64 treatment centres (run by the government and NGOs) in nine regions of the Punjab. Out of an estimated 21,431 total patients, 12,536 (58.5%) are included in the registry so far. The package includes a Registration Module (demographics), a Clinical Module and a treatment module.

Conclusion

TIF's e-Registry initiative

Umbrella organisations like TIF have a crucial role to play in the coordination of different registry initiatives. Such an organisation can bring together existing thalassaemia registries across the globe, establish registry standards to support cohesion and interoperability among registries, develop strategies to attract sustainable funding from government and other public or private sources to support the existing and promote the development of new registries, with particular focus on areas and countries of emerging economy and to promote the use of registry data for translational research to address current gaps in knowledge and improve patient care [3]. In addition, a patient-driven organisation such as TIF can ensure that patients will play an important role in the development and exploitation of disease registries by incorporating data related to the patients' perspective such as patient-related outcomes, as well as the use of registry findings to inform and support patients' advocacy.

TIF has long recognised the need for a well-coordinated initiative towards the development of an international, truly representative and quality thalassaemia registry, as well as the role that an umbrella organisation has to play in this regard. In this context, TIF has previously contributed to the development of an electronic registry system for the purposes of the European Network on Rare Anaemias (ENERCA) with the aim to serve as an epidemiological tool to improve the management of patient services and ultimately improve patient care [24]. Later on, TIF conceived and launched a project for the design, development and implementation of an electronic, web-based platform to host a global thalassaemia registry. The specific aims of this project were defined as follows:

- To generate reliable national and international epidemiological data.
- To identify and document the unmet clinical needs regarding the care of patients with haemoglobinopathies in order to plan and improve the provided services.
- To provide a structured approach to taking a patient's history, giving a physical examination and evaluating a haemoglobinopathy patient in order to enhance the clinical management of the disease.
- To allow the efficient sharing of records within a thalassaemia unit or between disparate units, hence enhancing physicians' interaction to improve healthcare provision.
- To promote and coordinate multidisciplinary care.
- To provide a platform for national and international networking for clinical and research purposes.
- To enhance the supervision and auditing of physicians.
- To address medico-legal and ethical issues.
- To promote awareness, education and training on haemoglobinopathies.

TIF's e-Registry aims at recruiting consecutive patients treated in thalassaemia centres across the world. To perform this task, TIF designed and developed a dedicated proprietary web-based electronic platform that combines the features of a structured electronic medical record and the features of a medical database for data processing and research use. This application complies with international security and data safety protocols regarding web-based electronic medical records and web-based medical databases, also safeguarding subject anonymity. To ensure widespread access, this application is accessed by common web browsing software, while an additional application for portable devices will be developed at a later stage. A pilot-phase project for the testing of the platform has already been launched. Feedback from this pilot project will be used to evaluate and update the platform structure and functions.

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