13. THE VALUE OF PATIENTS' ENGAGEMENT

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Introduction

Over the last 10 years, healthcare systems, as well as academic, research and industry stakeholders, have been increasing their efforts to integrate the patient voice into their work and decisions being taken.

The provision of a patient-centred element in a healthcare system requires the development of an environment that will truly foster engagement between patients and the healthcare team.

Transforming healthcare in the 21st century is a difficult and an extremely challenging task due to the many intricate layers that form part of, and influence the system. Political, economic and cultural factors are often constrained by value conflicts and resistance to change. In 2013, an international patient movement referred to as the 'Patient Revolution' was established to enlist patients who live and experience the healthcare system on a daily basis to help in designing care services that were better suited to their collective needs. Such initiatives mirror actions launched in other fields that rely on citizen science methods. The collective intelligence of large groups of people has been known to help address complex problems more effectively.

Engaging patients with chronic conditions, such as those living with haemoglobin disorders, will contribute significantly to the identification of those components (including quality standards and protocols of care) that require improvement and aid in the development of new initiatives that may positively impact patient care and improve their overall quality of life.

The valuable contribution of patients has been demonstrated through a number of published studies in addition to unpublished information, including that compiled by patient-oriented organisations, such as the Thalassaemia International Federation (TIF) through their work with patients. **TIF, for example, has worked since 1986 with patients in different parts of the world, in countries with different economies, different health and social care systems, cultures, religions and social beliefs and has evidenced the invaluable contribution of the patients' active involvement in achieving significant improvements in care policies.**

Patients often have great insight into many aspects of the provision of healthcare and how services can directly and indirectly affect the care they receive. They are essential key players in assessing service needs and are instrumental in finding ways in which these can be improved. It is necessary thus to discover and leverage the huge untapped resource of patients' knowledge and experience to better understand and recognise those components of their care that are less than obvious to medical specialists. One of the most important drivers for change is to promote and implement a sort of 'cultural shift' on the part of medical specialists, clinicians and scientists, in order to eventually forget the outdated image of a patient under the paradigm of paternalistic medicine. This shift will lead to the acceptance of what has been clearly demonstrated nowadays by many qualified 'expert patients'; that their involvement constitutes an added value to healthcare system improvements. In the field of haemoglobin disorders many old school paediatricians and haematologists across the world are still involved and lead patients' organisations, thus this change is difficult to achieve. Specialists in many fields of the healthcare system, in regulatory and decision-making institutions, have reported how important the full involvement of patients can be for implementing inspired and creative outcomes with a mutual benefit. It has been shown in almost every hospital, clinic or centre that has been successful in reforming and improving care services particularly those aimed at chronic patients, including those living with haemoglobin disorders, that top-down strategies related to restructuring care services are not the sole proponents to improving the quality of care. The creation of a truly patient-centred care system is particularly favourable to the chronic, 'frequent' visitors of the services, such as the patients with haemoglobin disorders who often need transfusions.

An obvious outcome of their 'satisfaction' with health services provided to them, for example, is their better concordance to the often difficult, on many occasions painful, lifelong protocols of treatment they are receiving. Concordance to treatment, which is related to better survival and quality of life (Truglio-Londrigan et al., 2012; Náfrádi, Nakamoto & Schulz, 2017), has indeed been, for many decades, a huge concern and a documented cause of negative clinical outcome amongst patients with transfusion-dependent thalassaemia (TDT), across all ages, sexes, different educational levels, ethnicities and cultures across all regions of the world (Gabutti & Piga, 1996; Vekeman et al., 2016). Better quality interaction between treating physicians and patients is significant in improving concordance (Zolnierek & Dimatteo, 2009), albeit competent health authorities should be interested and willing to facilitate such practices. For most high income countries in particular where advanced care is available and accessible to almost all patients, non-adherence to treatment protocols, particularly iron chelation therapy, constitutes an important and remaining challenge experienced by treating physicians.

Good concordance with lifelong treatment protocols can only happen if and when the patient is truly pleased with all aspects of the care he/she is receiving and when she/he is involved in the solution-finding processes. 'Treatment is for living and not living to be treated' is a phrase often used by one of TIF's leading patient advocates. Healthcare professionals should thus not wait for their institution or hospital or clinics to engage patients in discussions, as they can identify

together, in a timely manner, key areas of their care that can be improved without massive administrative intervention.

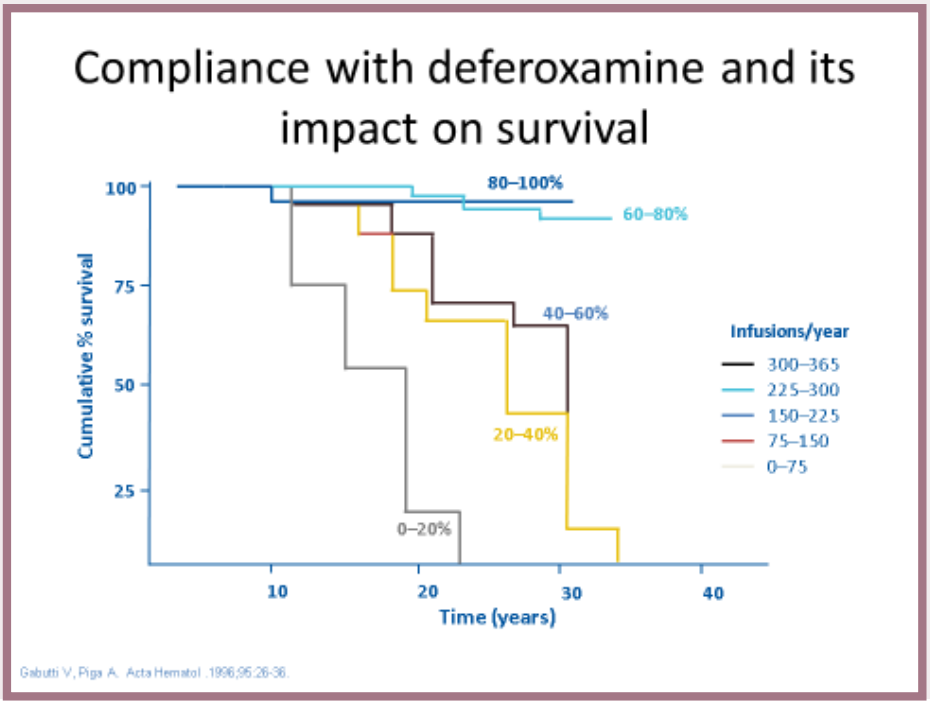


Figure 1 The relation between adherence and concordance and outcomes demonstrated (Gabutti V, Piga A 1996)

HOW ENGAGING PATIENTS CAN BE OF BENEFIT

Engaging patients in identifying gaps and weaknesses in the care that is provided to them, even when this is in accordance with disease specific guidelines, has proved a very strong tool for the Thalassaemia International Federation (TIF). This is particularly seen in, but not confined to, developing countries, where the absence or very limited existence of national registries, reference centres and published information could not facilitate TIF's understanding of the challenges patients with haemoglobin disorders are facing. Obtaining a reliable picture of the situation of a country or a region or even part of a county with regards to the quality of care provided to chronic patients can be extremely challenging without the active and meaningful involvement and participation of patient organisations themselves. Such information is crucial for TIF in order to support its work and to better tailor its activities and projects at the national, regional and international level based on the needs and concerns as expressed by the patients themselves. It must be underscore the invaluable contribution and collaboration of treating physicians and generally the healthcare professionals' community in identifying gaps and promoting measures and policies for improvement through well-structured and documented recommendations to policymakers.

The different perspective between patients and physicians was very well described in an informal survey circulated among the members of the European Reference Network (ERN) for Haematological Diseases (EuroBloodNet) [1]. Taking place in the very early stages of the Network being established (in 2016), it was clearly shown that in the context of seeking their opinion on the structure of the network what was mostly relevant for patients was less important for clinicians and vice versa (unpublished data communicated by a patient representative involved in EuroBloodNet). This is to confirm that indeed every contribution is important for policy-makers.

Engaging patients in the work of decision-makers at national and international levels

Patient supported proposals for improvements may complement those of the national competent authorities and healthcare professionals, and can (and indeed have been documented) to be of truly great value (Hertel et al., 2019; Bombard et al., 2018). In addition to national health authorities, patient involvement can be of benefit to regional or international health-related bodies, including the World Health Organisation (WHO). Patients' views and perspectives can greatly facilitate the better understanding of the hugely heterogeneous unmet needs of patients with different chronic conditions, in a country, across countries, and across different regions of the world. WHO and other official health-related bodies are in need of reliable, real-world data to more effectively tailor their work and actions, including revisiting general health or disease-specific resolutions and recommendations with the support and interaction of their Member States. Data on policy-related outcomes cannot be obtained in the absence of patient involvement and without truly 'capturing' the patient perspective and position.

The example of the European Union (EU)

For many years now in Europe, a very strong effort has been made to support rare diseases (RDs) through a number of European Union (EU) official recommendations, regulations, directives, and decisions. All of these include, as a prerequisite for their preparation and later implementation at national level, the full and meaningful engagement of patients and the clear expression of their position. In fact, the empowerment and recognition by the European Commission (EC) of the added value involved in addressing the huge unmet needs of RDs (Aymé, Kole & Groft, 2008) came into force initially in the 1990s from the active, persistent and very well-structured engagement of RD patients themselves through their European umbrella association, the European Organisation for Rare Diseases (EURORDIS) (De Santis et al., 2019). The methodology used by the EU in interacting and collaborating with the patient, and the weight given to the patients' position could indeed constitute a fine example of how official stakeholders

[1] EuroBloodNet results from a joint effort of the European Hematology Association (EHA), the European Network on Rare and Congenital Anaemias (ENERCA), the European haematology patient organisations represented in both the EURORDIS European Patient Advocacy Groups (ePAGS) and the EHA Patient Organisations Workgroup and it encompasses oncological and non-oncological rare haematological diseases, including rare anaemias. Its main goal is to improve the healthcare and overall quality of life of patients with a Rare Haematological Disease.

can truly involve the patient perspective in decision-making processes beyond Europe and across the world (TNS Qual+, 2012).

WHERE AND HOW PATIENTS CAN BE ENGAGED – EXAMPLES

In every country that has 'allowed' or encouaged such practices, it has proved to be extremely beneficial to engage the patient's perspective in developing new or in reforming existing official legislation and policies that are relevant to health, social care and education, among other matters. The involvement of patients within healthcare provision has been in place for quite a long time in Cyprus, with the Pancyprian Thalassaemia Association in the lead since the 1960s. Patient involvement (PI) furthermore, was made mandatory in Cyprus in 2016 through a new law [46(I)/2016)] that officially recognised patients as a valuable and equal stakeholder to the government. This has allowed their full and active engagement in almost every step of the very extensive healthcare reforms that the government has undertaken to implement in recent years. The contribution of patient engagement has been extremely valuable and greatly appreciated by government and all other official stakeholders involved in these reforms, acknowledging the very fact that Cyprus was committed to establishing a new, truly patient-centred healthcare system.

Patients in many countries today are involved at different levels in national health committees that may be disease-specific and/or public health/ healthcare system related.

The involvement of patients living with haemoglobin disorders in some countries across the world has resulted in the inclusion of their condition in a number of important, and where patients felt essential, disease-specific social, disability-oriented policies/legislation, including early retirement, travel remuneration, quotas for university admissions, employment, among many others, albeit different in each country.

The engagement of patients in many, if not all, decision-making committees of the EU is mandatory and has thus contributed significantly to having truly patient-centred decisions, recommendations, directives and regulations. The participation of patients is clearly described in most of these and an illustrative example is the European Directive (transposed into the national legislation of every EU Member State) 2011/24/EU (and its two Addenda 2014/286/EU and 2014/287/EU) for safeguarding the rights of patients with RDs in obtaining cross-border healthcare. In this, the establishment of the European Reference Networks (ERNs) for RDs (including rare anaemias and haemoglobin disorders) constitutes a key recommendation and full patient involvement is a prerequisite.

One must not ignore that further to the patient's wellbeing and social integration, which constitute the two major goals for an effective health and social care system in a country, practices which involve the patient's perspective contribute greatly to the system's sustainability. For example, their participation in Health Technology Assessment (HTA) bodies (Single et al., 2019) has, in many instances, been pivotal for price negotiations of many available but expensive drugs.

A 2019 Deloitte Report on patient access to innovative medicines in Europe (Deloitte Centre for Health Solutions, 2019), points out that early dialogue and partnership with regulatory and

important stakeholders including patients can provide a number of benefits to all and can aid pharma product pricing. Similarly, outside Europe, pharma organisations, more and more in current years, are engaging with payers and patients earlier, in much more constructive, collaborative and valuable ways. Such engagement helps pharma develop products that meet the priorities of the healthcare system and the unmet needs of patients and importantly enter into pricing negotiation to model and discuss a variety of potential contracting solutions to achieve market access. New innovative drug products and therapies need to be made available and to reach the patients in a timely way, particularly those with RDs.

The European-based pharmaceutical industry conducted in 2015 a qualitative interview study to identify the value and challenges of patient involvement (PI). In the conclusions of this work, many were uncertain about when, how and which patients to involve (Parsons et al., 2016).

Patients and the public's lack of knowledge and interest in the research and development (R&D) of medicines, and the pharmaceutical industry's lack of knowledge, interest and receptivity to PI were believed to be key challenges to increasing PI. Interviewees also believed that relationships between the pharmaceutical industry, patient organisations, patients and the public needed to change to facilitate PI in medicines R&D. Existing pharmaceutical industry codes of practice and negative media reporting of the pharmaceutical industry were also seen as negative influences on these relationships.

Along the lines of this argument, Levitan et al. (2018) argued that risk-adjusted financial models can actually assess the impact of patient engagement particularly in the context of clinical trials. A combination of empirical data and subjective parameter estimates show that engagement activities with the potential to avoid protocol amendments and/or improve enrolment, adherence and retention may add considerable financial value.

In the context of the new Regulation (EU) No. 536/2014 for clinical trials of medicinal products for human use, there is (in addition to many other benefits) a significant increase in transparency on clinical trial data and data generated with a greater involvement of the public and patients, with the mandatory introduction of a patient into the testing teams and the publication of a final report (Tenti et al., 2018) in language dedicated to the public and not the workforce.

In more recent years, patients' involvement along the whole chain of R&D has been greatly strengthened and placed on a more professional basis by the two major drug regulatory authorities and other official national bodies, including the European Medicines Agency (EMA), National Institute for Health and Care Excellence (NICE) and the Food and Drug Administration (FDA).

There is unequivocal evidence collected by EMA (EMA, Stakeholders & Communication Division, 2014) and the FDA on the valued contribution of patients' views and involvement in medicine R&D. Already EMA has taken significant steps in this direction through a number of its committees, in which patients participate on the Committee for Orphan Medicinal Products (COMP), Paediatric Committee (PDCO), the Committee for Advanced Therapies (CAT) and Pharmacovigilance Risk Assessment Committee (PRAC). In these bodies, patients' representatives may assume the status of full members including having the right to vote for the drugs' assessment and approval processes. Patients involved, however, should be free from

any conflict of interest and have no association at any level with the pharma industries so as to ensure the unbiased nature and full transparency of the approval process. In 2018, EMA reported that one in five scientific advice procedures involved patients and the scientific committee members (SAWAP) considered that in almost every case, patients provided an added value to the scientific advice and in about one in four cases, the scientific advice recommended that the development plan be modified to reflect patient advice (EMA, 2019).

The EMA is now proposing the fostering of earlier contact with patient/consumer organisations. It proposes to reach out to patients at the start of the evaluation of a new Marketing Authorisation Application (MAAs) so that patients can share their experience and concerns about their condition(s) and key aspects that are important for them, which the EMA can take into account in a timely manner during the assessment process. Aspects that are of particular importance to patients/carers, such as quality of life, how acceptable they think the standard treatments are and how these interfere with their lives, unmet therapeutic needs, what their expectations are with regards to the benefits they hope to have and the level of side effects they would consider acceptable. It will greatly facilitate the better understanding of whether there are large differences or similarities among groups of patients with the same kind of disease and certainly to note anything else that patients/carers feel is important for EMA to know (EMA/372554/2014-29/11/2020).

Similarly, in 2012, as part of the reauthorisation of the Prescription Drug Use Fee Act (PDUFA V), the FDA (Perfetto et al., 2015) established a programme to help ensure patients' experiences, perspectives, needs and priorities are captured and meaningfully incorporated into the development and review process. This was formalised as Patient-Focused Drug Development (PFDD). A number of activities and meetings are involved in this novel approach so as to gather input from patients who are willing to share their personal experiences of living with a disease or condition.

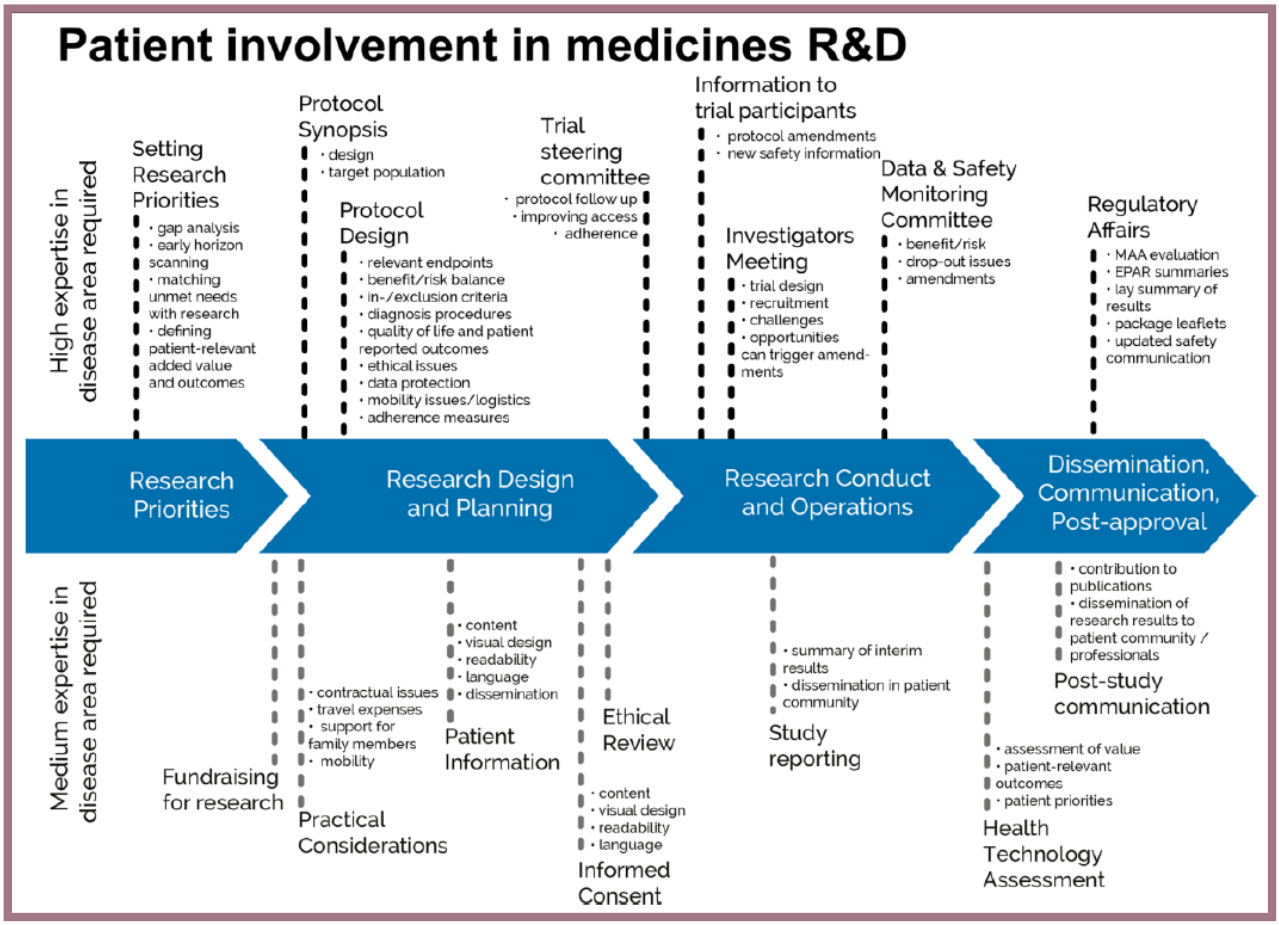
Patients and patients' organisations should be meaningfully engaged at all stages from defining research priorities to trial design, review of proposals, trial implementation and participation; indeed, this has become, especially in the last decade, a routine and in most cases a mandatory practice both by the academic research community and the industry.

In this context, published literature even provides description of a possible roadmap of patient involvement (PI) across the whole spectrum of the R&D life cycle (Table 1) and key areas and opportunities for PI within the early stage are identified (Geissler et al., 2017). In the course of such involvement, both the patients and research scientists gain a number of benefits for each party, some of which are mentioned below.

Table 1. Practical roadmap for patient involvement in medicine R&D. DIA Therapeutic Innovation & Regulatory Science 2018. Vol 52(2) 220-229. Assessing the Financial Value of Patient Engagement: A

A. Patients	• Gaining knowledge and research skills
	• Increased understanding of the nature and purpose of a clinical trial
	• Greater self-esteem and confidence of patient representation involved in the process
	• Acceptance of patients as equal partners
	• Utilising patient experience and knowledge of their condition, leading to development of healthcare and therapies that are more representative of patients' needs
B. Researc h	• Data and information exchange between users and industry during the post-marketing period and in the context of pharmacovigilance commitments
	• Ensuring research and research outcomes address patients' real unmet needs
	• Increased response and participation rates

Quantitative approach from CTTI's Patient Groups and Clinical Trials Project



It is true that many on the development side often fail to take into account real-world challenges when developing a clinical trial. They are more interested in determining the efficacy and safety of a drug rather than taking into consideration quality of life issues. **The contribution of the patient's perspective is in more recent years not only recognised but very importantly sought after and considered essential.** Collecting real patient data, for example, is a prerequisite in the context of certain types of authorisation licenses granted by EMA and FDA and mainly regarding innovative drugs/therapies, which may be granted accelerated procedures or authorisation under exceptional circumstances or conditional marketing authorisation.

These types of licenses are granted to address unmet medical needs of patients to either facilitate their accelerated access to a new medicine or because the drug cannot be approved under a standard authorisation as comprehensive data cannot be obtained due to disease rarity or because there are gaps in the scientific knowledge. These drugs are subject to specific post-authorisation obligations and monitoring and they are authorised on the basis of less comprehensive data than normally required to address unmet medical needs. Although the applicant needs to present data that indicate that the medicine's benefit outweighs its risk, the applicant should be in a position to provide the comprehensive clinical data in the future.

For such data to be collected, the continued, well-structured and coordinated patient engagement is absolutely essential. PI has steadily gained increased recognition, not only by the EU and the WHO which have, since the early 1990s, officially collaborated with patient-oriented non-government organizations (NGOs), but also by an increasing number of national health authorities across all regions of the world.

An expert patient advocate, Jan Geissler, leading the EUPATI (European Patients' Academy on Therapeutic Innovation – an excellent educational initiative originally launched by the Innovative Medicines Initiative (IMI) and hosted by the European Patients' Forum (EPF)), believes that 'involving patients while designing trials and developing drugs will help so that non-scientific factors that are still crucial to evaluating a drugs' efficacy can be taken into consideration' (Chakradhar, 2015).

ENGAGING PATIENTS IN EDUCATIONAL PROGRAMMES

Significant progress has also been made by medical bodies with respect to the recognition of the value of engaging patients in their programmes, mainly educational ones. The European Haematology Association (EHA) is a fine example in the case of haematological diseases including haemoglobin disorders. Since 1992 EHA has promoted in a very structured way (initially with scepticism and reservations to a certain level) a patients' advocacy group (in which TIF participates), the work of which through the years has proved to be of added value to the work of EHA. In 2018, the 'EHA Research Roadmap on Haemoglobinopathies and Thalassaemia: An update', includes 'the development of Patient Reported Outcomes (PRO) tools to support the work and collaboration with patient organisations' amongst its key recommendations (Iolascon et al., 2019). Such collaborations have developed through the years or are in development with other medically orientated groups including the International Society

of Blood Transfusion (ISBT), the European Blood Alliance (EBA), the European Association for the Study of the Liver (EASL) just to mention a few relevant to the work of TIF.

ACKNOWLEDGING THE VALUE OF PATIENT OUTCOMES IN HEALTHCARE DELIVERY

Patient reported outcomes are a major and invaluable tool developed to 'capture' in a more structured way patients' information and views that can be appropriately analysed and assessed in order to better understand their needs and expectations for the health, social and other specialised care they are receiving (Lavallee et al., 2016).

Collecting patient experiences and expectations in routine care is crucial in developing services that focus on patient-centred care. Often, changes with regards to service provisions are made by those who have the best intentions but no true or life experiences of the condition. As a result, their **perceived goals as to what their patients want may differ from those who live with the condition.** Having pragmatic insights into patients' experiences of symptoms, quality of life, values, preferences and goals in life are essential in providing any healthcare service that is effective for a medical condition.

Previously embraced in the research realm, patient-reported outcomes have started to play a role in successful shared decision-making, which can enhance the safe and effective delivery of healthcare. Present and future challenges need to be analysed and examined so as to provide the opportunity to healthcare systems to maximise the use of patient-reported outcomes in the clinic/hospital.

Reported outcomes, therefore, can be both disease-specific or general healthcare oriented ones. They can play a role in shared decision-making, which can in turn enhance safe and effective delivery of healthcare. Emerging practices consequent to patient reported outcomes have provided value to both patients and clinicians and have improved care services, albeit this tool is not to-date extensively applied.

THE KEY…

However, the key to meaningful and productive patient involvement lies largely on the very good knowledge and often relevant experience that the patient has in the particular area he/she is assigned to interact. In this context, European umbrella organisations such as the European Patients' Forum (EPF), the European Organisation for Rare Diseases (EURORDIS) and a number of disease-specific organisations at the European level have been very actively involved in developing very comprehensive educational programmes for patients with different diseases on a variety of health, drug and other research related topics in collaboration with experts and other stakeholders, including industry. These programmes aim at building a competent patient community that is knowledgeable enough to interact productively and advocate effectively for the rights to quality and safe care at the decision-making levels of countries and the European Union.

It is also a useful field of research to assess patient knowledge of their condition, both to establish patient involvement but also to assess self-efficacy in dealing with the complex demands of their treatment *[Kharyal R, Kumari V, Mrunalini VT, Naik M, Joshi P, Seth T. Disease Knowledge and General Self-Efficacy Among Adolescents with Thalassemia Major and Their Parents' Perspective. Indian J Hematol Blood Transfus. 2021 Apr;37(2):280-286. doi: 10.1007/s12288-020-01335-3. PMID: 33867735]*

On the other hand, TIF, the International Alliance of Patients' Organizations (IAPO) and other international disease-specific organisations have been struggling for decades now in the international arena whilst actively involved in safeguarding patient safety, drug and blood safety and equity of all patients to quality health and social care. TIF, particularly since its establishment in 1986, with the development and continual updating and upgrading of its educational programmes, aims to strengthen the knowledge of patients across the world and 'transform' them to become valuable and equal partners at the decision making level.

In this context, TIF has developed since 1989 an educational programme which is constantly strengthened and is based on three pillars:

1. Preparation, publication, translation (into many languages) and distribution of educational and informational material: books/factsheets etc.;
2. The organisation of events: workshops, seminars, conferences, symposia, meetings, courses, fellowships;
3. The development of electronic educational platforms for patients and healthcare professionals and more currently the organisation of virtual educational events including webinars.

In addition, in more recent years, TIF established in 2019 the TIF Patient Advocacy Group (T-PAG), comprised of 198 patient advocates from 62 countries. Many of these have developed adequate competency to actively advocate and interact productively at different levels of decision-making at the national, regional or international level, and still many others are under training and working mostly at the national level. This complements the vision of TIF to 'create' a large group of competent patient advocates across countries and regions of the world to make

the voice and position of the patients with haemoglobin disorders, when involved, strong and effective.

Below, Figure 2 and describes TIF's Patient Advocacy Group (T-PAG), its structure and membership, Figure 3 details the eligibility criteria for the inclusion of patients, and Figure 4 briefly describes their role as T-PAG members as well as TIF's responsibilities in supporting their educational work and meaningful engagement at all levels.

Figure 2.

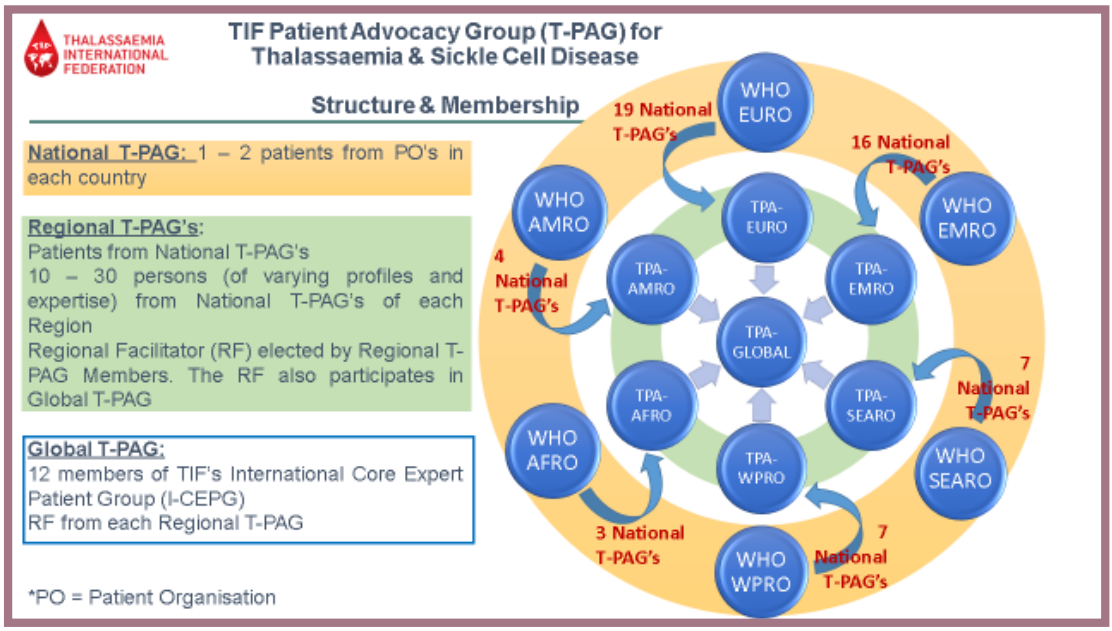


Figure 3.

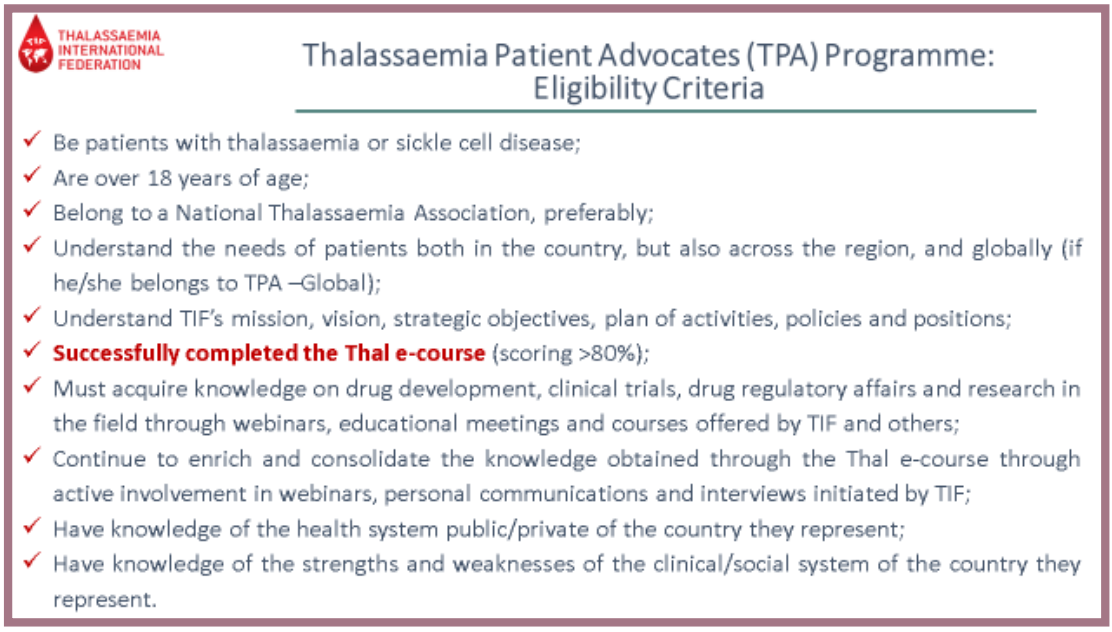
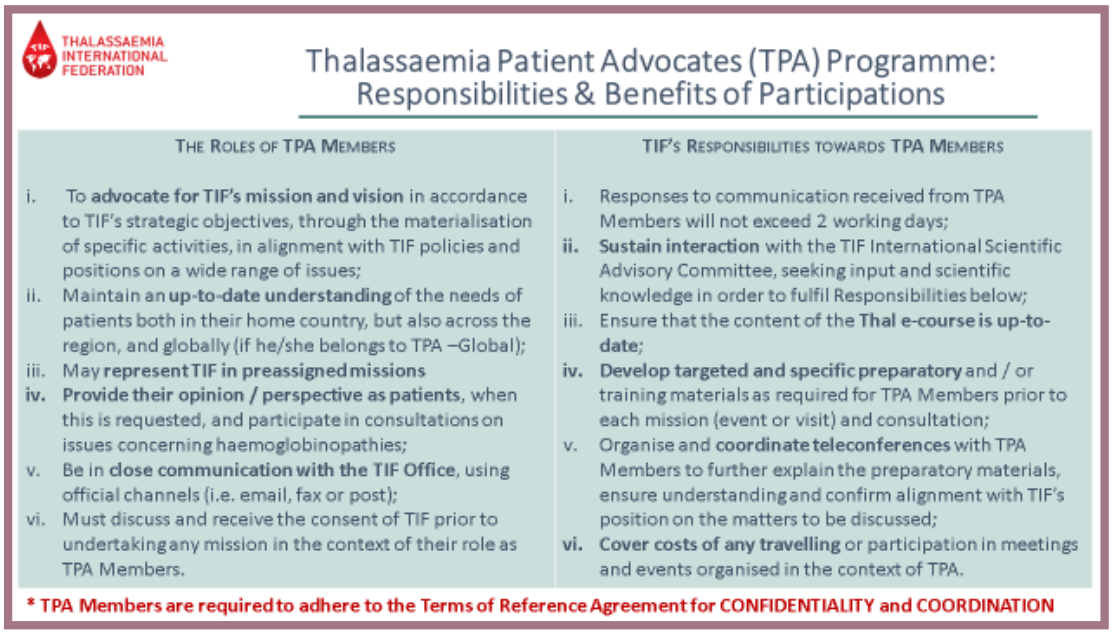


Figure 4.



WHO ARE REALLY PATIENT ADVOCATES?

Patient advocates can be defined as patients who have invested the time and energy needed to acquire a high level of disease-specific knowledge, i.e., on the research activity around their condition and the authorisation of therapies and drugs for their condition. These are patients themselves who know and truly represent the views of other patients and have a deep knowledge of their unmet needs as expressed by the patients they represent in their country. They certainly need to be well versed in the functioning of services offered by the healthcare system in their countries, as well as what is happening in countries of their region but also globally. To achieve this they need to be aware of the work of official health-related bodies in the region and globally, particularly the WHO, network with others in their country, region and internationally while keeping close and productive relations with the relevant healthcare professionals' communities at all levels. The support of TIF to its members in the context of education and provision of reliable and updated information is immense and the collaboration of every National Thalassaemia Association (NTA) with TIF should be safeguarded and highly embraced.

TIF AND ITS WORK ON PI

TIF, since its establishment in 1986, has strongly advocated for patient engagement and respect for the patient's perspective and position, and it has involved patients in every aspect of its work and activity at all levels. TIF was amongst the first, it not the first patient organisation, that annually organised since 1989 patient associations meetings, which is what we today describe as 'training programmes' for improving patients' knowledge, skills and competencies for advocacy.

The NTAs in the United Kingdom, Italy, Greece, Cyprus and the USA, founding members of TIF, are fine examples in exercising very active PI since the very early years of their establishment in the 1960s/1970s, and it is indeed the successful outcome of such involvement that gave TIF the strength and empowerment to extend this work across the world. Today, many patients through the 138 NTAs in 59 member-countries of TIF are actively involved at the national level or the regional level, and the outcomes of such involvement, as reported to and evidenced by TIF, are very encouraging and in many cases truly impressive.

Engagement of patients has been happening for many years now in the field of haemoglobin disorders, albeit in a less structured way and with greater scepticism and a slower pace in many countries outside Europe and other Western countries; however the achievements of PI in some developing countries are indeed quite remarkable. Patients must however continue to act through the strong, united voice of their national associations which bear the responsibility to build up educational programmes for strengthening the knowledge and advocacy skills of their patients, some of whom will reach an advocacy competency that would allow their interaction at the national or international decision-making level.

TIF, as a patient umbrella association, through its work has achieved the establishment of very important collaborations with valuable stakeholders whose support is substantial for achieving its mission. They include:

- ✓ the World Health Organisation (WHO) with which it has been in official relations since 1996;
- ✓ the United Nations Economic and Social Council (ECOSOC) with which it has had an active consultative status since 2017;
- ✓ the European Commission as a strategic partner in the field of health since 2018;
- ✓ the INGOs Conference of the Council of Europe as a member since 2019.

In addition, throughout the years TIF has established valuable collaborations and productive networks with over 200 national and international medical/scientific experts and with almost every relevant medical/scientific association or body. Importantly, TIF has gained the respect of competent national health authorities in more than 60 of its member-countries around the world; working with many in the context of special collaborations and/or official agreements.

Conclusions

In conclusion, the national health/social and every other competent authorities in a country need to invest in developing official, well-structured channels of PI at all levels of decision-making if the aim is to honour the many and important relevant resolutions/declarations signed by all members of the WHO and to achieve the UN 2030 SDGs. These include but are not confined to**: patient rights, universal health coverage, quality healthcare, respect for patients and human rights for equal access to quality health and other care,** and last but not least patient-centred healthcare systems across the globe.

Very importantly, patients and families need to invest in strengthening their voice and impact through promoting the infrastructure, activities and networking of their national associations. TIF's work towards strengthening the competency of NTAs has demonstrated that there is still considerable room for improvement in a large number of NTAs within and across countries (Table 2). TIF has made an effort to score, based on specific parameters (Annex I and Annex II), and subsequently to grade the services of NTAs (Table 3). This work is only a gross assessment, based on the best knowledge and information available to TIF, and is only a **basis for further work by NTAs, including more tailored TIF activities.** It is noteworthy that being a TIF Full Member contributes to closer and more active collaboration with TIF and better investment of the NTAs in activities and advocacy for the best interest of their patients. Indeed, 28/34 NTAs that score 20 and over and are graded as 'A' are TIF Full Members. From all parameters examined, TIF Full Membership stands out as the one factor related to greater interest and more active work on behalf of NTAs. The aspects of disease prevalence, political commitment and healthcare professional interest follow. National economic status and presence of other competing health priorities do not seem to contribute key factors to the activeness and strength of national thalassaemia associations.

Table 2. Summary of the implementation of TIF's Grading System for Assessing the Activities of TIF Member Associations (as described in Annex I)**

Scoring Category / Region	A	B	C	D
Europe	Azerbaijan, Cyprus, France, Greece, Italy, Netherlands, Turkey, United Kingdom	Azerbaijan, Germany, Ireland, Portugal, Sweden, United Kingdom	France	Albania, Belgium, Bulgaria, Germany, Israel, Italy, Luxembourg, Malta, Romania, Spain, Turkey
Eastern Mediterranean	Algeria, Egypt, Iran (Islamic Rep. of), Iraq, Jordan, Lebanon, Pakistan, Palestine (Occupied), Saudi Arabia, United Arab Emirates	Egypt, Iran (Islamic Rep. of), Pakistan, Saudi Arabia, Yemen	Iraq, Kuwait, Morocco, Pakistan, Saudi Arabia	Afghanistan, Bahrain, Iran (Islamic Rep. of), Iraq, Pakistan, Palestine (Occupied), Sudan, Syria, Tunisia, United Arab Emirates,
West Pacific	Australia, Hong Kong SAR, Malaysia, Viet Nam	Malaysia, Singapore	Australia, Philippines, Taiwan (China)	Cambodia, China, Malaysia, Philippines
South East Asia	Bangladesh, India, Indonesia, Maldives, Nepal	Bangladesh, India, Sri Lanka, Thailand	Bangladesh	India, Maldives
Americas	Canada, Trinidad & Tobago, USA			Argentina
Africa	Mauritius	Ghana, Nigeria		South Africa

***Countries with more than 1 TIF Member Association are indicated more than once.*

Table 3. Scoring interpretation

Scoring Category	Interpretation
A **≥ 20 units**	Describes Thalassaemia Associations which have a strong patient voice, established national presence with educational and advocacy activities and continual communication and participation in TIF's activities.
B **19 – 15 units**	Describes Thalassaemia Associations which have a patient voice, some national presence with educational and advocacy activities and occasional communication and participation in TIF's activities. These associations have a good potential to upgrade to category 'A' by undertaking more targeted actions.
C **14 – 10 units**	Describes Thalassaemia Associations which have some activities with rare participation in TIF's activities, with weak to poor effectiveness.
D **≤ 9 units**	Describes Thalassaemia Associations which have serious weaknesses, engagement in educational and advocacy activities is poor and communication with TIF or participation in TIF activities is non-existent.

Finally, as this chapter also features as a new addition of one of the key TIF publications – the Guidelines for the Management of Transfusion Dependent Thalassaemia – where recommendations by medical experts are incorporated, below are briefly listed some important disease-specific areas of possible patient engagement at national level (Table 4).

Table 4. Important areas for patient engagement at the national level

Patients should be engaged in the:
1. Design of national disease specific registries and/or patient health records;
2. Design of education or informational material that is prepared by health professionals and is focused on patient care, new drugs, research etc;
3. Planning of the transfusion services and the related whole chain of the transfusion process. TD patients spend considerable amount of their time throughout their lives in hospitals/ centres/ wards/ clincs for their one or two or more monthly transfusions. The timings of consultation and transfusion therapy are expected by patients to be less burdensome and more patient-friendly allowing the least interruption in their lives and profession;
4. Context of research and clinical trials at all stages of the process – prior, during and post;
5. Post authorisation process of drugs facilitating the collection of real patients' data on the value, effectiveness and safety of a drug;
6. Negotiations and discussions for pricing of and access to drugs and therapies;
7. Plan of actions prepared by national competent authorities for addressing an epidemic or pandemic crisis (e.g. COVID-10 pandemic);
8. Revisiting, revising or developing new recommendations and/or legislations that are related to their care and quality of lives;
9. Identifying gaps and weaknesses in the care provided for their condition in their particular hospital/ ward/ clinic/ centre and in the solutions suggested/ proposed;
10. Interactions concerning the designing of national studies on the cost effectiveness versus added value of a new drug/ therapy;
11. Preparation of protocols and/or guidelines with the aim to integrate their views and experience and to bring forward in any equation the element of quality of life, which is often 'forgotten' or underestimated in importance by medical/ scientific specialists and competent health/ social authorities;
12. Revisiting the process or development of new social care policies;
13. National health committees for raising awareness on the disease and blood donation campaigns.

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ANNEX I. TIF'S GRADING SYSTEM FOR ASSESSING THE ACTIVITIES OF TIF MEMBER ASSOCIATIONS

ASSESSMENT OF TIF MEMBER ASSOCIATIONS - SCORING			
NO.	COMPONENT*	INDICATOR	SCORE
1.	Association Leadership	Patient	4
		Parent	3
		Other	2
		Doctor	1
2.	Communication frequency with TIF	Regularly (at least monthly)	3
		Irregularly	2
		Rarely (less than 4 times a year)	1
		Never	0
3.	Participation in TIF educational activities (e.g. TIF e-Academy, webinars etc)	Several (more than 4)	3
		Few (2 – 3)	2
		Only 1	1
		No participation	0
4.	Participation in TIF Conferences	Several (more than 4)	3
		Few (2 – 3)	2
		Only 1	1
		No participation	0
5.	Celebration of International Thalassaemia Day – 8th of May	Organise an activity every year	3
		Occasionally organise activities	2
		Rarely organise activities	1
		No known activities organised	0
6.	Organisation of educational events for their members	Regularly	3
		Occasionally	2
		Rarely	1
		No known events organised	0
7.	Organisation of blood donation drives	Regularly (main organizers to serve the patient community needs)	3
		Occasionally (assist the organizing blood banks)	2
		Rarely	1
		Not part of the Associations' scope of activities (other services are responsible)	0
8.	Translation of TIF educational material	Have translated at least 3	3
		Have translated 2	2
		Have translated 1	1
		No known translations completed	0
9.	Undertake advocacy activities (e.g., meetings with MoH)	Regularly	3
		Occasionally	2
		Rarely	1
		Not engaged in advocacy	0
	*Based on the last 3 years		

Annex II. An assessment of TIF Member Associations across the world based on TIF's Grading System

·	TIF Member Association	Country	Region	Association Leadership	Communication frequency with TIF	Participation in TIF ed. Events	Participation in TIF Conf.	ITD - 8th May activities	Organise ed. Events	Organise blood drives	Translation of TIF ed. Material	Advocacy Activities	Grading of activities
F	Cyprus Thalassaemia Association	Cyprus	EUR	4	3	3	3	3	3	3	3	3	28
F	Greek Thalassaemia Federation (EOTHA)	Greece	EUR	4	3	3	3	3	3	3	3	3	28
F	Diwanyah Thalassaemia Association	Iraq	EMR	4	3	3	3	3	3	3	3	3	28
F	(ATODER) Adana Thalassaemia & Sickle Cell Anemia	Turkey	EUR	4	3	3	3	3	3	3	3	3	28
F	Bangladesh Thalassaemia Samity (Society)	Bangladesh	SEAR	3	3	3	3	3	3	3	3	3	27
F	Thalassemics India	India	SEAR	3	3	3	3	3	3	3	3	3	27
F	Yayasan Thalassaemia Indonesia	Indonesia	SEAR	3	3	3	3	3	3	3	3	3	27
F	Federation Of Malaysian Thalassaemia Societies	Malaysia	WPR	3	3	3	3	3	3	3	3	3	27
F	Emirates Thalassaemia Society	United arab emirates	EMR	3	3	3	3	3	3	3	3	3	27
G	Greek Thalassaemia Association	Greece	EUR	3	3	3	3	3	3	2	3	3	26
F	Egyptian Thalassaemic Friends Association	Egypt	EMR	3	3	3	3	3	3	3	2	3	26
F	Chronic Care Centre	Lebanon	EMR	2	3	3	3	3	3	3	3	3	26
G	Faith (Fight Against Thalassaemia)	Pakistan	EMR	4	3	3	3	3	3	3	0	3	25
F	Associazione Ligure Thalassemici Onlus (ALT)	Italy	EUR	4	3	3	3	3	3	0	3	3	25
F	Maldivian Thalassaemia Society	Maldives	SEAR	4	3	3	3	3	3	3	0	3	25
F	Thalassemia Patients Friends Society (TPFS Palestine)	Palestine (occupied)	EMR	1	3	3	3	3	3	3	3	3	25
F	Al-Madina Hereditary Blood Disorder Charity Society	Saudi arabia	EMR	1	3	3	3	3	3	3	3	3	25
F	The Society For Inherited & Severe Blood Disorders Trinidad And Tobago Limited	Trinidad and tobago	AMR	4	3	3	3	3	3	3	0	3	25

G	Federation Des Associations De Malades Drepanocytaires Et Thalassemiques	France	EUR	3	3	3	3	3	3	0	3	3	24
F	Iranian Thalassaemia Society	Iran (Islamic Republic Of)	EMR	4	2	3	3	3	2	1	3	3	24
F	United Onlus	Italy	EUR	3	3	3	3	3	3	3	0	3	24
F	Nepal Thalassaemia Society	Nepal	SEAR	3	3	2	3	3	3	3	1	3	24
G	Association "El Amani" Des Anemies Hemolytiques Congenitales	Algeria	EMR	3	3	2	3	3	1	3	3	2	23
F	Children's Thalassaemia Foundation Ltd	Hong Kong Sar	WPR	3	3	2	3	3	3	3	0	3	23
F	Thalassaemia And Sickle Cell Australia	Australia	WPR	4	3	3	3	3	3	0	0	3	22
F	Savab Dunyasi Thalassaemia Association	Azerbaijan	EUR	4	3	3	3	3	3	0	0	3	22
F	Thalassemia Foundation Of Canada	Canada	AMR	4	3	3	3	3	3	0	0	3	22
F	Thalassemia Association In Niniva	Iraq	EMR	3	3	1	1	3	3	3	2	3	22
F	Jordanian Thalassemia & Hemophilia Society	Jordan	EMR	1	3	3	3	3	3	3	0	3	22
F	United Kingdom Thalassaemia Society (Ukts)	United Kingdom	EUR	4	3	3	3	3	3	0	0	3	22
F	Cooley's Anemia Foundation	United States Of America	AMR	4	3	3	3	3	3	0	0	3	22
G	Thalassemia Society Of Mauritius	Mauritius	AFR	2	3	2	3	3	3	2	0	3	21
G	Oscar Nederland	Netherlands	EUR	3	3	3	3	3	3	0	0	3	21
F	Talasemi Federasyonu (Thalassemia Federation Of Turkey)	Turkey	EUR	4	1	2	3	3	3	3	0	2	21
G	Foundation Against Thalassaemia (Regd.)	India	SEAR	2	3	1	2	3	3	3	0	3	20
G	Unlimited Health Humanitarian Organization	Iraq	EMR	2	3	2	3	3	3	2	0	2	20
G	Vietnamese Thalassaemia Association	Viet Na	WPR	1	1	1	3	3	3	3	2	3	20
F	Lab One Foundation Of Thalassaemi	Bangladesh	SEAR	1	2	3	2	3	3	3	0	3	20
G	Bangladesh Thalassemia Foundation	Bangladesh	SEAR	1	3	1	1	3	2	3	2	3	19
G	National Thalassaemia Welfare Society (Regd)	India	SEAR	1	2	1	3	3	3	3	0	3	19

G	Thalassemians Welfare Organization	Pakistan	EMR	4	2	2	2	2	2	3	0	2	19
G	Al Ahsa Association Charity For Genetic Diseases	Saudi arabia	EMR	3	2	1	3	3	3	2	0	2	19
F	Yemen Thalassaemia & Genetic Blood Disorders Society	Yemen	EMR	3	3	1	2	3	3	3	0	1	19
G	Sickle Cell And Thalassaemia Ireland	Ireland	EUR	3	3	1	3	2	3	0	0	3	18
G	Pertubuhan Thalasaemia Pulau Pinang	Malaysia	WPR	2	2	2	3	3	3	0	0	3	18
G	Zainabia Blood Bank & Thalassaemia Centre	Pakistan	EMR	1	2	2	3	3	2	3	0	2	18
F	Thalassaemia Society (Singapore)	Singapore	WPR	4	3	1	3	3	3	0	0	1	18
G	Seltene Anaemien Deutschland (Sam)	Germany	EUR	3	3	3	3	1	1	0	2	1	17
G	Pakistan Thalassaemia Centre	Pakistan	EMR	2	3	0	2	2	3	3	0	2	17
G	Afzaal Memorial Thalassaemia Foundation (Amtf)	Pakistan	EMR	1	3	2	3	3	2	3	0	2	17
G	Associacao Portuguesa De Pais E Doentes Com Hemoglobinopatias	Portugal	EUR	4	3	2	2	2	2	0	0	2	17
F	Charity Foundation For Special Diseases	Iran (islamic republic of)	EMR	2	1	2	3	1	2	0	3	3	17
F	Thalassaemia Federation Of Pakistan	Pakistan	EMR	1	1	1	2	3	3	3	0	3	17
F	Thalassaemia Society Of Pakistan	Pakistan	EMR	1	1	1	2	3	3	3	0	3	17
F	Thalassaemia Foundation Of Thailand	Thailand	SEAR	1	1	2	3	3	3	0	2	2	17
F	Nebata (North Of England Bone Marrow & Thalassaemia Association)	United kingdom	EUR	3	3	3	3	3	3	0	0	1	17
G	Thalassemia Patients Friends Association	Egypt	EMR	2	3	1	2	3	2	0	0	3	16
G	Sickle Cell / Thalassaemia Association Of Nigeria	Nigeria	AFR	2	2	1	3	2	2	2	0	2	16
G	Kashif Iqbal Thalassaemia Care Centre (Trust)	Pakistan	EMR	1	2	1	2	3	2	3	0	2	16
G	The Swedish Blood Cancer Association	Sweden	EUR	2	3	2	3	0	2	0	1	3	16
F	Kurunegala Thalassaemia Association	Sri lanka	SEAR	1	1	1	2	2	3	3	0	3	16
G	Thalassemia Foundation Of Ghana	Ghana	AFR	3	2	1	1	3	1	2	0	2	15
G	Thalassaemic Charitable Trust Pgimer-Gmch, Chandigarh	India	SEAR	2	3	1	2	2	2	3	0	2	15
G	Mvr Welfare Foundation	India	SEAR	1	2	1	2	3	2	3	0	1	15

G	Durgapur Society For Prevention Of Thalassaemia And Aids	India	SEAR	2	3	1	2	2	2	3	0	1	15
G	Amina Bashir Memorial Trust	Pakistan	EMR	3	2	0	1	3	2	3	0	2	15
F	Azerbaijan Thalassaemia Society Insan	Azerbaijan	EUR	3	3	1	2	2	0	3	0	1	15
G	Jamila Sultana Foundation	Pakistan	EMR	1	2	1	1	2	2	3	0	2	14
G	Saudi Friends' Charity Of Thalassaemia & Sickle Cell Anemia Society	Saudi arabia	EMR	1	3	0	2	3	3	0	0	2	14
G	Taiwan Thalassaemia Association (Twta)	Taiwan	WPR	3	2	0	3	2	2	0	0	2	14
G	Jad-O-Jehad Foundation	Pakistan	EMR	3	2	0	1	2	2	2	0	1	13
G	Balikatang Thalassemia	Philippines	WPR	1	3	1	2	2	2	0	0	2	13
F	Moroccan Association Of Thalassaemia And Hemoglobin Diseases (Mathed)	Morocco	EMR	1	2	2	3	2	1	0	0	2	13
G	Association Francaise De Lutte Contre Les Thalassaemies (Aflt)	France	EUR	3	1	0	2	2	2	0	0	2	12
F	Thalassaemia Society Of New South Wales	Australia	WPR	4	1	1	1	2	2	0	0	1	12
G	Thalassaemia Welfare Centre-Bangladesh	Bangladesh	SEAR	1	2	0	1	2	1	3	0	1	11
G	Mercy Association For Thalassaemia Patients In Wasit	Iraq	EMR	2	1	0	2	3	1	1	0	1	11
G	Kuwait Thalassaemia Society	Kuwait	EMR	1	2	2	2	1	1	0	0	1	10
G	Association Marocaine De Thalassaemie Et Drepanocytose	Morocco	EMR	2	2	0	2	2	1	0	0	1	10
G	Asociacion De Talasemia Argentina	Argentina	AMR	2	3	0	0	2	1	0	0	1	9
G	Interessengemeinschaft Sichelzellkrankheit Und Thalassaemie E.V. (Ist E.V.)	Germany	EUR	3	2	1	2	0	1	0	0	0	9
F	Society For Health Education	Maldives	SEAR	2	0	0	0	0	3	3	0	1	9
G	Albanian Association Of Thalassaemia And Haemoglobinopathies	Albania	EUR	3	1	0	1	2	0	0	0	1	8
G	Federation Of Indian Thalassemics	India	SEAR	1	2	1	3	1	0	0	0	0	8
F	Thalassaemics' Organization In Bulgaria	Bulgaria	EUR	4	1	1	1	1	0	0	0	0	8
G	Thalassaemie Verein Ulm E.V.	Germany	EUR	3	1	0	2	0	1	0	0	0	7

G	Association Belge De Thalassemie Asbl	Belgium	EUR	3	0	1	1	1	0	0	0	0	6
G	Thalassaemia Chinese Federation	China	WPR	2	0	0	1	2	0	0	0	1	6
G	Blood Donors Association (Mauritius)	Mauritius	AFR	2	0	0	0	0	0	3	0	0	5
G	Alheta (Asociacion Espanola De Lucha Contra Las Hemoglobinopatias Y Talasemias)	Spain	EUR	4	0	0	0	0	0	0	0	0	4
G	Thalassemiac And Leukemic Patients	Turkey	EUR	4	0	0	0	0	0	0	0	0	4
F	Fondazione Italiana "L. Giambrone" Per La Guarigione Dalla Thalassemia	Italy	EUR	4	0	0	0	0	0	0	0	0	4
F	Asociatia Persoanelor Cu Talasemie Majora	Romania	EUR	4	0	0	0	0	0	0	0	0	4
G	Thalassaemia Foundation Of Argentina - Fundatal	Argentina	AMR	2	0	0	0	1	0	0	0	0	3
G	South East Asia Institute For Thalassaemia India	India	SEAR	2	1	0	0	0	0	0	0	0	3
G	Thalassaemia Awareness Maltese Association (Tama)	Malta	EUR	3	0	0	0	0	0	0	0	0	3
G	Pakistan Thalassaemia Welfare Society (Regd)	Pakistan	EMR	3	0	0	0	0	0	0	0	0	3
G	Mindanao Thalassemia Foundation Inc	Philippines	WPR	3	0	0	0	0	0	0	0	0	3
G	South African Thalassaemia Association	South africa	AFR	3	0	0	0	0	0	0	0	0	3
G	Tadad - Thalassemi Dayanisma Dernegi	Turkey	EUR	3	0	0	0	0	0	0	0	0	3
F	Albanian Thalassaemics Association (Ata)	Albania	EUR	3	0	0	0	0	0	0	0	0	3
F	Bulgarian Anti-Thalassaemic Organisation (Bata) - Sofia	Bulgaria	EUR	3	0	0	0	0	0	0	0	0	3
G	Social And Health Organization For Afghanistan(SOA)	Afghanistan	EMR		1	0	0	0	0	1	0	0	2
G	Cambodian Thalassaemia Association	Cambodia	WPR	2	0	0	0	0	0	0	0	0	2
G	Mumbai Thalassaemic Society	India	SEAR	2	0	0	0	0	0	0	0	0	2
G	Nivethan Trust	India	SEAR	2	0	0	0	0	0	0	0	0	2
G	Parents' Association Thalassaemic Unit Trust (Mumbai)	India	SEAR	2	0	0		0	0	0	0	0	2
G	Research Society Of Bjw Hospital For Children	India	SEAR	1	1	0	0	0	0	0	0	0	2
G	Thalassemia Society (Karnataka)	India	SEAR	2	0	0	0	0	0	0	0	0	2

G	The Thalassaemia Society Of India	India	SEAR	2	0	0	0	0	0	0	0	0	2
G	Esfahan Thalassaemia Society	Iran (Islamic Republic of)	EMR	2	0	0	0	0	0	0	0	0	2
G	The Galilee Foundation Of Thalassaemia & Sickle Cell Anemia	Israel	EUR	2	0	0	0	0	0	0	0	0	2
G	Johor Thalassaemia Society	Malaysia	WPR	2	0	0	0	0	0	0	0	0	2
G	Thalassaemia Association Of Malaysia	Malaysia	WPR	2	0	0	0	0	0	0	0	0	2
F	Palestine Avenir Foundation	Palestine (occupied)	EMR	2	0	0	0	0	0	0	0	0	2
G	Indian Association Of Blood Cancer & Allied Diseases	India	SEAR	1	0	0	0	0	0	0	0	0	1
G	Malabar T.H.A.S. Society (Kerala)	India	SEAR	1	0	0	0	0	0	0	0	0	1
G	Thalassemia And Sickle Cell Society	India	SEAR	1	0	0	0	0	0	0	0	0	1
G	Etudier, Combattre Les Maladies De L'hemoglobine	Luxembourg	EUR	1	0	0	0	0	0	0	0	0	1
G	Abbotonians Medical Association	Pakistan	EMR	1	0	0	0	0	0	0	0	0	1
G	The Sudanese Patients And Parents Society For Sickle Cell	Sudan	EMR	1	0	0	0	0	0	0	0	0	1
F	Bahrain National Hereditary Anaemia Society	Bahrain	EMR	1	0	0	0	0	0	0	0	0	1
F	Israeli Association Of Thalassaemia & Sickle Cell Anemia	Israel	EUR	1	0	0	0	0	0	0	0	0	1
F	Associazione Veneta Per La Lotta Alla Talassemia (Avlt)	Italy	EUR	1	0	0	0	0	0	0	0	0	1
F	Thalassaemia Patients And Hereditary Blood Diseases	Syrian Arab Republic	EMR	1	0	0	0	0	0	0	0	0	1
F	Alphatt Tunisie	Tunisia	EMR	1	0	0	0	0	0	0	0	0	1
F	Akdeniz Talasemi Dernegi	Turkey	EUR	1	0	0	0	0	0	0	0	0	1
G	Guangdong Thalassaemia Association	China	WPR	0	0	0	0	0	0	0	0	0	0
G	Guangxi Thalassaemia Federation	China	WPR	0	0	0	0	0	0	0	0	0	0
G	Iraqi Thalassaemia Association	Iraq	EMR	0	0	0	0	0	0	0	0	0	0
G	Rifah Welfare Foundation	Pakistan	EMR	0	0	0	0	0	0	0	0	0	0

G	Thalassaemia Patients & Parents Society Of Pakistan	Pakistan	EMR	0	0	0	0	0	0	0	0	0	0
G	Uae Genetic Diseases Association	United arab emirates	EMR	1	0	0	0	0	0	0	0	0	0
G	Oscar Sandwell	United kingdom	EUR	0	0	0	0	0	0	0	0	0	0
G	The Vancouver Thalassaemia Society Of B.C.	Canada	AMR										
G	Syllogos Pashonton Apo Mesogeiaki Anaimia Nomou Korinthias	Greece	EUR										
G	Associazione Lotta Alla Talassemia Di Ferrara	Italy	EUR										
G	Associazione Thalassemici Di Torino Onlus	Italy	EUR										