



PROGRESS OUTLINE 2021



Co-funded by the Health Programme of the European Union

**PILLAR 3:
POLICY
ADVOCACY**

*Activities
Impact*

TABLE OF CONTENTS

EXECUTIVE SUMMARY	2
INTRODUCTION	3
MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT	4
OVERVIEW OF ACTIVITIES (PILLAR 3 – WP 4).....	6
IMPACT ASSESSMENT.....	25

EXECUTIVE SUMMARY

The work of the Thalassaemia International Federation (TIF) can be categorised in four distinct pillars: a) Education; b) Awareness Raising; c) Policy Advocacy and d) Research. For TIF, policy advocacy is all about the rights, choices and capacities of patients and involves delivering messages that are intended to influence thoughts, perspectives and actions of leaders, politicians, policy makers, planners and others in authority. Aiming to prioritise haemoglobin disorders and their control (prevention and management) at European and international levels, TIF acts directly to increase people’s access to information about thalassaemia and other haemoglobinopathies and strives to enhance patients’ capabilities to influence policy processes that affect their lives.

In 2021, the intensive efforts put forward in 2018 - 2020 that yielded a thorough needs analysis of THALIA priority countries, namely France, Germany, Austria, Sweden and Serbia was further strengthened through delegation visits held virtually (on account of travel restrictions in place due to the COVID-19 pandemic) and offline email communication with stakeholders in the aforementioned countries (T4.1.). The Delegation visits consolidated partnerships and collaborations in addition to enabling a deeper penetration in making stakeholders aware of the specific challenges that thalassaemia encompasses as a chronic and rare disease across all THALIA target groups: patients (especially migrants and refugees with thalassaemia), healthcare professionals treating thalassaemia and sickle cell disease patients and decision-making bodies. Challenges, despite persistent efforts, to organise a delegation visit to Serbia impaired the organisation of the THALIA Twinning Programme (T4.2.). To support evidence-based policy-making, TIF continued the discussions for the deployment of an EU Electronic Health Record for thalassaemia despite delays encountered due to change in health priorities of authorities to deal with the health crises, simultaneously publishing country data on the prevalence of thalassaemia in EU Member States (T4.3). Through the dissemination of the EU Policy Recommendation and translation of Charters of Priorities for each THALIA country (T4.4) the distinct challenges faced by thalassaemia patients in accessing quality healthcare and the necessity for further physician education in the appropriate multidisciplinary clinical management of the disease were communicated to key decision-makers.

TIF’s activities in Work Package 4 have capitalised on previous efforts, and have ensured a continued interest of an increased number of EU-based stakeholders in thalassaemia and the need for developing specific policies for this increasing public health issue.

INTRODUCTION

About Us

The Thalassaemia International Federation (TIF) is a patient-oriented, non-profit, non-governmental umbrella federation, established in 1986 with Headquarters in Nicosia, Cyprus. Our mission is to promote access to optimal quality care for all patients with thalassaemia worldwide. To-date membership boasts 232 members from 60 countries across the globe. TIF works in official relations with the World Health Organization (WHO) since 1996 and enjoys active consultative status with the United Nations Economic and Social Council (ECOSOC) since 2017. Most remarkably, TIF has been awarded, in the context of the 68th World Health Assembly in May 2015, the 'Dr Lee Jong-wook Memorial Prize' for the Federation's outstanding contribution to public health. More information about the Federation is available at www.thalassaemia.org.cy.

About Haemoglobinopathies

Haemoglobin Disorders, mainly thalassaemia and sickle cell anaemia, are a group of hereditary (genetic) blood disorders. Approximately 7% of the global population is a carrier of an abnormal haemoglobin gene and more than 500,000 children are born each year with these disorders globally, due to the lack of implementation of effective national programmes for their prevention. In Europe, haemoglobin disorders fall within the official EU definition for rare diseases and it is estimated that approximately 44,000 patients with a haemoglobin disorder live in the region. However, the number of patients located in Europe is increasing due to migration flows from high prevalence countries of the Middle East, South East Asia and Africa.

About THALIA

Thalassaemia, a previously fatal childhood genetic disease, can today be effectively prevented and adequately treated, as a result of the medical and scientific advances that took place in the last three decades. However, thalassaemia's prioritisation on national health agendas and the development of national plans for its effective control in the EU has been hampered by the many challenges involved, mainly related to its rarity and migration.

"THALassaemia In Action" (THALIA) focuses on Europe, targeting patients with thalassaemia and other haemoglobinopathies, healthcare professionals and policymakers. THALIA has a special focus on:

- 1) countries that receive most refugees and migrants from countries with high prevalence in thalassaemia; namely France, Germany, Sweden;
- 2) major transit countries for migrants; namely Serbia and Austria.

About the impact of COVID-19

The continuing evolution of COVID-19 throughout 2021, resulted in the implementation of the COVID-19 Contingency and Mitigation Plan as described in the THALIA2021 SGA, to ensure the fulfilment of activity objectives whilst simultaneously ensuring the safety of participants (patients, healthcare professionals, policy-makers, TIF Staff and affiliates) at all times.

MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT

General objective

III.0. Prioritise haemoglobin disorders and their control (prevention and management) at international/United Nations (UN) and European Union (EU) levels

Task No	T4.1	T4.2	T4.3	T4.4
Target Audience	Patients Policy/ decision makers HCPs	Patients	Policy/ decision makers HCPs	Patients Policy/ decision makers
KPI Met	x	x	x	✓
Justification	✓	✓	✓	✓

Specific objectives

III.1. Facilitate the exchange of knowledge and good practices between national Thalassaemia associations.

Activity: T4.2: TIF EU Thalassaemia Associations' Twinning Programme

Results: The Programme did not materialise due to communication challenges with the patient community in Serbia.

Impact: KPI not met – Thalassaemia in Serbia is an ultra rare disease with very few patients in the indigenous and migrant populations. This is a key impediment to creating enough momentum in order to engage in such activities.

Impact Management / Mitigation Measures: Continued communication efforts with healthcare professionals and the authorisation of new therapies for the care and cure of thalassaemia may in the future form the basis of renewed interest from the Serbian thalassaemia community.

III.2. Support European countries with no tradition or experience in managing Thalassaemia and haemoglobinopathies and receive a high number of migrants and refugees.

Activity: T4.1: Establishment of national associations in France, Germany, Austria, Sweden and Serbia

Results: KPI not met – The establishment of a patient association in Serbia remained premature. TIF visited albeit virtually all countries of priority (France, Germany, Austria, Sweden) except Serbia where communication was pursued via email, and consolidated relationships and partnerships created in 2018 - 2020.

Impact: Thalassaemia patient groups have been established in Austria and Sweden and steps were made to strengthen existing groups in France and Germany, and to mobilise the establishment of a thalassaemia patient group in Serbia, as grass roots work increased the interest of all target audiences.

Impact Management / Mitigation Measures: N/A

III.3. Monitor the spread of Thalassaemia and haemoglobinopathies in Europe.

Activity: T4.3: Thalassaemia EU Electronic Health Record

Results: Prevalence of thalassaemia was published in a peer-reviewed article, while discussions continued in 6 centres for deployment. A marketing strategy and country profiles were developed as a means to communicate the value of the Health Record to national health authorities.

Impact: KPI not met – Hospital administrations in Europe continue to prioritise the management of the COVID-19 pandemic. As such, discussions and interest in adoption of the Health Record although present were slow. Outreach to national health authorities was delayed due to late completion of marketing strategy and country profiles.

Impact Management / Mitigation Measures: The interest of clinics will be utilised in 2022 to further promote the tool.

III.4. Improve EU policies on Thalassaemia

Activity: T.4.4: Policy Recommendation and position paper on Thalassaemia in Europe

Results: The Policy Recommendation on Thalassaemia in Europe has been disseminated to EU institutions and national health authorities as means to advocate for the development of disease-specific policies.

Impact: Online dissemination via TIF Website yielded a total of 59 downloads and an outreach to 230 recipients at DG SANTE, National Competent Authorities, WHO and other decision-making bodies were pursued in addition to the translation of the National Charters of Priority thus enabling patient organisations to have a key advocacy tool in their own language.

Impact Management / Mitigation Measures: N/A

OVERVIEW OF ACTIVITIES (PILLAR 3 – WP 4)

TASK	T4.1: Establishment of thalassaemia national associations in Serbia
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Medical Advisor, Dr Michael Angastiniotis (Leader) Policy Officer, Eleni Antoniou Communications Officer, Aikaterini Skari Administration Officer, Rawad Merhi Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Establishment of patient associations in Serbia (MS12) ▪ Associations involved: 1
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Delegation visit (virtual) to Germany: Jan, June & Nov 2021 ▪ Delegation visit (virtual) to Austria: Feb, June & Sept 2021 ▪ Delegation visit (virtual) to France: May 2021 ▪ Delegation visit (offline communication) to Serbia: Nov 2021 ▪ Delegation visit (virtual) to Sweden: Nov 2021 ▪ Country Profile – Austria: Dec 2021 ▪ Country Profile – Germany: Dec 2021 ▪ Country Profile – France: Dec 2021 ▪ Country Profile – Sweden: Dec 2021
DESCRIPTION OF THE ACTIVITY	
<p>A main constituent of TIF’s work globally and at the European level is provide support to local patient and healthcare communities and governments to create robust policy-making for the improvement of patient care. In this context a delegation team from TIF, comprising of medical specialists and patient advocates, travels to various countries every year to offer technical knowledge and experience on key issues touching on thalassaemia prevention and care.</p> <p>These delegation visits serve to establish partnerships with the local communities on the ground, especially in countries where thalassaemia is not found within the indigenous population but rather the result of migration flows from thalassaemia-prevalent areas of the world such as the THALIA priority countries (i.e. France, Germany, Sweden, Austria and Serbia).</p> <p>The TIF delegation team, in collaboration and with the consent of the local medical community and patients association (where one exists), observe a situation analysis through the documentation of (1) epidemiological data (taking into consideration the influence of migration and population movements), (2) the provided medical and other services and (3) unmet patient needs. Together with all stakeholders immediate and long-</p>	

term actions are considered for implementation to advocate for improvement of these.

Where an organised patient association does not exist TIF makes every effort to identify patients and parents who can provide feedback on their unmet needs, and proposes the establishment of a patient association as a priority activity, and provides expert assistance on how to proceed (TIF Publication - 'A Guide to Establishing a non-profit patient support organisation'¹). Where an association exists then TIF consider ways to strengthen it, providing patient education, and organising capacity building activities.

The foundations for collaboration across the THALIA priority countries was laid in 2018 where two delegation visits (one investigational and one follow up) took place, with a TIF delegation team comprised of an expert TIF Officer or Medical Adviser or Member of TIF's International Scientific Advisory Board and at least one patient from TIF's Expert Group. During the 1st visit, TIF delegation meets with medical specialists, national health authorities and national rare disease association (if exists) to map the situation and tailor the support according and secure the supporting of medical professionals in identifying patients for TIF. During the 2nd visit, TIF delegation meets with patients and parents (where necessary) to ensure support for the establishment of patients' associations with specific goals and timeframes. Further strengthening of relationships and partnerships, while also documenting progress on mutually agreed upon immediate and long-term actions was the focus of delegation visits that took place in 2019.

Seeking to capitalize on the efforts of the previous two years, in 2020 TIF sought to refine the short and long-term goals determined by the stakeholder groups in France, Germany Sweden and Austria through the organisation of alignment meetings and correspondence, which provided the foundation for the delegation visits that materialised during the year. It is noted that due to travel restrictions, national lockdown measures and fluctuating infection rate of SARS-CoV-2 across the EU throughout most of 2020, and most notably in the THALIA priority countries, the delegation visits took place in a virtual environment.

The empowerment of patients through activities defined in the THALIA Work Programme, in the period 2018 – 2020 particularly in the regular and frequent contact with TIF via correspondence and annual delegation visits (face-to-face or virtual) led to the development and strengthening of relationships and culminated in the successful establishment of two new thalassaemia patient associations (v. Austria and Sweden) and the strengthening of existing associations in France and Germany. Specific circumstances in Serbia mature the formation of a patient organisation.

In 2021, TIF continued to pursue the further strengthening of the newly founded associations and to support the work of existing ones through correspondence and the materialisation of virtual delegation visits to France, Germany, Sweden and Austria. An opportune time to organise a virtual delegation visit to Serbia was not identified, however efforts continued to be made to mobilise local communities.

¹ <https://thalassaemia.org.cy/publications/tif-publications/a-guide-to-establishing-a-non-profit-patient-support-organisation-2007-eleftheriou-a/>

The amalgamation of country-specific information for the creation of individual Country Profiles summarizing the local situation and transpiring the unmet patient needs as a result of the interactions undertaken in the THALIA Work Programme (2018 – 2021) has been completed for France, Germany, Austria and Sweden in 2021. This is an invaluable advocacy tool, together with the National Charters of Priority (v. T4.4; THALIA2020), that were translated in 2021 (see T4.4 below) and the EU Policy Recommendation (v.T4.4; THALIA2020), for patient associations as they pursue meaningful dialogues with national health authorities for the development of new or strengthening of existing policies / programmes / services that will improve the lives and health of thalassaemia patients.

Objectives of each Visit

The objectives of these virtual delegation visits, in accordance to the three main stakeholder groups involved in the control of thalassaemia, remain the identical to those of in-person delegation visits, and are:

Stakeholder Group 1: Healthcare professionals

- To inform healthcare professionals working in the field of haematology and paediatric haematology about the migration of thalassaemia (how the recent migration flows have led thalassaemia patients and carriers to Europe);
- To ascertain the epidemiology and prevalence of thalassaemia
- To discuss response mechanisms / programmes, including multidisciplinary care and prevention programmes;
- To seek guidance and support on how disseminate knowledge about thalassaemia to the other stakeholder groups (see below) as well as the general public (for community awareness and prevention purposes);
- To involve healthcare professionals in TIF's International Scientific Advisory Committee and;
- To provide information about TIF's tools for this stakeholder group, and how they can become involved (e.g. Healthcare Professionals Educational Platform, Publications – especially Guidelines for the Clinical Management of TDT, Global e-Registry & electronic health record, Preceptorships, Renzo Galanello Fellowship etc).

Stakeholder Group 2: Patients/Parents

- To empower and create core groups of patients, promoting the creation of a National Patients' Associations, for providing support (in kind and knowledge-based) to the patients and their families;
- To provide tools and education for the development of the necessary skills and capacities for advocacy and productive participation in decision making at the national level;
- To educate patients/parents on disease-specific knowledge, as well as the latest policies, projects and legislative developments in the fields of Haemoglobin disorders, rare diseases, medicines, patients' rights and mobility, reference networks, etc;
- To invite patients/parents to participate in specific TIF organized activities e.g. Capacity Building Workshop, Twinning Programmes etc;

- To provide information about TIF's tools for this stakeholder group, and how they can become involved (e.g. Thal e-Course, THALIA Mobile app, Publications etc).

Stakeholder Group 3: Health Authorities

- To discuss the policies relevant to the prevention and clinical management of haemoglobin disorders;
- To demonstrate the relation between migration and thalassaemia and possible implications for the healthcare system;

To deliberate regarding possible avenues of collaboration with TIF to increase and ensure access to optimum care² for all patients (e.g. Reference Centres, life-long learning opportunities for healthcare professionals, Global e-Registry & electronic health record etc.)

The visits in 2021 have yielded the following notable information (per country):

Delegation visit to Austria

February 2021

Introduction

A virtual TIF Delegation visit with stakeholders from Austria took place on 26 February 2021. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director) and Mr Anton Skafi (TIF Board Member). The Delegation was accompanied by Dr Eva-Maria Knoll (a Medical Anthropologist & passionate volunteer working with TIF in Austria).

The Delegation Team during the virtual meeting had the opportunity to meet with 47 patients, parents and treating physicians from Austria. The agenda of the meeting focused on the importance of patient advocacy, registries, multidisciplinary care and new therapies. Experts in the field Dr Christian Sillaber (Austria) and Dr Stephan Lobitz (Germany) engaged in the discussion also.

The newly-founded THALSIFO patient association in Austria launched the organisations' new logo and Facebook page during the meeting, where Dr Lobitz presented the work of the GPOH-Consortium Sickle Cell Disease in Germany which aims to improve the care of SCD patients, including updating clinical guidelines, hosting a patient registry, implementing of new-born screening and various educational efforts. Dr Lobitz also elaborated about the newly available drugs and explained how they work. He further reported very positive experiences with a booklet designed to accompany children with sickle cell disease through their multidisciplinary treatment entitled "The Sickle Cell Companion for Children"; the corresponding publication for adults is already available in Vienna, along with an Emergency Card.

1. ² As per TIF's Guidelines (3rd Edition), 2014 <http://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-management-of-transfusion-dependent-thalassaemia-3rd-edition-2014/>

During the meeting, the TIF Delegation Team had the opportunity to talk about the development of tools (e.g. registry) that would improve the visibility of thalassaemia and sickle cell disease in Austria and guide disease-specific policy-making in addition to the essential elements of multidisciplinary care as a means to improve patient quality of life.

Main Findings:

- The unavailability of a complete patient registry (children and adults) hinders not only the ability of health authorities to create targeted services, but also impacts the peer-to-peer support that can be offered by THALSIFO, thus combating isolation and loneliness among patients and their parents (if applicable). Awareness and knowledge about thalassaemia amongst healthcare professionals, patients, carriers, the migrant communities and the society at large is limited.
- Visibility of thalassaemia and sickle cell disease, and their distinct needs as multi-organ non-malignant haematological disorders is limited, as healthcare settings providing care for patients are mostly oncology driven.
- More emphasis on the provision of appropriate and timely multidisciplinary care by healthcare professionals is necessary.

June 2021

Introduction

A virtual TIF Delegation visit with stakeholders from Austria took place on 10 June 2021. The Delegation Team consisted of Mr George Constantinou (TIF. Ass. Secretary), Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer).

The Delegation Team during the virtual meeting had the opportunity to meet with Prof. Leo Kager (paediatric haematologist), a treating physician and Dr Eva-Maria Knoll (medical anthropologist, TIF collaborator in Vienna), on behalf of the patient community. The meeting aimed to achieve a more holistic and detailed understanding of the present situation regarding the clinical management of patients with thalassaemia in Austria and identify collaborative ways forward.

The discussion highlighted the important, diverse and quality care services provided to paediatric patients by healthcare professionals, and the need to strengthen the transition process to adult care whilst also conveying the high quality care protocols to adult clinics too. Moreover, Prof. Kager informed the meeting participants of the initiation of a haemoglobinopathies registry in his hospital in Vienna that will soon be extended to all treating centres across the country. Finally, the need for further patient empowerment and engagement was emphasized by Dr Knoll, who has been pivotal in the creation (in 2020) of THALSIFO – a patient association for patients with thalassaemia and sickle cell disease following TIF’s delegation visits in the context of THALIA2018 – 2019.

Closer and more frequent communication with TIF was agreed, so the Federation can offer its expertise and technical knowledge more promptly as the haemoglobinopathy community continues to grow in Austria.

Main Findings:

- Quality healthcare is provided to paediatric and adult patients with thalassaemia and sickle cell disease in Austria, especially those followed in centres located in Vienna.
- Strengthening of knowledge among healthcare professionals in other cities is necessary; currently a system of informal networking and exchange of best practices is employed between treating physicians.
- A patient registry is under development, based on TIF's electronic health record and registry (v. T4.3) and is hoped to raise visibility for thalassaemia and sickle cell disease.
- Patient empowerment has been initiated with the formation of THALSIFO but needs to be strengthened with additional educational activities.

September 2021

Introduction

A virtual TIF Delegation visit with stakeholders from Austria took place on 12 September 2021. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer). The Delegation was accompanied by Dr Eva-Maria Knoll (a Medical Anthropologist & passionate volunteer working with TIF in Austria).

The Delegation Team during the virtual meeting had the opportunity to meet with 20 patients, parents and treating physicians from Austria. The agenda of the meeting focused on new innovative therapies for thalassaemia and particularly luspatercept, including addressing patient concerns about adverse reaction reports.

Main Findings:

- i. Participation in educational activities about new therapies is essential for empowerment and knowledge acquisition for patients and healthcare professionals alike.
- ii. Knowledge on new therapies is limited and therefore more meetings focused on this topic are needed in order for patients to gain a deeper understanding.
- iii. Close monitoring by expert medical specialists is necessary when administering innovative therapies.

TIF continued to support the patient community across Austria throughout the year by responding to correspondence concerning new innovative therapies, particularly luspatercept (for transfusion dependent thalassaemia) and voxelotor (for sickle cell disease).

Delegation visit to Germany

January 2021

A virtual TIF Delegation visit with stakeholders from Germany took place on 19 January 2021. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer).

The Delegation visit was the result of an urgent request by the local patient organisation (SAM Deutschland e.V. AM - TIF Member Association), who wished to inform and seek the Federations' assistance regarding the resignation of the lead treating physician at the Universitätsklinikum Hamburg-Eppendorf (UKE).

The lead treating physician had achieved significant expertise in the clinical management of thalassaemia, a rare disease in Germany, and developed a good relationship with the patient community.

The discussion moderated by Mr Kostas Tsurlis (Vice-President of SAM Deutschland e.V. AM - TIF Member Association; TIF Patient Advocacy Group Member), resulted in concerted efforts on behalf of TIF to convey the importance of continuing the provision of expert care to thalassaemia patients to the hospital administration.

June 2021

Following the virtual delegation visit in January 2021 and subsequent efforts made by TIF to ensure the continuity of care for thalassaemia patients living in Hamburg, the position vacated by the lead treating physician continued to be void for over 6 months.

This was the main focus of the virtual Delegation Visit with stakeholders from Germany that took place on 11 June 2021. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Mr Rawad Merhi (TIF Countries Officer). Mr Kostas Tsurlis (Vice-President of SAM Deutschland e.V. AM - TIF Member Association; TIF Patient Advocacy Group Member) and Dr Sonja Hoppe (Board Member of SAM Deutschland e.V. AM - TIF Member Association) participated on behalf of the local patient association.

Consequently, communication between TIF and the hospital administration indicated that services are continuing to be provided to patients in both the adult and paediatric settings, whilst the hospital has also announced that they are receiving applications to cover the vacant consultant position. Moreover, this communication revealed the increasing numbers of patients in Hamburg (358 in 2018, 365 in 2019, 359 in 2020 and approx. 350 in 2021). TIF also sought the guidance and advice of other expert treating physicians on how to alleviate the situation and promote improved services for the patients living in Hamburg.

November 2021

Subsequent to efforts made on behalf of TIF and the local patient association to the hospital administration of the Universitätsklinikum Hamburg-Eppendorf (UKE), the position of lead treating physician has been filled by a qualified haematologist. Acquisition of knowledge and expertise on the clinical management of thalassaemia is imperative in accordance to international guidelines for this rare disease by the new clinical lead.

Main Findings:

- The value of policy advocacy through a united voice has become apparent to the patient groups in Germany, especially highlighted by the developing situation in Hamburg.
- Participation in educational activities about new therapies is essential for empowerment and knowledge acquisition.
- Knowledge on new therapies is limited and therefore more meetings focused on this topic are needed in order for patients to gain a deeper understanding.
- Patients unanimously agreed that thalassaemia & sickle cell disease do not only affect the condition of their health, but also education, professional and social opportunities. Therapeutic advances that will allow them to spend less time dealing with hospitals, doctors appointments etc. will enable them to focus efforts on the other areas of life.
- Patient Organisations are the most frequent source of information for patients on community news. Therefore, patient organisations are required to have the skills and capacities to provide reliable information.

TIF continued to support the patient community across Germany by responding to correspondence and holding regular meetings concerning new innovative therapies, particularly luspatercept (for transfusion dependent thalassaemia) and voxelotor (for sickle cell disease).

Delegation visit to France

May 2021

Introduction

A virtual TIF Delegation visit with stakeholders from France took place on 07 May 2021. The Delegation Team consisted of Ms Eleni Antoniou (TIF Policy Officer) and Mr Rawad Merhi (TIF Countries Officer).

The Delegation Team had the opportunity to participate in the online conference organised by the French Federation of Thalassaemia Associations “SOS Globi” on the occasion of International Thalassaemia Day (ITD) 2021. The webinar brought together more than 200 people with thalassaemia living in France and more than 20 speakers, amongst whom patient leaders and thalassaemia experts.

During the meeting TIF had the opportunity to present the history of ITD, this year's theme (Addressing Health Inequalities Across the Global Thalassaemia Community) and how TIF works. Furthermore, TIF presented the unmet needs of thalassaemia patients across the European region as identified through work undertaken in the context of the THALIA project.

The Conference, allowed the exchange of knowledge and nurtured the collaboration with the French patient community. As such, areas for improved social integration and education with the support of TIF were discussed.

Main Findings:

- Educational material should be developed in French to overcome any linguistic barriers and provide wider access to information amongst French-speaking physicians and patients/parents.
- The lack of peer-to-peer support is a major issue for patients and their families leading to social isolation; actions should be taken to foster networking between patients.

Delegation visit to Sweden

November 2021 (1st Meeting)

Introduction

A virtual TIF Delegation visit with stakeholders from Sweden took place on 02 November 2021. The Delegation Team consisted of Ms Lily Cannon (TIF Operations Manager) and Ms Stella Eleftheriou (Office Administration).

The Delegation Team during the virtual meeting had the opportunity to have a personal discussion with two patients who had recently moved to Sweden from Syria. The discussion focused on the multidisciplinary management of thalassaemia in Sweden, as well as the societal integration of patients. Both expressed their satisfaction with services, noting the robustness of the healthcare services for uninterrupted supply of blood and essential medications. This has enabled their health to improve, and for them to pursue further educational opportunities and professional development.

Main Findings:

- Guidelines for the management of thalassaemia patients are followed by healthcare professionals who offer high quality multidisciplinary care services.
- Patient education on disease-specific issues needs strengthening through the newly established thalassaemia association.
- COVID-19 has resulted in heightened anxiety and mental health issues especially among patients with chronic disorders, such as thalassaemia, thus necessitating the integration of qualified, professional psychological support in the multidisciplinary team.

November 2021 (2nd Meeting)

Introduction

A virtual TIF Delegation visit with stakeholders from Sweden took place on 19 November 2021. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor), Ms Lily Cannon (TIF Operations Manager) and Ms Eleni Antoniou (TIF Policy Officer).

The Delegation Team during the virtual meeting had the opportunity to have a personal discussion with Mrs Sawsan Ghzal (Vice Chairman of Kronisk Blodsjukdom (KBS) – Swedish Chronic Blood Disease Association), a parent of two adult thalassaemia children.

The meeting explored the quality of life of patients with haemoglobinopathies in Sweden, and identified avenues for attaining a closer partnership between KBS and TIF. Finally, the need for further patient empowerment and engagement was emphasized by Mrs Ghzal, noting that TIF's delegation visits in the context of THALIA2018 – 2020 have been pivotal in the creation (in 2020) of KBS – a patient association for patients with thalassaemia and sickle cell disease.

Main Findings:

- Improvement of knowledge and education, both for patients and healthcare professionals is imperative.
- Linguistic challenges are common among patients, who require brochures and information in their native languages or in Swedish.
- Further strengthening of efforts for the newly established thalassaemia patient organization is required to combat isolation and marginalisation.

November 2021 (3rd Meeting)

Introduction

A virtual TIF Delegation visit with stakeholders from Sweden took place on 30 November 2021. The Delegation Team consisted of Dr Androulla Eleftheriou (TIF Executive Director), Dr Michael Angastiniotis (TIF Medical Advisor) and Ms Lily Cannon (TIF Operations Manager). The Delegation Team during the virtual meeting had the opportunity to continue the conversation initiated on 19 November 2021 with Mrs Sawsan Ghzal (Vice Chairman of Kronisk Blodsjukdom (KBS) – Swedish Chronic Blood Disease Association) focusing on the management of thalassaemia in Sweden.

Highlighting that although a rare disease in Sweden, the level of care is high, with interested medical specialists adhering to international management guidelines. Nonetheless, more awareness is needed among healthcare professionals and the community, while the exact numbers of patients remains unknown due to the absence of a national registry. The discussion continued to explore ways in which TIF could further support the patient community in Sweden.

Main Findings:

- The exact number of patients in Sweden remains elusive on account of the unavailability of a national haemoglobinopathy register. This impacts the visibility of haemoglobinopathies to national health authorities.
- Improvement of knowledge and education, both for patients and healthcare professionals is imperative.

Delegation visit to Serbia

November 2021

Introduction

Efforts exerted in 2018 – 2020 to mobilise the three stakeholder groups (v. patients, healthcare professionals and national health authorities) in Serbia have remained fruitless in 2021. Hence, the exact number of patients in the country remains elusive on account of the unavailability of a national thalassaemia register, and limited interest on behalf of the healthcare professional community. This therefore impacts the visibility of thalassaemia to national health authorities.

An opportune time to organise a virtual delegation visit to Serbia was not identified, however efforts continued to be made to mobilise local communities. Furthermore, as a result of persistent efforts to continue communication with contacts made in previous years in Serbia and across Eastern Europe, representatives of the patient and healthcare professional communities from Macedonia participated in the Capacity Building Workshop (v. T2.2.1) and Educational Course for Healthcare Professionals (v. T2.2.2) respectively. This provided renewed optimism of the interest of a select few individuals in enlarging their knowledge about disease-specific and advocacy issues.

Main Findings:

- Improvement of knowledge and education, both for patients and healthcare professionals is imperative.
- Further strengthening of efforts for the creation of a thalassaemia patient community / organization is required to combat isolation and marginalisation.

**RESULTS
ACHIEVED**

- Strengthening of established and building new collaborations with key stakeholders in the medical and patient (where they exist) communities, in addition to other health bodies in each of the THALIA priority countries (FR, DE, SWE, SRB, & AUS).
- Empowerment of patients and associations (where they exist) with provision of patient educational material.
- Recognition of the social challenges that patients with thalassaemia in Europe face (isolation and marginalisation) in excess of other discriminations.
Acknowledgement of 'invisible' patients who are not part of the healthcare systems and the necessity to work with agencies dealing with migrants and refugees in order to find them.
- Dissemination of TIF's educational materials for patients and healthcare professionals as well as other initiatives (e.g. electronic healthcare record, registry, network of collaborating centres etc) to each of the THALIA priority countries (FR, DE, SWE, SRB, & AUS).

TASK	T4.2: TIF EU Thalassaemia Associations' Twinning Programme
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Policy Officer, Eleni Antoniou (Leader) Medical Advisor, Dr Michael Angastiniotis Communications Officer, Aikaterini Skari P.A. to the Executive Director, Maria Peletie Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Number of participants: 4
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Identification of participants (MS13): N/A ▪ Twinning Programme: N/A
DESCRIPTION OF THE ACTIVITY	
<p>To facilitate the exchange of knowledge and good practices between patients and associations throughout Europe, TIF has established a Twinning Programme between countries with newly established / inexperienced patient associations (where they exist) or active patients and expert patient associations.</p> <p>TIF's EU Twinning Programme in 2018 served the needs of the patient community in France (THALIA2018 priority country, see FPA No. 785243), and as a result a Thalassaemia Working Party was set up in France (See THALIA2019 Periodic Report). In 2019, the Twinning Programme focused on the building of a relationship between the patient communities of Germany (THALIA2019 priority country, see FPA No. 785243) and Greece, and as a result a focal person was designated to move forward the partnership with TIF and cultivate the ground for the creation of a German Thalassaemia Association Network (see T4.1).</p> <p>Reports from patients in all THALIA priority countries of the impact that COVID-19 national measures, especially social distancing and shielding, had on their mental health, resulted in a wider and extended Twinning Programme taking place between patients from Austria and Sweden (THALIA2020 priority countries, see FPA No. 785243) as well as the other THALIA countries which have newly established / inexperienced patient associations (where they exist) and patients from Greece, Italy, Cyprus that have established patient associations since the 1970s. The meeting empowered patients to seek adoption of TIF's guides on COVID-19 in their own countries, having tangible results as in France³, Germany and Austria⁴.</p>	

³ https://filiere-mcgre.fr/wp-content/uploads/2020/04/COVID19Thalassemie_Patient.pdf
https://filiere-mcgre.fr/wp-content/uploads/2020/04/COVID19_Thalassemie.pdf
https://filiere-mcgre.fr/wp-content/uploads/2020/04/InformationCOVID19_Patients_MCGRE_avril.pdf
⁴ <https://www.onkopedia.com/de/onkopedia/guidelines/coronavirus-infektion-covid-19-bei-patienten-mit-blut-und-krebserkrankungen/@@guideline/html/index.html>

In 2021, the Twinning Programme between the patient communities of Serbia (THALIA2021 priority country, see FPA No. 785243) and Greece did not materialise, as a result of continuous silence from the thalassaemia community in Serbia throughout the year.

Based on TIF interactions with patients and healthcare professionals as described in the THALIA2018, THALIA2019 and THALIA2020 Periodic Reports, it is deducible that the patient community is especially small and thus challenging to locate in Serbia, with little interest in engaging in advocacy or education opportunities.

**RESULTS
ACHIEVED**

N/A

TASK	T4.3: Thalassaemia EU Electronic Health Record
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Policy Officer, Eleni Antoniou (Leader) Medical Advisor, Dr Michael Angastiniotis Communications Officer, Aikaterini Skari</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Marketing Strategy (MS14) ▪ No. of Health Authorities approached: 20
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Peer-reviewed article published: April 2021 ▪ Licensing & Deployment procedures for 4 centres in Cyprus: Aug – Dec 2021 ▪ Discussions for Deployment to 2 centres in Austria: Dec 2021 ▪ Country Profiles for 7 EU Member States: Dec 2021
DESCRIPTION OF THE ACTIVITY	
<p>The development of an EU-wide comprehensive disease-specific database in the form of a thalassaemia-specific electronic health record, which provides data for an EU Thalassaemia Registry, is a pivotal tool for monitoring the spread of thalassaemia and haemoglobinopathies in Europe. This is especially important in the current climate, considering the influx of migrants from thalassaemia prevalent areas of the world to European countries where thalassaemia is not found in the indigenous population and hence there is limited expertise on the management of the disease or understanding of its medical, social and economic repercussions.</p> <p>The need for complex healthcare services for lifelong disorders like thalassaemia, make it essential to understand the real burden of disease; this is an important issue for budgetary and public health planning. Registries, health records and other databases are essential tools for gathering information, which help to define the epidemiology, clinical outcomes and the natural history of these rare conditions. Such information will help to improve quality of care and to plan services, as well as to assist in research initiatives including clinical trials and the recruitment of volunteer patients. Policies concerning reference centres, networking and cross-border health, make the development of registries at healthcare facility, national and international level, necessary tools to facilitate the creation and implementation of these policies.</p> <p>The current lack of reliable and comprehensive national registries for thalassaemia and haemoglobinopathies suggests a gross underestimation of the prevalence of these disorders in Europe. In addition, knowledge and understanding of the distribution of patients and prevalence of the disease in each country is a huge contributing factor to public health planning. Thus, in the effort to assist the development of targeted public health policies for the provision of quality healthcare for thalassaemia patients, TIF has in 2018 developed an</p>	

electronic health record for thalassaemia, with due consideration of EU GDPR⁵ legislation in regards to ethical and privacy issues.

The Thalassaemia EU Electronic Health Record was piloted to 6 EU centres in 2019 with further architectural refinements required, thus pushing the official launch into 2020 (See THALIA2019 Periodic Report). Centres in Greece and Cyprus officially declared their interest in adopting the Thalassaemia Electronic Health Record (See THALIA2019 Periodic Report), and procedures were initiated in late 2019 to reach agreements with hospital administrations regarding the installation of the software to ensure safety of data and server security. These procedures continued into early 2020, and a further 2 centres demonstrated interest in the Health Record.

Reprioritisation of hospital administrations and national health authorities in 2020 to deal with the COVID-19 pandemic, bureaucratic challenges regarding licensing and deployment to 4 centres in Cyprus and halt of discussions with health authorities in Greece on account of health priority adjustments caused significant delays in data entry. Seeking to continue the momentum for monitoring the spread of Thalassaemia and haemoglobinopathies in Europe a targeted literature review of all published information and websites concerning the prevalence of thalassaemia and migrants in Europe was undertaken and submitted for publication in late 2020 (See THALIA2020 Periodic Report).

The result, a peer-reviewed article was published in April 2021. The article may be accessed at <https://www.mdpi.com/2039-4365/11/1/9803>.

Focusing on the population movement trends towards Europe, from high prevalence countries of the world, the article provides bird's eye view of the prevalence of these disorders across EU Member States thus contributing to the further understanding of challenges met by both patients and healthcare professionals in the receipt and provision of quality healthcare respectively. Moreover, an overview of activities undertaken by TIF in the context of the THALIA2018 – 2020 to alleviate these challenges is included, seeking to pave the way to increased awareness, education and policy changes building on international expertise and knowledge that will enable the provision of state-of-art clinical management services thus guaranteeing an improved quality of life for patients.

Discussions with the Cyprus National Thalassaemia Committee, the State Health Services Organisation, treating doctors and patients through the Pancyprian Thalassaemia Association continued (M8) whereas interest on behalf of the treating doctors from Austria (M12) was demonstrated for implementing the Health Record and Registry in the country, as a result of the National Charter of Priorities – Austria (v.T4.4; THALIA2020). Discussions with health authorities in Greece did not resume in 2021, on account of other health priorities.

The amalgamation of country-specific information for the creation of individual Country Profiles for 7 EU Member States, summarizing the local situation and transpiring the unmet patient needs as a result of the interactions undertaken in the THALIA Work Programme (2018 – 2021), including the added value of adopting the Thalassaemia Electronic Health

Record and Registry has been completed in 2021 (M12). The Marketing Strategy (MS14) will subsequently be implemented with an outreach to national health authorities conveying the importance of monitoring the spread of haemoglobinopathies. This is expected to be completed in early 2022.

**RESULTS
ACHIEVED**

- Article published on the epidemiology of thalassaemia in Europe
- Licensing & deployment procedures continue for 4 centres in Cyprus.
- Interest for implementation in Austria.
- Prevalence of thalassaemia described in Country Profiles (dissemination planned for 2022).

⁵ General Data Protection Regulation
(<https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:32016R0679&from=EN>)

TASK	T4.4: Policy Recommendation and position paper on Thalassaemia in Europe
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Policy Officer, Eleni Antoniou (Leader) Communications Officer, Aikaterini Skari Office Administration, Stella Eleftheriou</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	N/A
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ EU Policy Recommendation dissemination: 08/2021 ▪ Translation of National Charters of Priorities for France, Germany, Austria and Sweden: Jan – September 2021
DESCRIPTION OF THE ACTIVITY	
<p>Acknowledging the information compiled by on-site visits to the THALIA priority countries in 2018–19 (FPA T.4.1) in addition to the data concentrated in the Thalassaemia EU Health Record (T4.3), the Haemobarometer and in other interactions with patients, parents, carriers, HCPs and policy-makers, TIF composed in 2020 a Policy Recommendation paper providing an overview of the multiple factors that impact the lives of people with Thalassaemia and Sickle Cell Disease living in the European Union and highlighting specific recommendations addressed to policymakers in order to address key challenges, unmet needs and policy gaps and ultimately improve the patients' health and lives.</p> <p>Although the situation amongst Member States is remarkably diverse and depends on several external and internal factors, including the historic prevalence of the disease, the policy advocacy team identified some recurring concerns that are of interest for the EU bodies and Member States to fill-in the existing policy gaps: the changing epidemiology of these diseases that is due to past and recent migration; the limited number of disease-specific registries; the absence of screening policies across Member States; the limited access of patients to appropriate multidisciplinary care; the social isolation of patients to the detriment of their mental health; the rights of patients that are at stake.</p> <p>The Policy Recommendation paper was subsequently summarised in succinct Charters of Priorities, tailored for the needs of each THALIA country of priority (i.e. Austria, France, Germany, Sweden) to be used as an advocacy tool by patient associations (See THALIA2020 Periodic Report).</p> <p>The late completion of the Policy Recommendation in December 2020, moved its dissemination to 2021. The paper was distributed via online activities (v. TIF website – available here and email to over 80 addresses). Recipients of the elaborate dissemination plan included the European Commissioner for Health, members of the European Health and Digital Executive Agency (HaDEA), H.E. Mr David Maria Sassoli, President of the</p>	

European Parliament, the EU Ministers of Health, and the following TIF Member Associations in Europe: Association Belge De Thalassemie (ASBL), Association Francaise De Lutte Contre Les Thalassaemies (AFLT), Federazione Des Associations De Malades Drepanocytaires Et Thalassemiques, Seltene Anaemien Deutschland (Sam) Interessengemeinschaft Sichelzellkrankheit Und Thalassaemie E.V. (IST E.V.), Thalassaemie Verein Ulm E.V., Syllogos Pashonton Apo Mesogeiki Anaimia Nomou Korinthias, Greek Thalassaemia Association, Sickle Cell And Thalassaemia Ireland, Associazione Lotta Alla Talassemia Di Ferrara, Associazione Thalassemici Di Torino Onlus, Thalassaemia Awareness Maltese Association (TAMA), Oscar Nederland, Associacao Portuguesa De Pais E Doentes Com Hemoglobinopatias, Alheta (Asociacion Espanola De Lucha Contra Las Hemoglobinopatias Y Talasemias), The Swedish Blood Cancer Association, Bulgarian Anti-Thalassaemic Organisation (Bata) – Sofia, Thalassaemics' Organization In Bulgaria, Cyprus Thalassaemia Association, Greek Thalassaemia Federation (EOTHA), Associazione Ligure Thalassemici Onlus (ALT), Associazione Veneta Per La Lotta Alla Talassemia (AVLT), Fondazione Italiana "L. Giambrone" Per La Guarigione Dalla Talassemia, United Onlus, Asociatia Persoanelor Cu Talasemie Majora, The Recommendation was also sent to members of the Thalassaemia Patient Advocacy Group (PAG) (see WP2).

Moreover the translation of the National Charters of Priorities for France, Germany, Austria and Sweden to FR, DE, SWE respectively was completed in M9.

**RESULTS
ACHIEVED**

- Dissemination of Policy Recommendation for Thalassaemia in Europe
- Translation of National Charters of Priorities for France, Germany, Austria and Sweden to overcome linguistic barriers.

IMPACT ASSESSMENT

Methodology (*The Impact Model*)

TIF's Impact Model serves to compile a complete set of questions which, when answered, allows a conclusive and comprehensive impact assessment of the annual activities. Did the activities fulfil the expectation of the THALIA stakeholders? What were the main outputs of THALIA? What effects did THALIA produce, directly and on the long term? These are examples of questions the impact assessment intends to answer. The Impact Model is focusing on the evaluation strand of the Logic Model.

In order to take the whole process of THALIA into account, TIF's Impact Model is structured according to four main stages: (1) inputs, (2) outputs, (3) outcomes and (4) impacts. The first stage (1) consider aspects that can be evaluated before or at the beginning of THALIA, whereas the three others stages (2-4) consider aspects that can be measured conclusively only after the programme has been finished. All have been analysed in the respective THALIA proposal and have been linked to specific indicators. More specifically:

1. Inputs: Inputs include not only financial means but also human resources, equipment, knowledge and ideas.
2. Outputs: Outputs represent the direct results of the activities realised.
3. Outcomes: Outcomes are defined as the effects of the outputs on the target audiences. Outputs may benefit in terms of increased knowledge, improved networking and cooperation skills or access to new markets.
4. Impacts: Impacts are the wider effects of TIF's THALIA activities. These are defined as the benefits for the immediate target audience and users of the outputs. The benefits for the society at large are called relative impacts.

To assess impact, it is important to have a set of basic criteria and compare them against the indicators set in the THALIA annual plan:

	CRITERIA	KEY QUESTIONS
1	RELEVANCE	Are the "general objective" and "specific objectives" still meaningful?
2	EFFECTIVENESS	Has the objective been achieved? How much contribution did the "outputs" make?
3	EFFICIENCY	To what extent have "inputs" been converted to "outputs"?
4	IMPACT	What positive or negative, direct or indirect effects have happened?
5	SUSTAINABILITY	To what extent will TIF be able to maintain the positive results of its activities?



Criteria	Relevance	Effectiveness	Efficiency	Impact	Sustainability
Tasks	<i>Are the “general objective” and “specific objectives” still meaningful?</i>	<i>Has the objective been achieved? How much contribution did the “outputs” make?</i>	<i>To what extent have “inputs” been converted to “outputs”?</i>	<i>What positive or negative, direct or indirect effects have happened?</i>	<i>To what extent will TIF be able to maintain the positive results of its activities?</i>
T.4.1: Establishment of national associations in France, Germany, Austria, Sweden and Serbia	Establishing national associations or networks of thalassaemia patients is key to support EU countries with no tradition in the prevention and management of thalassaemia.	Follow up delegation visits (conducted virtually on account of the COVID-19 pandemic) to the priority countries (FR, DE, AUS & SWE) allowed TIF to build on partnerships with local thalassaemia-related stakeholders created in 2018 – 20, and to further enrich TIF’s knowledge on the wide and deep implications of thalassaemia in the migrant communities of these countries. This enabled TIF to further encourage patients to join forces and take action to safeguard of their right to health and quality of life in addition to creating avenues for their psychological support and breaking social isolation and marginalisation.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners, contacts.	THALIA2021 further allowed patients to come together, develop synergies with doctors and participate in disease-specific policy dialogue. The very presence of TIF in all countries reactivated local communities and showed the way forward to more inclusive societies.	To maintain results and the momentum created, follow-up visits in each country were and regular communication with all stakeholders and local contacts will be continued so as to solidify partnerships and the new associations established as a result of the THALIA programme (v. Austria and Sweden). More targeted efforts in collaboration with local health authorities are needed to achieve greater results in Serbia.
T4.2: TIF EU Thalassaemia Associations’ Twinning Programme	This task is directly related to the general objective and serves to facilitate the exchange of best practices between national thalassaemia associations. The Twinning Programme is a promising tool to bring patients of Europe together and bridge the knowledge gaps between associations.	The specific objective was not achieved as the patient community in Serbia remains elusive.	Despite the programme not running in 2021, efforts were made towards its development and hence the “inputs” required for the implementation of this task were optimally used, namely: staff time, financial means, knowledge base, technology, partners.	N/A	Patients were invited to participate in all 2021 workshops organised by TIF. Associations were encouraged to maintain communication and also join TIF’s Thalassaemia Patient Connect platform in addition to completing the Thal e-course, thus ensuring their access to quality information.

<p>T4.3: Thalassaemia EU Electronic Health Record</p>	<p>This tool is essential for evidence-based policy making and is considered to be the best way to monitor the spread of thalassaemia and haemoglobinopathies in Europe.</p>	<p>The Electronic Health Record was promoted via a peer-reviewed article and discussions for licensing and deployment were continued with already interested clinics and initiated with new ones. The added-value of the Health Record transpired via specially developed Country Profiles.</p>	<p>The “inputs” required for the implementation of this task were used as best as possible, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.</p> <p>Impact of COVID-19 pushed timelines back as priorities of hospital administrations focused elsewhere.</p>	<p>A number of clinics from Cyprus & Austria have expressed their interest in using this tool and continued discussions in 2021.</p> <p>Clinics from Sweden, Germany and Greece have indicated that they will be open to continue the discussion once health priorities have been adjusted at the national level.</p>	<p>TIF will be sharing news on the tool’s development progress to increase visibility.</p>
<p>T4.4: Policy Recommendation and position paper on Thalassaemia in Europe</p>	<p>This document is essential for the European Commission and Member States to recognise the existing policy gaps and address them through targeted measures.</p>	<p>This activity was postponed in 2020, and implementation was carried out in 2021 for this key advocacy document that was been distributed widely to EU Commission, Parliament and National Health Authorities to raise awareness and promote the development of disease-specific policies for thalassaemia.</p>	<p>The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners.</p>	<p>Increased interest of policy-makers on public health issues pertaining to the migration of thalassaemia.</p>	<p>The simultaneous bottom up (with patients) and top down (with decision-makers) approach of TIF has resulted in successful policy changes throughout the years. The maintenance of this continual momentum with both stakeholders is the key.</p>

