



## PROGRESS OUTLINE 2018



Co-funded by  
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### PILLAR 2: AWARENESS RAISING



*Activities*

*Impact*

*Lessons Learned*

## TABLE OF CONTENTS

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EXECUTIVE SUMMARY .....	2
INTRODUCTION.....	3
MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT .....	4
OVERVIEW OF ACTIVITIES (PILLAR 2 – WP 3).....	5
IMPACT ASSESSMENT.....	14
LESSONS LEARNED.....	17

## EXECUTIVE SUMMARY

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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. Awareness raising is a key component in the work of TIF, as it supports the work of all pillars and builds online and offline communities directly or indirectly related to thalassaemia.

Raising awareness on the needs of people with thalassaemia and haemoglobinopathies, as well as TIF's work in the field is a multi-faceted challenge that necessitates an array of tools. For 2018, TIF drafted its annual dissemination and awareness plan to set the annual objectives, activities and corresponding milestones. TIF website was translated into the five languages of priority (T.3.2) to allow access to information to target audiences in Europe. The annual thalassaemia video challenge (T3.3.) welcomed 10 entries from EU countries, while more patients from Europe joined the Thalassaemia Patients Connect platform (T.3.4) to discuss all issues pertaining to their disease, seeking peer support. Moreover, a set of specifications were identified regarding the development of the THALIA Mobile App (T3.5), while the pocket guide for healthcare professionals was drafted, printed and disseminated in the majority of countries across Europe (T3.6).

These EU-focused activities increased the visibility and outreach of TIF activities in Europe, informing all target audiences about thalassaemia, sickle-cell disease, the migration of thalassaemia in Europe and TIF's work in general.

## INTRODUCTION

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### 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 204 members from 62 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](http://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 Europe. 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.

## MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT

### General objective

**II.0.** Raise awareness on Thalassaemia and the importance of optimal care among the public at large, as well as among THALIA target groups, namely carriers and patients with Thalassaemia, healthcare professionals in the fields of Haematology and Paediatrics and policymakers at national and European level and promote relevant activities amongst national associations.

Task No	T3.1	T3.2	T3.3	T3.4	T3.5	T3.6
<b>Target Audience</b>	TIF Staff	Patients & HCPs & General Public	Patients	Patients	Patients	HCPs
<b>KPI Met</b>	✓	✓	✓	✓	✓	✓
<b>Justification</b>	✓	✓	✓	✓	✓	✓

### Specific objectives

**II.1.** Ensure that all stakeholders are aware of TIF initiatives, publications, news and events.

**Activity: T3.2:** Translation of TIF Website

**Results:** The website was translated in French, German, Italian, Greek and Arabic.

**Impact:** KPI met - The TIF website was visited by a total of 5,483 unique EU-based visitors in 2018, with an average bounce rate (53.33%) and 3.17 pages visited per session. This corresponds to 18.49% of the total number of website visitors (29,537). The bounce rate is lower than in other regions of the world (global average 57.83%) and the number of pages higher (global average 2.89).

**Impact Management / Mitigation Measures:** Even if there is an obvious interest for thalassaemia and the work of TIF in EU countries, greater effort will be put to increase traffic towards website. The different language versions will be further promoted in 2019.

**II.2.** Raise awareness among the general public.

**Activity: T3.3:** Thalassaemia Video Challenge

**Results:** 10 entries from EU Member States – Participation was lower than anticipated because of language barriers and due to the patients' fear of social stigmatisation and hesitation to share their personal stories and shed light onto the needs, problems and challenges of their respective thalassaemia communities.

**Impact:** KPI not met – Only 10% of the anticipated number of videos were collected and these were not used for awareness raising campaigns due to GDPR issues.

**Impact Management / Mitigation Measures:** The consent of video producers has been sought to be able to edit and utilise the TVC videos in 2019.

**II.3.** Strengthen the connection and facilitate communication between patients and their social environment, including caregivers.

**Activity: T3.4:** Thalassaemia Patients Connect & **T3.5:** THALIA Mobile App

**Results:** The design of the Mobile App has started and its development will commence in 2019.

**Impact:** KPIs met – More than 100 EU-based patients joined the Thalassaemia Patients Connect platform, TIF's peer support tool, developed to facilitate communication between patients. The THALIA Mobile App has been designed and indicators of success set will be met in 2019.

**Impact Management / Mitigation Measures:** TIF will further promote its social communication channels to reach out to patients living in remote areas of Europe and especially refugees and migrants. The THALIA Mobile App, once developed, is expected to bring patients closer and fight the social isolation of patients.

**II.4.** Ensure healthcare professionals have immediate access to key information on the clinical management of Thalassaemia.

**Activity: T3.6:** Pocket Guide for Healthcare Professionals

**Results:** As a much needed publication on thalassaemia, the pocket guide was printed twice and distributed across Europe in 1,258 copies. It was also uploaded on TIF's website to ensure access to larger international audiences.

**Impact:** KPI met – The number of copies distributed exceeded expectations, as demand is increasing in Europe.

**Impact Management / Mitigation Measures:** As a key publication in high demand among healthcare professionals, distribution will continue in the years to come to reach even the most remote clinics that treat patients with thalassaemia.

## OVERVIEW OF ACTIVITIES (PILLAR 2 – WP 3)

TASK	<b>T3.1: Dissemination and awareness plan</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Educational Scientist, Dr Victoria Antoniadou (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	N/A
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Creation of annual dissemination and awareness plan for 2018: January 2018</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>A Dissemination and Awareness Plan was developed in January 2018 as a step-wise guide for the Task Team to ensure that all activities undertaken within Work Package 3 (Awareness Raising) and Work Package 6 (Dissemination of Results) are effectively distributed ensuring to all stakeholder groups (i.e. patients/parents, healthcare professionals, policymakers and the general public). The Plan would cover actions throughout 2018 and will be updated on an annual basis.</p> <p>In 2018, the Task Team focused on the following dissemination activities (further explanation provided in the corresponding Annual Progress Outlines of Work Package 3 and 6 respectively):</p> <ol style="list-style-type: none"> <li>1) The creation of the THALIA webpage integrated in TIF's website to publish and make freely available all THALIA project results and to ensure that THALIA objectives and outcomes are disseminated in all EU Member States.</li> </ol>	

- 2) Regular Social Media posting on delegation visits and all THALIA activities.
- 3) The organisation of 2 press conferences to communicate to the public the THALIA project, and to present and disseminate work programme results.
- 4) Publications of press articles to spread expert knowledge on thalassaemia worldwide.
- 5) Email blasts to inform target groups about the project's advances under the THALIA signature.

The Task Team developed and implemented the Annual Dissemination and Awareness Plan, ensuring visibility and awareness across all stakeholder groups. This entailed close monitoring of THALIA activities and their completion, messages and results. Together with other members of TIF Staff, the Task Team was active in the distribution of activities and news both relating to THALIA activities but generally about migration and thalassaemia in Europe.

**RESULTS  
ACHIEVED**

- Increased awareness amongst EU population about thalassaemia and THALIA.
- Steady increase of EU-based followers on TIF social media channels.
- More involvement and engagement of EU-based patients and healthcare professionals in TIF's activities in Europe.
- Establishment of collaboration with media outlets throughout Europe for subsequent publications in accordance to their specific guidelines.
- Information sharing on the relationship between migration, thalassaemia and implications for national health systems in Europe.
- Networking with migration agencies (UNHCR and IOM) for development of partnerships for implementing and disseminating THALIA activities across Europe.
- Dissemination of THALIA 2018 results to a broad audience.

<b>TASK</b>	<b>T3.2: Translation of TIF Website</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Educational Scientist, Dr Victoria Antoniadou (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>

<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Translation of TIF Website in 5 languages (FR, DE, GR, IT &amp; AR) (MS8).</li> <li>▪ Number of EU - based visitors: 5,000</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ol style="list-style-type: none"> <li>1. Translation of TIF Website in 5 languages (FR, DE, GR, IT &amp; AR): July – November 2018</li> </ol>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The website of the Thalassaemia International Federation (<a href="http://www.thalassaemia.org.cy">www.thalassaemia.org.cy</a>) constitutes a comprehensive amalgamation of information about thalassaemia (including medical, social and research news), as well as the activities of the Federation. The website content has been developed to serve the needs of three main stakeholder groups (i) patients with thalassaemia and their associations, (ii) healthcare professionals and (iii) supporters of the thalassaemia community (including but not limited to other umbrella patient associations, industry, research consortia etc).</p> <p>In 2018 the website was translated from English to five (5) languages, namely French, German, Greek, Italian and Arabic (MS8) as a means to increase the accessibility of information about thalassaemia amongst patients, parents and carriers, who form part of the newly emerging migrant communities, and healthcare professionals, across Europe. The selection of languages was based on the estimated number of patients, parents, carriers and healthcare professionals in the field of thalassaemia who speak each language in Europe.</p> <p>It is noted that thalassaemia is found in the indigenous populations of Greece and Italy<sup>1</sup>, where only approx. 34% of the population speak one additional language to their mother tongue<sup>2</sup>, hence requiring educational and informational tools to be developed in their native language. In addition, the migration influx of recent years has shown that the main recipients of these populations have been France, Germany and Sweden<sup>3</sup>, especially from Arabic-speaking countries. Hence, migrants are more likely to be able to communicate in the language of the host country, over English, in addition to their native language.</p> <p>These social and linguistic considerations, as well as profiling of our target audience has been pivotal in the efforts to overcome linguistic barriers and challenges and make quality information more accessible and equally available across the EU, free from language bias, thus reaching a larger audience and number of visitors contributing to raising awareness in the EU about thalassaemia.</p>	

<sup>1</sup> LI C-K, New trend in the epidemiology of thalassaemia, Best Practice & Research Clinical Obstetrics & Gynaecology (2016), doi: 10.1016/j.bpobgyn.2016.10.013

<sup>2</sup> <https://www.euronews.com/2018/09/26/european-language-day-which-country-speaks-the-most-foreign-languages-euronews-answers>

<sup>3</sup> The UN Refugee Agency – UNHRC, *Europe Keydata 2017*, Most common receiving EU countries, 2 March 2018, [data2.unhrc.org/en/situations/mediterranean](http://data2.unhrc.org/en/situations/mediterranean). See also *ibid.* Europe Keydata Q1-2018, 11 May 2018. Also: Migration Data Portal, [https://migrationdataportal.org/data?i=stock\\_abs\\_&t=2017&m=1&rm49=150](https://migrationdataportal.org/data?i=stock_abs_&t=2017&m=1&rm49=150)

The TIF website was visited by a total of 5,483 visitors in 2018, with an average bounce rate (53.33%) and 3.17 pages visited per session.

The website can be accessed at the following links:

Italian: <http://thalassaemia.org.cy/it/>

German: <http://thalassaemia.org.cy/de/>

Greek: <http://thalassaemia.org.cy/el/>

French: <http://thalassaemia.org.cy/fr/>

Arabic: <http://thalassaemia.org.cy/ar/>

#### RESULTS ACHIEVED

- Increase in awareness about thalassaemia across migrant communities in the EU.
- Improvement of accessibility and availability of information about thalassaemia.
- Reduction of language bias, by making information available in other languages other than English.
- Increase in Europe based visitors to TIF website.

TASK	<b>T3.3: Thalassaemia Video Challenge</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Educational Scientist, Dr Victoria Antoniadou (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Number of EU-based submissions: 100</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Announcement of Thalassaemia Video Challenge: March 2018</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The annual Thalassaemia Video Challenge established by TIF aims to enable the sharing of personal stories by patients, parents and other persons who are associated in one way or another with thalassaemia (i.e. family members, healthcare professionals etc). The videos are collected by TIF, adhering to the relevant GDPR legislation, and posted online where they can act as means to raise awareness amongst the general public about thalassaemia, provide inspiration to others in similar situations, give comfort that one is not alone in dealing with challenges (health or socially related) which may occur. The Thalassaemia Video Challenge is launched each year as part of the International Thalassaemia Day activities of TIF, since 2014.</p> <p>In 2018, the Thalassaemia Video Challenge was launched in May across TIF's social media channels  <a href="https://www.facebook.com/tif.thalassaemia/photos/a.457482921000980/1808759332539992/?type=3&amp;theater">https://www.facebook.com/tif.thalassaemia/photos/a.457482921000980/1808759332539992/?type=3&amp;theater</a>.</p>	

A second call was announced in August at <https://www.facebook.com/tif.thalassaemia/photos/p.1973637456052178/1973637456052178/?type=1&theater>

Moreover, an additional call with the following theme “How does thalassaemia affect your everyday activities and what special arrangements do you need to make?” was announced in October at <https://www.facebook.com/tif.thalassaemia/posts/2033033256779264>

The theme was chosen amongst a wide selection put forward by the Task Team to the International Selection Committee which comprised of members of TIF’s Board of Directors, Expert Patients and medical collaborators. It was designed to encourage patients to share their experiences about the multifarious aspects of thalassaemia, including migration with the ultimate aim to raise awareness about these topics in the general public.

A total of 10 videos from EU-based persons were submitted in 2018.

**RESULTS ACHIEVED**

- Launching of targeted Thalassaemia Video Challenge to European audience for the first time.

TASK	<b>T3.4: Thalassaemia Patients Connect</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Educational Scientist, Dr Victoria Antoniadou (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	Number of EU-based followers on TPC: 100
<b>CALENDAR OF ACTIVITIES</b>	N/A

## DESCRIPTION OF THE ACTIVITY

The Thalassaemia Patients Connect (TPC) is a platform of online communication tools that provides the opportunity for patients and parents to interact, ask for and share information on thalassaemia. Members of the Expert Patients Core Group and International Scientific Advisory Panel respond immediately to queries posed, whilst simultaneously ensuring adherence to guidance provided in the TIF Guidelines<sup>4</sup>, authored by international experts in the field of thalassaemia with long-term experience in the prevention and clinical management of the disease and TIF's policies and positions<sup>5</sup>.

The Platform includes the following tools:

Platform Website: <http://thalassaemiapatientconnect.weebly.com/>

Discussion Board: <http://thalassaemia-connect.proboards.com/>

Facebook Page: <https://www.facebook.com/thalassaemiapatientconnect/>

Facebook Group: <https://www.facebook.com/groups/ThalassaemiaPatientsConnect/>

Twitter: <https://twitter.com/ThalassaemiaTPC?lang=en>

WhatsApp chat group: Thalassaemia Connect

YouTube Channel: [https://www.youtube.com/channel/UC8X5lbdFTmD3ddss4Y\\_oKA](https://www.youtube.com/channel/UC8X5lbdFTmD3ddss4Y_oKA)

The social media tools (mainly Facebook and Twitter) are updated daily with a variety of educational and awareness raising content for thalassaemia patients, including blood safety, stem cell therapy, Thalassaemia epidemiology, clinical trial updates etc. Each post reaches an average of 140 persons in Europe, with the majority being located in Cyprus, Greece, United Kingdom, Italy, Netherlands, and Ireland, Belgium, Spain, France and Germany.

In addition, participants in the WhatsApp Group and Discussion Board are able to ask medical questions about a large scope of thalassaemia-related topics. These are responded to by a network of volunteer experts (patients and healthcare professionals) in order to ensure accuracy of the information given to the patients and consequently patients' safety.

All precautions are taken to ensure compliance to the new GDPR regulation.

The network of experts is currently made up of the following persons, with continuous additions:

<sup>4</sup> Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3<sup>rd</sup> Edition), 2014. Available at <https://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-management-of-transfusion-dependent-thalassaemia-3rd-edition-2014/> / Guidelines for the Management of Non-Transfusion Dependent Thalassaemias (2<sup>nd</sup> Edition), 2017. Available at <https://thalassaemia.org.cy/publications/tif-publications/guidelines-for-the-clinical-management-of-non-transfusion-dependent-thalassaemias-updated-version/> / Prevention of Thalassaemias and other Haemoglobin Disorders, Vol 1 (2<sup>nd</sup> Edition), 2013 Available at <https://thalassaemia.org.cy/publications/tif-publications/prevention-of-thalassaemias-and-other-haemoglobin-disorders-vol-1-2nd-edition-2013/> / Prevention of Thalassaemias and Other Haemoglobin Disorders, Vol. 2: Laboratory Protocols (2<sup>nd</sup> Edition), 2012. Available at <https://thalassaemia.org.cy/publications/tif-publications/prevention-of-thalassaemias-and-other-haemoglobin-disorders-vol-2-laboratory-protocols-2012/> / Emergency Management of Thalassaemia, 2012. Available at <https://thalassaemia.org.cy/publications/tif-publications/emergency-management-of-thalassaemia-2012/>

<sup>5</sup> <https://thalassaemia.org.cy/download/tifs-positions-in-a-nutshell/>

- Dr Michael Angastiniotis (TIF Medical Advisor - Cyprus)
- Dr Dimitrios Farmakis (TIF collaborator - Greece)
- Dr Mahammad Farnouch (TIF collaborator - Iran)
- Dr George Kaltsounis (TIF Collaborator – Greece)
- Dr Perla Eleftheriou (TIF Collaborator – UK)
- Dr Antonio Piga (TIF Collaborator – Italy)
- Dr M. Naveed (TIF Collaborator – UAE)
- Mr Anton Skafi (TIF Board Member – Expert Patient - Palestine)
- Mr Ahmet Varoglu (TIF Collaborator - Expert Patient – Cyprus)
- Mr Angelo Loris Brunetta (TIF Board Member – Expert Patient - Italy)
- Mrs Maria Hadjidemetriou (TIF Collaborator - Expert Patient – USA)
- Ayesha Mehmood (TIF Collaborator - Expert Patient – Pakistan)
- Riyadh Elbard (TIF Board Member – Expert Patient - Canada)
- Madan Chawla (TIF Collaborator - Expert Patient – India)

The main achievements of TPC to date are: a) the creation in 2017 for the first time of a highly responsive platform of tools where patients and parents can receive quality, evidence-based, accurate information to their queries; b) constituting the main feature of the International Thalassaemia Day 2017 campaign, under the theme ‘Get Connected’ (<https://thalassaemia.org.cy/international-thalassaemia-day/international-thalassaemia-day-2017-2/>); c) Building and expanding the network of experts (both patients and healthcare professionals) who are involved in TPC and provide information to requests.

In 2018, the network of experts supporting the TPC platform tools was expanded (from 3 expert patients in January to 7 in December, and 3 expert healthcare professionals in January to 7 in December).

Visitors/followers increased steadily throughout 2018 from EU countries, meeting the indicators set (100 EU-based followers), across the following TPC channels which have shown to be the most popular:

	<b>January 2018</b>	<b>December 2018</b>	<b># of European followers in December 2018</b>
Facebook Page:	450	800	129
Facebook Group:	600	950	95
WhatsApp chat group:	56	170	42

<b>RESULTS ACHIEVED</b>	<ul style="list-style-type: none"> <li>▪ Increase in awareness about thalassaemia across migrant communities in the EU.</li> <li>▪ Facilitation of interaction with expert healthcare professionals for medical queries.</li> <li>▪ Increase in Europe based visitors to TPC Platform tools.</li> </ul>
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<b>TASK</b>	<b>T3.5: THALIA Mobile App</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Educational Scientist, Dr Victoria Antoniadou (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	Number of EU-based users: 100
<b>CALENDAR OF ACTIVITIES</b>	Finalize specifications and obtain quotes for development (MS9): August 2018
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The THALIA mobile app (entitled 'Thal-Pal') aims provide thalassaemia patients with a virtual assistant, based on thalassaemia specific patient reported outcomes, helping them with the management of their disease on a daily basis, providing them with medical information, encouraging their adherence to treatment, socialisation and informing them about their rights.</p>	
<b>RESULTS ACHIEVED</b>	<ul style="list-style-type: none"> <li>▪ Receipt of one (1) complete and detailed quotation for the development of the THALIA Mobile App.</li> </ul>

<b>TASK</b>	<b>T3.6: Pocket Guide for Healthcare Professionals</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b> Medical Advisor, Dr Michael Angastiniotis (Leader)</p> <p><b>Supervising Staff:</b> Executive Director, Dr Androulla Eleftheriou</p>
<b>INDICATORS</b>	<ul style="list-style-type: none"> <li>▪ Number of copies distributed to countries of priority (i.e. France, Germany, Sweden, Austria &amp; Serbia): 1,000</li> <li>▪ Number of copies distributed to other European countries: 280</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Dissemination: January – December 2018</li> <li>▪ Online publication on TIF Website: February 2018</li> <li>▪ Re-printing: November 2018</li> </ul>

## DESCRIPTION OF THE ACTIVITY

A Pocket Guide for the Management of Transfusion Dependent Thalassaemia was drafted at the end of 2017, based on the 'Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3<sup>rd</sup> Edition)', authored by international experts in the field of thalassaemia.

The Pocket Guide addressed for healthcare professionals working in the field of thalassaemia (especially haematologists, paediatricians, paediatric haematologists etc) is meant to serve as an easy-to-carry pocket reference for physicians in their daily consultations, with prompts to revisit the long version of the Guidelines for additional facts and a thorough review of the evidence supporting each recommendation included in this manuscript.

Through the Pocket Guide, clinicians have access to quality, evidence based information to help them in their efforts to provide the best possible care for the management of thalassaemia, a chronic disease that becomes more complex as the patient grows in years.

In 2018, the Pocket Guide was designed and printed twice in order to meet distribution expectations. Moreover, the Pocket Guide was made available on TIF's website to facilitate access of healthcare professionals. TIF distributed 1,308 copies across Europe in 2018.

### RESULTS ACHIEVED

- Provision of Pocket Guide to treating doctors in THALIA priority countries.
- Increased knowledge of appropriate treatment protocols for thalassaemia patients.
- Improvement of knowledge about thalassaemia as a rare disease amongst the medical community in THALIA priority countries, with a large migrant community.

## IMPACT ASSESSMENT

### Methodology (*The Impact Model*)

TIF's Impact Model serves to compile a complete set of questions which, when answered, allow 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 THALIA2018 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?

<b>Criteria</b>	<b>Relevance</b> <i>Are the "general objective" and "specific objectives" still meaningful?</i>	<b>Effectiveness</b> <i>Has the objective been achieved? How much contribution did the "outputs" make?</i>	<b>Efficiency</b> <i>To what extent have "inputs" been converted to "outputs"?</i>	<b>Impact</b> <i>What positive or negative, direct or indirect effects have happened?</i>	<b>Sustainability</b> <i>To what extent will TIF be able to maintain the positive results of its activities?</i>
<b>Tasks</b>					
<b>T3.1: Dissemination and awareness plan</b>	This plan is considered a key internal coordination tool to achieve the general and specific objectives.	The plan was fully implemented in 2018.	The awareness raising activities increased interest in Europe regarding thalassaemia and haemoglobinopathies.	Smooth internal communication resulted to efficient external communication – key messages were successfully conveyed.	This is an annual deliverable and key coordination tool, indispensable for any communication strategy.
<b>T3.2: Translation of TIF website</b>	Overcoming language barriers is necessary to ensure that all stakeholders have access to knowledge.	The launch of a multi-lingual website allowed EU populations to get informed about TIF's work, thalassaemia and the migration of thalassaemia.	There was increased traffic from EU countries to TIF website, since the several language versions were launched.	Outreach was expanded to a greater number of people; TIF established its online presence and increased the impact of its work.	As multilingualism is a major challenge in Europe, TIF will continue translating content either with available resources or with the help of volunteer translators/Translators without Borders.
<b>T3.3: Thalassaemia Video Challenge</b>	This annual activity brings out the personal stories of patients and it is a proven way of communicating messages across the general public.	N/A	N/A	N/A	Surpassing data protection issues will allow TIF to utilise this powerful tool and raise awareness about the needs of patients among the general public.
<b>T3.4: Thalassaemia Patients Connect</b>	This is TIF's peer support tool to combat social isolation and bring patients together, providing them with the opportunity to discuss issues and have a sense of belonging.	The focus of TIF on Europe caused an increase in the number of EU-based subscribers and followers; this facilitated the communication of TIF with grass roots and	TPC allowed TIF to reach EU-based patients in urban, rural and remote areas, empowering them to be more active and stand for their needs.	As social isolation is a key issue for patients in Europe, TPC allows them to feel part of a larger community. The increase of the number of EU-based patients highlighted the problem of	TIF will need to consider ways of surpassing language-related issues and work towards making TPC more inclusive. Integrating an automatic translation tool to the platform in

		highlighted the need of EU patients to know more about their disease and peers.		multilingualism, as TPC is only available in English. Patients could not participate in conversations and hesitated to express themselves because of language barriers.	2019 could ease communication in the years to come.
<b>T3.5: THALIA Mobile App</b>	A Mobile App easing the daily life of patients and bringing them closer to each other and the community is essential to strengthen connection and facilitate communication.	N/A	N/A	N/A	In 2018 the Mobile App was designed. Its development in 2019 is expected to support TIF efforts to address the social isolation of EU-based patients.
<b>T3.6: Pocket Guide for Healthcare Professionals</b>	This is a key publication to raise awareness on thalassaemia management and care among healthcare professionals.	Its size makes it easy to use and immediately accessible, thus highly effective.	Resources were utilised in the best possible way and allowed the publication of a highly useful guide.	In 2018, there was a very high demand for this specific tool, as healthcare professionals felt the need to know more about the management of transfusion-dependent thalassaemia, a disease new to their clinics. This has most probably resulted to better quality of services provided to patients (to be assessed in 2019)	Further dissemination is needed to reach all healthcare professionals in Europe treating patients with thalassaemia and other haemoglobinopathies. Moreover, this is a tool to be shared with NGOs that directly come in contact with migrants and refugees (e.g. Doctors without Borders).

## LESSONS LEARNED

TIF's awareness-raising activities in 2018:

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> <li>▪ reached all target audiences;</li> <li>▪ ignited interest on the migration of thalassaemia and other haemoglobinopathies to Europe;</li> <li>▪ strengthened TIF's capacity to reach linguistically diversified audiences;</li> <li>▪ proved that patients in Europe feel the need to share their stories and make their voices heard;</li> <li>▪ allowed EU-based patients to join a global peer support community;</li> <li>▪ set the ground for more effective targeted communication between patients and their caregivers;</li> <li>▪ provided healthcare professionals with a useful informational and educational tool;</li> <li>▪ brought thalassaemia to the forefront.</li> </ul>	<ul style="list-style-type: none"> <li>▪ were not qualitatively assessed, due to time limitations;</li> <li>▪ were delayed by issues pertaining to the protection of personal data and intellectual property rights;</li> <li>▪ stressed the need for a more intensive effort to translate content into as many EU languages as possible.</li> </ul>
OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> <li>▪ Lack of awareness provides TIF with the opportunity to improve its communication methods to reach as many people as possible;</li> <li>▪ Multilingualism in Europe is an opportunity to create new language versions and further ease access to knowledge and education among patients, healthcare professionals and the general public;</li> <li>▪ The limited but existing interest of patients to share their stories is an opportunity to strengthen their voices at the policy making level;</li> <li>▪ THALIA2018 gave rise to the problem of social isolation of patients and stressed the need to invest on social networking and communication;</li> <li>▪ The creation of a short guide proved that target audiences are in need of brief effective communication; this provides TIF with the opportunity to further grow and improve its awareness raising tools.</li> </ul>	<ul style="list-style-type: none"> <li>▪ Language diversity in Europe remains a major threat, especially as regards to patients sharing their stories and participating in English-speaking platforms;</li> <li>▪ All material produced needs to stay updated, following latest advances – this requires more intensive efforts and close follow-up of new developments in the area of clinical research.</li> </ul>