



## PROGRESS OUTLINE 2020



Co-funded by the Health Programme of the European Union

### PILLAR 2: AWARENESS RAISING

*Activities*  
*Impact*

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## **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 2020, TIF drafted its annual dissemination and awareness plan to set the annual objectives, activities and corresponding milestones (T3.1). TIF website was visited by a significant number of visitors however the target for EU-based visitors was narrowly missed (T.3.2) despite a huge increase since 2019. Moreover, the THALIA Mobile App (T3.5) was officially launched in four languages (EN, DE, FR & GR), with the first users providing overwhelmingly positive feedback. The pocket guide for healthcare professionals was disseminated in the majority of countries across Europe (T3.6) despite disruptions in postal services.

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 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](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 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 nature of many of THALIA2020 activities include travel and physical interaction to better assess the community needs and deliver efficient educational and policy-making tools. Therefore, the surgent COVID-19 pandemic required a stringent vigilance throughout 2020 by the Internal Evaluation Committee (IEC) and TIF Board of Directors so as on the one hand to ensure the materialisation of activities, and on the other hand to ensure the safety of involved parties. Close monitoring by the IEC of the evolving epidemiological situation and the measures being taken across EU countries to further inform and revise the mitigation measures for each activity continued through the year, so as to identify new ways to fulfil the objective of the activity (e.g. virtual attendance) or to proceed as planned changing some features (e.g. selecting an alternative venue with the same profile characteristics), aiming to ensure the safety of participants (patients, healthcare professionals, policy-makers, TIF Staff and affiliates) at all times.

## 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 originating from migrant countries, 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	T3.5	T3.6
Target Audience	TIF Staff	Patients & HCPs & General Public	Patients	HCPs
KPI Met	✓	✗	✗	✓
Justification	✓	✓	✓	✓

### Specific objectives

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

**Activity: T3.2:** TIF Website – Structural & Content Updating and Upgrading

**Results:** The website was enriched with structural upgrades to improve functionality and user-friendliness, as well as content to reflect the interests of the thalassaemia community (v. COVID-19 guides).

**Impact:** KPI not met –The TIF website was visited by a total of 17,980 unique EU-based visitors in 2020. This corresponds to 26% of the total number of website visitors (69,154) representing a 123.2% increase of EU-based visitors from 2019.

**Impact Management / Mitigation Measures:** More concentrated efforts will be made in 2021 to divert visitors to TIF's website.

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

**Activity: T3.5:** THALIA Mobile App

**Results:** Completion of development, testing and translation culminated in the launching (although delayed) of the THALIA Mobile App for Android and iOS devices.

**Impact:** KPIs not met – Due to delays occurring as a result of the extenuating circumstances resulting from the COVID-19 pandemic, the THALIA Mobile App was not launched on time.

**Impact Management / Mitigation Measures:** The THALIA Mobile App will be broadly marketed across TIF's communication channels (website, social media, newsletters) as well as in face-to-face meetings and communication in order to meet the relevant KPI in 2021.

**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 distributed widely across Europe through a combined (offline / online) 2,121 copies.

**Impact:** KPI met – The number of copies distributed (2,121) surpassed the target KPI with the largest majority being e-copies, on account of postal disruptions due to COVID-19.

**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)

<b>TASK</b>	<b>T3.1: Dissemination and awareness plan</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>          Communications Officer, Aikaterini Skari (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 2020: January 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>A Dissemination and Awareness Plan was developed in January 2020 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 covered actions throughout 2020 and is updated on an annual basis.</p> <p>In 2020, 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) Continual updating 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> <li>2) Regular Social Media posting on all THALIA activities.</li> <li>3) Distribution of quarterly newsletters with THALIA activities to subscribers.</li> </ol> <p>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.</p>	
<b>RESULTS ACHIEVED</b>	<ul style="list-style-type: none"> <li>▪ Increased awareness amongst EU population about thalassaemia and THALIA.</li> <li>▪ Dissemination of THALIA2020 activities &amp; results to a broad audience.</li> <li>▪ Steady increase of EU-based followers on TIF website &amp; social media channels.</li> <li>▪ More involvement and engagement of EU-based patients and healthcare professionals in TIF's activities in Europe.</li> </ul>

TASK	<b>T3.2: TIF Website</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Communications Officer, Aikaterini Skari (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 visitors: 28,000</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Structural &amp; content upgrading: Jan – June 2020</li> <li>▪ COVID-19 webpage &amp; helpdesk: Apr 2020</li> <li>▪ Haemoglobin Disorders &amp; COVID-19 series of e-resources &amp; guides: Mar – Nov 2020</li> <li>▪ Sickle Cell Disease webpage: June 2020</li> <li>▪ Pyruvate Kinase Deficiency webpage: Sept 2020</li> </ul>
<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>The translation of the website in 2018 from English to five (5) languages, namely French, German, Greek, Italian and Arabic has increased 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. Moreover, seeking to increase the accessibility of information, in 2019 technical developments (v. PubMed RSS &amp; Twitter feed). This resulted in a growth of 33% in visitors compared to 2018. Furthermore, the e-glossary created for web-publishing and entitled 'Thalassaemia from A-Z' is comprehensive educational tool can be used by carriers, patients and parents as well as other interested stakeholders to gain a better understanding of complex medical terminology.</p>	
<p>In 2020, the TIF website continued to be updated on a weekly basis with news features thus remaining a source of reference for information relating to thalassaemia and TIF activities. Undergoing restructuring and redesigning, including content updating (M1 – M6) in an effort to facilitate navigation and become more user friendly, the TIF website became richer providing more comprehensive and updated information about thalassaemia, clinical trials, TIF activities, THALIA news and activities, and other topics of interest to the thalassaemia</p>	

community. The improved navigation experience, with a more intuitive and responsive web design, has added functionality and manageability and enhanced media support, thus offering visitors an enhanced experience. Responding to the needs and requests of the patient and medical communities for reliable information, the website has been broadened to include dedicated pages for [Sickle Cell Disease](#) and [Pyruvate Kinase Deficiency](#) (M5 – M6).

As the COVID-19 pandemic unfolded throughout Europe, the patient community across the Member States looked to TIF for advice and guidance, who responded with the development of a series of educational tools, resources and recommendations (see [here](#)) many of which constituted a compass for treating physicians and national health authorities as they announced measures to protect their populations against SARS-CoV-2. A dedicated [webpage](#) on TIF's website was created with a Helpdesk and Communication Line. During the height of the pandemic (M4 – M5), TIF's website saw an exponential growth, in both its users' traffic and sessions initiated by users, that exceeded 80%.

The TIF website was visited by a total of **69,154 visitors in 2020**, **68,628** were **new users**, **with an average bounce rate (63.05%)** and **2.21 pages visited per session**. Of these, 26% were from Europe, constituting 17,980 unique visitors from Europe.

TIF WEBSITE USER COMPARATIVE TABLE: 2019 & 2020			
	Jan–Dec 2020	Jan–Dec 2019	Change
<b>Users</b>	<b>69,154</b>	<b>43,742</b>	<b>↑ 58.1%</b>
<b>New Users</b>	<b>68,628</b>	<b>42,835</b>	<b>↑ 60.2%</b>
<b>Sessions</b>	<b>89,582</b>	<b>60,671</b>	<b>↑ 47.7%</b>
<b>Page Views</b>	<b>199,237</b>	<b>150,521</b>	<b>↑ 32.4%</b>
<b>Europe based Users</b>	<b>17,980</b>	<b>8,055</b>	<b>↑ 123.2%</b>

*Demographic data collection of EU visitors (December 2020)*

#### RESULTS ACHIEVED

- Increase in awareness about thalassaemia across migrant communities in the EU.
- Improvement of accessibility and availability of information about thalassaemia.
- Increase in Europe based visitors to TIF website.

TASK	<b>T3.5: THALIA Mobile App</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Communications Officer, Aikaterini Skari (Leader)            Policy Officer, Eleni Antoniou            Office Administration, Stella Eleftheriou</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 users: 200</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Mobile App Development: Jan – Sept 2020</li> <li>▪ Beta testing: Feb - Aug 2020</li> <li>▪ Translation: Oct – Nov 2020 (MS9)</li> <li>▪ Launch: Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The THALIA Mobile App aims to 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> <p>The main feature of the application is a calendar, tailored to the needs of people with haemoglobin disorders, that can be easily synchronized with the user’s personal calendar on his mobile phone. In it, users will be able to note everything related to the management and treatment of his disease, such as upcoming blood transfusions, doctor appointments and medication reminders, to score pain levels, as well as record and track other symptoms of the disease, for instance fatigue and mood swings.</p> <p>In addition, the THALIA App will enable patients to share, if they wish so, useful statistics for their health, such as haemoglobin and ferritin levels, the frequency of blood transfusions, etc., with their treating and supervising physicians, thus allowing them to form a comprehensive picture on the course of their patients’ disease management.</p> <p>Through the application, users will also have the opportunity to access a wealth of disease-specific information, learn interesting scientific news and discover the vast educational material and the publications of the Thalassaemia International Federation.</p> <p>The development of design specifications with feedback from the thalassaemia patients’ community in Europe as to their expectations and requirements was completed in 2018 in addition to initiating the search for experienced collaborators to undertake the development of the mobile application. Following two rounds of market research, finalization of app specifications and the validation of the patient – reported outcomes (PRO) tool in 2019, an experienced agency in mobile app development was selected.</p>	



The THALIA Mobile App consists of the following interface sections:

1. My Calendar
2. My Profile
3. Haemoglobin Disorders
4. Education
5. Get Involved *\*Including the PRO tool*
6. TIF
7. About THALIA
8. FAQs

In 2020, the THALIA Mobile App continued its development phase (M1 – M9), including testing (beta testing to a group of five expert patients and two healthcare professionals) and refinement (M2 – M9), and translated into two languages (DE, FR) (M10 – M11) (MS9) before official launching in M12 for Android and iOS devices. Delays experienced in development were due to the extenuating circumstances resulting from the COVID-19 pandemic in the first 6 months of 2020.

A total of 117 persons have downloaded the THALIA Mobile App since its launch in 30 countries.

**RESULTS  
ACHIEVED**

- Launching of THALIA Mobile App to the patient community in the EU.

<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)            Communications Officer, Aikaterini Skari            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 copies distributed across Europe: 1,000</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ EU-wide Dissemination (MS10): Jan – Dec 2020</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>The “<i>Pocket Guide for the Management of Transfusion Dependent Thalassaemia</i>” is an abridged, easy-to-carry pocket reference based on 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.</p> <p>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.</p> <p>Following two re-prints in 2018 to meet distribution expectations, the Pocket Guide was also made available on TIF’s website to facilitate access of healthcare professionals. Printed and electronic copies were distributed throughout 2019.</p> <p>In 2020, distribution has continued to healthcare professionals working in the field of thalassaemia in Europe, as well as TIF’s European network of associations and collaborators, National Health Authorities and other stakeholders who have requested copies. The Pocket Guide has been distributed to healthcare professionals based in Germany, Austria, France, Italy, Greece and Cyprus.</p> <p>The updating of the Clinical Guidelines for Transfusion-Dependent Thalassaemia (3<sup>rd</sup> edition) following the unanimous decision of the authors, international experts in the field of thalassaemia, members of TIF’s International Advisory Board and consultants to TIF’s Educational Programme, was halted in 2019 as a result of the continuing announcements of ground-breaking research which would have a bearing on the clinical management of the disease. Resuming work in early 2020, the 4<sup>th</sup> edition of the publication will reflect the regulatory approvals of advanced therapies and medicinal products (ATMP’s)<sup>1</sup> for patients with transfusion-dependent thalassaemia (TDT). The extenuating circumstances brought about by the COVID-19 pandemic has delayed completion of the publication, which is</p>	

<sup>1</sup> REBLOZYL® – first in class innovative medicinal product (EMA approval June 2020) ; ZYNTEGLO® – gene therapy (EMA approval June 2019)

expected to be finalized in Q1 of 2021. Consequently, the Pocket Guide will be updated and re-printed at that time.

TIF distributed 26 hard copies of the Pocket Guide across Europe in 2020 (MS10) **and 2,095 e-copies**. It is noted that the further distribution of the publication via traditional means (v. post) was not possible on account of postal restrictions imposed by the Cyprus Postal Service as a consequence of the COVID-19 pandemic<sup>2</sup>.

In addition, TIF placed 1 post on its Facebook social media pages, targeting specifically to encourage healthcare professionals to learn about the Pocket Guide, read it online and/or download it from the Federation's website.

The results are summarized below:

- (1) Facebook Post <https://www.facebook.com/tif.thalassaemia/posts/3823433721072533>  
(19/09/2020)  
5,958 People Reached – 1,201 Total Engagements

#### **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 amongst the medical community in THALIA priority countries.

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<sup>2</sup> <https://www.cypruspost.post/en/news-covid/3>

## IMPACT ASSESSMENT

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### 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 2020.	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: TIF website</b>	Continuous upgrades and updates, both structural and content, necessary to ensure that all stakeholders have fast and reliable access to knowledge while meeting erupting health crises.	The creation of topic-specific webpages enabled 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 upgrades were implemented and more COVID19-relevant content uploaded.	Outreach was expanded to a greater number of people; TIF established its online presence and increased the impact of its work.	The continual updating of information in English and the five other languages will be continued either with available resources or with the help of volunteer translators/Translators without Borders.
<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 – Activity Ongoing	N/A – Activity Ongoing	N/A – Activity Ongoing	N/A – Activity Ongoing
<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.	The continuous interest of healthcare professionals in Europe to be informed of the appropriate clinical management of thalassaemia indicates a surge in patients with this rare disorder, and the need for its effective management.	Upon updating (in accordance the 4 <sup>th</sup> edition of the TDT Guidelines) dissemination will continue – reaching many of the recipients of the previous version so they have the most up-to-date information.

