



## PROGRESS OUTLINE 2021



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### 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 2021, 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 meeting the target for EU-based visitors (T.3.2) demonstrating a huge increase since 2019. Moreover, the THALIA Mobile App (T3.5) was promoted and translated in an additional language (GR), with a steady user-base which unfortunately narrowly missed the target of EU-based users. The pocket guide for healthcare professionals (T3.6) continued to be disseminated while its contents have been updated to reflect the new edition of the Clinical Guidelines for Transfusion Dependent Thalassaemia.

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 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

**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 – Translations and New Features

**Results:** The website was enriched with the application of structural upgrades to additional language versions, translation of the e-glossary and dedicated pages to pyruvate kinase deficiency and new features (v. webinars and real-world evidence).

**Impact:** KPI met –The TIF website was visited by a total of 32,737 unique EU-based visitors in 2021. This corresponds to 23,4% of the total number of website visitors (139,904) representing an 82% increase of EU-based visitors from 2020.

**Impact Management / Mitigation Measures:** N/A

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

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

**Results:** Promotion of the THALIA Mobile App and translation to an additional language culminated in an increased number of users.

**Impact:** KPI met – The THALIA Mobile App was downloaded by 634 users in 2021 from 18 Member States.

**Impact Management / Mitigation Measures:** The THALIA Mobile App will be broadly marketed across TIF's communication channels (website, social media, newsletters) in 2022.

**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 distribution (68 printed copies / 1,826 e-copies), whilst the 2<sup>nd</sup> edition was completed in Dec 2021.

**Impact:** KPI met – The number of copies distributed (1,894 in total) surpassed the target KPI with the largest majority being e-copies.

**Impact Management / Mitigation Measures:** N/A

## 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>            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 2021: January 2021</li> </ul>
<b>DESCRIPTION OF THE ACTIVITY</b>	
<p>A Dissemination and Awareness Plan was developed in January 2021 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 2021 and is updated on an annual basis.</p> <p>In 2021, 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 THALIA2021 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)            Medical Advisor, Dr Michael Angastiniotis            Policy Officer, Eleni Antoniou</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: 30,000</li> <li>▪ e-glossary translation (FR, DE, IT, GR &amp; AR) (MS10)</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ New content: Jan – Dec 2021</li> <li>▪ Real world evidence webpage: Feb 2021</li> <li>▪ Webinar webpage: May 2021</li> <li>▪ Pyruvate Kinase Deficiency Charter of Priorities: June 2021</li> <li>▪ Structural changes to translated versions (FR, IT, GR): Jul – Aug 2021</li> <li>▪ e-glossary translation (FR, IT, AR): Aug – Oct 2021</li> <li>▪ Pyruvate Kinase Deficiency webpage translations: Aug – Oct 2021</li> <li>▪ Pyruvate Kinase Deficiency White Paper: Dec 2021</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. A reference source for information relating to thalassaemia and TIF activities, the website underwent restructuring in 2020 which has facilitated user navigation thus providing a richer and more comprehensive experience seeking information on clinical trials, THALIA news and activities, and other topics of interest to the thalassaemia.</p>	

Broadening its scope with dedicated pages for [Sickle Cell Disease](#) , [Pyruvate Kinase Deficiency](#) and [COVID-19](#) as well as the development of a series of educational tools, resources and recommendations on COVID-19 (see [here](#)), many of which constituted a compass for treating physicians and national health authorities, TIF's website saw an exponential growth, in new users exceeding 60% compared to the previous year. both its users' traffic and sessions initiated by users, that exceeded 80% in 2020.

In 2021, the TIF website continued to be updated on a weekly basis and hosted a multitude of resources, activities and information while its resonance on an ever-increasing audience continued to grow. Aiming to fulfill the linguistic needs of patients, parents and caregivers living in THALIA priority countries, the structural changes made to the main (English – language) website were applied to the translated versions of the website, namely FR, IT & GR (M8). It is noted that the restriction of the languages from five (FR, DE, GR, IT & AR) to three represents the result of a cost-benefit analysis, that: a) removed German from the list of languages, because English is widely spoken in Germany<sup>1</sup>; b) removed Arabic which although widely spoken among refugees and migrants, they preferred to navigate the English version.

Furthermore, the e-glossary 'Thalassaemia from A-Z' was translated to FR, IT & AR (M10, MS10). The final selection of languages was made by the Internal Evaluation Committee following investigation with the local thalassaemia associations in the THALIA priority countries as to their preferred language for this resource.

Overcoming linguistics barriers constituted the impetus for translating contents of the dedicated page to Pyruvate Kinase Deficiency to FR, DE, IT, AR & ES (M10). In addition, specific educational and advocacy resources were developed and published, namely the [Charter of Priorities](#) (M6) and [White Paper: Reflections on the Patient Experience to Support Treatment and Care](#) (M12).

Ensuring the accessibility of webinars (v. T2.1.2 and T2.1.4) even after their live transmission has led to the development of a dedicated [Webinar](#) webpage (M5) to host recordings, that can be viewed on demand by patients, parents, healthcare professionals and other interested individuals such ensuring that the knowledge is communicated to a broader audience encompassing the migrant communities in the EU and accommodating for social, professional and other commitments as well as learning styles.

Gaps in provision of services, perceived inequalities in care and social integration and assessing the true burden of disease have been identified through TIF's website, acting as a portal for gathering [real-world evidence](#) (M2) from patients with thalassaemia and their families. The information gathered from EU-based patients and caregivers that form part of the migrant populations in Member States have been subsequently integrated in TIF's [Global Thalassaemia Review 2021](#), a landmark publication documenting the existing situation concerning thalassaemia in each country across 12 thematic areas. Specific information for THALIA priority countries have been distilled in Country Profiles (for more information see WP4, T4.1).

The TIF website was visited by a total of 139,904 visitors in 2021, 138,493 were new users, with an average bounce rate (73.05%) and 2.24 pages visited per session. Of these, 23,4% were from Europe, constituting 32,737 unique visitors from Europe.

<b>TIF WEBSITE USER COMPARATIVE TABLE: 2019, 2020 &amp; 2021</b>				
<b>TIF Website</b>	<b>Jan-Dec 2021</b>	<b>Jan-Dec 2020</b>	<b>Jan-Dec 2019</b>	<b>Change (from 2019 to 2021)</b>
<b>Users</b>	<b>139,904</b>	<b>69,154</b>	<b>44,328</b>	<b>↑ 216%</b>
<b>New Users</b>	<b>138,493</b>	<b>68,628</b>	<b>43,468</b>	<b>↑ 219%</b>
<b>Sessions</b>	<b>172,820</b>	<b>92,787</b>	<b>61,565</b>	<b>↑ 181%</b>
<b>Page Views</b>	<b>321,789</b>	<b>204,870</b>	<b>154,715</b>	<b>↑ 108%</b>
<b>Europe based Users</b>	<b>32,737</b>	<b>17,980</b>	<b>8,055</b>	<b>↑ 306%</b>

*Demographic data collection of EU visitors (December 2021)*

**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.

<sup>1</sup> <https://www.ef.com/wwen/epi/>



TASK	<b>T3.5: THALIA Mobile App</b>
<b>RESPONSIBLE STAFF, SUPERVISING STAFF</b>	<p><b>Responsible Staff:</b>            Communications Officer, Aikaterini Skari (Leader)            Medical Advisor, Dr Michael Angastiniotis            Policy Officer, Eleni Antoniou            P.A. to the Executive Director, Maria Peletie            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 users: 400</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ Marketing strategy &amp; campaign: Jan – Dec 2021</li> <li>▪ User manual publication: Jan 2021</li> <li>▪ Translation to Greek: June – Sept 2021</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 patients 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</p>	

specifications and the validation of the patient – reported outcomes (PRO) tool in 2019, an experienced agency in mobile app development was selected.

The THALIA Mobile App was officially launched for Android and iOS devices in December 2020 in three languages (EN, FR & DE). The App is available for download on Google Play [here](#) and the App Store [here](#).

In 2021, the promotion of the THALIA Mobile App was pursued using all TIF's online communication channels. This was evidenced via a notable placement on the TIF Website homepage and accompanying a [user manual](#) accessible via the THALIA Mobile App webpage on TIF's website. Furthermore, 8 posts were made via TIF's social media channels throughout the year. The THALIA Mobile App was featured in TIF's Newsletter (October issue) (v. T6.1.3).

Responding to great interest from engaged patients from Greece and Cyprus, as well as Greek-speaking patients who frequently travel in the EU, the THALIA Mobile App was translated and made available in Greek (M9).

A total of 1,684 persons have downloaded the THALIA Mobile App since its launch (Dec 2019) in 59 countries, including 899 users from 18 EU Members States. In 2021, 634 persons from the EU downloaded the THALIA Mobile App.

**RESULTS  
ACHIEVED**

- Promotion of THALIA Mobile App to the patient community in the EU.
- Translation of THALIA Mobile App to Greek.
- Continued uptake among patients in EU Member States.

<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)            Administration Officer, Rawad Merhi            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 copies distributed across Europe: 1,000</li> </ul>
<b>CALENDAR OF ACTIVITIES</b>	<ul style="list-style-type: none"> <li>▪ EU-wide Dissemination (MS11): Jan – Dec 2021</li> <li>▪ Guidelines for TDT (4<sup>th</sup> edition) published: June 2021</li> <li>▪ Content Updating (based on TDT Guidelines): Jul – Dec 2021</li> <li>▪ Pocket Guide (2<sup>nd</sup> edition) published: Dec 2021</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 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. 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 and 2020.</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>2</sup> for patients with transfusion-dependent thalassaemia (TDT). The extenuating circumstances brought about by the COVID-19 pandemic significantly delayed completion of the publication, which was finalized in June 2021. Subsequently, the content of Pocket Guide has undergone updating to reflect the new edition of the Guidelines (M7 – M12). This 2<sup>nd</sup> edition of the Pocket Guide was completed in December 2021. Re-printing is expected in early 2022.</p>	

<sup>2</sup> REBLOZYL® – first in class innovative medicinal product (EMA approval June 2020) ; ZYNTGLO® – gene therapy (EMA approval June 2019)

In 2021, 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 in EU Member States (v. Belgium, Germany and Greece) and the wider European region (v. Switzerland and United Kingdom).

TIF distributed 68 hard copies of the Pocket Guide across Europe in 2021 (MS11) and 1,826 e-copies. It is noted that the further distribution of the publication via traditional means (v. post) was not possible on account of distancing restrictions imposed by the Cyprus Postal Service as a consequence of the COVID-19 pandemic.

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/4967476616668232>

3,798 People Reached – 1,544 Total Engagements

**RESULTS  
ACHIEVED**

- Provision of Pocket Guide to treating doctors in EU Members States.
- Publication of Guidelines for the Clinical Management for Transfusion Dependent Thalassaemia (4<sup>th</sup> edition).
- Publication of 2<sup>nd</sup> edition of Pocket Guide for HCPs.
- Increased knowledge of appropriate treatment protocols for thalassaemia patients.
- Improvement of knowledge about thalassaemia amongst the medical community in THALIA priority countries.

## 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 THALIA2021 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 2021, contributing to the significant improvement of the programme’s visibility.	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-wise, translated to meet linguistic requirements and necessary to ensure that all stakeholders have reliable and regular access to knowledge.	The translation of content (webpages and resources) 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 translations and new features were implemented.	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 other languages will be continued either with available resources or with the help of volunteer translators (e.g. “Translators without Borders”)
<b>T3.5: THALIA Mobile App</b>	A Mobile App easing the daily life of patients and providing them with useful information on how to address challenges, whether mental or physical, is essential to empower them and facilitate communication with TIF and the community.	The promotion of the Mobile App as a means of providing a suite of tools to simplify daily thalassaemia management was met as users grew.	Self-management among the patient community in THALIA countries was strengthened, with the use of translated versions of the Mobile App (FR, DE, GR).	The increasing number of users indicates the usefulness of this tool to the daily life of patients.	Feature updates will be necessary in the future to reflect changing management protocols.
<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.	The publication of the 2 <sup>nd</sup> edition will necessitate the initiation of a coordinated dissemination reaching many of the recipients of the previous version so they have the most up-to-date information.

