PROGRESS OUTLINE 2019

PILLAR 2: AWARENESS RAISING

Activities

Impact

Co-funded by
the Health Programme
of the European Union

THALIA

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EXECUTIVE SUMMARY

The work of the Thalassaemia International Federation (TIF) can be categorised in four distinct pillars: a) Education; b) Awareness Raising; c) Policy Advocacy and d) Research. 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 2019, TIF drafted its annual dissemination and awareness plan to set the annual objectives, activities and corresponding milestones. TIF website was visited by a significant number of visitors however the target for EU-based visitors was narrowly missed (T.3.2) Moreover, the design specifications and eligible experience companies for the development of the THALIA Mobile App (T3.5) led to delays in the launching however the Patient-Reported Outcome Tool was developed and validated thus being ready for installation. The pocket guide for healthcare professionals was 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

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 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.

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 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	✓	✓	x	x
Justification	✓	✓	✓	✓

Specific objectives

II.1. Ensure that all stakeholders are aware of TIF initiatives, publications, news and events.
Activity: T3.2: TIF Website – Technical & Content Updating and Upgrading
Results: The website was enriched with technical upgrades to improve visitability and user-friendliness, as well as an e-glossary of important thalassaemia-related definitions.
Impact: KPI not met - The TIF website was visited by a total of 8,055 unique EU-based visitors in 2019. This corresponds to 18.05% of the total number of website visitors (41,327).
Impact Management / Mitigation Measures: More concentrated efforts will be made in 2020 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: Feedback from the user community has been obtained in order to shape the design specifications, the PRO tool has been developed and validated, experienced collaborators have been sourced. Completion is expected in 2020.
Impact: KPIs not met – Due to delays concerning the identification of experienced collaborators, obtaining feedback from the thalassaemia patients community and the development and validation of the PRO tool, the THALIA Mobile App was not piloted and launched on time.
Impact Management / Mitigation Measures: Upon the completion of the THALIA Mobile App in 2020, it 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.

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 in 709 copies.

Impact: KPI not met – The number of copies distributed (709) did not reach the target KPI due to the increased number of e-copies downloaded from EU-based healthcare professionals signifying the urgency in obtaining reliable information on the appropriate management of thalassaemia.

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	**T3.1: Dissemination and awareness plan**
RESPONSIBLE STAFF, SUPERVISING STAFF	**Responsible Staff:** Communications Officer, Aikaterini Skari (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi **Supervising Staff:** Executive Director, Dr Androulla Eleftheriou
INDICATORS	N/A
CALENDAR OF ACTIVITIES	▪ Creation of annual dissemination and awareness plan for 2019: January 2019

DESCRIPTION OF THE ACTIVITY
A Dissemination and Awareness Plan was developed in January 2019 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 2019 and will be updated on an annual basis. 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):
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.
2) Regular Social Media posting on delegation visits and all THALIA activities.
3) Distribution of quarterly newsletters with THALIA activities to subscribers.
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. ▪ Information sharing on the relationship between migration, thalassaemia and implications for national health systems in Europe. ▪ Dissemination of THALIA 2019 results to a broad audience.

TASK	**T3.2: TIF Website**
RESPONSIBLE STAFF, SUPERVISING STAFF	***Responsible Staff:*** Communications Officer, Aikaterini Skari (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi ***Supervising Staff:*** Executive Director, Dr Androulla Eleftheriou
INDICATORS	▪ Number of EU - based visitors: 15,000 ▪ Implementation of new technical features (RSS feed, Twitter feed, did-you-know, newsletter subscription etc) ▪ Creation of an e-glossary entitled 'Thalassaemia from A to Z') (MS10) ▪ Number of visitors/users of glossary: 300
CALENDAR OF ACTIVITIES	▪ e-glossary content development: May - November 2019 ▪ Technical Developments: August - September 2019

DESCRIPTION OF THE ACTIVITY

The website of the Thalassaemia International Federation (www.thalassaemia.org.cy) 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).

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.

Seeking to build on this increase of accessibility of information, in 2019 technical

developments have been made to boost engagement and access to information. Specifically:

- a PubMed RSS feed to automatically inform users of new scientific content of interest on thalassaemia and sickle cell disease from the free full-text archive of biomedical and life sciences journal literature at the U.S. National Institutes of Health's National Library of Medicine. This is complemented by a PubMed Update section in TIF's website which can be found here https://thalassaemia.org.cy/news-events/ ✔
- a Twitter feed to raise users' level of activity on the website, whilst in parallel promoting TIF's Twitter page ✔
- pop-ups to attract users' attention on gripping website content and increase subscriptions to TIF's newsletter prior to exiting are scheduled for early 2020.

Moreover, an e-glossary entitled 'Thalassaemia from A-Z' has been developed encompassing more than 150 terms and definitions on all important concepts of thalassaemia including treatment, infections, organ complications etc. This is a comprehensive educational tool that can be used by carriers, patients and parents as well as other interested stakeholders to gain a better understanding of complex medical terminology. The content has been reviewed by TIF's International Scientific Advisory Board, experts in the field of thalassaemia. The e-glossary will be uploaded and available to be downloaded in December 2019.

The TIF website was visited by a total of 41,327 visitors in 2019, 40,480 were new users, with an average bounce rate (63,97%) and 2.52 pages visited per session.

Of these, 18,05% were from Europe, mainly from Southern Europe, constituting 8,055 unique visitors from Europe.

Demographic data collection of EU visitors (November 2019)

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	T3.5: THALIA Mobile App
RESPONSIBLE STAFF, SUPERVISING STAFF	***Responsible Staff:*** Communications Officer, Aikaterini Skari (Leader) Policy Officer, Eleni Antoniou Administration Officer, Rawad Merhi ***Supervising Staff:*** Executive Director, Dr Androulla Eleftheriou
INDICATORS	Number of EU-based users: 100
CALENDAR OF ACTIVITIES	▪ Development of PRO components (M3-M4) ▪ Market research (1st round): M5 ▪ Validation of PRO tool: M9 – M10 ▪ Market research (2nd round): M10 ▪ Selection of external collaborator: M11 ▪ Mobile App Development: M11-M12

DESCRIPTION OF THE ACTIVITY

The THALIA mobile app 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.

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.

In 2019, the search continued in order to meet the transparency standards and code of ethics of TIF. A first round of market research was conducted in M5 and a second in M10, following the validation by 50 European patients of components of the patient-reported outcomes (PRO) tool (MS11) relating to the clinical care, social burden and quality of services available for thalassaemia. The second round of market research resulted to the collection of four quotes from experienced mobile app developers which were evaluated based on the lowest price and the portfolio of companies. The company Aylon Value was selected based on their proven track record and collaboration with major media companies in Cyprus.

The scope of the application is to provide educational material and resources to all patients to improve prevention and management of Thalassaemia. The application consists of two major content categories; the first focuses on the provision of material and news/announcements, while the second is an interactive calendar that provides ways for the patients to track/log their transfusions, their mood, appointments and administered medicines, as well as reminders for all of the above.

The scope of work has been broken down into the following parts:
- 21 static pages with content (Available in 5 languages)

- 2 auto-updated pages (Content will be fetched from the website, available only in English)
- Multilingual support (English, French, German, Greek and Italian)
- Anonymous user statistics (The application will log user behaviours and demographics in the application using Google Analytics)
- Management calendar/Patient Log (The user will be able to log their transfusions, their mood, their appointments, their medication, and be able to view overall statistics and history, as well as to receive reminders)
- Functionality for push notifications

The THALIA Mobile App consists of the following interface sections:

1. Thalassaemia Section
Thalassaemia section provides static content information about each subsection contained. The subsections are the following:
- α-Thalassaemia
- β-Thalassaemia
- Other haemoglobinopathies
- Epidemiology
- About THALIA

2. Management Section
The management section provides the user with access to an interactive calendar in which they may enter the following information:
- Transfusions: The user can enter the pre-transfusion and post-transfusion HB levels. The application must calculate the next transfusion date based on these levels and the rate of deterioration and receive reminders.
- Mood: The user can enter pre and post transfusion, his/her mood from a predefined list.
- Appointments: The user can enter his/her appointments from a predefined list (MRI, Dexa, etc.) and receive reminders.

In this section the user has also the ability to view a graph showing the average days between transfusions, receive notifications about upcoming appointments and export appointments to the device calendar.

3. Education Section
Education section provides the user with static content about each subsection contained. The subsections are the following:
1. Conferences
2. Workshops
3. e-Academy
4. A to Z in Thalassaemia

4. Patient-reported outcomes
Patient-reported outcomes section provides the user with static content about each subsection contained. The subsections are the following:
- Definitions & relevance
- Questionnaire (external page shown inside the application)

5. TIF

TIF section provides the user with static content about each subsection contained. The subsections are the following:

- About
- Pillars of work
- Publications

6. News & Events

News & Events section provides the user with dynamic content about each subsection contained. The information is retrieved from the current website of TIF, through JSON endpoints. The subsections are the following:

- Latest news
- Upcoming Events

7. Thalassaemia Community

Thalassaemia Community section provides the user with static content, i.e. external links that will navigate the user to different websites.

8. About

About section provides the user with static content.

9. FAQs

FAQs section provides the user with static content.

The following timeline has been agreed with the external collaborator:

Milestone		Tasks	Reporting/ Deliverables	Completion
Analysis & Design	1.1	Analysis and design stage, gather data and create system mock-up	Kick-off meeting with Client	November 2019
	1.3	User interface design. Design wireframes and final layouts for all the screens of the mobile application	Send wireframes and final layouts to the Client for review	December 2019
Development	2.1	Implement data fetching and parsing	None	January 2020
	2.2	Implement local database	None	January 2020
	2.5	Integrate independent components	None	January 2020
	2.6	Implement user interface	None	January 2020
	2.7	Implement additional functionality	None	February 2020
	2.8	Finalise first working version	None	February 2020
Testing	3.1	Alpha testing	Email report	March 2020
	3.2	Fix bugs and implement changes	None	March 2020
	3.3	Beta testing	Beta version of the application	March 2020
	3.4	Fix bugs and implement changes	None	April 2020
	3.5	Production version	Production version of the application	April 2020
Deployment	4.1	Submit iOS production version to Apple for review	None	April 2020
	4.2	Prepare store listings	Email report	April 2020
	4.3	Publish in App Store and Play Store	None	April 2020

RESULTS ACHIEVED	▪ Finalisation of mobile application design specifications and selection of external collaborator. ▪ Development of a validated PRO tool for thalassaemia patients.

TASK	## T3.6: Pocket Guide for Healthcare Professionals
RESPONSIBLE STAFF, SUPERVISING STAFF	*Responsible Staff:* Medical Advisor, Dr Michael Angastiniotis (Leader) *Supervising Staff:* Executive Director, Dr Androulla Eleftheriou
INDICATORS	▪ Number of copies distributed across Europe: 1,000
CALENDAR OF ACTIVITIES	▪ EU-wide Dissemination (MS12): January – November 2019

DESCRIPTION OF THE ACTIVITY

The ''*Pocket Guide for the Management of Transfusion Dependent Thalassaemia''* is an abridged, easy-to-carry pocket reference based on on the 'Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)', authored by international experts in the field of thalassaemia.

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.

In 2019, 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.

Scientific research in thalassaemia which has seen an upsurge in recent years, has yielded some ground-breaking results (gene therapy, gene editing, treatment methodologies etc) throughout 2019, and as such these will have bearing on the clinical management of the disease as described in the *'Guidelines for the Clinical Management of Transfusion-Dependent Thalassaemia (3rd Edition)'*. Hence the authors, international experts in the field of thalassaemia, members of TIF's International Advisory Board and consultants to TIF's Educational Programme, have unanimously agreed to halt the completion of the revision of this publication until early 2020, whence updates and new advances could be included in the publication. Consequently, the Pocket Guide would be updated and re-printed at that time.

TIF distributed 709 copies of the Pocket Guide across Europe in 2019.

In addition, TIF placed 2 paid ads and 1 post on its Facebook and Twitter social media pages, targeting specifically European-based clinicians and encouraging them to learn about the Pocket Guide, read it online and/or download it from the Federation's website.

The results for each one of the aforementioned, promoted or orga campaigns are summarized below:

(1) Facebook Campaign http://bit.ly/35E72Rc (21/11/2019)
    23,278 People Reached – 1,011 Total Engagements

(2) Twitter Campaign http://bit.ly/34GhcRv (23/11/2019)
    19,889 Impressions – 385 Total Engagements

These campaigns led to 407 total downloads of the Pocket Guide for the time period 21/11-29/11/2019. (data extracted on 29/11/2019)

(3) Facebook Campaign http://bit.ly/2IQmjrI (02/02/2019)
    6,034 Impressions - 774 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.

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. <u>Inputs</u>: Inputs include not only financial means but also human resources, equipment, knowledge and ideas.
2. <u>Outputs</u>: Outputs represent the direct results of the activities realised.
3. <u>Outcomes</u>: 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. <u>Impacts</u>: Impacts are the wider effects of TIF's THALIA activities. These are defined as the benefits for the immediate target audience and users of the outputs. The benefits for the society at large are called relative impacts.

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

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

Criteria / Tasks	Relevance — *Are the "general objective" and "specific objectives" still meaningful?*	Effectiveness — *Has the objective been achieved? How much contribution did the "outputs" make?*	Efficiency — *To what extent have "inputs" been converted to "outputs"?*	Impact — *What positive or negative, direct or indirect effects have happened?*	Sustainability — *To what extent will TIF be able to maintain the positive results of its activities?*
T3.1: Dissemination and awareness plan	This plan is considered a key internal coordination tool to achieve the general and specific objectives.	The plan was fully implemented in 2019.	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.
T3.2: TIF website	Continuous upgrades and updates, both technical and content, necessary to ensure that all stakeholders have fast and reliable access to knowledge.	The implementation of RSS and Twitter feeds 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 technical upgrades were implemented and more EU-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.
T3.5: THALIA Mobile App	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
T3.6: Pocket Guide for Healthcare Professionals	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	Upon updating (in accordance the 4th edition of the TDT Guidelines) dissemination will continue – reaching many of the recipients of the previous version

				this rare disorder, and the need for its effective management.	so they have the most up-to-date information.