



PROGRESS OUTLINE 2019



THALIA DISSEMINATION OF RESULTS

Activities
Impact



Co-funded by
the Health Programme
of the European Union

TABLE OF CONTENTS

EXECUTIVE SUMMARY	2
INTRODUCTION.....	3
MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT	4
OVERVIEW OF ACTIVITIES (PILLAR 4 – WP 5).....	5
IMPACT ASSESSMENT.....	10

EXECUTIVE SUMMARY

To further enhance THALIA visibility and engagement across target audiences, TIF implemented a cross-cutting dissemination strategy using online and offline media. The official website of TIF and its members were utilised to promote THALIA (T6.1.1), while 48 posts were published on social media (T6.1.2). Moreover, quarterly newsletters (T6.1.3) were sent to TIF contacts and subscribers, containing updates and announcements on THALIA activities. To further promote THALIA activities, an article is currently being prepared for publication by media outlets across Europe (T6.2.1).

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:

- To provide the maximum visibility and public awareness of THALIA's key vision and planned activities by developing and following a sound dissemination and communication strategy.

Category	T6.1: Online Media			T6.2: Traditional Media
Task No	T6.1.1: TIF & TIF Members Websites	T6.1.2: TIF social media	T6.1.3: Newsletters	T6.2.1: Articles in Press
Target Audience	All target audiences (general public, healthcare professionals, patients, policymakers)			
KPI Met	✓	✓	✓	x
Justification	✓	✓	✓	✓

Specific objectives:

- To ensure a strong online presence for TIF using all available online media means (website, social media pages, newsletters, mobile apps);

Activity: T6.1: Online Media

Results: THALIA activities were promoted on TIF website (T6.1.1) and social media pages (T6.1.2), while newsletters (T6.1.3) were sent to TIF's database of contacts.

Impact: The TIF website was visited by a total of 8,055 unique EU-based visitors in 2019 (KPI not met), with an average bounce rate (58.64%) and 2.81 pages visited per session. On social media, THALIA-related posts were shared 706 times, liked by 5,000 people, engaged 18,450 followers (KPI met) and viewed by an audience of 150,460 people. Newsletters were distributed to 15,866 persons (KPI met). Online dissemination of results was deemed successful.

Impact Management / Mitigation Measures: More concentrated efforts will be made in 2020 to divert visitors to TIF's website.

- To reach people with low digital literacy via traditional means (Press);

Activity: T6.2: Offline Media

Results: One article focused on the new therapeutic advances in thalassaemia and their impact on thalassaemia patients who form part of migrant communities in Europe is under preparation and will be published in December 2019.

Impact: N/A

Impact Management / Mitigation Measures: To ensure the relevant impact, which may be affected by late publication, TIF will continue its efforts for publication of the article in early 2020 too.

OVERVIEW OF ACTIVITIES (PILLAR 4 – WP 5)

TASK	T6.1: Online Media T6.1.1: TIF & TIF Members websites
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Communications Officer, Aikaterini Skari Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	Number of visitors from EU countries in 2019: 15,000
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Updating of THALIA webpage: January – November 2019 ▪ Uploading activities and results of THALIA2019: Continuous
DESCRIPTION OF THE ACTIVITY	
<p>Seeking to increase visibility and public awareness about THALIA, the dedicated THALIA-webpage was periodically updated with the results and activities of the project. The webpage aims to inform the following target audiences: (1) General Public, (2) Patients, (3) Healthcare Professionals, (4) Policy-makers and (5) EU and International Bodies. The page includes a brief description of THALIA, its goals and objectives, with a separate section of related publications, patients' stories and useful links.</p> <p>The THALIA webpage was developed in 2018 and integrated in TIF's website. It is available in French (spoken by 19.71% of the EU population), Italian (spoken by 14.31% of the EU population), Greek (spoken by 2.43% of the EU population), and Arabic (spoken by 0.9% of the population in European countries), in order to increase accessibility to visitors originating from EU countries.</p> <p>The webpage can be accessed using the following link: https://thalassaemia.org.cy/thalassaemia-in-action-the-thalia-project/</p> <p>In addition, a number of news and activities updates falling within the themes of THALIA can also be found in other sections of TIF's website, such as the "News & Events", the "Education" and the "Country Work" sections, within which there is an explicit reference in THALIA and its substantial contribution.</p> <p>Indicative examples are provided below:</p> <p>http://bit.ly/37YL5OE</p> <p>http://bit.ly/2OZKLqm</p> <p>http://bit.ly/3819qDR</p>	

RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ Increased visibility of TIF’s website and THALIA across EU countries. ▪ Number of visitors to TIF’s website from EU countries in 2019: 8,055 ▪ Increased awareness about thalassaemia in the EU and THALIA.
-------------------------	---

TASK	T6.1: Online Media T6.1.2: TIF social media
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Communications Officer, Aikaterini Skari Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Number of Facebook followers: 9,000 ▪ Number of Twitter followers: 2,000
CALENDAR OF ACTIVITIES	N/A
DESCRIPTION OF THE ACTIVITY	
<p>The social media channels of TIF are instrumental to the dissemination of information regarding THALIA activities and to raising awareness about thalassaemia and migration in Europe.</p> <p>In 2019, TIF intensified its awareness-raising efforts via its social media channels (mainly Facebook and Twitter) and conducted a series of targeted sponsored marketing campaigns in order to spread knowledge and awareness about thalassaemia to both local and migrant population, and expand on its mission to establish efficacious thalassaemia control policies and infrastructures in countries of need across the EU.</p> <p>More specifically, TIF’s social media channels yielded the following in 2019:</p> <p><u>Facebook:</u> 10,470 followers globally from 67 countries. 3,051 followers from EU countries including France, Germany, Cyprus, Italy, UK, Romania, Spain, Serbia, Austria, Sweden, Denmark, Belgium, Ireland, Albania, and Greece.</p> <p><u>Twitter</u> 1,781 followers on Twitter with 430 new followers from August to November 2019. Until the end of December 2019, Twitter followers are expected to exceed 2,000.</p> <p>2019 Facebook posts (to-date):</p> <ol style="list-style-type: none"> 1. http://bit.ly/2UqTUja (30/01/2019) 2. http://bit.ly/2JJjDMW (04/02/2019) 	

3. <http://bit.ly/2IQmirl> (06/02/2019)
4. <http://bit.ly/2FA6WQy> (18/02/2019)
5. <http://bit.ly/2FyJ53u> (27/02/2019)
6. <http://bit.ly/2us1TuT> (04/03/2019)
7. <http://bit.ly/2JGD8WB> (06/03/2019)
8. <http://bit.ly/2usleMD> (07/03/2019)
9. <http://bit.ly/2TyKvz1> (12/03/2019)
10. <http://bit.ly/2TZffxS> (13/03/2019)
11. <http://bit.ly/2wxtegd> (02/04/2019)
12. <http://bit.ly/2YTdd0i> (16/04/2019)
13. <http://bit.ly/2YQezc8> (19/04/2019)
14. <http://bit.ly/2MgL02j> (09/05/2019)
15. <http://bit.ly/2WdCuuc> (17/05/2019)
16. <http://bit.ly/2YQdKQA> (20/05/2019)
17. <http://bit.ly/30ULqib> (20/05/2019)
18. <http://bit.ly/2I4Bfio> (28/05/2019)
19. <http://bit.ly/2JpZuYX> (14/06/2019)
20. <http://bit.ly/2JPDIDI> (14/06/2019)
21. <http://bit.ly/2NvuhJd> (26/06/2019)
22. <http://bit.ly/2XIWAhD> (27/06/2019)
23. <http://bit.ly/2XHBgTY> (03/07/2019)
24. <http://bit.ly/2NTIXBU> (08/07/2017)
25. <http://bit.ly/2JMTkCc> (11/07/2019)
26. <http://bit.ly/32t6nkW> (12/07/2019)
27. <http://bit.ly/2Yb5rCl> (17/07/2019)
28. <http://bit.ly/2Jlzmdac> (18/07/2019)
29. <http://bit.ly/2O8N8tR> (19/07/2019)
30. <http://bit.ly/2kKfYTz> (05/08/2019)
31. <http://bit.ly/2mqGOAr> (03/09/2019)
32. <http://bit.ly/2IZvmeQ> (05/09/2019)
33. <http://bit.ly/2KDyLJY> (23/09/2019)
34. <http://bit.ly/2Xu30rO> (27/09/2019)
35. <http://bit.ly/2O7faUB> (02/10/2019)
36. <http://bit.ly/2O206HM> (12/10/2019)
37. <http://bit.ly/35gyvbx> (13/10/2019)
38. <http://bit.ly/2rTWWNt> (16/10/2019)
39. <http://bit.ly/334kPPa> (18/10/2019)
40. <http://bit.ly/2OyqSGy> (22/10/2019)
41. <http://bit.ly/2D0xmZv> (25/10/2019)
42. <http://bit.ly/2KyhNfV> (31/10/2019)
43. <http://bit.ly/2C2kx0n> (01/11/2019)
44. <http://bit.ly/2Ouo79g> (01/11/2019)
45. <http://bit.ly/33037fP> (02/11/2019)
46. <http://bit.ly/2r5EBNh> (03/11/2019)
47. <http://bit.ly/2D0lhnd> (05/11/2019)
48. <http://bit.ly/35tl0Wf> (15/11/2019)

RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ Steady increase of EU-based followers on TIF social media channels. ▪ Dissemination of THALIA activities via TIF social media channels. ▪ Increased awareness amongst EU population about thalassaemia. ▪ Percentage of EU-based followers on TIF social media channels: 29.1% on Facebook and 19% on Twitter.
-------------------------	---

TASK	T6.1: Online Media T6.1.3: Newsletters
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Communications Officer, Aikaterini Skari Policy Officer, Eleni Antoniou P.A. to the Executive Director, Maria Peletie</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Number of newsletters to be distributed in 2019: 4 ▪ Number of recipients: 11,500 ▪ Number of recipients from EU countries: 400
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> ▪ Distribution of quarterly newsletters in April, June, September and December 2019.
DESCRIPTION OF THE ACTIVITY	
<p>The distribution of quarterly newsletters to communicate to Patients, Healthcare Professionals, Policy Makers, and EU and International Bodies from around the world, news about the activities of TIF from THALIA and globally, began in early 2019.</p> <p>The first edition, distributed in April 2019 contained an extensive reference to the THALIA2018 activities in addition to THALIA2019 activities.</p> <p>Subsequently another 2 newsletters were prepared and distributed with the final newsletter for 2019 projected to be disseminated in December 2019.</p> <p>The Newsletters are available at:</p> <p>April - https://mailchi.mp/d7bd9684c10b/tif-newsletter-april-2019 June – https://mailchi.mp/7b31e81bf9cb/tif-newsletter-june-569479 September - https://mailchi.mp/38a223c662e1/tif-newsletter-september-602423</p> <p>The Newsletters are received by 15,866 individuals globally, including 5,193 recipients from EU countries.</p>	

RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ Dissemination of THALIA activities via TIF social media channels. ▪ Increased awareness amongst EU population about thalassaemia.
-------------------------	--

TASK	T.6.2: Traditional Media T6.2.1: Articles in Press
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Policy Officer, Eleni Antoniou (Leader) Communications Officer, Aikaterini Skari P.A. to the Executive Director, Maria Peletie</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> ▪ Number of articles to be published: 1 article ▪ Readership: a total of 5,000 persons.
CALENDAR OF ACTIVITIES	N/A
DESCRIPTION OF THE ACTIVITY	
<p>In the context of THALIA, an article is currently being prepared, aiming at publication within December 2019.</p> <p>Publication has been delayed due to the overdue selection of topic by TIF's International Advisory Committee considering the latest developments in the field of thalassaemia in regards to the approval of new drugs and therapies. These new advances, have seen authorization by the EMA, and as such affect the quality of treatment of thalassaemia patients in Europe, who form part of the migrant communities.</p> <p>The article will be diffused and published in distinguished European media outlets and, thus, raise awareness on thalassaemia and the importance of optimal care for patients amongst the public at large, as well as among THALIA target groups at European level who have low social media presence.</p> <p>It will be forwarded to media outlets in 10 European countries, including the United Kingdom, Italy, Spain, France, Germany, Sweden, Austria, Greece, Serbia, and Portugal, along with an accompanying text explaining briefly the article's content and purpose to the journalists.</p>	
RESULTS ACHIEVED	<ul style="list-style-type: none"> ▪ N/A

IMPACT ASSESSMENT

Methodology (*The Impact Model*)

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

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

Criteria	Relevance <i>Are the “general objective” and “specific objectives” still meaningful?</i>	Effectiveness <i>Has the objective been achieved? How much contribution did the “outputs” make?</i>	Efficiency <i>To what extent have “inputs” been converted to “outputs”?</i>	Impact <i>What positive or negative, direct or indirect effects have happened?</i>	Sustainability <i>To what extent will TIF be able to maintain the positive results of its activities?</i>
Tasks					
T6.1: Online Activities	Directly relevant to the objectives set.	Indicators overall were largely met and objectives achieved.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, volunteer hours, knowledge base, technology, partners, contacts.	The impact of activities was overall satisfactory.	THALIA results will continue to be disseminated in the years to come.
T6.2: Offline Activities					

