



PROGRESS OUTLINE 2018



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THALIA DISSEMINATION OF RESULTS



Activities

Impact

Lessons Learned

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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 a number of posts were published on social media (T6.1.2). Moreover, email blasts (T6.1.4) were sent to specific audiences, containing updates and announcements on THALIA activities. To further promote THALIA activities, an article was published by media outlets in Greece (T6.2.1), while a television interview (T6.2.2) was arranged to inform the general public. TIF also organised two press conferences, one to announce the official launch of THALIA and the other to highlight the first findings and conclusions. To compensate for the non-delivery of newsletters, TIF's Internal Evaluation Committee decided to prepare and share a THALIA-dedicated bulletin in early 2019.

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 204 members from 62 countries across the globe. TIF works in official relations with the World Health Organization (WHO) since 1996 and enjoys active consultative status with the United Nations Economic and Social Council (ECOSOC) since 2017. Most remarkably, TIF has been awarded, in the context of the 68th World Health Assembly in May 2015, the 'Dr Lee Jong-wook Memorial Prize' for the Federation's outstanding contribution to public health. More information about the Federation is available at www.thalassaemia.org.cy.

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 | | T6.3: Events and Conferences |
|-----------------|---|--------------------------|---------------------|----------------------|---------------------------|------------------------|------------------------------|
| Task No | T6.1.1: TIF & TIF Members Websites | T6.1.2: TIF social media | T6.1.3: Newsletters | T6.1.4: Email blasts | T6.2.1: Articles in Press | T6.2.2: TV appearances | T6.3.1: Press Conferences |
| Target Audience | All target audiences (general public, healthcare professionals, patients, policymakers) | | | | | | |
| KPI Met | ✓ | ✓ | ✗ | ✓ | ✓ | ✓ | ✓ |
| 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 email blasts (T6.1.4) were sent to specific audiences. Newsletters (T6.1.3) were not sent to TIF's database of contacts.

Impact: The TIF website was visited by a total of 5,483 unique EU-based visitors in 2018, with an average bounce rate (53.33%) and 3.17 pages visited per session. On social media, THALIA-related posts were shared 104 times, liked by 917 people, engaged 4,178 followers and viewed by an audience of 23,072 people. Email blasts were sent to a target audience of about 200 people. Despite the non-delivery of newsletters, online dissemination of results was deemed successful as all indicators were met.

Impact Management / Mitigation Measures: More intensive efforts will be put in 2019 to increase outreach and engage more people in THALIA-related activities.

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

Activity: T6.2: Offline Media

Results: One TV interview was arranged and one promotional article was published to disseminate THALIA results.

Impact: The impact was limited to Greek-speaking audiences, as activities targeted the Greek and Cypriot media outlets.

Impact Management / Mitigation Measures: To compensate for limited impact, TIF will implement a number of offline activities targeting EU-wide media.

- To keep the general public informed about work programme progress by organising events and press conferences;

Activity: T6.3: Events and conferences

Results: Two press conferences were organised to officially launch THALIA and announce its preliminary results, respectively.

Impact: All target audiences were effectively reached and indicators were met.

OVERVIEW OF ACTIVITIES (PILLAR 4 – WP 5)

| TASK | <p style="text-align: center;">T6.1: Online Media T6.1.1: TIF & TIF Members websites</p> |
|---|---|
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Educational Scientist, Dr Victoria Antoniadou Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p> |
| INDICATORS | Number of visitors from EU countries in 2018: 1,500 |
| CALENDAR OF ACTIVITIES | <ul style="list-style-type: none"> ▪ Creation of THALIA specific webpage, July 2018 ▪ Development THALIA branding (logo, banner etc), July 2018 |
| DESCRIPTION OF THE ACTIVITY | |
| <p>Seeking to increase visibility and public awareness about THALIA, a web banner, displayed on TIF website home page was created. Moreover, the vision and planned activities of the THALIA were included on a webpage specifically dedicated to the THALIA and integrated in TIF’s website. This was subsequently translated from English into 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 was aimed at informing 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 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 (MS14).</p> <p>Indicative examples are provided below:</p> <p>https://thalassaemia.org.cy/news/tif-news/thal-e-course-for-patients-new-class-to-start-march-1st/</p> <p>https://thalassaemia.org.cy/delegation-visits/delegation-visit-2018/delegation-visit-to-sweden-november-2018/</p> <p>https://thalassaemia.org.cy/news/tif-news/thalia-press-conference/</p> | |

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| 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 2018: 5,338 ▪ Number of visitors to THALIA webpage on TIF’s website: 678 ▪ Increased awareness about thalassaemia in the EU and THALIA. |
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| TASK | T6.1: Online Media T6.1.2: TIF social media |
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Educational Scientist, Dr Victoria Antoniadou Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p> |
| INDICATORS | <ul style="list-style-type: none"> ▪ Number of Facebook followers: 8,000 (including 1,000 from EU countries) ▪ Number of Twitter followers: 1,500 (including 500 from EU countries) |
| 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 2018, 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 2018:</p> <p><u>Facebook:</u> 7,412 followers globally from 46 countries. 1,021 followers from EU countries including France, Germany, Cyprus, Italy, UK, Netherlands, Romania, Spain, and Greece.</p> <p><u>Twitter</u> 1,120 followers on Twitter with 172 new followers from September to December 2018.</p> | |

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| 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 (MS14). ▪ Increased awareness amongst EU population about thalassaemia ▪ Percentage of EU-based followers on TIF social media channels: 13.8% on Facebook and 22% on Twitter. |
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| TASK | T6.1: Online Media T6.1.3: Newsletters |
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Educational Scientist, Dr Victoria Antoniadou Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p> |
| INDICATORS | <ul style="list-style-type: none"> ▪ Number of newsletters to be distributed in 2018: 12 ▪ Number of recipients per email blast: 11,000 globally ▪ Number of recipients per email blast from EU countries: 500 |
| CALENDAR OF ACTIVITIES | N/A |
| DESCRIPTION OF THE ACTIVITY | |
| <p>The distribution of monthly 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, was deviated as a result of the on-going Internal Evaluation Committee's supervision of TIF Staff work (load and flow).</p> <p>Indeed, the Internal Evaluation Committee, together with the TIF Board of Directors and Executive Director, decided that in order for the TIF Staff to materialise effectively and with greater impact the many activities encompassed within the THALIA work programme, it would be wiser to accumulate the information of the monthly newsletters into a dedicated news bulletin to be published at the end of 2018 with all THALIA2018 related activities and results.</p> <p>The accumulation of information was initiated however, due to delay in the completion of (1) reports from the delegation visits of Work Package 4 and (2) the launching of Thal e-course and Thal-e-Ed from Work Package 2, the publication of the bulletin was delayed further into 2019, to be combined with the first quarterly newsletter to be published at the end of March 2019.</p> | |
| RESULTS ACHIEVED | N/A |

| TASK | T6.1: Online Media T6.1.4: Email blasts |
|---|--|
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Administration Officer, Rawad Merhi (Leader) Educational Scientist, Dr Victoria Antoniadou Policy Officer, Eleni Antoniou</p> <p>Supervising Staff: Operations Manager, Lily Cannon</p> |
| INDICATORS | <ul style="list-style-type: none"> ▪ Number of recipients per email blast: 11,000 globally ▪ Number of recipients per email blast from EU countries: 500 |
| CALENDAR OF ACTIVITIES | N/A |
| DESCRIPTION OF THE ACTIVITY | <p>TIF has in recent years utilized the practice of email blasts to communicate to Patients, Healthcare Professionals, Policy Makers, and EU and International Bodies around the world breaking news in the field of thalassaemia (including recent scientific advancements, achievements at the national level etc) or activities of the Federation globally, in specific regions or nationally. These target groups include TIF members, contacts and/or collaborators whose data has been collected and is utilized in compliance with the EU GDPR legislation.</p> <p>Email blasts are single email messages sent to a large group of recipients either for information purposes, announcing new activities, projects, services or publications or indeed to make stakeholders aware of TIF activities in their specific countries and/or regions.</p> <p>Thus, 14 email blasts were sent in 2018 regarding the following THALIA activities:</p> <ol style="list-style-type: none"> 1. Pocket Guide for Healthcare Professionals (T3.6) 2. Capacity building course for newly established patients' associations (France) and patients with Thalassaemia and haemoglobinopathies (T2.2.1) 3. Establishment of national associations in France, Germany, Austria, Sweden and Serbia <p>Initial email blasts were sent globally and were received by 14,577 number of recipients including 962 new contacts from Europe. Subsequent email blasts were distributed to segmented recipients in our mailing list (i.e. per region, per country or per audience group). This reflects marketing best practices with more targeted efforts to reach the audiences that were directly involved in these activities.</p> <p>The frequency of the email blasts for each activity depended on the progress of each activity and its materialisation.</p> |

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| RESULTS ACHIEVED | <ul style="list-style-type: none"> ▪ Widespread information was disseminated amongst all target audiences in relation to specific activities (see above). ▪ Increased visibility about THALIA globally and in Europe. ▪ Responses to email blasts from EU-based recipients interested to work with TIF on these activities: 324 |
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| TASK | T.6.2: Traditional Media T6.2.1: Articles in Press |
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Policy Officer, Eleni Antoniou (Leader)</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 50,000 persons. |
| CALENDAR OF ACTIVITIES | N/A |
| DESCRIPTION OF THE ACTIVITY | |
| <p>In the context of THALIA, an article was prepared with the aim to be diffused and published by 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>The article, entitled ‘THALassaemia In Action – THALIA’: Europe’s response to the growing health problem of thalassaemia’ presents the emerging challenges posed by the increase of patients with thalassaemia and sickle cell disease in Europe, due to the uninterrupted migratory flows, and emphasizes TIF’s substantial contribution to the control, prevention and clinical treatment of thalassaemia, both over the course of last decades and, more specifically, through THALIA implementation.</p> <p>The article was drafted in English and was subsequently translated to Greek and German to facilitate publication in national media outlets.</p> <p>It was forwarded to 70 media outlets of 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> <p>The article has been published, by the end of 2018, in the Greek informative portals www.healthreportaz.gr and www.patient.gr and can be accessed using the following links: https://bit.ly/2RchhbM https://bit.ly/2QFmHg7</p> | |

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| RESULTS ACHIEVED | <ul style="list-style-type: none"> ▪ Publication of 1 article in Greece thus contributing to increased awareness and knowledge about THALIA specifically and thalassaemia generally. ▪ Establishment of collaboration with media outlets throughout Europe for subsequent publications in accordance to their specific guidelines. |
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| TASK | T.6.2: Traditional Media T6.2.2: TV appearances |
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Policy Officer, Eleni Antoniou (Leader)</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p> |
| INDICATORS | <ul style="list-style-type: none"> ▪ Number of TV appearances focused on thalassaemia: 1 ▪ Viewers of TV appearance: min. 25,000 |
| CALENDAR OF ACTIVITIES | <ul style="list-style-type: none"> ▪ TV interview on 22 September 2018 |
| DESCRIPTION OF THE ACTIVITY | |
| <p>The Hellenic Broadcasting Corporation (ERT) Television network hosted a TV interview of Dr Androulla Eleftheriou (TIF Executive Director).</p> <p>The interview focused on the following themes:</p> <ol style="list-style-type: none"> 1) The current developments in the field of thalassaemia, 2) Recent advances and their implications for the treatment protocols, 3) Present challenges faced by patients in Europe, 4) Migratory flows to European countries of patients with thalassaemia who originate from high prevalence areas of the world, 5) The particular needs of patients arriving in European countries, including alleviation of social isolation, education about the appropriate management of the disease, empowerment etc, 6) TIF's collaboration with the European Commission to support the thalassaemia migrant communities through activities in a four year plan entitled 'Thalassaemia In Action', 7) The impact of the "Train the Trainers" Capacity- Building Workshop for Patients (for more information see D2.1). <p>ERT3 broadcasted the interview via its TV channel (Viewership: 20% of the population¹) and uploaded it to the channels YouTube (Subscribers: 20,449). The interview can be accessed at: https://www.youtube.com/watch?reload=9&v=K2u5Avo8pgQ&feature=share</p> | |
| RESULTS ACHIEVED | <ul style="list-style-type: none"> ▪ Distribution to a wide audience across Greece and the diaspora in the THALIA countries. ▪ Dissemination of THALIA activities via media outlet. |

¹ <http://www.digitalnewsreport.org/survey/2018/greece-2018/>

| TASK | <p style="text-align: center;">T.6.3: Events and Conferences T6.3.1: Press conferences</p> |
|---|---|
| RESPONSIBLE STAFF, SUPERVISING STAFF | <p>Responsible Staff: Policy Officer, Eleni Antoniou P.A. to the Executive Director, Maria Peletie</p> <p>Supervising Staff: Operations Manager, Lily Cannon (Leader)</p> |
| INDICATORS | <ul style="list-style-type: none"> ▪ Number of Press Conferences to be organized in 2018: 2 ▪ Number of participants attending each Press Conference: 30 |
| CALENDAR OF ACTIVITIES | <ul style="list-style-type: none"> ▪ THALIA Kick Off Press Conference, 10 September 2018 ▪ THALIA 2018: Presentation of Results Press Conference, 21 December 2018 |
| DESCRIPTION OF THE ACTIVITY | |
| <p>Two (2) Press Conferences regarding THALIA were organised in Nicosia, Cyprus with the objective to inform the following target audiences: (1) General Public, (2) Patients, (3) Healthcare Professionals, (4) Policy-makers and (5) EU and International Bodies about THALIA, its premise, goals and activities.</p> <p>The <u>first Press Conference</u> was held on 10 September 2018 at the EU House in Nicosia, Cyprus. Attended by over 35 journalists and other stakeholders, including the Minister of Health of Cyprus, Ambassadors and representatives of Embassies from the THALIA priority and affiliated countries (i.e. FR, GER, SWE, AUS, SER, GR & IT), TIF Board Members, patients/parents from the Cyprus Thalassaemia Association, medical experts from the Cyprus Thalassaemia Centre and Cyprus Institute of Neurology and Genetics, representatives of the Ministry of Health, the National Committee for Thalassaemia, the National Rare Disease Committee, and the Cyprus Alliance for Rare Disorders in addition to other interested stakeholders in public health and academia.</p> <p>The Press Conference formally announced the official collaboration between TIF and the European Commission for THALIA, and highlighted the issue concerning the movement of populations from thalassaemia – prevalent countries of the Middle East, North Africa and Asia to European countries, where thalassaemia has thus so far been extremely rare or indeed absent. Moreover, the medical, social and financial implications of the ‘<i>introduction</i>’ of thalassaemia to the national health systems of these countries were outlined.</p> <p>The following speakers provided statements reflecting their organisations perspective and experience regarding the movement of populations and recent migration influx which Europe has witnessed:</p> <ul style="list-style-type: none"> ▪ Mr. Christos Stylianides, European Commissioner for Humanitarian Aid & Crisis Management (https://youtu.be/xSekJkjKy7A) ▪ Mr. Ierotheos Papadopoulos, Head of the European Commission Representation in Cyprus ▪ Mr. Constantinos Ioannou, Minister of Health – Cyprus | |

In particular, the Conference was covered by 4 local media outlets, disseminating THALIA's objectives and added value throughout Cyprus.

Following the Press Conference, a press release was distributed in Greek, to media outlets in Cyprus.

The following media outlets published the press release or covered the event:

Newspapers (printed and online):

Phileleftheros (Readership: 55,206):

<http://www.philenews.com/koinonia/eidiseis/article/579120/i-thalassaimia-metanastevei-apo-ton-noto-ston-borra-poso-etoimi-einai-i-evropaiki-enosi>

Kathimerini (Readership: 11,736): <http://www.kathimerini.com.cy/gr/kypros/kypros-ygeia/polla-ta-peristatika-ipatitidas-b-se-metanastes>

Health News (Readership: Data not available):

<http://healthnews.reporter.com.cy/health/article/10085/-metanasteftikes-roes-stin>

TV channels:

Ant 1 Cyprus (Ratings: 13.6% of the population):

<https://www.ant1.com.cy/news/cyprus/article/312885/i-kupros-ekpaideuei-tin-ee-gia-ti-thalassaimia/>

CYBC 1 (Ratings: 8.2% of the population):

<http://www.riknews.com.cy/index.php/news/ygeia/item/71614-i-doth-kalei-se-synergasia-tis-xores-tis-evropis-gia-antimetopisi-xronion-kai-spanion-pathiseon>

The second Press Conference was held on 21 December 2018 at the Ministry of Health in Nicosia, Cyprus. Attended by 32 journalists and other stakeholders, including the Minister of Health of Cyprus, the Permanent Secretary of the Ministry of Health, the Representation of the European Commission in Cyprus, the International Organisation of Migration (IOM) - Cyprus, the Office of the United Nations High Commissioner for Refugees (UNHCR), the National Blood Transfusion Services, the Cyprus Blood Bank, TIF Board Members, patients/parents from the Cyprus Thalassaemia Association, medical experts from the Cyprus Thalassaemia Centre, the National Committee for Thalassaemia, the National Rare Disease Committee, and the Cyprus Alliance for Rare Disorders in addition to other interested stakeholders from university medical schools.

Aimed at presenting and disseminating the results of THALIA activities to-date in addition to providing additional perspectives on migration flows and the health of migrants by Mr. George Ailiotis (representative of the UNHCR’s Office in Cyprus), and Mrs. Abdi Nasiyo Mohammed, (representative of the IOM in Cyprus). Moreover, migration remains a priority of the European Commission, a position expressed and extrapolated by Mr. Michael Stylianos, Political Analyst of the Representation of the European Commission in Cyprus. Welcome addresses were provided by Mr. Panos Englezos, TIF President and Dr. Christina Yiannaki, Permanent Secretary of the Ministry of Health.

In particular, the Conference was covered by 3 local media outlets, disseminating THALIA’s objectives and added value throughout Cyprus.

Following the Press Conference, a press release was distributed in Greek, to media outlets in Cyprus.

The following media outlets published the press release or covered the event:

TV channels:

Ant 1 Cyprus (Ratings: 13.6% of the population):

<https://www.ant1.com.cy/news/cyprus/article/323787/to-programma-thalassaimias-en-drasei-gia-tin-adimetopisi-tis-/?expandedarticle=true>

Newspapers (printed and online):

Offsite (Readership: 509,400): <https://www.offsite.com.cy/eidiseis/topika/i-kypros-ston-agona-antimetopisis-tis-thalassaimias-stin-eyropi>

**RESULTS
ACHIEVED**

- Increased awareness about THALIA at Cyprus and European audiences.
- Information sharing on the relationship between migration, thalassaemia and implications for national health systems in Europe.
- Networking with migration agencies (UNHCR and IOM) for development of partnerships for implementing and disseminating THALIA activities across Europe.
- Dissemination of THALIA 2018 results to a broad audience.

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 were 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. Offline activities only had an impact on Greek-speaking audiences. | THALIA results will continue to be disseminated in the years to come. |
| T6.2: Offline Activities | | | | | |
| T6.3: Events and conferences | | | | | |

LESSONS LEARNED

TIF's activities for the dissemination of THALIA results:

| STRENGTHS | WEAKNESSES |
|--|---|
| <ul style="list-style-type: none"> ▪ were implemented using an array of communication tools and channels; ▪ reached all target audiences; ▪ achieved the expected impact; ▪ made THALIA known to all thalassaemia and migration-related stakeholders. | <ul style="list-style-type: none"> ▪ were partially limited to Greek-speaking audiences. |
| OPPORTUNITIES | THREATS |
| <ul style="list-style-type: none"> ▪ THALIA provides TIF with the opportunity to showcase its EU-based work and the valuable collaboration with the European Commission. ▪ The dissemination of THALIA results has given hope and a sense of belonging to patients living in Europe and needs to be continued and intensified. | <ul style="list-style-type: none"> ▪ Language barriers to further disseminate THALIA results are a major concern for TIF – All messages will be translated in as many languages as possible in 2019. ▪ Access to migrants and refugees – Reaching out migrant populations is a challenge to effectively disseminate THALIA results – TIF will adjust its strategy accordingly in the years to come. |