

YEARLY HANDBOOK

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EXECUTIVE SUMMARY

This Yearly Handbook outlines TIF’s networking activities that took place in the course of the first semester of 2022, providing useful insights on the selection of partners, messages and the context of collaboration. Focusing on blood safety and availability, as well as access to new therapies, TIF’s efforts to raise awareness and initiate joint advocacy efforts were addressed to decision-makers, healthcare professionals, patient groups and other alliances working in each field. Interactions were successful, leading to the organisation of joint events during the second semester of 2022.



The Yearly Handbook is available online at <https://thalassaemia.org.cy/thalia2022/>

INTRODUCTION

A network is defined as “an arrangement of intersecting horizontal and vertical lines; a group or system of interconnected people or things”¹. Therefore, TIF works (applies thought, commitment, and effort) to create, grow, use, assist and enable its own net (network) of contacts. By bolstering and expanding its network in Europe, the Thalassaemia International Federation (TIF) utilises a powerful lever to increase awareness about thalassaemia, its optimal care and increase the visibility of its work in the context of THALIA2022.

This Yearly Handbook analyses the expansion of TIF’s Stakeholder Network in the context of the region-specific work programme of the Federation, as part of WP3 – Networking and Collaborations. It serves as both an internal reporting tool and a practical guide to patient organisations for the expansion of their own respective networks. It also serves as means to enhance the Federation’s transparency and inform the wider community of the Federation’s contacts, discussions and partnerships in 2022.

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 226 members from 66 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 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

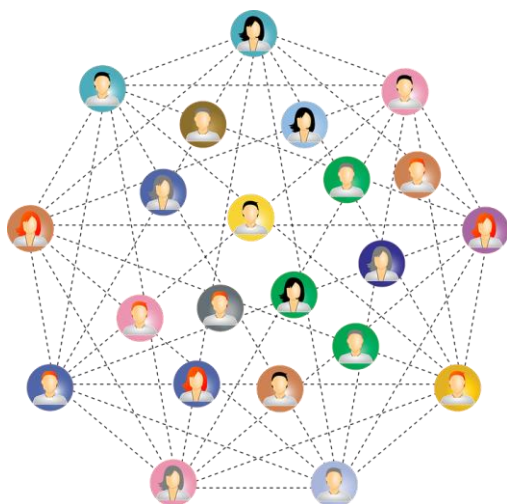
Thalassaemia, a previously fatal childhood genetic disease, can today be effectively prevented and adequately treated, as a result of the medical and scientific advances that took place in the last three decades. However, thalassaemia’s prioritisation on national health agendas and the development of 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 2022” (THALIA2022) focuses on Europe, targeting patients with thalassaemia and other haemoglobinopathies, healthcare professionals, policymakers and the general public to:

- a) Reduce the burden of non-communicable diseases by reducing health inequalities and promoting access to healthcare
- b) Strengthen health systems to improve their responsiveness in times of health emergencies
- c) Improve the availability, accessibility and affordability of medicinal products and devices, including innovative therapies
- d) Promote the implementation of best practices through the utilisation of digital transformation means.

¹ Oxford English Dictionary (2005 revised edition)

MATCHING OBJECTIVES TO ACTIVITIES AND IMPACT



This deliverable has been developed following the completion of Task 3.1 under WP3, i.e. a round of meetings with different stakeholders, active in the field of the clinical management of haemoglobinopathies. The selection of stakeholders was based on the cornerstones of thalassaemia treatment, namely regular blood transfusions and chelation therapy. Therefore, i) blood safety and availability; and ii) access to medicines, essential and novel; were the main selection criteria to enable TIF to advance its positions on the two matters and raise awareness regarding its work in the context of THALIA2022.

The following table aligns this effort with the corresponding general and specific objectives of the work programme, noting the activity's impact and outcomes:

	Met?
General Objective 2: To raise awareness on thalassaemia and other haemoglobinopathies, with a specific focus on the importance of health and social care amongst the public at large, as well as amongst THALIA target audiences, at national and EU levels by expanding the Federation's Network and engaging in active dialogue with EU-based partners in the context of meetings, conferences and other events - Theme: Diagnosis & Clinical Management of Thalassaemia	✓
Specific Objective: h. To activate TIF's EU network of stakeholders related to thalassaemia and other haemoglobinopathies and share information on addressing crisis-related challenges by holding a round of meetings and presenting the outcome in a Yearly Handbook (T3.1)	✓
Activity/Task 3.1: Round of Meetings with Haemoglobinopathies-related Stakeholder Organisations (8 meetings in total between February and June 2022). To be held virtually and include the participation of a patient expert and medical specialist.	✓
Results: <ul style="list-style-type: none"> More than 10 meetings and interactions with different organisations, active in the areas of blood safety & availability and access to medicines between M1 and M6. 	✓
Impact: <ul style="list-style-type: none"> KPI met: 8 Meetings with 8 different stakeholders relevant to haemoglobinopathies (policymakers, healthcare professionals, researchers, patient groups) 	✓
Justification <ul style="list-style-type: none"> Agenda & Meeting Minutes 	✓

OVERVIEW OF ACTIVITY

TASK	T3.1: Stakeholder Network Development
RESPONSIBLE STAFF, SUPERVISING STAFF	<p>Responsible Staff: Senior Policy Officer, Eleni Antoniou (Leader)</p> <p>Supervising Staff: Executive Director, Dr Androulla Eleftheriou</p>
INDICATORS	<ul style="list-style-type: none"> 8 meetings with 8 different haemoglobinopathies-related organisations
CALENDAR OF ACTIVITIES	<ul style="list-style-type: none"> <u>February 2022:</u> European Haematology Association; World Duchenne Organization; European Medicines Agency <u>March 2022:</u> TRANSFORM MEP Interest Group <u>April 2022:</u> EURORDIS <u>May 2022:</u> European Blood Alliance; European Commission <u>June 2022:</u> International Society of Blood Transfusion; TRANSFORM MEP Interest Group; Oxford University

More specifically:

Access to Safe and Adequate Blood

	Entity/ies met	Subject(s)	Date of Interaction	Location
1	International Society of Blood Transfusion	<ul style="list-style-type: none"> Identification of common areas of interest (education of HCPs on blood safety & availability; promotion of safe blood donation practices) Collaboration opportunities (participation in conferences; co-development of educational material) 	14 June 2022	Virtual
2	World Health Organization	<ul style="list-style-type: none"> Annual Meeting of the WHO Collaborating Centres and Partners on Blood Transfusion Safety and Blood Products meeting: Updates & Trans-regional Cooperation 	19 May 2022	Virtual
3	European Blood Alliance	<ul style="list-style-type: none"> Updates on SoHO Regulation Occasional blood shortages in Southern Europe International Thalassaemia Day World Blood Donor Day Patients' International Blood Alliance 2nd meeting of the Global Forum on Access to Safe Blood Products for Patients in Need of Regular Transfusion 	04 May 2022	Virtual
4	European Haematology Association	<ul style="list-style-type: none"> Recommendations on Reducing Bureaucracy in Clinical Trials Blood & Beyond recommendations to safeguard and optimise Europe's blood supply 	07 February 2022	Virtual

Access to Medicines

	Entity/ies met	Subject(s)	Date of Meeting	Location
1	TRANSFORM MEP Interest Group	<ul style="list-style-type: none"> Fit For ATMPs? Creating an EU Regulatory Framework that Works for Transformative Therapies 	16 June 2022	Virtual
2	Oxford University	<ul style="list-style-type: none"> UK's "Innovative Medicines Fund": A solution to the access problem? 	07 June 2022	Virtual
3	European Commission	<ul style="list-style-type: none"> Withdrawal from Europe of the first EMA-approved gene therapy for beta thalassaemia: Lessons learned & the way forward 	10 May 2022	Virtual
4	EURORDIS	<ul style="list-style-type: none"> EURORDIS Round Table of Companies: Case Study - Withdrawal from Europe of the first EMA-approved gene therapy for beta thalassaemia 	27 April 2022	Virtual
5	TRANSFORM MEP Interest Group	<ul style="list-style-type: none"> How to Pave the Way to Access to Authorized ATMPs for Patients 	31 March 2022	Virtual
6	World Duchenne Organization	<ul style="list-style-type: none"> 2nd International Conference on Rare Diseases: Case Study - Withdrawal from Europe of the first EMA-approved gene therapy for beta thalassaemia 	22 February 2022	Virtual
7	European Medicines Agency	<ul style="list-style-type: none"> Withdrawal of the manufacturing company of the first EMA-approved gene therapy for beta thalassaemia: Lessons learned & the way forward 	07 February 2022	Virtual

DESCRIPTION OF THE ACTIVITY	
<p>Numerous meetings were held with a plethora of stakeholders thus maintaining the existing and developing new strategic partnerships for TIF.</p>	
METHODOLOGY APPLIED	<ul style="list-style-type: none"> Prior identification of: i) key stakeholders; ii) common areas of interest; iii) possible collaboration options; iv) methods of approach (i.e. email communication; virtual meetings; follow-ups; email blasts) Definition of messages to be conveyed, applying the "7Cs of Communication" approach Round of meetings on (inter alia) blood safety & adequacy and access to medicines Defining the way forward at each interaction
RESULTS ACHIEVED	<p><u>Short-term</u></p> <ul style="list-style-type: none"> Increased visibility of THALIA2022 activities Continued engagement of network stakeholders Network expansion with new contacts <p><u>Long-term (anticipated)</u></p> <ul style="list-style-type: none"> Wider adoption of TIF Guidelines on the clinical management of transfusion-dependent thalassaemia Improved quality of care across EU Member States

THE METHODOLOGY EXPLAINED

To further expand its network, TIF applied the following 4-step approach (IDHM):

1. Identify:

- key stakeholders;
- common areas of interest;
- possible collaboration options;
- methods of approach (i.e. email communication; virtual meetings; follow-ups; email blasts)

How? Collection of information; preparatory work before meetings

2. Define:

- Messages to be conveyed, applying the “7Cs of Communication” approach

How? Current topics of concern & TIF’s Positions

3. Hold a round of meetings on blood safety & adequacy / access to medicines (based on 2022 Theme: Diagnosis & Management of Haemoglobin Disorders): Define the way forward at each interaction

How? Agree on action tasks & timelines

4. Maintain communication

How? Email blasts on news and updates; participation in events; follow-ups

1. IDENTIFY network members

- Four (4) categories:

A. Policymakers	B. Healthcare Professionals	C. Patient Groups	D. Multi-stakeholder Groups
World Health Organization	International Society of Blood Transfusion	EURORDIS	TRANSFORM MEP Interest Group
European Union / European Commission	European Blood Alliance	World Duchenne Organization	Oxford University
European Medicines Agency	European Haematology Association		

A. Policymakers

World Health Organization

Website	https://www.who.int/
Location / HQs	Geneva, Switzerland
About	The World Health Organization (WHO) is a specialized agency of the United Nations responsible for international public health. It has six regional offices and 150 field offices worldwide. The WHO's mandate seeks and includes: working worldwide to promote health, keeping the world safe, and serve the vulnerable. It advocates that a billion more people should have: universal health care coverage, engagement with the monitoring of public health risks, coordinating responses to health emergencies, and promoting health and well-being. It provides technical assistance to countries, sets international health standards, and collects data on global health issues. The WHO also serves as

	a forum for discussions of health issues.
Relevance to TIF's work (Keywords)	Public Health; Universal Health Coverage; thalassaemia; sickle cell disease; genetic disorders; social health determinants; health of migrants; blood safety; blood availability; safety of medicines; availability of medicines; Essential Medicines List; communicable diseases; non-communicable diseases; mental health
Relationship	In official relations since 1996
Areas of Collaboration	Education; advocacy

European Union / European Commission

Website	https://european-union.europa.eu/index_en
Location / HQs	Brussels, Belgium; Luxembourg; Strasbourg, France
About	The European Union (EU) is a supranational political and economic union of 27 member states that are located primarily in Europe. Its fundamental values are defined in the Treaty of Lisbon: human dignity, freedom, democracy, equality, rule of law, and human rights. The main European Institutions are: the European Council, the European Commission, the Council of the European Union and the European Parliament. The Directorate-General for Health and Food Safety (DG SANTE) is a directorate-general of the European Commission. The DG is responsible for the implementation of European Union laws on food safety and health.
Relevance to TIF's work (Keywords)	blood safety and availability; innovation; clinical trials; access to medicines; safety of medicines; cross-border healthcare; social health protection
Relationship	Strategic Partnership since 2018
Areas of Collaboration	Education; advocacy/public policy improvement; awareness-raising

European Medicines Agency

Website	http://www.ema.europa.eu/ema/
Location / HQs	Amsterdam, The Netherlands
About	The European Medicines Agency is an agency of the European Union in charge of the scientific evaluation, supervision & safety monitoring of human & veterinary medicines in the EU.
Relevance to TIF's work (Keywords)	safety of medicines; advanced therapies for haemoglobin disorders; patient-reported outcomes
Relationship	Official collaboration; participation in committees
Areas of Collaboration	Patient views on medicines under evaluation; review of patient leaflets; education; awareness-raising

Healthcare Professionals

International Society of Blood Transfusion

Website	https://www.isbtweb.org/
Location	Amsterdam, The Netherlands
About	ISBT is a global community of professionals sharing knowledge to enhance transfusion practice. ISBT does this by: providing opportunities for advancing knowledge and education & by advocacy for the welfare of blood donors and patients. Its vision is a world of safe and sufficient blood.
Activities (keywords)	(i) organising international and regional congresses in locations around the world and virtually, as well as many other educational activities such as webinars, live journal clubs and workshops; (ii) advocating for the welfare of blood donors and patients through promotion of the ISBT "Code of Ethics" and ISBT is Non-State Actor in official relations with WHO.

Relevance to TIF's work (Keywords)	The ISBT Working Parties are topic-driven groups that promote science research and best practice across in their areas of expertise across the transfusion chain. Currently, ISBT has a total of 15 Working Parties, some of them work closely together. Each Working Party has a formal committee structure and is coordinated by a Chair or Co-Chairs. The different topics covered are: Blood Components; Blood Supply Management; Cellular Therapies; Transfusion Medicine; Clinical Transfusion; Donors and Donation; Global Blood Safety; Granulocyte Immunobiology; Haemovigilance; Immunohaematology; Information Technology; Platelet Immunobiology; Quality Management; Rare Donors; Red Cell Immunogenetics and Blood Group Terminology; Transfusion Transmitted Infectious Diseases.
Relationship	Existing collaboration (maintenance; strengthening)
Areas of Collaboration	Education of healthcare professionals (workshops; conferences)

European Blood Alliance

Website	https://europeanbloodalliance.eu/
Location/HQs	Amsterdam, The Netherlands; Brussels, Belgium
About	To contribute to a safe, sustainable and affordable blood, tissues and cells supply for Europe
Activities (keywords)	Education; advocacy
Relevance to TIF's work (Keywords)	Blood safety & adequacy at the core of the EBA's work (an alliance of European blood establishments): Educational meetings, symposiums and conferences addressed to blood establishments EBA and the International Federation of Blood Donor Organizations (FIODS) have agreed on formal relations through a Memorandum of Understanding, as one of EBA's objectives is to best support and protect the donors.
Relationship	Existing collaboration (maintenance; strengthening)
Areas of Collaboration	Education of healthcare professionals / laboratory scientists (workshops; conferences)

European Haematology Association

Website	https://ehaweb.org/
Location/HQs	Brussels, Belgium
About	To promote excellence in patient care, research, and education in hematology.
Activities (keywords)	Networking; Supporting career development and research; Harmonizing hematology education; Advocating the interests of hematologists and hematology
Relevance to TIF's work (Keywords)	Educational meetings, symposiums and conferences addressed to healthcare professionals and researchers in the field of haematology
Relationship	Existing collaboration (maintenance; strengthening)
Areas of Collaboration	Education of healthcare professionals; advocacy

Patient Groups

EURORDIS

Website	https://www.eurordis.org/
Location/HQs	Paris, France; Brussels, Belgium; Barcelona, Spain
About	The European Organisation for Rare Diseases is a non-governmental patient-driven alliance of patient organizations and individuals active in the field of rare diseases, that promotes research on rare diseases and commercial development of orphan drugs.
Activities (keywords)	Rare disease policy; research; diagnosis; European Reference Networks; treatments; holistic care
Relevance to TIF's work (Keywords)	Joint advocacy efforts on public policy improvement (health and social care); improvement of healthcare services/clinical management of rare diseases: Rare Diseases International; NGO Committee for Rare Diseases; Rare Disease Day; European Conference on Rare Diseases; Council of European Rare Disease Federations
Relationship	Existing collaboration (maintenance; strengthening)
Areas of Collaboration	Patient education; global and EU advocacy

World Duchenne Organization

Website	https://www.worldduchenne.org/
Location/HQs	Veenendaal, The Netherlands
About	World Duchenne Organization is a worldwide organisation dedicated to finding a cure and viable treatments for DMD, to promoting good standards of care, and to informing parents around the globe.
Activities (keywords)	education; research; advocacy
Relevance to TIF's work (Keywords)	International Conference on Rare Diseases; international advocacy on rare diseases (diagnosis; clinical management; holistic care)
Relationship	New collaboration in 2022 (access to innovative medicines)
Areas of Collaboration	Patient education; global and EU advocacy

Multistakeholder Groups

TRANSFORM MEP Interest Group

Website	https://transformalliance.eu/mep-interest-group/
Location/HQs	Brussels, Belgium
About	The TRANSFORM MEP Interest Group is an informal group that brings together cross-party Members of the European Parliament (MEPs) who are committed to ensuring that innovative and life-changing therapies can timely reach all patients across Europe.
Activities (keywords)	Public policy improvement on ensuring access to Advanced Therapy Medicinal products (ATMPs)
Relevance to TIF's work (Keywords)	Policy asks/recommendations on policies strengthening the access of patients to innovative medicines and therapies; awareness-raising/advocacy events
Relationship	New collaboration in 2022 (access to innovative medicines)
Areas of Collaboration	EU advocacy

Oxford University
Center for the Advancement of Sustainable Medical Innovation (CASMI)

Website	https://www.rdm.ox.ac.uk/news/official-launch-of-casmi
Location/HQs	London/Oxford, United Kingdom
About	The Centre for the Advancement of Sustainable Medical Innovation (CASMI), a joint effort of Oxford University and University College London, was officially launched in 2013 at The Wellcome Trust. CASMI collaborates with patient groups, academia, industry, government, NHS and other important bodies to create sustainable models for medical innovation. The Centre is an Observer of the work of TRANSFORM, a multi-stakeholder European Alliance raising awareness on cell and gene therapies.
Activities (keywords)	Consultancy & policy projects; research on the accessibility of new therapies
Relevance to TIF's work (Keywords)	Access to new therapies; strengthening national health systems
Relationship	New collaboration in 2022 (access to innovative medicines; Innovative Medicines Fund)
Areas of Collaboration	EU advocacy

2. DEFINE messages

Current topics of concern & TIF's Positions

The THALIA experience has allowed TIF to gain useful insights with regard to the unmet needs of patients and healthcare professionals in the EU. As 2022 was a year dedicated to the management of haemoglobinopathies, TIF focused on the two cornerstones of thalassaemia treatment, i.e. regular blood transfusions and chelation therapy. Based on these two essential components of treatment, TIF had to give emphasis on advocating for safe and available blood (in light of the temporary yet frequent blood shortages in Southern Europe) and for access to novel therapies (given the withdrawal from Europe of the company manufacturing Zynteglo, the first EMA-approved gene therapy for beta-thalassaemia).

Blood Safety and Availability

Promotion and full dependence on **voluntary, non-remunerated blood donation** practices in every country worldwide;

Strengthening existing, and promoting the creation of new, **National Transfusion Programmes**, in accordance to internationally accepted Guidelines of the World Health Organisation and other official bodies, and strengthening of national Hepatitis B vaccination programmes;

Implementation of state-of-art blood banking practices, including a **haemovigilance** programme.

Access to Novel Therapies

The provision of **free-of-charge access** of thalassaemia patients to the three chelating agents and other drugs relating to the clinical management of the disease, as per the relevant international clinical guidelines¹;

The adoption of national policies for the identification of **counterfeit/ substandard medicinal products**;

Equitable, prompt and affordable access to essential iron chelating drugs and other drugs necessary for the multi-organ disease and treatment-related complications of thalassaemia, including viral hepatitis;

National and regional **pricing and reimbursement policies** that will facilitate the faster accessibility of novel therapies to patients.

Transmission of messages: Principles

To effectively communicate its positions to different stakeholders, TIF applies the 7 Cs of Communication², i.e.:

- 1. Clear (Clarity):** Be clear about the goal of your message and the purpose of the message. Present one idea at a time making it easier for the recipient to understand. Do not leave them guessing what the message is about and having to fill in the gaps themselves. Set a goal or outcome for what you want to communicate and work towards that.
- 2. Concise (Conciseness):** Keep to the point and keep it short and simple. Do not use unnecessary words. Do not repeat the same point in different ways. This will also make any communication more engaging and easier to understand.
- 3. Concrete (Concreteness):** Be clear, not fuzzy. Ensure there is enough detail to get the message across but not too much so that the recipient will be lost and that the message is factual. Adding too much 'noise' around your main points can mean these are missed. Make sure your main points and any conclusions are clear to the recipient.
- 4. Correct (Correctness):** Check the information you are providing is accurate and, in written communication, ensure it is free from grammatical and spelling errors. Check the technical parts of your content are understandable by the person receiving the information. Preparation will help here to make sure you can be sure about what you are communicating or a chance to read what you have written.
- 5. Coherent (Coherence):** Make sure your message flows well and is laid out logically. The points you make should all be linked to the main topic and should help you to deliver the objective you originally set out to achieve. Make sure the tone of the message is the same throughout. Consider using a structure for your communication to help here.
- 6. Complete (Completeness):** Ensure the recipient has everything they need to understand your message and take action if needed. If action is needed, ensure your message includes a 'call to action'. Also, ensure that any specific details are clear and included. Do not leave the recipient with lots of questions to ask. Think about how you will check for understanding. For example, you could ask questions to check their understanding.
- 7. Courteous (Courtesy):** Your message should be polite, friendly, professional, open and honest. Think about your message from the recipient's point of view and you are empathetic towards their needs. This will help you to deliver the message in a way that's easy to understand and buy into. Also, communicating to or writing for the reader can make your communication more engaging.

² Explanation at <https://www.revolutionlearning.co.uk/article/the-7-cs-of-communication/> (Last accessed on 28 December 2022).

3. HOLD a round of meetings

To engage different stakeholders and create, deepen or expand collaboration, it is necessary to maintain communication and identify different joint activities, e.g. joint position papers, workshops, meetings, etc. Therefore, at each interaction with its partners, TIF further discussed patients' concerns, the different unmet needs in Europe and also explored ways of strengthening collaboration, as described above.

4. MAINTAIN communication

As a reliable partner, TIF keeps track of its interactions, action tasks and follow-up activities to ensure that no opportunity falls through the cracks. Using a spreadsheet and calendar system, TIF team notes:

- Who it contacted
- How it knows them
- When the contact took place
- What it discussed
- What actions it needs to take
- When it will complete those actions

Partners always appreciate it as you respond and communicate in a timely manner. Interaction with the above list of stakeholders and many more continued in the course of 2022 on a high note to maximise visibility of TIF positions and further strengthen the impact of the Federation's activities.

IMPACT ASSESSMENT

Methodology (*The Impact Model*)

TIF's Impact Model consists of 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 focuses 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 THALIA 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					
T3.1: Stakeholder Network Development	Networking activities remain a key component to raise awareness on thalassaemia and other haemoglobinopathies and the development of synergies to address the different unmet needs of the clinical management of these disorders.	The round of meetings held in S1/2022 resulted to the participation of TIF and its partners in joint awareness-raising and educational activities that took place in S2/2022, e.g. TIF’s Global Forum on Access to Safe Blood Products for Patients in Need of Regular Transfusion (November 2022) that brought together all blood-related stakeholders and TRANSFORM’s high-level multi-stakeholder event at the European Parliament (October 2022) that shed light onto the accessibility of new therapies.	The “inputs” required for the implementation of this task were optimally used, namely: staff time, planning time, and knowledge base.	Through the interactions and joint events, TIF further strengthened its collaboration with partners, developed its network and thus enhanced visibility and impact of its activities in the context of THALIA and globally.	Following its networking methodology, TIF shall maintain contacts to ensure that collaboration with each stakeholder continues on a high note, for the benefit of patients.
