8. SOCIAL HEALTH PROTECTION AND THALASSAEMIA: ADDRESSING THE SOCIAL DETERMINANTS OF HEALTH FOR IMPROVED HEALTH OUTCOMES TIF'S PERSPECTIVE

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ABSTRACT

The social determinants of health are those factors that contribute to the health status and well-being of each individual, supporting social inclusion and integration: the lower an individual's socio-economic position, the higher their risk of poor health is. To assess the level of social integration of people with thalassaemia, based on the social determinants of health, we have collected data through targeted literature reviews (2013-2023) and a global survey that was conducted between 2022-2023. Despite fragmented data, coming from specific regions of the world, it is evident that in countries where multidisciplinary care is provided free of charge, in the context of Universal Health Coverage, and combined with social benefits, patients have a better quality of life, in terms of ageing and access to education, the labour force, and family planning. Our study has also identified policy gaps with regard to the social inclusion of migrant populations and research gaps, especially with regard to the patients' work- or education-life-treatment balance, and their access to psychological support, given that the mental health aspect has not yet been acknowledged enough by any country of the world.

Keywords: social determinants of health; social inclusion; thalassaemia; haemoglobinopathies

INTRODUCTION

The Millennium Development Goals (MDGs), which started a global effort in 2000 to tackle the indignity of poverty, were succeeded by the Sustainable Development Goals (SDGs) in 2012, which aimed at meeting urgent environmental, political and economic challenges facing our world, while leaving no one behind. As a call to action for all countries of the world, 17 SDGs and 169 associated targets were defined, to be reached by 2030.

Despite all efforts to meet the SDGs, widening inequalities, public health threats, climate change, protracted conflicts, widespread hazards and environmental degradation, rapid urbanisation and the overconsumption of natural resources have driven systemic risks and instabilities to new and unprecedented levels, heavily affecting patients, one of the most vulnerable population groups. People with thalassaemia, in particular, depending on where they may live, are either still fighting for essential healthcare or highly specialised treatment, while having to deal, to a lesser or greater extent, with multiple external factors that determine their well-being and quality of life.

This Chapter outlines and assesses these external factors that determine the level of **inclusion** [1] [UN 2016] and subsequent **integration** of patients into society, known as "**Social Determinants of Health**". The social determinants of health are the social conditions in which people are born, grow, live, work and age that have a direct impact on their health and well-being, causing health inequities across countries and regions: the lower an individual's socio-economic position, the higher their risk of poor health. Despite considerable attention to the problem of health inequities since 1978 [2], [3], [4], [5] [WHO 1978, 1986, 2011, 2021A], striking differences

in health still exist among and within countries, linked to several social factors: education, income level, employment status, housing and environment, and systems of preventing and treating ill health [CSDH 2008].

Addressing the social determinants of health, both for vulnerable groups and the general population, is key to create equitable, economically productive, inclusive and healthy societies. Any action toward this direction, especially in low-resource settings, would contribute to the fight against poverty that is stifling development and is usually due to the exorbitant costs of healthcare, the reduction of premature deaths and the increase of life expectancy.

The concept of "Leaving No One Behind" alludes to social inclusion. The United Nations provide the following definitions [1][UN 2016]:

- Social inclusion is defined by the United Nations as "the process of improving the terms of participation in society, particularly for people who are disadvantaged, through enhancing opportunities, access to resources, voice and respect for rights".
- Social integration is the end-goal, i.e. "a society for all, in which every individual, each with rights and responsibilities has an active role to play".
- Social cohesion follows social integration and is defined as "the absence of fractures or divisions within society and the ability to manage such divisions. A cohesive society creates a sense of belonging, promotes trust, fights exclusion and marginalization and offers its members the opportunity of upward mobility".
- Social protection is the vehicle to achieve social integration and subsequently cohesion, taking the form of social benefits addressed to vulnerable groups.
- Social determinants of health are a number of factors (social, economic, environmental) that contribute to the health status and well-being of each person, supporting social inclusion and subsequent integration.

Table 1. The Social Determinants of Health. Source: Henry J. Kaiser Family Foundation [Artiga et al. 2018]

Economic Stability	Neighbourhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
- Employment - Income - Expenses - Debt - Medical bills - Support	- Housing - Transportation - Safety - Parks - Playgrounds - Walkability - ZIP code / geography	- Literacy - Language - Early childhood education - Vocational training - Higher education	- Hunger - Access to healthy options	- Social integration - Support systems - Community engagement - Discrimination - Stress	- Health coverage - Provider availability - Provider linguistic and cultural competency - Quality of care
Health Outcomes Mortality, Morbidity, Life Expectancy, Health Care Expenditure, Health Status, Functional Limitation					

Despite the global consensus for action across sectors to adopt a "Health in all Policies" approach and reduce health inequities, set out in a dedicated Resolution of the World Health Assembly (WHA62.14) [6] [WHO 2009], no significant progress has been made in the majority of countries. The lack of access to medically necessary health care for thalassaemia, as described in previous chapters, still has significant social and economic repercussions, which remain unmet, often forcing patients into poverty and out of the workforce.

In many countries, out-of-pocket expenditure for access to essential health care services forces people to choose between paying for care and paying for other family and business necessities, reaching the catastrophic levels of more than 40% of household income net of subsistence [ILO 2020] and the unavoidable increase of mortality rates amongst the affected communities.

In this context, social protection or security, in the form of state social benefits, is necessary to alleviate the burden caused by ill health and reduce the indirect costs of disease and disability, such as lost years of income due to short- and long-term disability, care of family members, lower productivity, and the impaired education and social development of children [ILO 2008, 2020 and 2021]. Defined as "all measures providing benefits in cash or in kind to guarantee income security and access to health care" [UN 2018], social health protection is considered as key to achieve universal health coverage and social justice and inclusion for people with thalassaemia.

The right to social security and protection is recognised in numerous human rights instruments, including the Universal Declaration of Human Rights (Article 22) and the International Covenant on Economic, Social and Cultural Rights (Article 9) and is crucial for guaranteeing a life in dignity. As a fundamental human right, social security is a potent tool to combat discrimination and an essential instrument for reducing poverty and promoting social inclusion. It aims to provide income security and support at every stage of life for everyone, with particular attention to the most marginalised.

An effective social health protection system provides universal access to needed health care and financial protection that is i) accessible to cover all persons, especially those belonging to the most disadvantaged and marginalized groups, without discrimination; ii) available under domestic law to ensure that benefits are effectively administered and supervised; iii) adequate so that everyone may realise his or her rights to family protection and assistance, a reasonable standard of living and access to health care; and iv) affordable to reduce inequalities.

Considering the above, this Chapter aims to present how the social determinants of health currently affect the global thalassaemia community and identify the social protection schemes currently available to people with thalassaemia with the aim to highlight certain areas of concern for policy consideration, based on the four aforementioned pillars.

METHODOLOGY

Targeted Literature Review – Social Integration and Thalassaemia

A first targeted literature review was conducted to update the Global Thalassaemia Review 2022 findings and identify those social determinants of health that affect the thalassaemia community. Articles with open access and drafted in English were selected. Eighty-eight articles have been reviewed, published between 2013 and 2023 and coming from all six WHO regions.

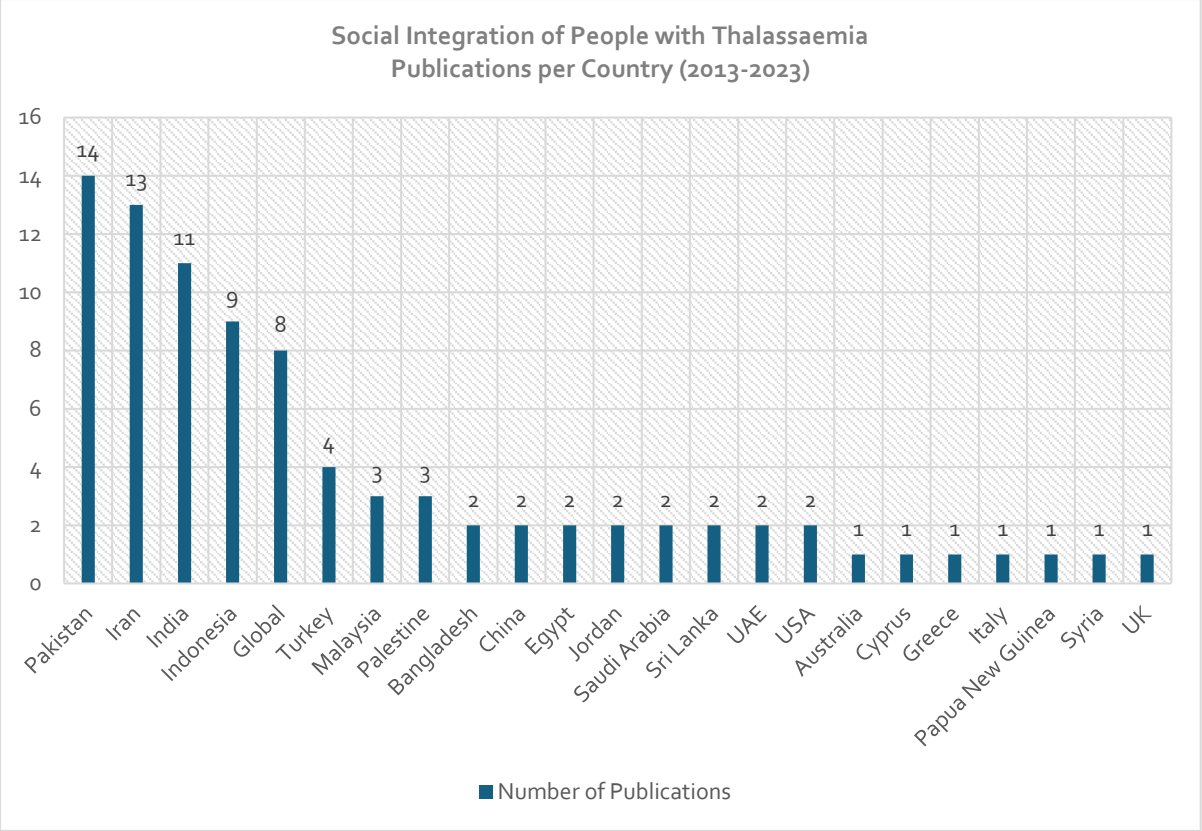

Figure 1. Social Integration of People with Thalassaemia, Publications per Country (2013-2023)

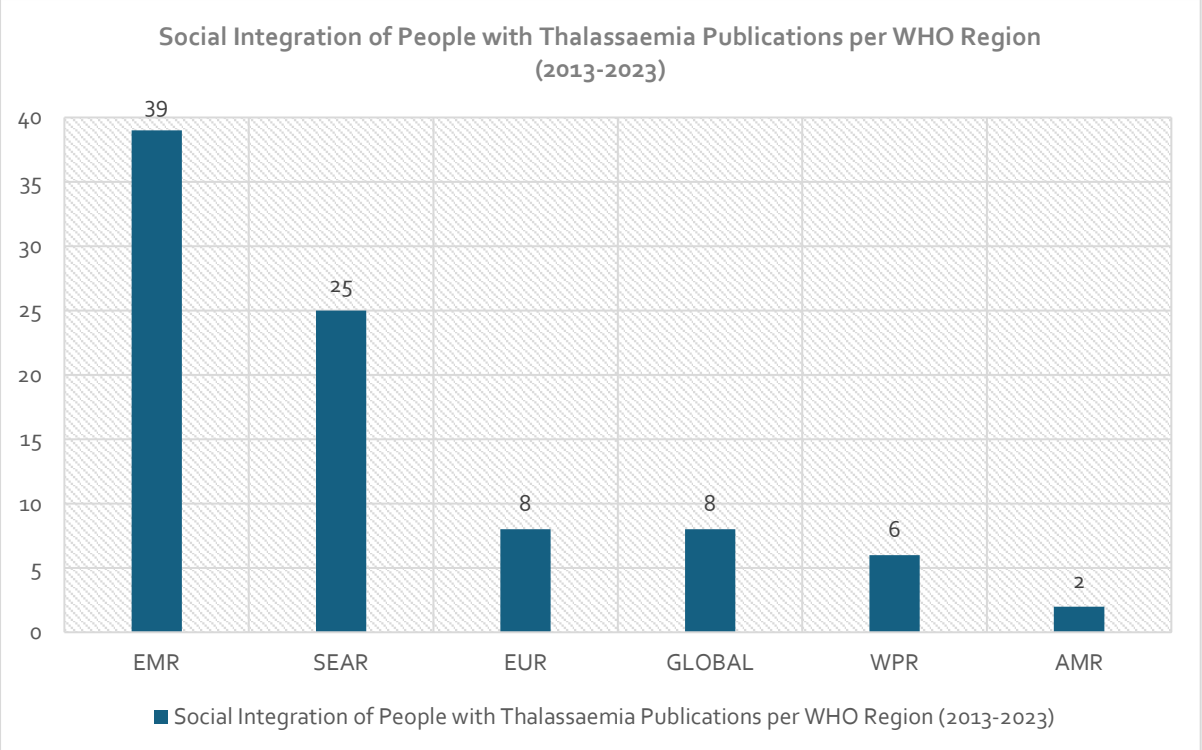

Figure 2. Social Integration of People with Thalassaemia, Publications per WHO Region (2013-2023)

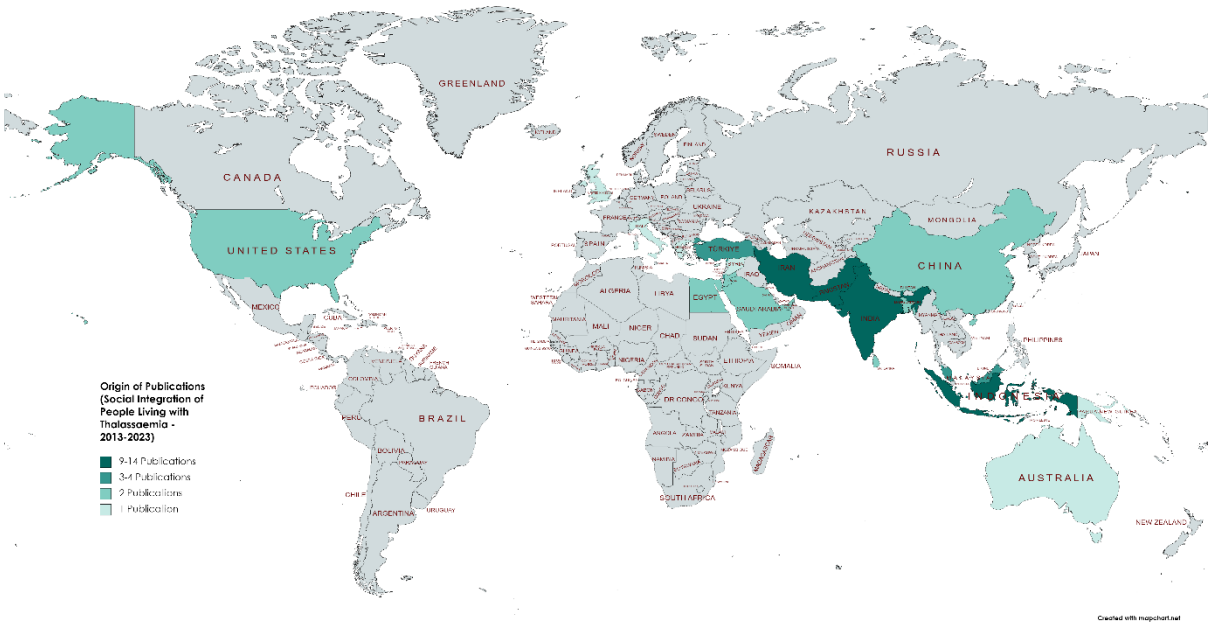

Figure 3. Origin of Publications (Social Integration of People Living with Thalassaemia, 2021 – 2023)

Fourteen (14) articles focus on people with thalassaemia living in Pakistan, 13 on Iran, 11 on India and 9 on Indonesia. Other publications come from Turkey (4), Malaysia and Palestine (3 per country), Bangladesh, China, Egypt, Jordan, Saudi Arabia, Sri Lanka, United Arab Emirates, United States (2 per country), Australia, Cyprus, Greece, Italy, Papua New Guinea, Syria, United Kingdom (1 per country). Eight publications provide a global image of the social integration of people living with thalassaemia. Most reviewed articles were published in the Eastern Mediterranean and South-East Asian regions that host the majority of the global thalassaemia population (see Chapter 1 on epidemiology).

A steady increase in the number of publications was noted between 2019 and 2023. This correlates with the emergence, spread and containment of the Covid-19 pandemic and the rise of mental health issues that heavily affected both patients and their caregivers. (https://www.who.int/teams/mental-health-and-substance-use/mental-health-and-covid-19)

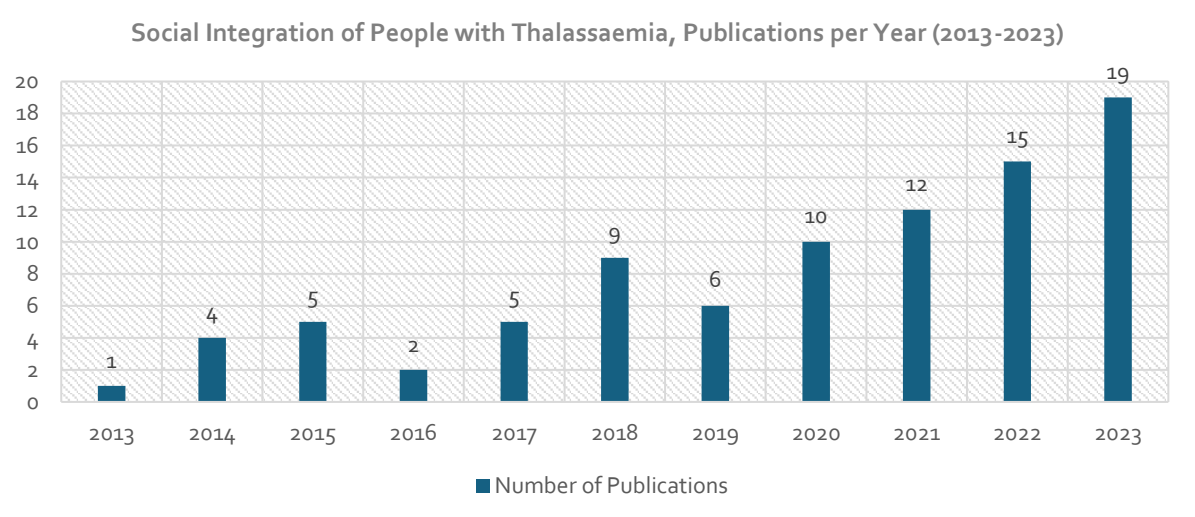

Figure 4. Social Integration of People with Thalassaemia, Publications per Year (2013-2023)

Targeted literature review findings were then compared to the findings of the TIF Global Surveys 2022-2023 ("Latest Survey") and 2020-2021 ("Past Survey") and are presented further below.

Targeted Literature Review – Social Benefits and Thalassaemia

A second targeted literature review aimed at identifying the current provision of social and disability benefits for patients with haemoglobin disorders (thalassaemia and sickle cell disease) in 38 countries. Country selection was based on three criteria: i) prevalence of haemoglobin disorders; ii) presence of a patient association (Member of TIF); and iii) availability of data. Research work was thus organised in three phases, starting from a more specific research framework focusing on a smaller population (i.e., people with haemoglobin disorders) and ending with a more general one (i.e., people with disabilities). Phase 1 was designed to identify disease-specific allowances and yielded a very limited number of results, mainly focusing on four countries: Cyprus, Greece, Italy and India. Phase 2 had a slightly broader scope, focusing on the identification of benefits for people with haematological diseases, congenital diseases, non-communicable diseases or rare diseases, an umbrella group in which people with thalassaemia are usually included. Results were even less. We then proceeded to Phase 3, based on the fact that people with haemoglobin disorders often present a number of hidden or invisible or silent disabilities, linked to their age and progression of the disease, that are not immediately apparent and include but are not limited to chronic pain, sight or hearing impairments, diabetes, osteoporosis, endocrine or cardiac complications and functionality challenges. This more general approach to the subject in question allowed us to clarify the perception of different countries on disability and how they support affected people on their daily struggle. Key sources used were the publicly available database of the International Social Security Association that gathers information directly from the Ministries of Social Affairs of more than 180 countries and presents data in a concise manner, as well the World Social Protection Report (2017-2019) of the International Labor Organization.

TIF GLOBAL SURVEY 2022-2023

Until September 2023, TIF received 2071 responses, in both paper and electronic format, from patients and parents living in 48 countries of the world. Most responses (54.76%) came from lower-middle income countries of the Eastern Mediterranean and South-East Asia regions, as is the case of literature review articles.

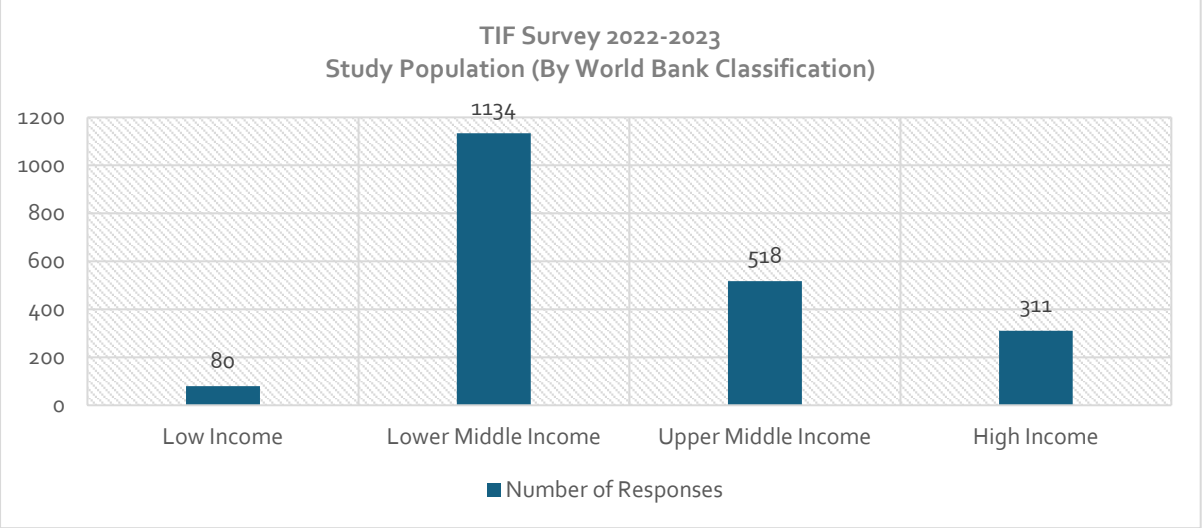

Figure 5. TIF Survey 2022-2023, Study Population (By World Bank Classification

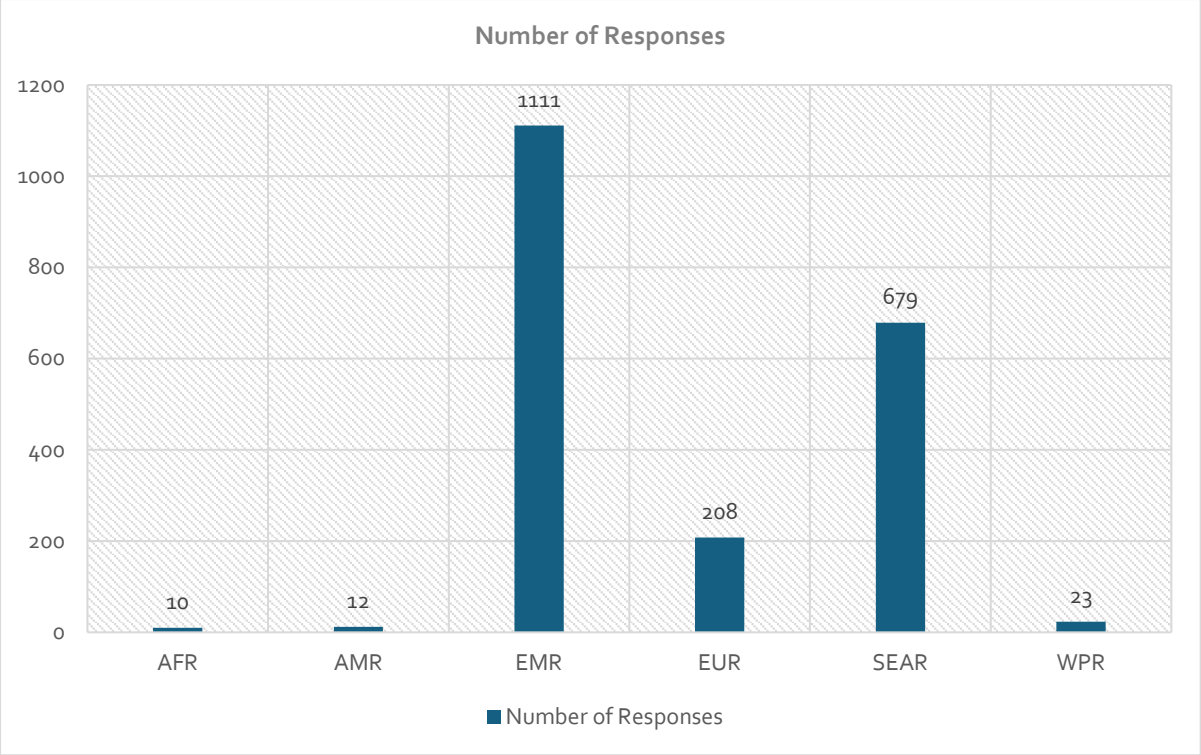

Figure 6. TIF Survey 2022-2023, Study Population (By WHO Region)

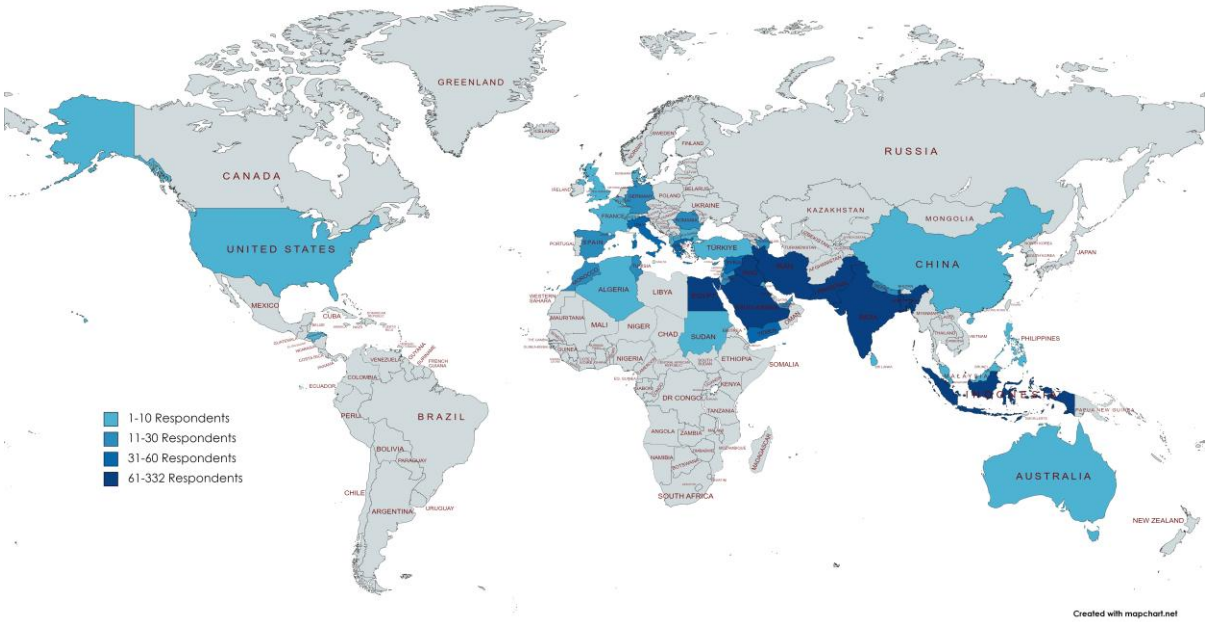

Figure 7. TIF Global Survey 2022 – 2023 respondents

The European region had the highest mean age of respondents (41.1 years old) and the South-East Asia region the lowest (21.4 years old). 1452 (70.11%) patients and 574 parents (27.72%) responded overall, more of whom were women (1075 – 51.9%) than men (868 – 41.91%). Questions focused, inter alia, on the status of employment, relationship status, out-of-pocket expenses, accessibility of treatment, loss of education or work due to treatment, factors that contribute to the patients' quality of life.

FINDINGS

Targeted Literature Review (Social Integration and Thalassaemia)

Overview

All publications focus on different psychosocial issues related to thalassaemia. Mental health issues are reported in the majority of articles (55 – 62.5%), while about one third of the reviewed publications shed light onto the importance of support systems, especially caregivers (e.g., parents, families, nurses). Four themes are also frequently discussed by the research community:

i. the importance of disease-specific education for the social integration of patients
ii. the correlation between patient's quality of care and quality of life
iii. the financial burden of healthcare and its negative impact on the social integration and quality of life of patients
iv. social integration as a multi-factorial challenge for people with thalassaemia.

Thirteen authors refer to the limited availability of services, especially psychological support, while ten note that people with thalassaemia are socially marginalised. Community engagement through awareness-raising campaigns is another method for social integration, frequently cited in literature. Transportation from and to hospitals, access to healthy options and provider competency are also reported in the reviewed documents.

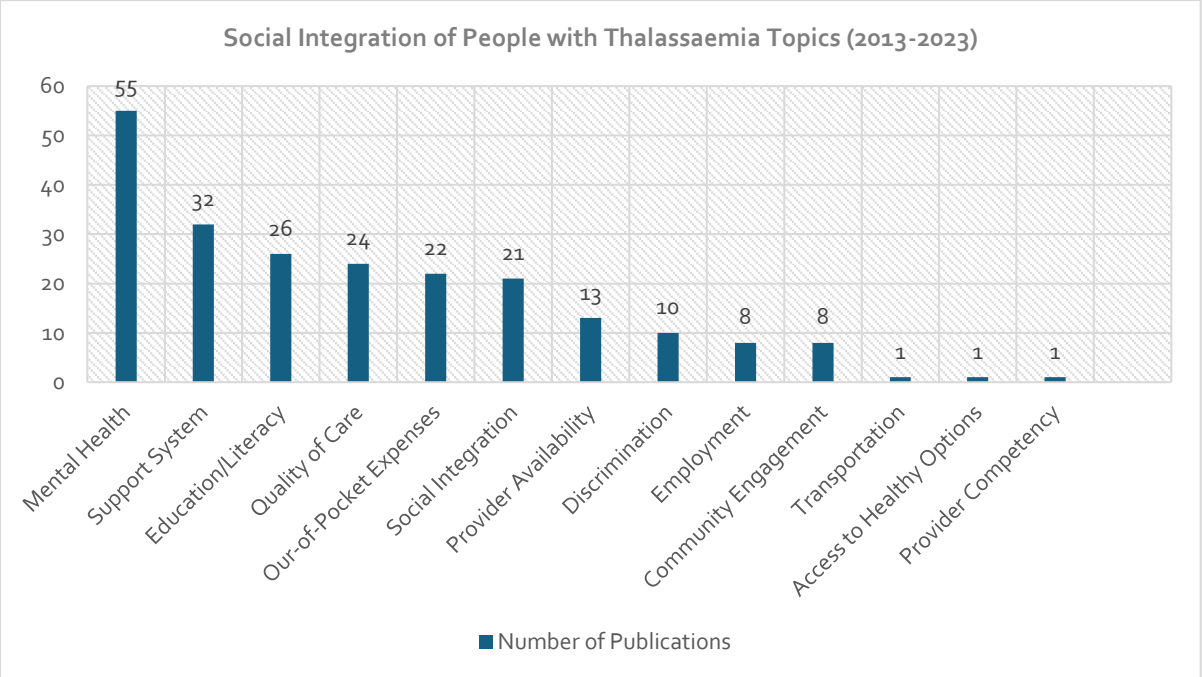

Figure 8. Social Integration of People with Thalassaemia Topics (2013-2023)

The above topics in focus fall under the social determinants of health (i.e., Economic Stability, Neighbourhood and Physical Environment, Education, Food, Community and Social Context, Healthcare System), as defined by the World Health Organisation. (https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1)

African Region

No publication from the region has been identified.

Region of the Americas

Topics of interest vary according to region, and the different needs of the patient community. Publications from the region of the Americas mainly focus on the financial burden of the disease for patients and their families and on the added value of social benefits for the social inclusion and integration of people with thalassaemia. This focus indicates that further social support is needed in the region for patients to have access to appropriate care.

Table 2. AMR Publications

Abbreviation of Article	Country
Abdelaziz et al. 2023	United States
Afzal et al. 2023	United States

Eastern Mediterranean Region

The Eastern Mediterranean region focuses on the financial burden of the disease, as well, highlighting the challenges of families, as caregivers and the affordability of essential treatment and testing. The loss of productivity at work due to absenteeism is repeatedly mentioned in literature, as well, indicating the need to raise community awareness and strengthen support systems, whether community-based or national.

Table 3. EMR Publications

Abbreviation of Article	Country
Al Sabbah et al. 2017	Egypt
Alam et al. 2021	Pakistan
AlHamawi et al. 2023	Palestine
Ali Syed et al. 2020	Jordan
Al-sayed et al. 2022	Saudi Arabia
Alshamsi et al. 2021	Iraq
Amid et al. 2015	UAE
Angastiniotis et al. 2022	Pakistan
Bagul et al. 2023	Iran
Batool et al. 2022	Pakistan
Behdani et al. 2015	Jordan
Bibi et al. 2021	Iran
Chattoo et al. 2014	Iran
Dini et al. 2020	Pakistan
Ghada 2016	Pakistan
Ghorbanpoor et al. 2020	Pakistan
Greco et al. 2022	Syria
Greco et al. 2022 (2)	Iran
Heidari et al. 2020	Palestine
Henny et al. 2017	Iran

Abbreviation of Article	Country
Hossain et al. 2023	Iran
Imtiaz et al. 2020	Iran
Irsa et al. 2022	Iraq
Ishfaq et al. 2018	Iran
Isler et al. 2018	Pakistan
Jajhara et al. 2021	Iran
Jeesh et al. 2018	Egypt
John et al. 2013	Saudi Arabia
Karakul et al. 2022	Pakistan
Khodashenas et al. 2021	Pakistan
Kohlbry et al. 2023	Palestine
Kumar et al. 2018	Pakistan
Kumaravel et al. 2016	Pakistan
Lintang et al. 2020	UAE
Maheri et al. 2018	Iran
Mahnoudi et al. 2019	Pakistan
Mardhiyah et al. 2022	Pakistan
Mardhiyah et al. 2023	Iran

European Region

Researchers in the European region have raised the alarm on the mental health state of patients and the availability of multidisciplinary care at their treatment centres. What remains challenging in some countries is access to appropriate care by patients living in rural or remote areas and in most countries the loss of a significant number of days from school and work. It is evident that patients seek education-work-life-treatment balance.

Table 4. EUR Publications

Abbreviation of Article	Country
Maryam et al. 2019	Cyprus
Mathhiesson et al. 2023	UK
Mettananda et al. 2019	Turkey
Mettananda et al. 2021	Greece
Mikael et al. 2018	Turkey
Naderi et al. 2021	Italy
Nagiria et al. 2021	Turkey
Nargis et al. 2023	Turkey

Southeast Asia Region

People with thalassaemia living in the South-East Asia region that hosts the majority of the global thalassaemia population still face major challenges in their daily lives. Literature indicates that patients and their families are financially drained, as universal health coverage is not available in the vast majority of countries. This, combined with the loss of days from school and work, heavily affects their quality of life. Researchers thus stress the importance of the quality of care and explain why, combined with social support, may improve the overall well-being of the patient community.

Table 5. SEAR Publications

Abbreviation of Article	Country
Punaglom et al. 2019	Bangladesh
Ramadan et al. 2022	Indonesia
Rashid et al. 2020	Indonesia
Raza et al. 2015	Bangladesh
Rubab et al. 2023	India
Sahu et al. 2023	India
Saldanha et al. 2015	India
Saqlain et al. 2023	Indonesia
Sarhan et al. 2022	Indonesia
Septyana et al. 2019	Indonesia
Sevinç 2023	Sri Lanka
Sevinç 2022	Sri Lanka
Shafi et al. 2021	India
Siddiqui et al. 2014	Malaysia
US Social Security Administration 2023	India
Sodani 2017	Indonesia
Suaan et al. 2023	India
Taheri et al. 2020	India
Thiyagarajan et al. 2019	Indonesia
Uchil et al. 2023	India
Ul Hassan et al. 2020	India
Venty et al. 2018	India
Wangi et al. 2023	Indonesia
Yousuf et al. 2022	Indonesia

Western Pacific Region

Researchers living in the Western Pacific region reports that mostly patients and their families bear the financial burden of treatment, noting that adherence to treatment is also an issue to be addressed. There is a special interest in education and a discussion on how disease-specific literacy may the overall quality of life of patients.

Table 6. WPR Publications

Abbreviation of Article	Country
Zaheer et al. 2015	Australia
Zakiyah et al. 2018	Papua New Guinea
Zeykani et al. 2018	Malaysia
Zhang et al. 2023	China
Zhen et al. 2023	China

The mixed picture, briefly described above, shows that health inequalities exist within and across countries and regions of the world. It is evident, however, that in the last years and in all regions, the COVID-19 pandemic and subsequent geopolitical crises have exacerbated existing inequalities and further stressed the need to provide patients with social protection.

Abbreviation of Article	Country
Nasiri et al. 2014	Review (Global)
Othman et al. 2022	Review (Global)
Palanisamy et al. 2017	Review (Global)
Phang et al. 2021	Review (Global)
Platania et al. 2017	Review (Global)
Prajapati et al. 2021	Review (Global)
Pranandita et al. 2021	Review (Global)

Targeted Literature Review (Social Benefits and Thalassaemia)

In the context of this study, we perceive social benefits as essential interventions to address the social determinants of health in each country and ensure a better quality of life for patients. (Hakeem, G.L.A., Mousa, S.O., Moustafa, A.N. et al. Health-related quality of life in pediatric and adolescent patients with transfusion-dependent ß-thalassemia in upper Egypt (single center study). Health Qual Life Outcomes 16, 59 (2018). https://doi.org/10.1186/s12955-018-0893-z)

People with haemoglobin disorders are entitled to three categories of benefits: i) General Population Benefits, i.e., benefits on their status as citizens, in the context of the contributory social insurance schemes of each country (child and family, maternity, sickness, unemployment, employment injury, survivors, old age, invalidity and disability benefits); ii) Disability Benefits, i.e., benefits on their status as disabled persons, either contributory (under the social security legislation) or non-contributory (under the disability legislation), provided in the context of the disability assessment policy in place and if patients are deemed eligible; and iii) Disease-specific Benefits, i.e., benefits on their status as people with haemoglobin disorders, either contributory (under the social security legislation) or non-contributory (under the disability legislation), in the context of disease-specific policies in place.

OVERVIEW

General Population Benefits

While not all countries globally have ratified the social security conventions of the International Labour Organization, they all have at least one social protection programme or scheme anchored in national legislation, either contributory or non-contributory. Contributory programmes provide for social insurance benefits, addressed to employed or self-employed persons, based on their level of contributions to one or more dedicated national funds. These may include benefits or quotas to support children and families, education, maternity, sickness, unemployment, old age, invalidity or disability caused at work. Non-contributory programmes are rarer and addressed to people who are unable to work for various reasons and often live in poverty, not being able to cover housing, subsistence, education or healthcare costs.

Based on our findings, inequities do exist between countries and regions, as high-income countries have more robust and inclusive social security systems, while low-resource countries focus on essential provisions, mostly linked to old age. This leaves the social determinants of health unaddressed to a large extent in most countries with high prevalence in thalassaemia, forcing patients to enter into poverty and limiting their access to appropriate health and other care.

Disability Benefits

Disability benefits are granted, fully or partially, under either the social security or disability laws, to those who fulfil the national disability assessment criteria, varying significantly between high, medium and low resource countries (World Bank Group (2015). Assessing Disability in Working Age Population: A Paradigm Shift from Impairment and Functional Limitation to the Disability Approach, at: http://documents1.worldbank.org/curated/en/272851468164970738/pdf/Disability-Assessment-Report-June-18-2015.pdf). In high-income countries, disability assessment follows the World Health Organization's International Classification of Functioning, Disability and Health (ICF), which was approved by all WHO member states in 2002. A mixed method is adopted that takes into account the level of impairment, the functional capacity and the level of disability (visible and invisible) of patients. Most medium-income countries perceive disability as physical impairment (e.g., Argentina, India, China). Low-income countries (e.g., Bangladesh, Cambodia, Nepal, Republic of Congo), have either not adopted a disability definition or follow informal procedures for disability assessment, based on medical reports (International Social Security Association – Country Profiles (2019) at https://ww1.issa.int/country-profiles).

Our findings indicate that the vast majority of countries cover the needs of disabled persons through the national social security programmes or schemes and have thus not adopted a national legislation dedicated to disability. This explains why the vast majority of countries do not provide or provide very confined non-contributory benefits to disabled persons, creating inequities and not supporting the social determinants of health.

Disease-specific Benefits

Disease-specific benefits addressed to people with thalassaemia are provided in a limited number of countries (Cyprus, Greece, Italy, India, United Arab Emirates), where disease-specific policies exist under the existing social insurance or disability laws.

The table in Annex II summarises our findings, presenting data collected for 38 countries worldwide regarding available benefits.

African Region

Countries of the region lag behind the implementation of social policies in support of patients and their families. No disease-specific benefits are available, while disability benefits are linked to the social insurance contributory schemes in each country.

Region of the Americas

While most countries of the region provide both general population and disability benefits, no disease-specific benefits are available.

Eastern Mediterranean Region

There is vast heterogeneity within the region with regard to the provision of social benefits, which is generally considered limited. Only the United Arab Emirates provide limited disease-specific benefits to people with thalassaemia and their families:

UNITED ARAB EMIRATES: In the United Arab Emirates, people with thalassaemia, Emirati nationals (irrespective of being patients or not) receive a monthly allowance from the Ministry of Community Development that varies between $1,500–$2,000 (if patients are under the age of 18) and $3,000–$5,000 (if patients are over the age of 18). They also receive support from the H.H Sheikh Sultan Bin Khalifa Al Nahyan Humanitarian & Scientific Foundation to either join the national bone marrow transplant programme, have access to job-specific training or find employment.

European Region

While all countries have ratified the ILO Social Security Conventions and provide general population and disability benefits, a heterogeneity is noted in the level of implementation and effectiveness of these measures. Disease-specific benefits are available in Cyprus, Greece and Italy that showcase the highest level of social integration for people with thalassaemia. More specifically:

CYPRUS: In Cyprus, people with thalassaemia patients are not considered disabled persons but may apply for a disability assessment if they wish so. There is a number of disease-specific state social benefits provided though, including a monthly allowance of €75–€150 for their transport to and from the thalassaemia centres, depending on their place of residence, a municipal tax reduction of 40%–50% (regarding waste collection), facilitation of employment in the public sector and access to public universities in the context of the disability law (10% of available positions must be taken from people from all disabilities groups). Patients may also participate for free in sports classes provided by the Cyprus Sports Organization

GREECE: In Greece, disease-specific social benefits include the annual provision of 22 leave days for patients and their parents for blood transfusions, the coverage of transport expenses for patients that live far from their treating centres, a monthly allowance as financial support, the right to full retirement after 15 years of employment, facilitated access (by quotas) to higher education and employment. People with a 67% disability can claim a disability pension after 5 years of employment and are entitled to tax exemption for the purchase of a car.

ITALY: In Italy, social benefits for people with thalassaemia are granted either pursuant to specific disease-specific legislation or to provisions pertaining to people with disabilities, if patients undergo a disability assessment. Under the Economic Law of 2002, article 39, DPR 448/01, people with thalassaemia over 35 years of age and with at least 10 years of social insurance contributions are entitled to a monthly allowance of c. €500. Other disease-specific benefits include the coverage of expenses for transportation for patients that live far from their treating centre (valid in Sicily), the provision of a bi-monthly financial support for all the people with permanent damages due to unsafe blood transfusions or mandatory vaccination (according to Law 210/92), a tax reduction of 19% (as per the personal income tax legislation), a 19% reimbursement of healthcare expenses, tax reductions for the purchase of cars, computers, phones and tablets and additional leave days of parents taking their children to thalassaemia centres. A number of benefits are also provided based on disability-specific legislation and assessment. More specifically, a disability pension is provided if disability exceeds 67%, while parents of children with disabilities receive an allowance only if their income is below a given threshold. Early retirement and easier access to higher education are also possible based on the outcome of the disability assessment.

South-East Asia Region

While there are limitations to the provision of social benefits and low rates of implementation of social legislation based on the ILO Conventions, India is the only country in the region that has passed legislation on disability that includes people with thalassaemia. More specifically:

INDIA: In India, people with thalassaemia, sickle cell disease and haemophilia having a disability of 40% and above ("benchmark disability") are considered disabled persons under the Rights of Persons with Disabilities Act (RPWD) of 2016 and are provided with a Disability Certificate that gives them access to numerous social benefits. These include the provision of a long-term allowance (of at least 2 years) to unemployed people with thalassaemia registered with Special Employment Exchange, a care-giver allowance to address high support needs; a comprehensive insurance scheme, incentives to employers in the private sector to ensure that at least 5% of their workers are disabled persons, facilitation of access to higher education institutions by reserving 5% of available positions to persons with benchmark disabilities. Moreover, people with haemoglobin disorders are given priority in attendance and treatment, loans at concessional rates including that of microcredit, allotment of agricultural land and housing also at concessional rates, access to developmental schemes and programmes and financial aid if they are facing cardiac, liver, endocrine complications, bone disease/ deformity/ osteopenia or are affected with Hepatitis B, C and/or HIV.

Western Pacific Region

This is a two-speed region, given that countries such as Australia and China have general population benefits available, while Cambodia has no such policy in place.

SURVEY

INDIA: In India, people with thalassaemia, sickle cell disease and haemophilia having a disability of 40% and above ("benchmark disability") are considered disabled persons under the Rights of Persons with Disabilities Act (RPWD) of 2016 and are provided with a Disability Certificate that gives them access to numerous social benefits. These include the provision of a long-term allowance (of at least 2 years) to unemployed people with thalassaemia registered with Special Employment Exchange, a care-giver allowance to address high support needs; a comprehensive insurance scheme, incentives to employers in the private sector to ensure that at least 5% of their workers are disabled persons, facilitation of access to higher education institutions by reserving 5% of available positions to persons with benchmark disabilities. Moreover, people with haemoglobin disorders are given priority in attendance and treatment, loans at concessional rates including that of microcredit, allotment of agricultural land and housing also at concessional rates, access to developmental schemes and programmes and financial aid if they are facing cardiac, liver, endocrine complications, bone disease/ deformity/ osteopenia or are affected with Hepatitis B, C and/or HIV.

1. The majority of people with thalassaemia living in developing countries of the world are not employed and/or not in position to work due to disability. This is in sharp contrast with developed countries, where most patients are employed full-time and in retirement.
2. Most people with thalassaemia living in developed countries are married. This indicates that patients living in these regions have a good quality of life, consider personal life and seek companionship.
3. The level of education of people with thalassaemia greatly varies across the globe, with the region of the Americas hosting the most educated patients – holders of a master's degree. This very fact highlights the correlation between the level of care and education, as well as the existing inequalities between regions of the world.
4. Countries of the South-East Asian region lag behind with the implementation of universal health coverage policies as patients report out-of-pocket expenses for essential treatment, i.e. transfusion and chelation drugs. This indicates that access to healthcare is cumbersome for patients and their families, who already deal with an alarming increase in poverty rates.
5. People with thalassaemia living in the European region benefit the most from access to state-provided, free healthcare.
6. Accessibility of treatment in the Eastern Mediterranean region is reportedly difficult, mostly due to the high cost of both travel to the treating centres and treatment.
7. In all regions globally, patients lose more than 16 days annually in education/work. This signals a need for work-life-treatment balance, a need to sensitise the school and professional settings of thalassaemia and its impact on the daily lives of patients.

Survey findings are presented in **Annex I.**

African Region

In the African region, most people with thalassaemia are unemployed but looking for work (40%). A significant percentage (60%) is cohabiting with their partners, with marriage not being generally preferred (20%). About one third of survey respondents are high school graduates and another third hold a master's degree. Two thirds of respondents pay out of pocket for chelation drugs, laboratory tests and MRI tests, and half of them for multidisciplinary care. In the absence of universal health coverage, the financial burden of treatment is mostly borne by patients themselves and their families (80%), is deemed difficult (60%) and costly (50%). Access to treatment centres is poor and patients lose more than 16 days per year from education and work.

Region of the Americas

Survey respondents living in the region of the Americas, namely Honduras, Trinidad and Tobago and the United States, report that they are employed, working full-time (58.30%), while a significant percentage of 16.70% is neither employed nor looking for work. With regard to relationship status, almost half of the respondents are married (41.70%), with an equal percentage being single. The cost of treatment is mainly borne by patients and their families (50%), even if access thereto is considered easy (41.70%). People with thalassaemia living in the region lose more than 16 days per year from education or work.

Eastern Mediterranean Region

More than one third (35%) of people with thalassaemia living in the region are unemployed and looking for work. With regard to their relationship status, about one third reports being married, while 11% of respondents are divorced, the highest rate globally. The education level amongst respondents varies, with 29.30% not being able to graduate from high school and 27.80% being university graduates. Out-of-pocket expenses are necessary for access to essential treatment and testing, borne by patients and their families (58.33%). The accessibility of treatment is deemed rather difficult, mostly because of the high cost of treatment (25.60%).

European Region

The majority of people with thalassaemia living in the region are employed, working full-time (40.90%) and married (46.60%). About one third of respondents are high school graduates and one third university graduates, holders of a bachelor's degree. While healthcare is state-provided and free for patients, patients report that out-of-pocket expenses occur for MRI tests (14.42%) and multidisciplinary care (26.44%). Access to treatment is considered very easy (19.70%) and easy (38.00%). While 29.30% of respondents note that no day from education or work is lost for treatment purposes, 42.30% reports losing more than 16 days per year.

South-East Asia Region

More than half of the respondents living in the region (52.40%) are not employed nor looking for work and prefer cohabitation with their partners (42.00%). The majority of respondents report that they did not manage to graduate from high school. Despite access to healthcare services is deemed easy (49.80%), patients and their families (73.64%) need to pay for essential care and tests, with one in five respondents finding it difficult to travel to the treating centres and have access to treatment due to high costs for travel and treatment,

respectively. More than 74% of respondents lose more than 11 days per year from education or work for their treatment.

Western Pacific Region

In the Western Pacific region, the majority of respondents are employed and full-time workers (43.50%). Almost half of them are married (47.80%) and almost half (47.80%) single. Education levels vary, with 26.10% not being able to graduate from high school and 30.40% being holders of a bachelor's degree. While the accessibility of treatment is relatively easy (30.40%), patients and their families need to pay out of pocket for essential healthcare (56.52%). The majority of respondents lose between 1 and 5 days from education or work for treatment purposes.

Combining findings from the Targeted Literature Review and TIF Survey 2022-2023

The vast heterogeneity within and across regions of the world indicates that social integration remains a huge global challenge. It is evident that in countries where healthcare is provided free of charge, in the context of universal health coverage, and combined with social benefits, patients have a better quality of life, i.e., they have a greater life expectancy, are able to get married and have a family, study and pursue a career, live independently without support from their families. As literature and patient testimonies have shown, thalassaemia places such a toll on the patients' lives that causes severe mental health issues both to them and their families who undertake the role of caregivers. This is not yet recognised enough even in developed countries and regions of the world, forcing patients to pay out of pocket for access to psychological support. This shows that a holistic approach in healthcare is needed, combined with targeted social measures to alleviate the daily burden of the disease and allow an easier social integration.

The combination and comparison of findings is available in Annex III below.

DISCUSSION

A. Quality of Life: Encompassing Quality of Care and Social Protection

The quality of life of people with thalassaemia and other haemoglobin disorders depends on two major factors: i) the quality of medical care they receive, including access to multidisciplinary care; and ii) their access to social protection schemes that safeguard them from the impact of the social determinants of health on their health outcomes [Klonizakis et al., 2023]. It is thus evident that the two factors need to be present in harmony and in an equilibrium in a national setting in order to achieve the optimal well-being and successful social integration of patients and thus alleviate the medical, public health, social and economic burden of the disease.

This can be easily understood by comparing the quality of services and the level of social integration of patients between developed and developing countries that present great discrepancies in terms of poverty, availability and effectiveness of services and social benefits. The general idea is that in countries where quality treatment

and multidisciplinary care are indeed available and so experience fewer or milder complications in vital organs, as set out in the previous chapters of this Review, patients are more easily integrated into society by having access to education, work and other opportunities. This allows them to become part of their country's ageing population and are thus entitled to social benefits that are available to either the general public or other vulnerable groups. Social benefits ease their access to both treatment and social life, allowing them to fully enjoy all their rights.

In Cyprus, a country of the developed world, thalassaemia has been prioritised on the national health agenda since the 1970s, in recognition of the immense medical, social, economic and public health repercussions that the disease would have by 2000, if an effective national control programme was not implemented. Such a programme allowed for the provision of services to focus on the appropriate and timely clinical management of patients, to enable them to live a longer, more fulfilling and active life. Today boasting one of the oldest thalassaemia patient populations in the world, evidenced by patients living into their 50s and 60s, Cyprus has also achieved significant strides in the social, educational and professional integration of patients. According to the latest available data [Angastiniotis et al., 2022], 53% of patients are university graduates, with an additional 40% having completed secondary education. Similar to the non-thalassaemia population, 53% of thalassaemia patients have chosen to marry. Most notably, however, is that an average of 61.6% of female patients of child-bearing age became mothers with approx. 291 pregnancies and giving birth to 328 children. At the same time there is a state-run social protection scheme in place that helps patients adhere to their treatments (transport allowances, flexible working hours at the thalassaemia centres to accommodate work-life-treatment needs), present less complications and have a better quality of life. This indicates that patients in Cyprus do enjoy an excellent quality of care that allows them to be fully integrated into society.

India, a large country, highly populated, with a high prevalence and a high number of annual affected births with haemoglobin disorders, felt the necessity in 2016 to include thalassaemia and sickle cell disease in its national disability legislation, in an effort to support and improve the survival and quality of life of these patients. This initiative was taken because of the absence of a national universal health coverage system, the highly heterogeneous level of health services and taking into account the very low socioeconomic status of the vast majority of patients. While the national disability legislation is comprehensive and includes a plethora of social benefits for all disabled persons, it does not directly support the access of patients to the national healthcare services. Therefore, the limited access of patients to quality care and the decentralised system of governance that assigns state authorities with the responsibility of implementing federal acts, according to budget availability, lead to poor health outcomes, with the quality of life of patients with such chronic, complex disorders, currently reaching a nadir.

It thus comes as no surprise that the disease-specific social protection scheme of India has not yielded concrete results yet for the thalassaemia population of the country that still struggles to address poverty-related challenges and to ultimately have access to basic treatment and care, covered by a universal health coverage scheme. In such a setting, any effort to support the social integration of patients would collapse, as the overall clinical condition of patients is the only factor allowing them to enjoy social security.

Consequently, the access of patients to appropriate care and social protection schemes that address the social determinants of health are prerequisites for a better quality of life.

B. Migrant populations in the European Union as part of the picture: Leaving no patient behind

In recent times, population movements have introduced new issues for displaced patients, whether they have migrated for economic reasons or are victims of forced migrations. Even though people have been travelling and moving from traditional homes for centuries, the 20th and 21st centuries have seen more mass movements, partly because travel is easier and partly because of political unrest and changes.

The economic gap between nations, especially in the post-colonial era, has led to a South to North movement which inevitably means from tropical and sub-tropical regions with a high prevalence of haemoglobin disorders to Northern areas which are also more economically robust, are often the ex-colonial powers and where these disorders are rare in the indigenous population. In addition, these 'Southern' states are arenas of political disturbance in the 21st century while Europe, which was in turmoil during the 20th and past centuries, has now found stability through economic partnerships and political groupings.

Sickle cell syndromes and the thalassaemia syndromes are becoming increasingly more common in the regions where they were previously rare and exotic medical entities and are forcing health services of host countries to adapt and consider services previously felt unnecessary; for example, neonatal screening to detect sickle cell and other variants is being adopted in Germany, Ireland, France and other EU Member states.

Beyond however the need to meet the medical requirements of patients, authorities need to consider the health-related social support. Chronic congenital conditions such as these require health insurance coverage which precludes out of pocket expenses while the medical needs are constant and many.

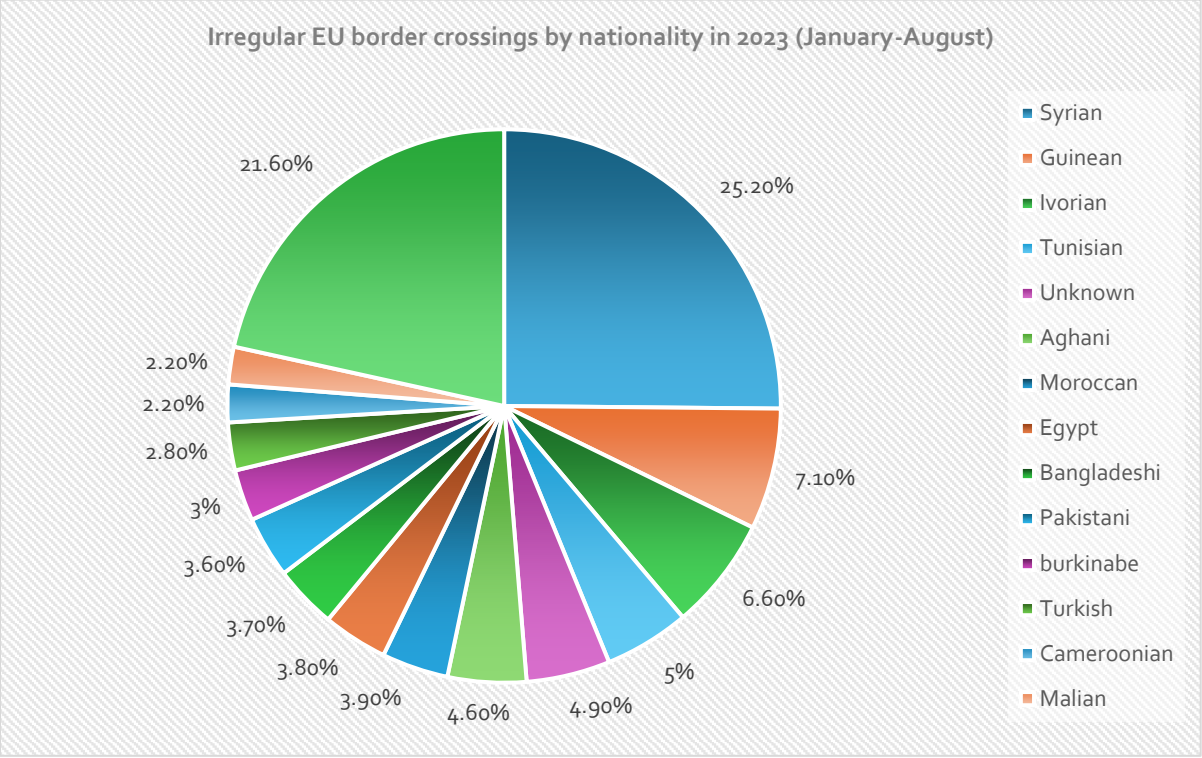

Figure 9. Irregular EU border crossings by nationality in 2023 (January-August). Source: https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/promoting-our-european-way-life/statistics-migration-europe_en

Settlers can be people who have been living in a host country for a long time and may have become naturalised citizens and to some extent integrated. The experience of integration over time may serve as an example for health authorities to deal with a new wave of migrants. Such new arrivals, however, face many problems, especially if unregistered in the host country. Language difficulties, often coupled by illiteracy lead to poor communication. Cultural barriers to issues related to prevention must be understood. New arrivals often have poor knowledge of their rights, are not aware of the local facilities and especially health insurance, and yet inadequate or inappropriate information is often offered to them. The plight of those living in detention or reception areas for long periods, including poor living conditions, poor finances, xenophobia, racism, gender inequalities, not being considered in public health measures (e.g., COVID-19). All these issues are inevitably political, and authorities must take notice.

A child needing blood transfusion and then regular follow-ups or a patient in acute vaso-occlusive crisis often visit inexperienced health professionals and services and may be asked to pay with money that they do not have. For health systems and welfare services to respond effectively, they need resilience in coping with new challenges. This depends on political and budgetary support but also on understanding of the issues and epidemiological knowledge, such as how many new patients and where in the country they are located. Social determinants must be known and support offered at all levels. Planning must include decisions concerning neonatal screening policies, the application of clinical standards to meet the needs of patients and to organise social support with, if need be, counselling on all issues in the language of the migrant.

The first priority is to provide health insurance coverage even to unregistered migrants. Access to care, including assistance for transport; recognising the need of the family as a whole for income and lodging is important; directing families to NGOs who can possibly offer support. All these are elements of immediate social support while long-term support for education and access to innovative therapies should also be considered.

In 2010, Atkin and Anionwo in the UK wrote: "Little more than twenty years ago, sickle cell and thalassaemia disorders could be dismissed as conditions of little interest to health and social care agencies." In 2023 we feel that these conditions are now a priority for these agencies.

C. The disease burden of thalassaemia: A new research field?

In light of the above, thalassaemia progressively causes a certain disease or disability burden, often quantified in terms of quality-adjusted life years (QALYs) or disability-adjusted life years (DALYs). Both of these metrics quantify the number of years lost due to disability (YLDs), sometimes also known as years lost due to disease or years lived with disability/disease. According to the Lancet Global Burden of Diseases, Injuries, and Risk Factors Study (GBD), published in 2019, people with thalassaemias, mostly living in low-resource countries of South-East Asia, indeed lose a number of healthy and productive years due to disability, consequent to suboptimal health and social care. The discussion on whether thalassaemia may be considered as a disability is presented in a separate chapter.

In general, accurate information on the burden of the disease remains fragmented due to the confined number of surveys and/or publications on this subject, the absence of national registries in most countries and consequently, the confined data available regarding the age distribution of the patient population, the life expectancy of patients or the cause of their death. The fragmentation is shown in Annex III, as data available is rather confined. Therefore, this is a field urgently calling for further investigation, research and policy action.

CONCLUSION

People with the most severe forms of thalassaemia syndromes need regular, lifelong blood transfusions and concomitant chelation therapy to stay alive. This means that they need to have uninterrupted access to treatment every 2–3 weeks, to the detriment of their education, as children, and work, as adults. To be able to have such access and at the same time a decent quality of life:

- Healthcare needs to be provided free of charge, as part of a national universal health coverage scheme, to alleviate parents and subsequently patients from the heavy financial burden of treatment
- Healthcare needs to be multidisciplinary and include mental health support services, given that patients often suffer from social isolation
- The general public, including schoolteachers and employers, need to understand the challenges of the disease and show compassion and solidarity to patients and their families
- Patients themselves need to know the clinical and non-clinical requirements for the management of their disease to feel empowered enough to pursue them in their respective national settings.

While heading towards 2030, the United Nations' Member States should take account of all tools available to "promote physical and mental health and well-being, and to extend life expectancy for all" and "achieve universal health coverage and access to quality health care" [UN Agenda for Sustainable Development], not leaving anyone behind, a commitment expressed in the 2030 Agenda for Sustainable Development. Unarguably, emphasis needs to be given to the provision of both quality health care and inclusive, individualised and disease-sensitive social care to address the social determinants of health and achieve optimal outcomes.

The position of the Thalassaemia International Federation is provided in Annex IV.

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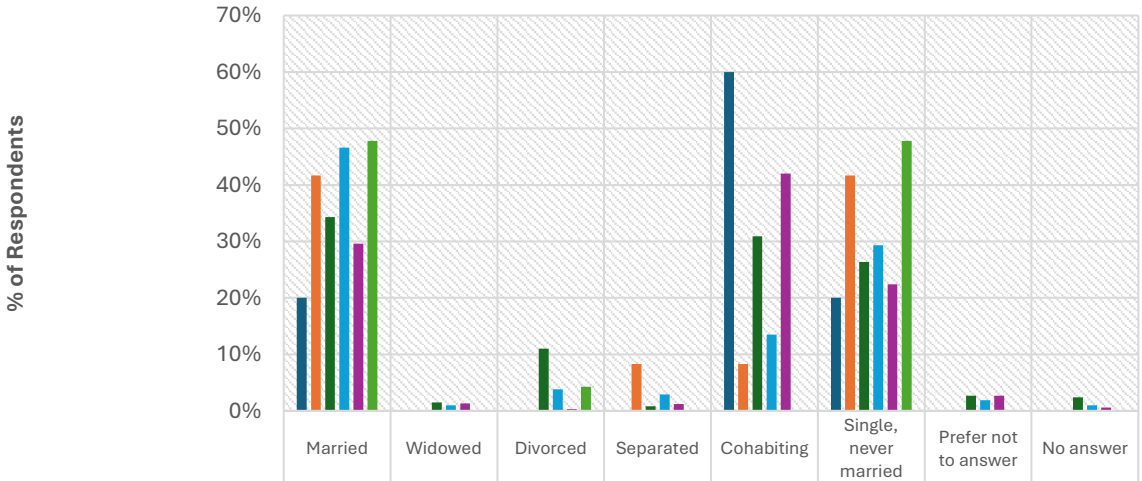
ANNEX I: Survey Results (Per Region)

Employment Status

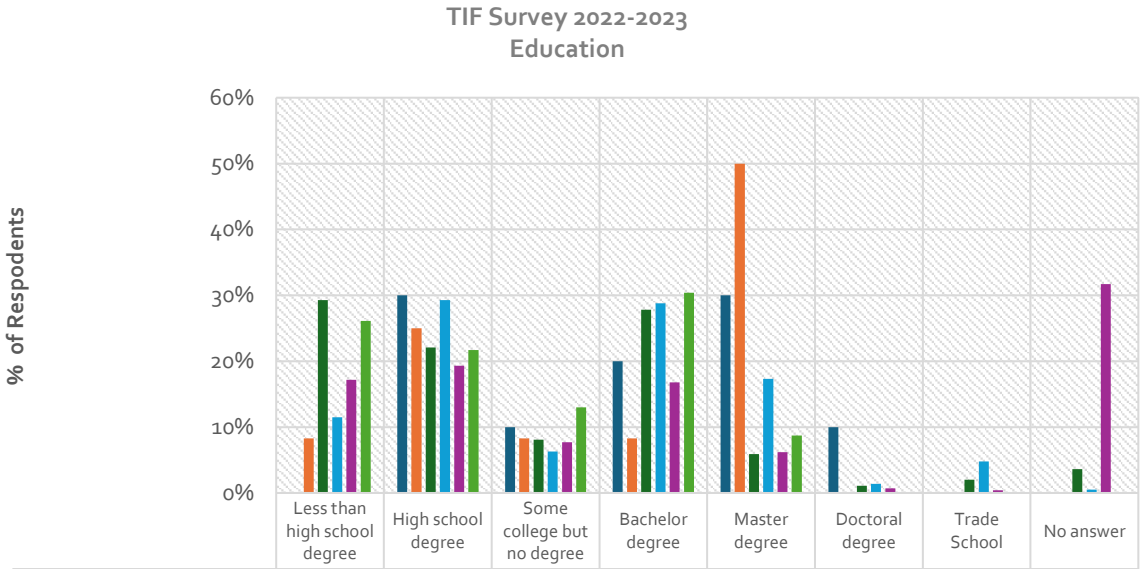
	Employed, working full-time	Employed, working part-time	Not employed, looking for work	Not employed, NOT looking for work	Retired	Disabled, not able to work	No answer
African Region	30%	10%	40%	20%	0%	0%	0%
Region of the Americas	58.30%	8.30%	8.30%	16.70%	0%	8.30%	0%
Eastern Mediterranean Region	20.60%	9.50%	35.10%	12.50%	2.10%	17.40%	2.80%
European Region	40.90%	12.00%	11.50%	6.70%	20.20%	7.20%	1.40%
South-East Asian Region	21.80%	7.70%	14.00%	52.40%	0.40%	2.90%	0.70%
Western Pacific Region	43.50%	8.70%	34.80%	4.30%	4.30%	4.30%	0%

Relationship Status



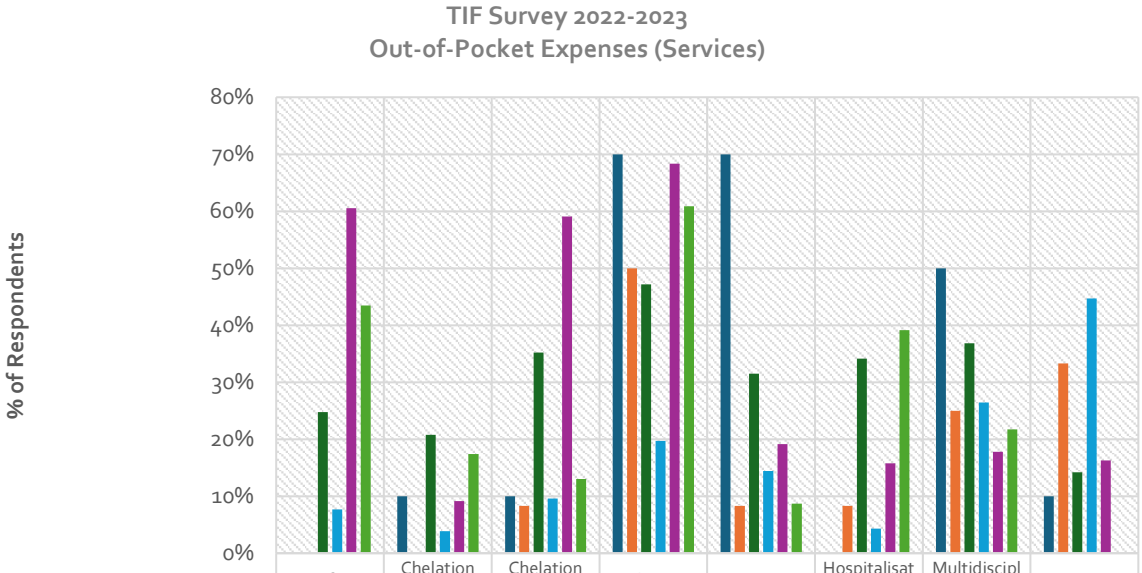
	Married	Widowed	Divorced	Separated	Cohabiting	Single, never married	Prefer not to answer	No answer
African Region	20%	0%	0%	0%	60%	20%	0%	0%
Region of the Americas	41.70%	0%	0%	8.30%	8.30%	41.70%	0%	0%
Eastern Mediterranean Region	34.30%	1.50%	11.00%	0.80%	30.90%	26.40%	2.70%	2.40%
European Region	46.60%	1.00%	3.80%	2.90%	13.50%	29.30%	1.90%	1.00%
South-East Asian Region	29.60%	1.30%	0.30%	1.20%	42.00%	22.40%	2.70%	0.60%
Western Pacific Region	47.80%	0%	4.30%	0%	0%	47.80%	0%	0%

Education



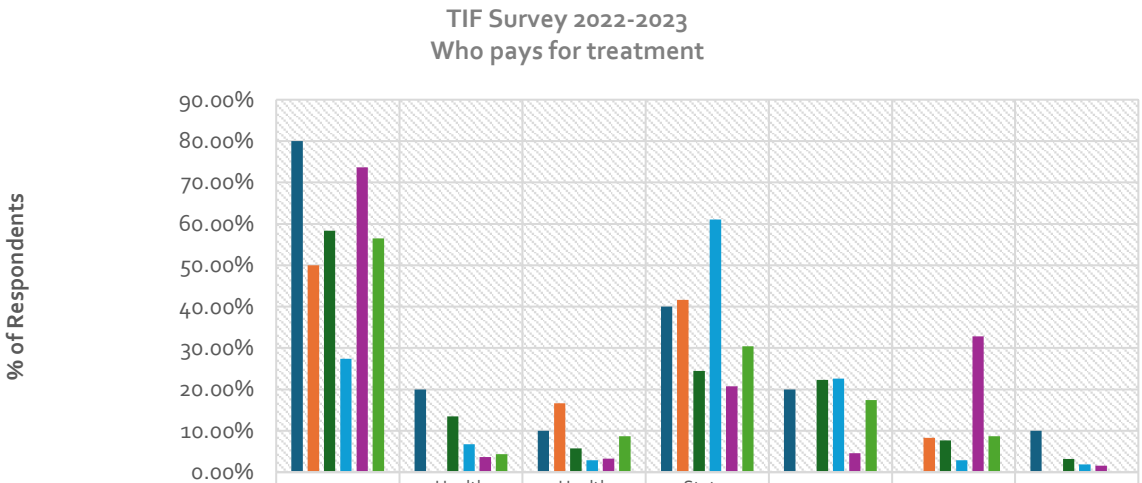
	Less than high school degree	High school degree	Some college but no degree	Bachelor degree	Master degree	Doctoral degree	Trade School	No answer
African Region	0%	30%	10%	20%	30%	10%	0%	0%
Region of the Americas	8.30%	25.00%	8.30%	8.30%	50.00%	0%	0%	0%
Eastern Mediterranean Region	29.30%	22.10%	8.10%	27.80%	5.90%	1.10%	2.00%	3.60%
European Region	11.50%	29.30%	6.30%	28.80%	17.30%	1.40%	4.80%	0.50%
South-East Asian Region	17.20%	19.30%	7.70%	16.80%	6.20%	0.70%	0.40%	31.70%
Western Pacific Region	26.10%	21.70%	13.00%	30.40%	8.70%	0%	0%	0%

Out-of-Pocket Expenses



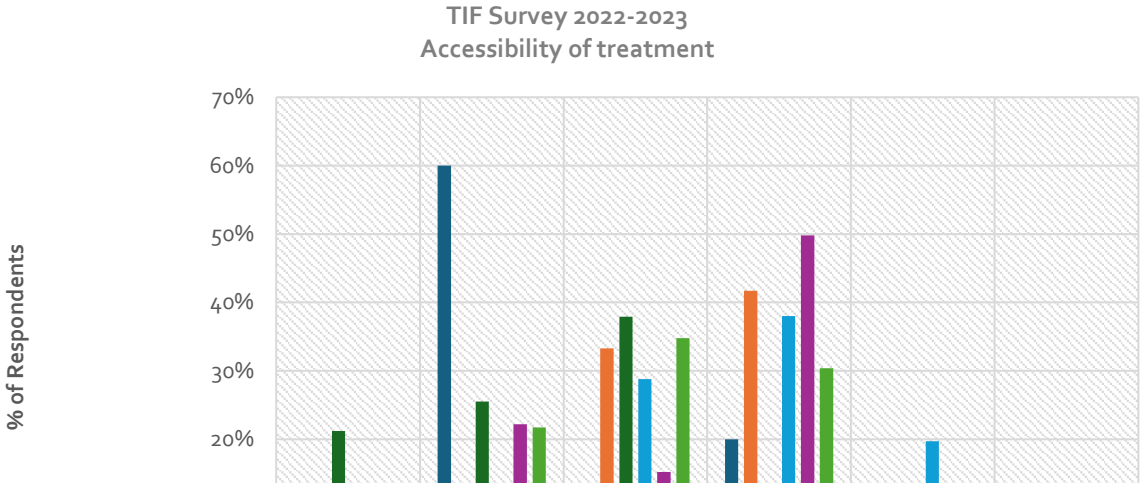
	Transfusion	Chelation pumps	Chelation drugs	Lab tests	MRI	Hospitalisation	Multidisciplinary Care	No answer
African Region	0%	10%	10%	70%	70%	0%	50%	10%
Region of the Americas	0%	0%	8.33%	50%	8.33%	8.33%	25%	33.30%
Eastern Mediterranean Region	24.75%	20.79%	35.19%	47.16%	31.50%	34.11%	36.81%	14.20%
European Region	7.69%	3.85%	9.62%	19.71%	14.42%	4.33%	26.44%	44.70%
South-East Asian Region	60.53%	9.13%	59.06%	68.34%	19.15%	15.76%	17.82%	16.30%
Western Pacific Region	43.48%	17.39%	13.04%	60.87%	8.70%	39.13%	21.74%	0

Who bears the financial burden of treatment



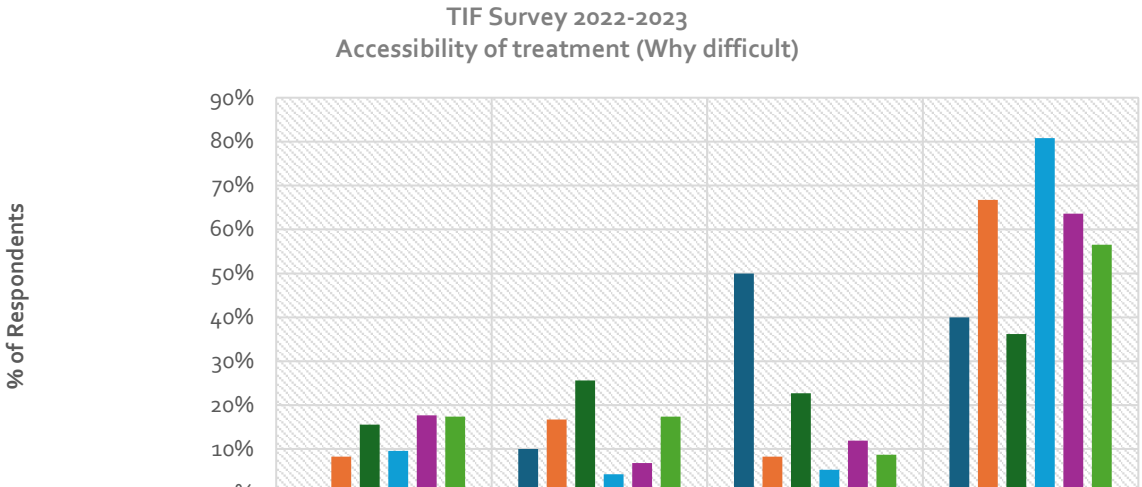
	Myself/My family	Health Insurance (private): mine	Health insurance (private): my employer's	State-provided free healthcare	State-provided, partly free	Other	No answer
African Region	80.00%	20.00%	10.00%	40.00%	20.00%	0.00%	10.00%
Region of the Americas	50.00%	0.00%	16.67%	41.67%	0.00%	8.33%	0.00%
Eastern Mediterranean Region	58.33%	13.50%	5.76%	24.48%	22.32%	7.65%	3.20%
European Region	27.40%	6.73%	2.88%	61.06%	22.60%	2.88%	1.90%
South-East Asian Region	73.64%	3.68%	3.24%	20.77%	4.57%	32.84%	1.60%
Western Pacific Region	56.52%	4.35%	8.70%	30.43%	17.39%	8.70%	0.00%

Accessibility of Treatment



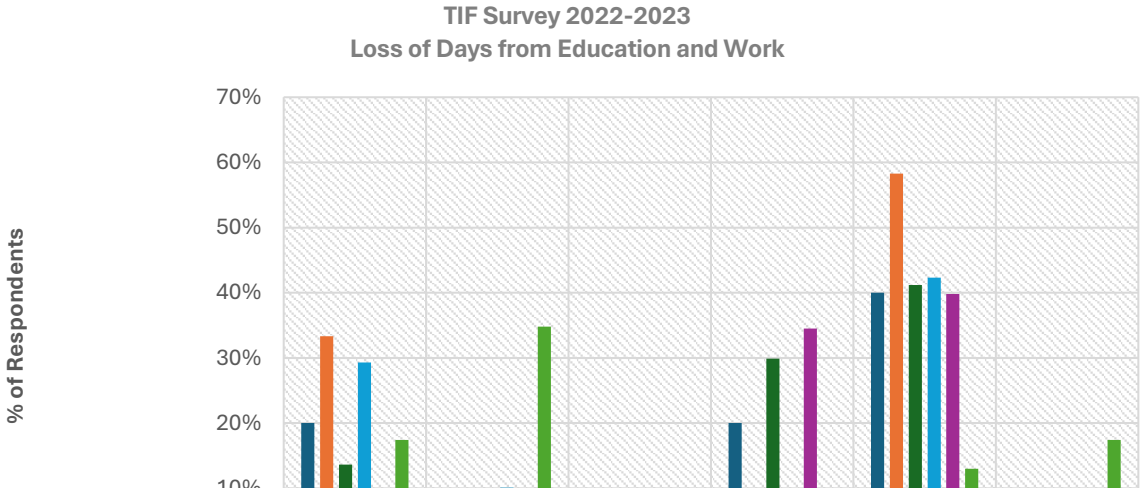
	Very difficult	Difficult	Neutral	Easy	Very easy	No answer
African Region	10%	60%	0%	20%	10%	0%
Region of the Americas	8.30%	8.30%	33.30%	41.70%	8.30%	0%
Eastern Mediterranean Region	21.20%	25.50%	37.90%	10.20%	2.80%	2.40%
European Region	3.40%	10.10%	28.80%	38.00%	19.70%	0%
South-East Asian Region	5.90%	22.20%	15.20%	49.80%	6.20%	0.70%
Western Pacific Region	4.30%	21.70%	34.80%	30.40%	8.70%	0%

Reasons for difficulty in access to treatment



	High cost of travel to treating center	High cost of treatment	High cost of both travel to the treating centre and treatment	No answer
African Region	0%	10%	50%	40%
Region of the Americas	8.30%	16.70%	8.30%	66.70%
Eastern Mediterranean Region	15.60%	25.60%	22.70%	36.20%
European Region	9.60%	4.30%	5.30%	80.80%
South-East Asian Region	17.70%	6.80%	11.90%	63.60%
Western Pacific Region	17.40%	17.40%	8.70%	56.50%

Loss of Days from Education and Work



	None	1-5 days	6-10 days	11-15 days	16 or more days	No answer
African Region	20%	10%	10%	20%	40%	0%
Region of the Americas	33.30%	0%	8.30%	0%	58.30%	0%
Eastern Mediterranean Region	13.60%	8.50%	4.50%	29.90%	41.20%	2.30%
European Region	29.30%	10.10%	5.80%	9.60%	42.30%	2.90%
South-East Asian Region	8.50%	9.90%	4.40%	34.50%	39.80%	2.90%
Western Pacific Region	17.40%	34.80%	8.70%	8.70%	13.00%	17.40%

ANNEX II: Social benefits provided to people with haemoglobin disorders

		Benefits to which people with Hb disorders are entitled																								
		1									2				3											
		General Population Benefits									Disability Benefits				Disease-specific Benefits											
		Ratification of International Labour Organization (ILO) Social Security Conventions & Implementation through National Social Security Legislation									Provided upon disability assessment under the national Social Security / Disability Laws				Provided under the Social Security / Disability Laws to people with haemoglobinopathies											
		Source: ILO, World Social Protection Report 2017-19: Universal social protection to achieve the Sustainable Development Goals									Source: International Social Security Association (ISSA)				Source: TIF Survey & Questionnaire (2020)											
		Child and Family	Maternity	Sickness	Unemployment	Employment Injury	Survivors	Old age	Disability / Invalidity	Effective Coverage (%) - Severe Disabilities (2015)	Contributory (Social Insurance)	Contributory (Provident Fund)	Non-Contributory (Universal)	Non-Contributory (Means-tested)	Contributory (Social Insurance)	Non-Contributory (Disability Law)	1) Monthly Allowance	2) Early Retirement	3) Higher Education Facilities	4) Employment Facilities	4) Tax Reduction	5) Reimbursement for perm. damages	6) Afternoon Clinics	7) Leave days for transfusions	8) Travel Allowance
European Region																										
1	Albania									...		None		None	None	None	—	—	—	—	—	—	—	—	—
2	Austria									93.3		None	None	¢	None	None	—	—	—	—	—	—	—	—	—
3	Azerbaijan									100		None		None	None	None	—	—	—	—	—	—	—	—	—
4	Belgium									100		None	None	None	None	None	—	—	—	—	—	—	—	—	—
5	Bulgaria									100		None		None	None	None	—	—	—	—	—	—	—	—	—
6	Cyprus									26.5		None	None	¢			•	•	•	•	•	None	•	None	•
7	France									100		None	None	None	None	None	—	—	—	—	—	—	—	—	—
8	Germany									73.6		None	None	None	None	None	—	—	—	—	—	—	—	—	—
9	Greece									...		None	None	None			•	•	•	•	•	None	None	•	•
10	Italy									100		None	None	None			•	•	•	None	•	•	None	•	•
11	Sweden									100		None	None	None	None	None	—	—	—	—	—	—	—	—	—
12	Turkey	None								5		None	None	None	None	None	—	—	—	—	—	—	—	—	—
13	United Kingdom									100		None			None	None	—	—	—	—	—	—	—	—	—
Eastern Mediterranean Region																										
14	Egypt	None								...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
15	Iran									...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
16	Lebanon				None					...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
17	Morocco									...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
18	Oman	None	¢	None	None					...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
19	Saudi Arabia	None	¢	¢						...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
20	United Arab Emirates	...	¢	...	¢	...	...	...	...	...	...	...	...	...	...		•		None	•	None	None	None	None	None
South-East Asia Region																										
21	Bangladesh	None			¢					18.5	None	None	None		None	None	—	—	—	—	—	—	—	—	—
22	India	None								5.4			None				•	None	•	•	None	•	None	None	None
23	Nepal	None	¢	¢	¢					...	None			None	None	None	—	—	—	—	—	—	—	—	—
24	Sri Lanka		¢	o	¢					20.8	None		None	None	None	None	—	—	—	—	—	—	—	—	—
25	Thailand									35.7		None	None	None	None	None	—	—	—	—	—	—	—	—	—
Western Pacific Region																										
26	Australia									100		None		None	None	None	—	—	—	—	—	—	—	—	—
27	Cambodia	None			¢		i	i	i	0.7		None	None	None	None	None	—	—	—	—	—	—	—	—	—
28	China									...		None	None	None	None	None	—	—	—	—	—	—	—	—	—
29	Singapore				None					...	None		None	None	None	None	—	—	—	—	—	—	—	—	—
30	Viet Nam									9.7		None	None	None	None	None	—	—	—	—	—	—	—	—	—

African Region																										
31	Algeria	□		□	□	□	□	□	□	□	3.6	□	None	None	None	None	None	—	—	—	—	—	—	—	—	—
32	Mauritius	...	...	...	...	...	...	...	...	...	...	None	None	None	None	None	None	—	—	—	—	—	—	—	—	—
33	Republic of Congo	□	□	¢	None	□	□	□	□	...	□	None	None	None	None	None	—	—	—	—	—	—	—	—	—	
Region of the Americas																										
34	Argentina	□	□	□	□	□	□	□	□	□	...	□	None	None	□	None	None	—	—	—	—	—	—	—	—	—
35	Brazil	□	□	□	□	□	□	□	□	100	□	None	None	□	None	None	—	—	—	—	—	—	—	—	—	
36	Canada	□	□	□	□	□	□	□	□	67.2	□	None	None	None	None	None	—	—	—	—	—	—	—	—	—	
37	Trinidad and Tobago	□	□	□	¢	□	□	□	□	...	□	None	None	□	None	None	—	—	—	—	—	—	—	—	—	
38	United States	□	□	□	□	□	□	□	□	100	□	None	None	□	None	None	—	—	—	—	—	—	—	—	—	

	Information related to adjacent cells
	Countries that ratified ILO conventions on social security
□	Countries with at least one programme anchored in national
i	Legislation not yet entered into force
¢	Limited provision
o	Only benefit in kind
...	Incomplete information available

ANNEX III: Combination/Comparison of Findings

	Region					
	AFR	**AMR**	**EMR**	**EUR**	**SEAR**	**WPR**
Social Benefits Available (Overall)	Limited	Yes	Limited (UAE thal-specific)	Yes (CY, GR, IT thal-specific)	Limited (India thal-specific)	Limited
Social Determinants of Health						
Economic Stability						
Employment - Expenses/ Debt/ Medical Bills						
Literature Review	**No data available**	Financial burden	Financial Burden / Affordability of treatment / Loss of days from work	Loss of days from work	Financial burden Loss of days from work	Financial burden
TIF Survey 2022-2023	Unemployed but looking for work / Loss of days from work	Employed, working full time / Financial burden / Loss of days from work	Unemployed but looking for work / Loss of days from work / Financial burden	Loss of days from work / Out-of-pocket expenses for multidisciplinary care	Not employed and not looking for work	Financial burden
Financial Support / Universal Health Coverage						
Literature Review	Not available	Added value of social benefits for access	Not available in all countries	State-provided / free healthcare	Not available / Need for social support	**No data available**
TIF Survey 2022-2023	**No data available**	**No data available**	**No data available**	**No data available**	Not available / Need for social support	Not available in all countries
Neighbourhood and Physical Environment						
Transportation						
Literature Review	**No data available**	**No data available**	**No data available**	Access to treatment centres remains challenging for specific countries	**No data available**	**No data available**
TIF Survey 2022-2023	Poor access to treatment centres	**No data available**	**No data available**	Easy access to treatment in general	Access to treatment centres remains challenging for specific countries	**No data available**
Education						
Literacy / Education						
Literature Review	**No data available**	**No data available**	**No data available**	Loss of days from school	Loss of days from school	Need for disease-specific literacy (problem of adherence)
TIF Survey 2022-2023	Loss of days from school	Loss of days from school	**No data available**	Loss of days from school	Loss of days from school	Loss of days from school

Community and Social Context						
Support systems (incl. caregivers)						
Literature Review	**No data available**	**No data available**	Support to caregivers needed Need to strengthen support systems	**No data available**	**No data available**	**No data available**
TIF Survey 2022-2023	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**
Community engagement						
Literature Review	**No data available**	**No data available**	Need to raise community awareness	**No data available**	**No data available**	**No data available**
TIF Survey 2022-2023	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**
Stress / Mental Health						
Literature Review	**No data available**	Psychological support needed	Psychological support needed	Psychological support needed	Psychological support needed	Psychological support needed
TIF Survey 2022-2023	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**
Healthcare System						
Health coverage						
Literature Review	Not available	**No data available**	Not available	Yes	Not available	Not available
TIF Survey 2022-2023	Not available	**No data available**	Not available	**No data available**	Not available	Not available
Provider availability						
Literature Review	**No data available**	**No data available**	**No data available**	Multidisciplinary care not always available	**No data available**	**No data available**
TIF Survey 2022-2023	Limited	**No data available**	Limited	Yes	Limited	**No data available**
Quality of care						
Literature Review	**No data available**	**No data available**	**No data available**	**No data available**	Not available thus needed	**No data available**
TIF Survey 2022-2023	Limited	**No data available**	**No data available**	**No data available**	**No data available**	**No data available**

ANNEX IV: The position of the Thalassaemia International Federation

The Thalassaemia International Federation,

Recalling the below-mentioned policy documents:

Document Title	Highlights
Alma-Ata Declaration (1978)	*"V. Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate **health and social measures**. A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life."*
World Health Assembly Resolution 58.23 (2005)	*"The Fifty-eighth World Health Assembly URGES Member States (4) to take all necessary steps for the reduction of **risk factors contributing to disabilities** during pregnancy and childhood; and (6) to implement, as appropriate, family counselling programmes including premarital confidential testing for diseases such as anaemia and **thalassemia** along with prevention counselling for intra-family marriages;"*
World Health Assembly Resolution 58.33 (2005)	*"The Fifty-eighth World Health Assembly URGES Member States (4) to plan the **transition to universal coverage** of their citizens so as to contribute to meeting the needs of the population for health care and improving its quality, to reducing poverty, to attaining internationally agreed development goals, including those contained in the United Nations Millennium Declaration, and to achieving **health for all**"*
United Nations Convention on the Rights of Persons with Disabilities (2006)	*"Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."* *"Article 19: States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and **their full inclusion and participation in the community**, including by ensuring that: b) Persons with disabilities have **access to** a range of in-home, residential and other **community support services**, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community"*
World Health Assembly Resolution 62.14 (2009)	*The Sixty-second World Health Assembly URGES Member States (3) to take into account **health equity in all national policies that address social determinants of health**, and to consider developing and strengthening universal comprehensive social protection policies, including health promotion, disease prevention and health care, and promoting availability of and access to goods and services essential to health and well-being"*
World Health Report 2010	*"There are many ways to promote and sustain health. Some lie outside the confines of the health sector. The circumstances in which people grow, live, work, and age strongly influence how people live and die. **Education, housing, food and employment all impact on health. Redressing inequalities in these will reduce inequalities in health**."*
World Health Report 2013	*"The goal of universal health coverage is to ensure that everyone can use the health services they need **without risk of financial ruin or impoverishment**. These services range from clinical care for individual patients to the public services that protect the health of whole populations, coming from both within and beyond the health sector."*

Document Title	Highlights
UNGA Resolution A/RES/67/81 (2012)	*"The General Assembly, (4) invites Member States to adopt a multisectoral approach and to work on determinants of health within sectors including, as appropriate, through the **health-in-all-policies approach**, while taking into consideration the social, environmental and economic determinants of health, with a view to reducing health inequities and enabling sustainable development, and (14) recognizes that it is essential to take into consideration the needs of vulnerable segments of society, including the poorest and marginalized segments of the population, indigenous peoples and **persons with disabilities**, in accordance with the principle of social inclusion, in order to enhance their ability to realize their right to the enjoyment of the highest attainable standard of physical and mental health"*
UNGA Resolution A/RES/70/1 (2015)	*"We envisage a world free of poverty, hunger, disease and want, where all life can thrive. A world with equitable and universal access to quality education at all levels, to **health care and social protection**, where physical, mental and social well-being are assured."* *"23. We are committed to ending poverty in all its forms and dimensions, including by eradicating extreme poverty by 2030. All people must enjoy a basic standard of living, including through social protection systems."* *"26. To promote physical and mental health and well-being, and to extend life expectancy for all, we must achieve universal health coverage and access to quality health care. **No one must be left behind**."*
UN Political Declaration of the High-level Meeting on Universal Health Coverage (2019)	*"10. Recognize the need to **tackle health inequities and inequalities** within and among countries through political commitment, policies and international cooperation including those that address social, economic and environmental and other determinants of health"* *"14. Recognize the fundamental importance of equity, social justice and social protection mechanisms as well as the elimination of the root causes of discrimination and stigma in health-care settings to ensure universal and equitable access to quality health services without financial hardship for all people, particularly for those who are vulnerable or in vulnerable situations"*
International Labor Organization Social Health Protection Principles (2020)	*"The lack of **affordable quality health care and income security** in case of sickness for the majority of the world's population creates a risk of impoverishment, with greater impact on the most vulnerable."* *"Social health protection principles provide a rights-based approach to achieve universal population coverage"*
WHO Executive Board Report EB148/24 (2021)	*"3. The world has seen considerable health gains over the last century, but their distribution is vastly unequal. **Inequities** in many health outcomes exist both within and between countries."* *"13. **Commitment** at global, national and subnational levels is essential to tackle health inequities and their causes."*

1. URGES Member States of the United Nations:

(a) to recognise that at the heart of social health protection lies the protection of patients and their families against economic vulnerability.

Living in or being vulnerable to poverty, fundamentally undermines the access of patients to quality health care in most countries of the world, often with lifelong and life-threatening consequences, directly impacting their

opportunity to access quality social services and, destructively, undermining their dignity, confidence and overall well-being.

(b) to acknowledge that an optimal level of quality of life is produced by combining access to quality health care and state-provided social protection schemes.

While quality of care is the key determining factor of the presence or absence of co-morbidities, subsequent to iron load and suboptimal care in most countries of the developing world, social protection schemes assist patients in their efforts to adhere to treatment and be socially active.

2. Recommends:

The establishment and/or strengthening of social health protection systems in order to provide universal access to needed health care and financial protection that is:

i. **accessible** to cover all persons, especially those belonging to the most disadvantaged and marginalized groups, without discrimination
ii. **available** under domestic law to ensure that benefits are effectively administered and supervised
iii. **adequate** so that everyone may realise his or her rights to family protection and assistance, a reasonable standard of living and access to health care; and
iv. **affordable** to reduce inequalities.