

NATIONAL MASTER PLAN

On Thalassemia Prevention,
Control and Management

2024-2034

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Executive Summary

The 10-year Thalassemia Prevention and Control Plan for the Maldives (2024-2034) represents a comprehensive strategy aimed at enhancing the health outcomes of individuals affected by thalassemia. This document, developed collaboratively by the National Blood Transfusion Service of Sri Lanka and the National Thalassemia Centre, outlines a series of strategic objectives and actionable recommendations designed to tackle the multifaceted challenges posed by thalassemia. The Maldivian government has demonstrated its commitment to this initiative, aligning with the President's 14-week pledge to prioritize thalassemia prevention, management, and control. This government support is crucial for the successful implementation of the plan.

At its core, the plan advocates for the restructuring of the Maldivian Blood Service (MBS) to foster better coordination and the establishment of robust policies supporting thalassemia prevention, treatment, and management. A key focus is on enhancing early detection through widespread and effective screening programs, which will be supported by national protocols and increased coverage.

Moreover, the plan emphasizes the importance of improving transfusion services by addressing donor recruitment, quality assurance, stock management, and the implementation of a hemovigilance reporting system. Treatment enhancement initiatives include improving compliance with iron chelation, enhancing the quality of life for patients, and introducing comprehensive training programs for healthcare staff. Special attention is given to the provision of tailored care and support services for older thalassemia patients, ensuring a holistic approach to patient management that includes psychological support and lifestyle guidance.

The integration of information technology is highlighted as a critical component for improving data management, accuracy, and efficiency. This includes the development of a digital information management system to standardize data collection, enhance analytics, and improve accessibility. The plan also underscores the need for continuous monitoring and evaluation to ensure the effectiveness of implemented strategies, with specific indicators and work plans laid out for each objective.

Advancing thalassemia care in the Maldives requires strategic partnerships, innovative approaches, and a focus on improving patient outcomes. With the dedicated efforts of all stakeholders, the Thalassemia Prevention and Control Plan is poised to make significant strides in enhancing the quality of life of thalassemia patients and reducing the burden of thalassemia. This aligns with the vision of a nation that excels in thalassemia prevention, control, and management.

Foreword



Thalassaemia and the haemoglobinopathies are a major health problem, placing an immeasurable emotional, psychological and economic burden on individuals and families affected. This comprehensive National Thalassaemia Master Plan embarks on a focused and long-term strategy to address the Thalassaemia situation in the country. It is a testament of the current administration's commitment to enhance and sustain the crucial services for individuals living with Thalassaemia. It gives me immense pleasure to note the Maldivian government's renewed dedication to enhancing the lives of those affected by Thalassaemia. The launch of this comprehensive 10-year Thalassaemia National Master Plan is a momentous occasion, marking the first time our nation has embarked on such a focused and long-term strategy to address this condition. It stands as a testament to the current administration's commitment to providing sustained and crucial services for individuals living with Thalassaemia.

The current prevalence of Thalassaemia in the Maldives, with a beta thalassaemia rate of 16%, makes it imperative that we address this condition with a robust and sustainable plan. The 10-year Master Plan, with its seven strategic areas presents a roadmap and framework for tackling the challenges ahead.

I extend my appreciation to His Excellency President Dr. Mohammed Muizzu for his leadership in this endeavor. Since assuming the presidency, His Excellency has shown remarkable perseverance in addressing the challenges faced by Thalassaemia patients, leading to significant strides in their care. The increased opportunities for bone marrow transplants, easier access to vital medications, modern diagnostics, and the strengthening of our blood banking system are some notable examples of the positive changes brought about under his guidance. His Excellency's vision for a dedicated Thalassaemia Hospital in Hulhumale further underscores the government's commitment to providing specialized care for those affected.

The current prevalence of Thalassaemia in the Maldives, with a beta thalassaemia rate of 16%, makes it imperative that we address this condition with a robust and sustainable plan. The 10-year Master Plan, with its seven strategic policies and clear KPIs, offers a roadmap for the next generation and provides a framework for tackling the challenges ahead.

I sincerely appreciate the invaluable support from the World Health Organization, and acknowledge the expertise and facilitation by the Sri Lanka NBTS, local NGOs, and other relevant stakeholders in the development of this Master Plan. This plan has been developed with invaluable support from the World Health Organization (WHO), Sri Lanka NBTS, local NGOs, and other relevant stakeholders. I extend my gratitude to the dedicated staff of the Maldivian Blood Services for their tireless efforts in this cause. The support and cooperation of the World Health Organization, Sri Lanka NBTS, and all those involved are deeply appreciated.

As we embark on this journey to implement the Thalassaemia National Master Plan, on Thalassaemia Prevention, Control and Management, I call upon all stakeholders to unite in a renewed spirit of cooperation. Together, let us strive to bring this plan to fruition, ensuring a better and hopeful future filled with hope and healing for the children of the Maldives to all persons living with Thalassaemia.

A stylized, handwritten signature in blue ink, consisting of several loops and a long horizontal stroke at the bottom.

Abdulla Nazim Ibrahim
Minister of Health

Foreword



Thalassemia remains a significant public health concern in Maldives, particularly the beta-thalassemia trait, which has been found to have a relatively high prevalence in the population. The burden of this genetic disorder on individuals, families, and the healthcare system is profound, requiring a comprehensive and coordinated approach to prevention, management, and control.

The launch of the 10-year National Masterplan on Thalassemia Prevention, Control and Management for the Maldives (2024-2034) is a major milestone in addressing this pressing health issue. This document developed through a collaborative effort between WHO Maldives, WHO South-East Asia, Maldivian Blood Services and the Ministry of Health provides a robust plan to improve the health outcomes of those affected by thalassemia. Technical expertise was provided by the National Blood Transfusion Service of Sri Lanka (a WHO Collaborating Centre for Transfusion Services). It outlines strategic objectives and actionable recommendations that respond to the complex challenges of prevention, screening, treatment, and care for individuals with thalassemia.

I commend the Government of Maldives for its unwavering commitment to this initiative. The alignment with the His Excellency President's pledge to prioritize thalassemia prevention, management and control reflects the importance of this plan and underscores the Government's dedication to achieving tangible health outcomes for the people of Maldives. The successful implementation of this plan is contingent on this sustained governmental support, which is essential for building the foundation for long-term success.

World Health Organization Maldives is proud to have provided comprehensive technical support throughout every stage of this process, from inception to completion. Our role included conducting an assessment via a field visit, engaging with relevant stakeholders, and drafting the plan, all of which were pivotal in aligning this strategy with national health priorities and the vision of our Regional Director for WHO South East Asia Ms Saima Wazed. This initiative exemplifies the strength of partnership and collaboration where WHO's support extended across all levels working together to provide the necessary expertise and resources. Such collaboration underscores the collective commitment to advancing health equity and addressing thalassemia in a coordinated and sustainable manner.

Together, we share a common vision for the future: a nation where every individual has the opportunity to live a healthy and fulfilling life, free from the burdens of Thalassemia. The Thalassemia Prevention, Control and Management Master Plan is not just a document; it is a commitment to the people of the Maldives, ensuring that the fight against thalassemia remains at the forefront of public health efforts in the coming decade. Let us all continue working hand in hand to turn this vision into reality.

A handwritten signature in blue ink that reads "Nazneen Anwar". The signature is fluid and cursive.

Dr Nazneen Anwar

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- The Ministry greatly appreciates the active participation of and valuable contributions of the members from relevant stakeholders which made the development of the action plan possible.

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Table of Contents

Executive Summary	I
Foreword	II
Foreword	III
Editors and Contributors	IV
Acknowledgements	V
Contributors	V
Table of Contents	VI
List of Figures	VII
List of Tables	VII
List of Abbreviations	VII
Background	01
Overview of Thalassemia	01
Overview of Maldives	03
Health Care System in Maldives	04
Thalassemia in Maldives	06
Approaches and Strategic Objectives	07
Process of Development of the National Master Plan on Thalassemia Prevention, Control and Management (2024-2034)	07
Vision	08
Mission	08
Goals	08
Strategic objectives	09
Guiding Principles	10
Strategic Objective 1: Establish Robust Policies And Governance Framework For Thalassemia Care	11
Strategic Objective 2: Enhance Early Detection And Prevention Of Thalassemia	12
Strategic Objective 3: Ensure The Reliability And Quality Of Transfusion Services	14
Strategic Objective 4: Optimize Evidence Based Thalassemia Care And Treatment	15
Strategic Objective 5: Develop Tailored Care And Support Services For Older Thalassemia Patients	17
Strategic Objective 6: Digitalize Thalassemia Care And Management Data Into An Integrated Health Information System	19
Strategic Objective 7: Strengthen Human Resources And Research Capacity	21
MONITORING AND EVALUATION FRAMEWORK FOR MASTERPLAN (2024-2034)	23
References	51
Annex 1	52

List of Figures

Figure 1: Clinical Classification, Screening and Diagnosis for Thalassemia

Figure 2: Organogram of Ministry of Health Maldives

Figure 3: Suggested restructuring model of MBS

Figure 4: Suggested Administrative Structure and responsible persons

Figure 5: Reporting structure

List of Tables

Table 1: Government health facilities in the atolls, 2021

Table 2: Health system entities, 2021

List of Abbreviations

TDT	Transfusion dependent Thalassemia	IEC	Information, Education, and Communication
NTDT	Non-Transfusion Dependent Thalassaemia	ELISA	Enzyme-Linked Immunosorbent Assay
BMT	Bone Marrow Transplant	CIA	Chemiluminescence Immunoassay
BTS	Blood Transfusion Service	EQA	External Quality Assurance
WHO	World Health Organisation	ISO	International Organization for Standardization
MBS	Maldivian Blood Service	AABB	Association for the Advancement of Blood & Biotherapies
PHU	Public Health Unit	TIF	Thalassemia International Federation
SHE	Society for Health Education	CSO	Civil Society Organizations
CVS	Chorionic Villus Sampling	NAT	Nucleic Acid Testing
HLA	Human Leucocyte Antigen	NBTS	National Blood Transfusion Service
MOH	Ministry of Health	NBTS	National Blood Transfusion Service
PBM	Patient Blood Management	IST	In-Service Training
CME	Continuous medical education		
NGOS	Non-Government Organisations		
VNRD	Voluntary Non remunerated Donors		

Background

Overview of Thalassemia

Thalassemia is the commonest monogenic disorder of Haemoglobin production, with autosomal recessive genetic inheritance.⁽¹⁾ Thalassemia or thalassemia variants are characterised by reduced synthesis of Alpha or Beta globin chains or production of structurally abnormal haemoglobin.⁽²⁾ Such abnormalities will cause ineffective production of red cells leading to premature destruction, giving rise to a state known as anaemia.⁽²⁾ It affects the body's ability to maintain a normal haemoglobin content of the body, which can result in fatigue, weakness, and other complications related to anaemia and blood transfusion. There are various types and severities of thalassemia, ranging from mild to severe forms requiring regular blood transfusions and medical management. The Thalassemia syndrome which includes Transfusion dependent Thalassemia (TDT) and Non-Transfusion Dependent Thalassemia (NTDT) will show phenotypic variation as per the genetic makeup.⁽³⁾ The comprehensive management of a thalassemia patient includes, proper transfusion regime, iron chelation, diagnosis and management of complications through multidisciplinary team approach.

The burden of thalassemia includes healthcare costs, the need for blood transfusions, and associated complications, making it a significant concern for healthcare systems and communities globally.⁽⁴⁾ Efforts to raise awareness, improve screening and genetic counselling, are essential. Curative treatments like Bone Marrow Transplant (BMT) are beneficial while advanced treatments like Luspatercept and gene therapy are available with resource rich settings.⁽⁵⁾

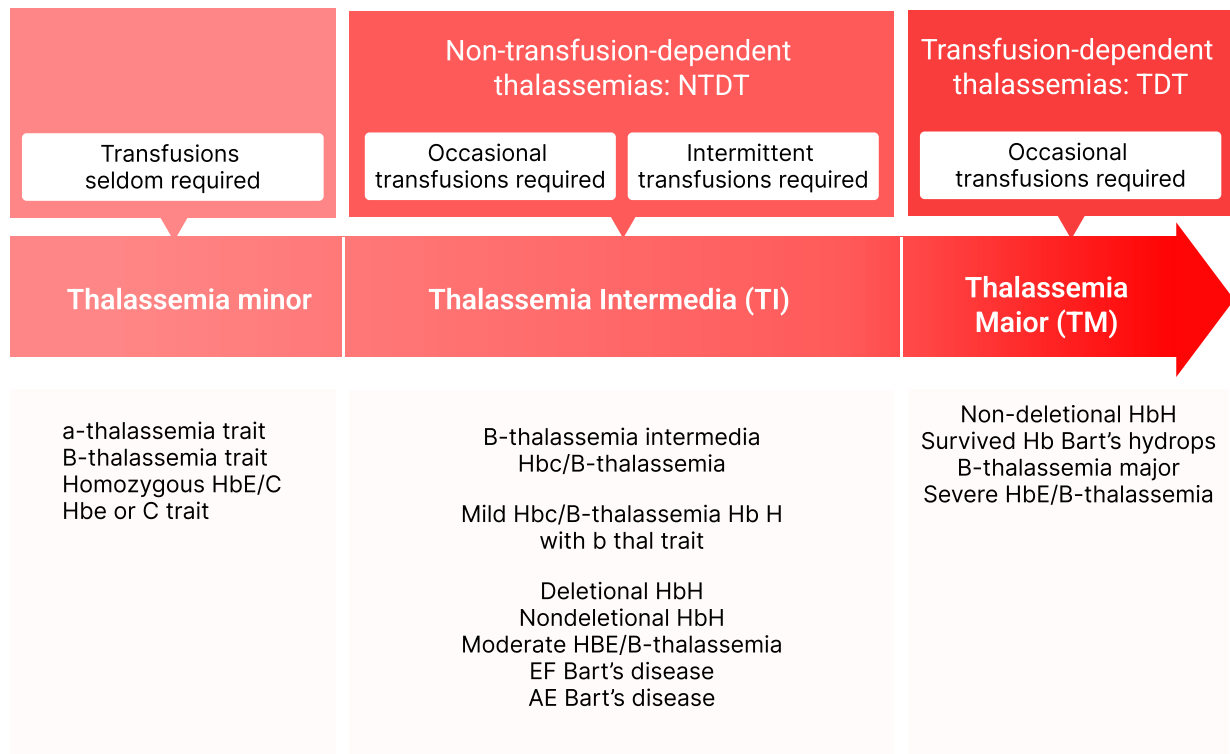


Figure1: Clinical Classification, Screening and Diagnosis for Thalassemia ⁶

Overview of Maldives

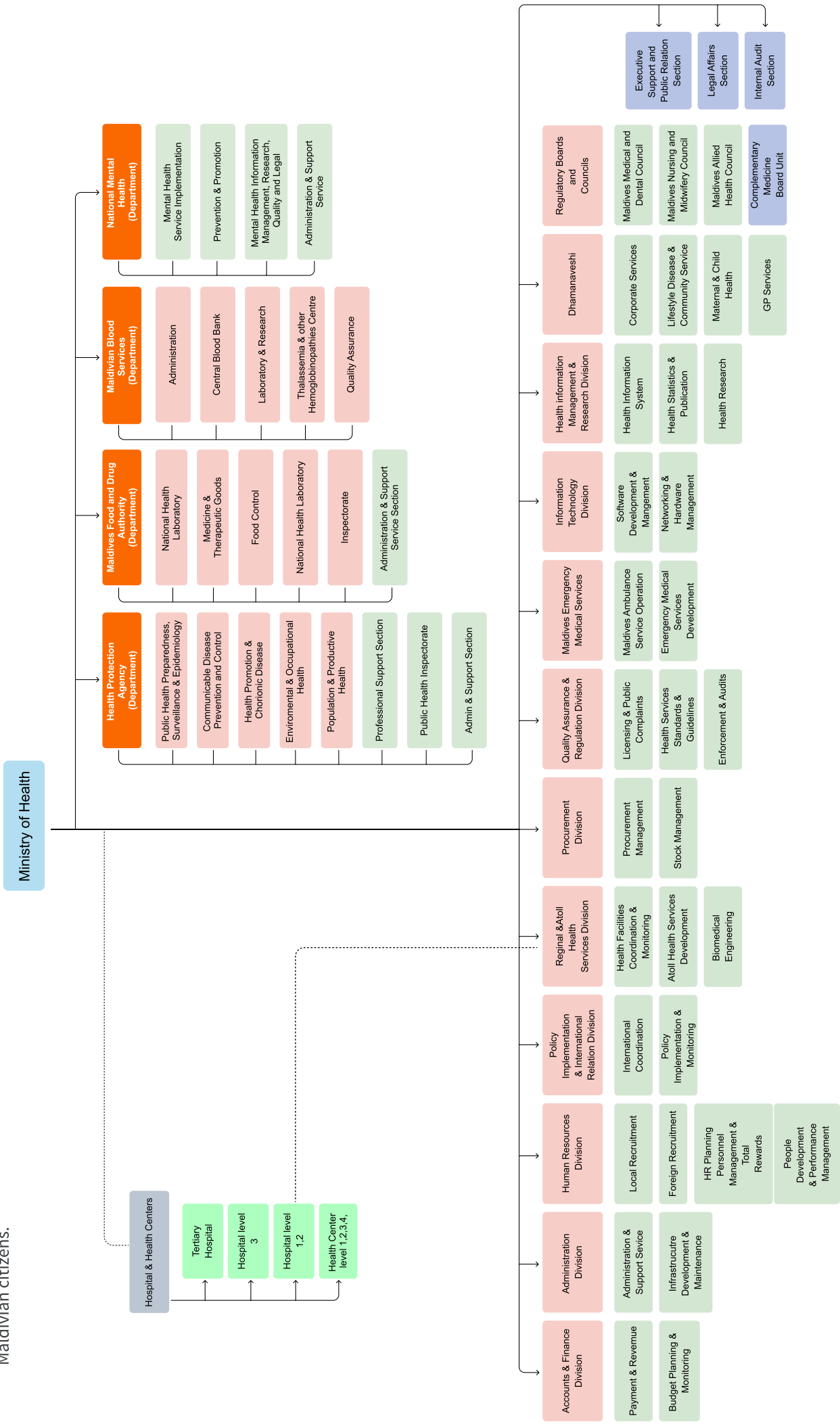
Maldives, being an island nation in the Indian Ocean, is made up of 1192 islands, 26 natural Atolls scattered over a large geographical area of 820 km in length and 130 km in width. Maldives is located in a territorial area of 859,000 sq. km of Indian Ocean but has a total land size of 298 sq. km only, with 200 islands inhabited. The country is composed of 20 administrative Atolls with Male being the capital city.⁽³⁾

Maldives has a population of 515,132 (Census 2022), with 382,639 Maldivians and 132,493 foreigners.⁽⁸⁾ The total dispersion of the citizens shows 41% located in Greater Male' Region (Male', Hulhumale, Villimale & Hulhule) while 46% of the resident population lives in the Atolls and 10% of the resident population lives in resorts. At the time of census, the majority (69%) of the resident Maldivians (15 years and above) were married, 9% divorcees and 19% of the resident Maldivians were eligible for marriage. With a birth rate of 10/1000 population and 5917 total number of births in 2021. Census also shows that 33% of the population is currently attending school/ training institutions.⁽⁴⁾

The Human development Index (health, education, standard of living) of the Maldives in 2021, had a score of 0.747 which placed it 90th out of 191 countries. This enabled Maldives to fall into the category of "high human development".⁽⁵⁾ According to estimates 448,649 persons or 99.4% of the adult population (aged 15 years and above) in Maldives are able to read and write.⁽⁶⁾ There were 435,800 internet users in the Maldives at the start of 2024, when internet penetration stood at 83.9 percent. The Maldives was home to 363,300 social media users in January 2024, equating to 69.9 percent of the total population.⁽⁷⁾ All citizens of Maldives are entitled to the National health insurance scheme "Aasandha" which is solely financed by the Government of Maldives. The scheme ensures healthcare for all without a ceiling protection limit and annual cap of MVR 100,000 per person per year of the previous scheme was removed. 365,306 Maldivians had used the services of Aasandha in 2022 ⁽⁸⁾, with the government spending 30 million MVR yearly for Thalassemia care provision.

Health Care System in Maldives

The Ministry of Health, under the governance of the Maldivian government, serves as the central authority offering direction and support to safeguard the health and wellbeing of Maldivian citizens.



Health Protection Agency (HPA), Maldives Food and Drug Authority (MFDA), Maldivian Blood Services (MBS), and Dhamanaveshi (Urban Primary Health Care Centre) function as departments under Ministry of Health, while Maldives Medical and Dental Council, Maldives Nursing and Midwifery Council, and Maldives Allied Health Council regulates the health professionals. Maldives health care delivery system is organized into tertiary hospitals, regional and atoll hospitals and health centres. Out of a total of 190 government run health facilities (excluding two small scale clinics), 183 are located across various Atolls.⁽⁹⁾ Four tertiary level hospitals have been established in the country.

<p>TERTIARY HOSPITAL</p> <p>01 Tertiary hospital in the atolls. This hospital is in S Atoll.</p>	<p>HEALTH CENTRES</p> <p>164 health centres (HCs) in the Maldives (refer to Annex for the detail list of health centres)</p>																									
<p>REGIONAL / ATOLL HOSPITALS</p> <p>18 Regional / atoll hospitals. These facilities are situated in the following islands:</p> <table border="1"> <tr> <td>HA Dhidhoo</td> <td>ADh Mahibadhoo</td> <td>R Ungoofaru</td> <td>Dh Kudahuvadhoo</td> <td>GDh Thinadhoo</td> </tr> <tr> <td>Sh Funadhoo</td> <td>HA Dhidhoo</td> <td>B Eydhafushi</td> <td>Th Veymandoo</td> <td>Gn Fuvahmulah</td> </tr> <tr> <td>N Manadhoo</td> <td>Sh Funadhoo</td> <td>Lh Naifaru</td> <td>V Felidhoo</td> <td></td> </tr> <tr> <td>HDh Kulhudhuffushi</td> <td>N Manadhoo</td> <td>AA Rasdhoo</td> <td>L Gan</td> <td></td> </tr> <tr> <td>R Ungoofaru</td> <td>HDh Kulhudhuffushi</td> <td>F Nilandhoo</td> <td>GA Villingili</td> <td></td> </tr> </table>		HA Dhidhoo	ADh Mahibadhoo	R Ungoofaru	Dh Kudahuvadhoo	GDh Thinadhoo	Sh Funadhoo	HA Dhidhoo	B Eydhafushi	Th Veymandoo	Gn Fuvahmulah	N Manadhoo	Sh Funadhoo	Lh Naifaru	V Felidhoo		HDh Kulhudhuffushi	N Manadhoo	AA Rasdhoo	L Gan		R Ungoofaru	HDh Kulhudhuffushi	F Nilandhoo	GA Villingili	
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Table 1: Government health facilities in the atolls, 2021

<p>TIER 3: TERTIARY</p> <p>GOVERNMENT HEALTH SERVICES</p> <p>National referral hospital IGMH AEH</p> <p>BUSINESS AND CIVIL SERVICES</p> <p>Private Hospitals in GMR ADK, Treetop</p> <p>State Trading Organization (STO), private pharmacies, Health suppliers, Health focused civil society</p>	<p>TIER 2: SECONDARY</p> <p>GOVERNMENT HEALTH SERVICES</p> <p>Other public hospitals Hulhumale' hospital, Villimale' hospital, Senahiya Military Hospital)</p> <p>Regional / Atoll hospitals 18- KRH, URH, GRH, ASMH, MRH & Atoll hospitals</p> <p>BUSINESS AND CIVIL SERVICES</p> <p>Other Private Hospitals Medica, IMDC</p> <p>organisations, Youth and women's groups</p>	<p>TIER 1: PRIMARY</p> <p>GOVERNMENT HEALTH SERVICES</p> <p>Health Centres (164)</p> <p>Dhamanaveshi</p> <p>BUSINESS AND CIVIL SERVICES</p> <p>Private Clinics</p>
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Table 2: Health system entities, 2021

Thalassemia in Maldives

Thalassemia is a significant public health concern in the Maldives. Studies conducted in the Maldives have shown a relatively high prevalence of thalassemia, particularly the beta-thalassemia trait. This prevalence is attributed to the genetic makeup of the population, with a historical background of intermarriage and genetic isolation.

Thalassemia requires lifelong management, including regular blood transfusions, iron chelation therapy, and other supportive care measures. The cost and logistics of managing thalassemia can be a strain to the national economy. In the 2024 budget, there is an allocation of MVR 7,459.4 million to enhance and extend healthcare services for the public. The annual cost of treating a thalassemia child in Maldives is approximately US \$6,000/patient.⁽¹⁰⁾

Thalassemia and other haemoglobinopathies centre under the Maldivian Blood Service (MBS), is given the legal mandate by the Thalassemia Control Act (2012). It outlines the responsibilities and scope of activities for the Thalassemia and Other Hemoglobinopathies Centre, including implementing preventive screening programs, national projects on thalassemia control, and conducting education, training, and awareness programs. It mandates the collection of prevalence data, monitoring trends, and establishing laboratories with adequate staff and resources. The Act requires every Maldivian child under 18 to be tested for thalassemia and for thalassemia children's names to be registered at the Centre upon diagnosis. Comprehensive treatment and care, including covering the costs of services and bone marrow transplants, are provided by the State. The State is also responsible for arranging transportation for thalassemia patients, when necessary, services are unavailable in their locality. Additionally, a Thalassemia Fund is established to support control efforts and the treatment system.

The National Blood Policy (2018) focuses on establishing a well-coordinated national blood transfusion service to ensure a safe and adequate supply of blood and blood products. It emphasizes the importance of voluntary, non-remunerated blood donations and the elimination of unsafe practices. Key strategies include the creation of a National Blood Council to oversee blood services, implementation of WHO guidelines for blood screening, enhancing public awareness, and ensuring the rational use of blood through proper clinical guidelines.

The treatment and registering of thalassemia patients are the sole responsibility of the Maldivian Blood Service. At the end of 2023, the total number of registered Thalassemia patients were 944 of which 659 were alive. Out of the living patients 361 were followed at the MBS and 293 were followed up at the islands. There are two guidelines used with regards to Thalassemia management in the Maldives. The Management of Transfusion Dependent Thalassemia's (TDT) in the Maldives published by the Maldivian Blood Service (2022) and National Guideline on clinical use of blood published by the Ministry of Health Maldives (2022). Bone Marrow transplant for thalassemia patients is undertaken for selected patients using the Aasandha insurance scheme in overseas hospitals. The process requires a sibling or parent with 100% Human Leucocyte Antigen Match (HLA) match. Up to year 2022, 72 bone marrow transplants were done out of which 66 were successful.

Approaches and Strategic Objectives

Process of development of the national master plan on thalassemia prevention, control and management (2024-2034)

Thalassemia, poses a significant public health concern in Maldives. Recognizing this challenge, the current Maldivian government has prioritized strengthening Thalassemia prevention, management, and control efforts. It aligns with the President's 14-week pledge, highlighting the government's commitment to addressing this critical public health concern. The Ministry of Health (MoH) Maldives had sought WHO's support to conduct a comprehensive assessment of the current Thalassemia services, following which a technical consultant team was appointed to do a desk review, field visit and compile a situation analysis report.

The formulation of the National Master Plan on Thalassemia Prevention, Control and Management (2024-2034) used recommendations of the stakeholders and technical experts and integrated key aspects from the National Blood Policy, the Thalassemia Control Act, and the guidelines from the Thalassemia International Federation (TIF), ensuring a comprehensive and informed approach to addressing Thalassemia in the country. The draft plan was reviewed by key stakeholders from the Ministry of Health, Maldivian Blood Service and Civil Society Organizations (CSOs) and Non-Government Organisations (NGOs). Following consensus by all parties, the final master plan was approved for adoption.

VISION



Together as a nation for excellence in thalassemia prevention, control and management.

MISSION



To control thalassemia through prevention, early detection, and comprehensive care. Empowering communities by enhancing awareness, providing accessible screening, and offering continuous support for affected individuals.

GOALS



To significantly reduce incidence of thalassemia within 10 years through the implementation of evidence-based policies, comprehensive screening, and access to advanced therapies, improving the overall health and well-being of affected individuals.



Enhance prevention, early detection, and quality of care, in order to improve the quality of life for thalassemia patients

Strategic objectives

The following seven strategic objectives outlined, aim to address the comprehensive management and prevention of thalassemia.

STRATEGIC OBJECTIVE 1



Establish robust policies and governance framework for thalassemia care

STRATEGIC OBJECTIVE 5



Develop tailored care and support services for older thalassemia patients

STRATEGIC OBJECTIVE 2



Enhance early detection and prevention of thalassemia

STRATEGIC OBJECTIVE 6



Digitalize thalassemia care and management data into an integrated health information system

STRATEGIC OBJECTIVE 3



Ensure the reliability and quality of transfusion services

STRATEGIC OBJECTIVE 7



Strengthen human resources and research capacity

STRATEGIC OBJECTIVE 4



Optimize evidence-based thalassemia care and treatment

Guiding Principles

The guiding principles outlined here serve as the foundation for the strategic approach to thalassemia care and management.



Universal health coverage



Evidence and data-driven decision making



Patient-centred care



Quality Improvement



Education, awareness and research



Multi-sectoral actions and multi-stakeholder involvement

STRATEGIC OBJECTIVE 1

Establish robust policies and governance framework for Thalassemia care

GOAL: BY 2034

Establish a comprehensive and sustainable policy and governance framework that ensures equitable access to quality assured thalassemia care for all Maldivians, characterized by clear roles and responsibilities, adequate financing, and effective program management and monitoring.

OBJECTIVE 1.1

Develop and implement a robust policy framework for thalassemia prevention, treatment, and management

- Conduct a comprehensive review of existing policies, guidelines and programs related to thalassemia management and revise Thalassemia act to align with national health policies, international standards, and best practices.
- Establish clear roles and responsibilities for key stakeholders involved in thalassemia care (government agencies, healthcare providers, patient organizations, and communities).
- Develop a sustainable financing mechanism for thalassemia care and services, ensuring equitable access and affordability.

OBJECTIVE 1.2

Strengthen the governance and management structure of the thalassemia program.

- Establish a multidisciplinary steering committee to oversee Thalassemia program implementation.
- Develop a clear organizational re-structure for thalassemia services (within Maldivian Blood Services), defining roles, responsibilities, and reporting lines for all involved personnel (Annex 1- Proposed model to restructure MBS).
- Designated focal points (e.g. trained registered nurse) to work with the Maldivian Blood Service to be identified from each hospital and health centre.
- Implement a performance management framework to monitor and evaluate program performance, track progress, identify challenges, and inform decision-making (biannual review in first year and annual review thereafter).

STRATEGIC OBJECTIVE 2

Enhance early detection and prevention of thalassemia

GOAL: BY 2034

Significantly reduce the incidence of thalassemia in Maldives through comprehensive approach that includes nationwide carrier screening for individuals aged 18 years and above, enhanced prenatal diagnosis services and effective public awareness campaigns. This will be achieved by increasing access to genetic counselling, establishing robust referral systems, and addressing social barriers to prevent and manage thalassemia effectively.

OBJECTIVE 2.1

Expand and optimize carrier screening program

- Achieve 100% coverage of carrier screening programs for the eligible population (above 18 years old) by 2034.
- Develop and implement a standardized carrier screening protocol for Male' and Atolls.
- Integrate carrier screening into school screening programs (grade 10) and in routine health check-ups for adolescent and young adults.
- Establish additional screening/ sample collection centres, particularly in selected islands/atolls to enhance accessibility.
- Establish a national carrier registry.

OBJECTIVE 2.2

Enhance public awareness and education

- Develop and implement a comprehensive public awareness campaign targeting different population segments, including school children, adolescents, young adults, and the general public.
- Utilize mass media, social media and community events to disseminate information about thalassemia, its prevention and available services.
- Collaborate with schools, government agencies, NGOs, and CSOs to promote thalassemia awareness and integrate it into school curriculum.

- Organize educational workshops, seminars, and community events to address misconceptions and provide accurate information.
- Develop appropriate educational materials and resources tailored to different target audiences.
- Monitor and evaluate the impact of awareness campaigns using key performance indicators and feedback mechanisms.

OBJECTIVE 2.3

Strengthen genetic counselling and support services

- Develop standardized genetic counselling protocols and guidelines, ensuring ethical and evidence-based practices.
- Utilizing tele-health to improve access to genetic counselling at atoll level.
- Strengthen pre-marital counselling services in atolls, including genetic counselling for informed decision-making, with a focus on couples at risk.
- Ensure confidentiality, ethical practices, and informed consent in genetic counselling and support services.
- Provide ongoing support and follow-up for individuals and families affected by thalassemia, including psychosocial support and referrals to relevant services.

OBJECTIVE 2.4

Enhance genetic screening facilities

- Invest in infrastructure to establish or upgrade genetic screening facilities in the public sector, ensuring accessibility and affordability.
- Ensure quality assurance and accreditation of genetic screening laboratories.
- Implement a referral system for specialized genetic testing, including guidelines for sample transportation to the central.
- Make genetic screening affordable and accessible to the target population through the national health insurance scheme (Aasandha).

OBJECTIVE 2.5

Improve timely Referrals for prenatal diagnostic and treatment

- Develop and implement standardized referral protocols to ensure consistent and timely referrals across all healthcare facilities.
- Establish robust referral networks connecting primary care providers with specialized prenatal diagnostic and treatment facilities.
- Reduce referral delays through effective communication and coordination.
- Monitor referral outcomes to identify areas for improvement.

OBJECTIVE 2.6

Improve prenatal diagnosis and prevention services.

- Increase the uptake of prenatal diagnosis among at-risk couples by 50% by 2034.
- Provide comprehensive counselling and support to couples at risk of having a child with thalassemia, including information on available options and support service.
- Expand access to prenatal diagnostic services, including chorionic villus sampling and amniocentesis, in accredited facilities with qualified personnel.

- Develop and implement standardized protocols for prenatal care and management of thalassemia risk, including early foetal surveillance and management.
- Ensure timely and accurate communication of prenatal diagnosis results, including support services and referrals.
- Evaluate the effectiveness of prenatal diagnosis programs and identify opportunities for improvement.

OBJECTIVE 2.7

Expand access to prenatal diagnostic and treatment services

- Increase the number of accredited specialized prenatal diagnostic and treatment facilities.
- Establish an accredited genetic testing laboratory in the government sector.
- Conduct feasibility studies for pre-implantation genetic diagnosis.
- Develop a designated healthcare facility for comprehensive prenatal diagnostic and treatment procedures, including specialized care and support services.
- Ensure equitable access to prenatal diagnostic services across different regions.

OBJECTIVE 2.8

Address cultural, religious, and social barriers

- Facilitate dialogues with religious leaders to discuss the health implications of thalassemia and gain support for prenatal diagnosis and treatment options.
- Include prenatal thalassemia diagnosis and treatment details in the maternal health education program for risk couples.
- Develop culturally sensitive educational materials and programs.

STRATEGIC OBJECTIVE 3

Ensure the Reliability and Quality of Transfusion Services

GOAL

Establish a robust and efficient blood transfusion service that guarantees the safe and timely provision of high-quality blood and blood components to thalassemia patients.

OBJECTIVE 3.1

Optimize blood collection and distribution through centrally coordinated blood bank system

- Establish a centralized blood bank coordination system with 5 regional blood banks in atolls and 1 centre in Greater Male' Region, to ensure availability of blood and blood products to the catchment population.
- Establish blood transfusion facilities in selected government health centres in periphery, and ensure access to blood and blood products through regional banks.
- Centralize component production services in 5 regional blood banks (e.g. Quadruple bags to prepare platelet concentrates).
- Ensure 100% blood component preparation from whole blood donations.
- Implement a two-way blood bank coordination, stock management and communication system to ensure adequate supply to catchment population and reduce wastage.
- Centralize procurement system for equitable distribution of reagents and consumables.
- Implement efficient blood transportation and distribution systems.

OBJECTIVE 3.2

Enhance blood donor recruitment and retention through various strategies

- Convert directed donations to 100% Voluntary Non-Remunerated Donors (VNRDs) by 2034 (10 years).

- Establish donor education, recruitment and motivation programs (youth based, school based, university & college based low risk community-based programs).
- Introduce blood donation calendar for government institutions.
- Develop attractive donor promotion materials (IEC) for donor education, motivation, recruitment & retention.

OBJECTIVE 3.3

Strengthen blood safety and quality assurance

- Establish a robust, centrally coordinated quality management system for blood transfusion services.
- Develop and implement national blood banking standards.
- Implement comprehensive testing for blood and blood components.
- Consider Nucleic Acid Amplification Test (NAT) testing to enhance blood safety.
- Develop TTI reactive donor management protocols.
- Participate in proficiency testing and accreditation programs (International Organization for Standardization (ISO)/ Association for the Advancement of Blood & Biotherapies (AABB), National Accreditation Board for Hospitals & Healthcare Providers (NABH) and any other National Accreditation Programs).

OBJECTIVE 3.4

Establish haemovigilance and reporting system to enhance transfusion practice and patient safety

- Establish donor, process and patient haemovigilance reporting and reviewing system to monitor adverse events.
- Implement patient blood management (PBM) protocols to the clinical setup, with guidelines, SOPs and training modules.
- Identify focal point from each facility for haemovigilance reporting and oversee transfusion practices.
- Establish Hospital Transfusion Committees (HTC's) and monitor transfusion practices, discards, transfusion reactions and blood stock.

STRATEGIC OBJECTIVE 4

Optimize Evidence Based Thalassemia Care and Treatment

GOAL

Provide evidence-based, comprehensive, and patient-centred care for individuals with thalassemia, addressing their physical, emotional, and social needs.

OBJECTIVE 4.1

Enhance thalassemia treatment and management

- Establishment of a thalassemia care centre with preventive, diagnostic, therapeutic and management capacity under one building.
- Establish a multidisciplinary care team for comprehensive patient management and schedule regular follow-up appointments every 3-6 months.
- Establish a multi-sectoral committee comprising administrators, healthcare professionals, government representatives (e.g. education, social department), NGOs, CSOs and community leaders to facilitate thalassemia care.
- Ensure access to necessary drugs, equipment (pumps, needles, accessories) and supplies for chelation therapy.
- Follow an evidence-based approach for iron chelation therapy with specific diagnostic protocols for evaluations (as per thalassemia management guideline).
- Improve iron chelation compliance through regular assessment and monitoring by medical staff.

- Support patients and caregivers in adhering to chelation therapy through a collaborative approach involving clinical doctors, nurses, and psychologists/counsellors.
- Provide age-appropriate education and counselling on chelation, including benefits and possible adverse effects.

OBJECTIVE 4.2

Improve quality of life for thalassemia patients

- Develop and implement strategies to enhance the quality of life for thalassemia patients, including psychosocial support and patient education.
- Establish support services to identify and refer health and social issues at primary care level to the relevant multidisciplinary specialties.
- Establish patient support groups and advocacy networks.
- To develop periodic assessment of Health-Related Quality of Life (HRQoL) of thalassemia patients.

OBJECTIVE 4.3

Advance thalassemia care

- Implement evidence-based management of complications by reinforcing multidisciplinary patient monitoring on a case-by-case basis.
 - Follow an evidence-based approach for monitoring complications with specific time lines for evaluations (as per Thalassemia management guideline).
 - Introduce Tele-consultation for distant referral.
 - Establish weekly or biweekly multidisciplinary clinics where a team oversee complex cases (including referral), ensuring guidance and supervision by experienced specialist.
 - Collaborate and network with other regional and international centres of excellence to facilitate management of difficult thalassemia cases.
 - Implement evidence-based approach for management of thalassemia complications as recommended by TIF. (15)
-

OBJECTIVE 4.4

Implement bone marrow transplant (BMT) & gene therapy

- Conduct a feasibility study to implement advanced treatment options such as bone marrow transplantation and gene therapy.
 - Develop a guideline for patient & donor selection for BMT (mechanism of prioritizing among all eligible patients) and monitoring of patients from pre BMT, during BMT and post BMT.
-

STRATEGIC OBJECTIVE 5

Develop Tailored Care and Support Services for Older Thalassemia Patients

GOAL

Provide individualized, holistic care to individuals with thalassemia throughout their lifespan. As life expectancy for thalassemia patients increases, develop a comprehensive management plan that focuses on medical management, psychological support, emotional counselling, financial assistance, and community-based services to ensure their overall well-being.

OBJECTIVE 5.1

Establish a child-to-adolescent transition care program

- Develop and implement a comprehensive plan to support individuals living with thalassemia as they transition from childhood to adolescence and from adolescence to adulthood.
- Provide education and support to families to help them understand treatment and management options and the future possibilities for their child with thalassemia.
- Ensure that younger patients receive comprehensive health and social care to achieve normal and healthy growth and well-being.
- Monitor adherence to transfusion, chelation, and regular monitoring regimens during the transition period.
- Implement strategies to address potential complications and comorbidities during adolescence and early adulthood, leading to improved quality of life.

OBJECTIVE 5.2

Establish comprehensive care for older thalassemia patients

- Ensure regular monitoring by doing health check-ups focusing on common complications in older thalassemia patients, such as blood transfusion and iron chelation, cardiac issues, diabetes, osteoporosis, and liver disease.

- Establish multidisciplinary care teams or link to such services including haematologists, physicians, transfusion specialists, cardiologists, endocrinologists, nutritionist and other specialists to provide coordinated care.
- Develop guidelines for the care of older thalassemia patients, addressing specific needs and challenges.
- Develop individualized treatment plans that consider the patient's age, comorbidities, and overall health status. Collaborate with inpatient services for flexible transfusion days and hours which facilitate the patient's work schedule.
- Provide access to psychological services, including counselling and support groups, to address anxiety, depression, and other issues.
- Nutritional counselling through personalized nutritional advice to help manage complications and maintain overall health.

OBJECTIVE 5.3

Implement Evidence-Based Management Of Complications:

- Enhance the comprehensive management of complications by reinforcing multidisciplinary patient monitoring case-by-case basis.
 - Establish specific timelines for evaluations to effective monitoring and management of complications, including:
 - Chelation and blood transfusion regimens, Regular follow-ups, monitoring, and assessments to prevent and manage developing and developed complications, liver and hepatic diseases, cardiology diseases, endocrinology issues (delayed puberty, growth deficiency, hypogonadism, hypothyroidism), bone health, pregnancy care and conception.
-

OBJECTIVE 5.4

Improve access to care and support

- Develop safe and appropriate exercise programs to improve physical fitness and well-being.
 - Facilitate peer support networks to connect older thalassemia patients with others who share similar experiences.
 - Provide continuous patient education on managing thalassemia and its complications, emphasizing the importance of adherence to treatment plans.
 - Encourage self-management strategies to empower patients to take an active role in their health care.
 - Educate family members about the specific needs and challenges of older thalassemia patients to enhance their support.
 - Engage community organizations to provide social support and reduce isolation among older patients.
-

OBJECTIVE 5.5

Ensure financial sustainability and social support

- Explore options for financial sustainability to reduce the economic burden on thalassemia patients and their families.
 - Collaborate with government and non-governmental organizations to provide social support services.
 - Increase public awareness about the challenges faced by older thalassemia patients to garner broader support and understanding.
 - Advocate for policies that support the needs of older thalassemia patients, including access to specialized care.
-

STRATEGIC OBJECTIVE 6

Digitalize thalassemia care and management data into an integrated health information system

GOAL: BY 2034

Establish and fully operationalize a comprehensive, integrated digital health information system for thalassemia care and management. This system will cover thalassemia screening, clinical management, referrals, blood donation, transfusion services, and inventory management, enabling efficient operations, data-driven decision making, and improved patient outcomes.

OBJECTIVE 6.1

Develop a comprehensive data capturing system for thalassemia screening, control and management

- Establish a centralized, national thalassemia database to capture and analyse related data from all health facilities.
- Develop standardized data collection tools and protocols to ensure consistency and accuracy of data entry.
- Integrate population-based thalassemia screening information into the centralized national thalassemia database (comprehensive patient data, including demographics, clinical information, treatment history, and outcomes).
- Establish a real-time thalassemia referral system (including a tracking and timely follow up mechanism for patients).
- Ensure compatibility and integration with existing national healthcare information systems.
- Conduct regular audits to ensure data quality and comprehensiveness.
- Implement robust data privacy and security measures to protect patient and donor information according to the national and international laws and guidelines.

OBJECTIVE 6.2

Establishment of centralized blood bank information management system

- Introduce a standardized donor and donation identification system (compatible with International Society of Blood Transfusion (ISBT) 128 barcode guide).
- Implement a digital health database to assist in the real time monitoring and planning of day-to-day activities related to of blood collection, component production, blood stock management and donor deferral management.
- Establish a real time stock management system to optimize inventory and manage blood stocks, to reduce the high discard rate.

OBJECTIVE 6.3

Enhance data utilization and analysis

- Utilize data to monitor program performance, identify trends, and evaluate the impact of interventions.
 - Establish a mechanism to routinely monitor and evaluate the screening data to achieve and achieving the national targets.
 - Conduct regular data analysis to inform and support policy changes and program improvements.
 - Develop user-friendly reports and dashboards to visualize data and communicate findings effectively.
 - Implement mobile data entry solutions for use in remote or resource-limited settings (capacity of offline data entry and when system back online offline data synchronize with online database).
 - Develop clear policies for data sharing and assess the ethical aspect while ensuring patient privacy and data security.
-

STRATEGIC OBJECTIVE 7

Strengthen human resources and research capacity

GOAL: BY 2034

To have in place a highly skilled and motivated healthcare workforce with strong research capacity to advance thalassemia care and management in the Maldives.

OBJECTIVE 7.1

Enhance healthcare workforce capacity

- Establish mentorship programs and facilitate continuing medical education (CME) and professional development opportunities.
- Conduct regular in-service training programs, retraining and competency assessments about thalassemia treatment for all healthcare staff.
- Training community health ambassadors to advocate and educate within their communities.
- Implement patient and caregivers' education programs with regards to the importance of iron chelation and adherence to treatment protocols.

OBJECTIVE 7.2

Strengthen training and education

- Develop and implement comprehensive training programs for healthcare providers on thalassemia diagnosis, management, and counselling.
- Provide regular training and workshops for healthcare providers on the prenatal thalassemia management.
- Integrate thalassemia education into national curriculum (medical, nursing and allied health).
- Ensure all relevant technical staff are trained in genetic screening procedures and technologies.
- Expand Training Programs by increasing the number of genetic counselling training programs in local tertiary education institutions.
- Facilitate participation in international training programs/workshops and seminars relevant to Thalassemia management and blood transfusion.

OBJECTIVE 7.3

Enhance blood banking and transfusion services capacity

- Incorporate transfusion medicine into the curriculum of medical, nursing and allied health professionals.
- Develop training and orientation programs for blood banking and transfusion services staff.
- Teaching and caregiving institutions to collaborate with international transfusion services to develop a comprehensive teaching and training module related to blood banking and thalassemia management for medical professionals.
- Implement continuing medical education (CME) programs and competency assessment.

OBJECTIVE 7.4

Strengthen research capacity

- Promote collaborative research initiatives, incentivize funding allocation, and establish centralized data/research repositories to support research to improve thalassemia prevention, diagnosis, treatment, and management.
 - Facilitate the conduction of studies/ research with regards to thalassemia patient outcomes (area of improvement).
 - Collect and analyse data on the aging thalassemia population to inform future care strategies and improve outcomes.
 - Encourage participation in clinical trials focusing on older thalassemia patients to explore new treatments and interventions.
 - Facilitate the translation of research findings into policy and clinical practice.
 - Collaborate with national and international research institutions.
-

OBJECTIVE 7.5

Improve data management and analytical capacity

- Provide comprehensive training on data collection, management, and utilization for healthcare providers.
- Provide adequate training for healthcare providers and administrative staff on data entry, management, and utilization.
 - Examples of some data requirements of thalassemia control and prevention.
 - Number of screening programs conducted, and island coverage
 - Number of awareness programs conducted
 - Number of school screening programs conducted
 - Number of premarital counselling and screening done
 - Develop a team of data analysts to support research and program evaluation.

MONITORING AND EVALUATION FRAMEWORK FOR MASTERPLAN (2024-2034)



STRATEGIC OBJECTIVE 1

ESTABLISH ROBUST POLICIES AND GOVERNANCE FRAMEWORK FOR THALASSEMIA CARE (M&E)

01

KPI

Thalassemia Act reviewed and updated

DEFINITION (NUMERATOR/DENOMINATOR)

Review and update Thalassemia Act

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0	Revised Act	Gazette Notification	-
RESPONSIBILITY		REPORTING	IMPLEMENTATION TIMELINE
MBS, PIIR, Legal division of MOH		Parliament through MOH	Short term (2024-2026)

02

KPI

Percentage of hospitals and health centres with designated focal points for thalassemia care

DEFINITION (NUMERATOR/DENOMINATOR)

Number of hospitals and health centres with designated focal points / Total number of hospitals and health centres providing thalassemia care (estimated 190)

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0	100%	Hospital records, appointment letters	Annually
RESPONSIBILITY		REPORTING	IMPLEMENTATION TIMELINE
MBS, RAHSD		Ministry of Health	Short term (2024-2026)

03

KPI

Percentage of program performance indicators monitored

DEFINITION (NUMERATOR/DENOMINATOR)

Number of program performance indicators monitored / Total number of identified indicators to be monitored

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0	100%	program records	Annually
RESPONSIBILITY		REPORTING	IMPLEMENTATION TIMELINE
MBS		Ministry of Health	Long term (2024-2034)

04

KPI

Percentage of specialized positions recruited as per restructured model of MBS

DEFINITION (NUMERATOR/DENOMINATOR)

Number of specialized cadres recruited/total number of specialized cadres proposed

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
30%	100% (87 specialized cadres)	HR records/Appointment letters	Annually
RESPONSIBILITY		REPORTING	IMPLEMENTATION TIMELINE
MBS, HR		Ministry of Health	Long term (2024-2034)



STRATEGIC OBJECTIVE 2

ENHANCE EARLY DETECTION AND PREVENTION OF THALASSEMIA (M&E)

01

KPI

Percentage coverage of carrier screening program for 18 years and above

DEFINITION (NUMERATOR/DENOMINATOR)

Number of carrier screening completed/ Total number of eligible populations for screening

BASELINE 34%	TARGET 100%	MEANS OF VERIFICATION Thalassemia screening registry	FREQUENCY Annually
RESPONSIBLE MBS	REPORTING Ministry of Health	IMPLEMENTATION TIMELINE Long term (2024-2034)	

02

KPI

Percentage coverage of school-based carrier screening program for grade 10 student

DEFINITION (NUMERATOR/DENOMINATOR)

Number of carrier screening completed/ Total number of school children in grade 10

BASELINE 63%	TARGET 100%	MEANS OF VERIFICATION Thalassemia screening registry
FREQUENCY Annually	RESPONSIBLE MBS	REPORTING Ministry of Health
IMPLEMENTATION TIMELINE Long term (2024-2034)		

03

KPI

Number of health education programs for school children

DEFINITION (NUMERATOR/DENOMINATOR)

Total number of health education programs conducted for school children/ Total number of education programs for school children planned.

BASELINE 24	TARGET 24 programs per year)	MEANS OF VERIFICATION Program records, school education reports
FREQUENCY Annually	RESPONSIBLE MBS, Ministry of Education,	REPORTING Annual program reports to MOH, Ministry of Education
IMPLEMENTATION TIMELINE Long term (2024-2034)		

04

KPI

Establish additional screening/ sample collection centres, particularly in selected islands/atolls to enhance accessibility

DEFINITION (NUMERATOR/DENOMINATOR)

The number of additional screening/ sample collection centres, established in remote and underserved areas / The total number of additional screening/ sample collection centres targeted to be established.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Facility records	
FREQUENCY Annually	RESPONSIBLE MOH, MBS, RAHSD	REPORTING Ministry of Health	IMPLEMENTATION TIMELINE Mid term (2024-2030)

05

KPI

Strengthen pre-marital counselling services in atolls, including genetic counselling for informed decision-making, with a focus on couples at risk

DEFINITION (NUMERATOR/DENOMINATOR)

The number of couples that underwent pre-marital counselling services / total number of married couples per year.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Counselling records	
FREQUENCY Annually	RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre	REPORTING MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

06

KPI

Ensure quality assurance and accreditation of genetic screening laboratories

DEFINITION (NUMERATOR/DENOMINATOR)

Number of genetic screening laboratories following a quality assurance program and undergone accreditation / Total number of genetic screening laboratories

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Accreditation certificates	
FREQUENCY Annually	RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre	REPORTING MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

07

KPI

Implement a referral system for specialized genetic testing, including guidelines for sample transportation to the central.

DEFINITION (NUMERATOR/DENOMINATOR)

% completion of referral system & sample transportation guideline / The completed referral system & sample transportation guideline.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Completed Guideline	FREQUENCY Annually
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING MBS	IMPLEMENTATION TIMELINE Mid term (2024-2030)

08

KPI

Develop and implement standardized referral protocols to ensure consistent and timely referrals across all healthcare facilities.

DEFINITION (NUMERATOR/DENOMINATOR)

% completion of referral protocol / Completed & approved referral protocol

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Completed Protocol	FREQUENCY Biannual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING MBS	IMPLEMENTATION TIMELINE Short term (2024-2026)

09

KPI

Increase the uptake of prenatal diagnosis among at-risk couples by 50% by 2034

DEFINITION (NUMERATOR/DENOMINATOR)

The number of at-risk couples who actually undergo prenatal diagnosis / The total number of at-risk couples who are eligible for prenatal diagnosis

BASELINE 0%	TARGET 50% increase from baseline	MEANS OF VERIFICATION Diagnosis records	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

10

KPI

Develop and implement standardized protocols for prenatal care and management of thalassemia risk, including early foetal surveillance and management.

DEFINITION (NUMERATOR/DENOMINATOR)

% completion of standardized protocols for prenatal care and management of thalassemia risk / Completed & approved standardized protocols for prenatal care and management of thalassemia risk

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Completed Protocol	FREQUENCY Biannual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING MBS	IMPLEMENTATION TIMELINE Short term (2024-2026)

11

KPI

Increase the number of accredited specialized prenatal diagnostic and treatment facilities.

DEFINITION (NUMERATOR/DENOMINATOR)

Number of prenatal diagnostic and treatment facilities with accreditation/Total number of prenatal diagnostic and treatment facilities.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Accreditation certificates	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

12

KPI

Develop a designated healthcare facility for comprehensive prenatal diagnostic and treatment procedures, including specialized care and support services.

DEFINITION (NUMERATOR/DENOMINATOR)

% completion of Prenatal diagnostic Centres / Completed Prenatal diagnostic Centre

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Facility records	FREQUENCY Annual
RESPONSIBLE Head of MBS / Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Ministry of Health, Ministry of Finance	IMPLEMENTATION TIMELINE Long term (2024-2034)

13

KPI

Include prenatal thalassemia diagnosis and treatment details in the maternal health education program for risk couples.

DEFINITION (NUMERATOR/DENOMINATOR)

Number of couples who received maternal health education that included prenatal thalassemia diagnosis and treatment details / Total number of couples eligible for maternal health education programs

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Programme records	FREQUENCY Annual
RESPONSIBLE Head of MBS / Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Ministry of Health	IMPLEMENTATION TIMELINE Long term (2024-2034)



STRATEGIC OBJECTIVE 3

ENSURE THE RELIABILITY AND QUALITY OF TRANSFUSION SERVICES (M&E)

01 KPI
Establish a centralized blood bank coordination system with 5 regional blood banks in atolls and 1 centre in greater male' region, to ensure availability of blood and blood products to the catchment population

DEFINITION (NUMERATOR/DENOMINATOR)

% completion development of coordination system / Completed fully operational coordination system developed

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0%	100%	Government circular, Regional blood centre reports	Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Midterm (2024-2030)

02 KPI
Establish blood transfusion services in all government health facilities in periphery, and ensure access to blood and blood products through regional banks

DEFINITION (NUMERATOR/DENOMINATOR)

Number of government health facilities with established transfusion services / Total number of government health facilities identified for transfusion services

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
108	100%	Government circular	Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Midterm (2024-2030)

03 KPI
Centralize component production services in 5 regional blood banks (e.g. quadruple bags to prepare platelet concentrates)

DEFINITION (NUMERATOR/DENOMINATOR)

Number of regional blood centres implementing centralized component production using efficient technologies / Total number of regional blood centres.

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0%	100% Target 5	Government circular, Regional blood centre reports	Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Midterm (2024-2030)

04

KPI**Ensure 100% blood component preparation from whole blood donations****DEFINITION (NUMERATOR/DENOMINATOR)**

Number of whole blood donations from which components have been prepared / Total number of whole blood donations collected.

BASELINE 50%	TARGET 100%	MEANS OF VERIFICATION Blood bank monthly statistics reporting form	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Midterm (2024-2030)

05

KPI**Convert directed donations to 100% Voluntary Non-Remunerated Donors (VNRDs) by 2034 (10 years)****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of voluntary non-remunerated donations (VNRD) achieved / The total number of blood donations

BASELINE 15%	TARGET 100% By 2034	MEANS OF VERIFICATION Blood bank monthly statistics reporting form	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

06

KPI**Implement 100% TTI testing using more sensitive and quality assured methods (ELISA/ CIA) in the proposed blood banks.****DEFINITION (NUMERATOR/DENOMINATOR)**

Number of proposed blood banks implementing TTI testing using sensitive methods (ELISA or CIA) / Total number of proposed blood banks

BASELINE 16%	TARGET 100%	MEANS OF VERIFICATION Testing records, method validation reports, Blood bank monthly statistics reporting form	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Midterm (2024-2030)

07

KPI**Participate in proficiency testing and accreditation programs (international organization for standardization (iso)/ association for the advancement of blood & biotherapies (aabb), national accreditation board for hospitals & healthcare providers (nabh) and any other national accreditation programs)****DEFINITION (NUMERATOR/DENOMINATOR)**

Number of laboratories taking part in proficiency testing and EQA programs / Total number of targeted laboratories to take part in proficiency testing and EQA programs.

BASELINE 16%	TARGET 100%	MEANS OF VERIFICATION Proficiency testing records, EQA report, Accreditation records	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

08

KPI

Establish donor, process and patient haemovigilance reporting and reviewing system to monitor adverse events.

DEFINITION (NUMERATOR/DENOMINATOR)

Percentage completion of hemovigilance reporting and review system / completed hemovigilance reporting & review system.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Hemovigilance reports	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Midterm (2024-2030)

09

KPI

Identify focal point from each facility for haemovigilance reporting and oversee transfusion practices.

DEFINITION (NUMERATOR/DENOMINATOR)

Number of hospitals and health care centres with designated focal points for haemovigilance reporting / Total number of hospitals & health care facilities targeted for implementation.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Focal point identification records	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Short term (2024-2026)

10

KPI

Establish Hospital Transfusion Committees (HTC's) and monitor transfusion practices, discards, transfusion reactions and blood stock.

DEFINITION (NUMERATOR/DENOMINATOR)

Number of hospitals with established HTCs / Total number of hospitals.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION HTC reports	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MBS	IMPLEMENTATION TIMELINE Short term (2024-2026)



STRATEGIC OBJECTIVE 4

OPTIMIZE EVIDENCE BASED THALASSEMIA CARE AND TREATMENT (M&E)

01

KPI

Establishment of a thalassemia care centre with preventive, diagnostic, therapeutic and management capacity under one building

DEFINITION (NUMERATOR/DENOMINATOR)

Percentage completion of thalassemia care centre / completed thalassemia care centre

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0%	100%	Monthly construction progress reports.	Annually
RESPONSIBLE		REPORTING	IMPLEMENTATION TIMELINE
Project Manager		Ministry of Health	Long term (2024-2034)

02

KPI

Appoint a multidisciplinary care team for comprehensive patient management and schedule regular follow-up appointments every 3-6 months

DEFINITION (NUMERATOR/DENOMINATOR)

The number of specialized staff appointments made / The total number of required specialized staff appointments planned.

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
0%	100%	Staff appointment records	Annual
RESPONSIBLE		REPORTING	IMPLEMENTATION TIMELINE
Head of Thalassemia & Other Hemoglobinopathies Centre		Ministry of Health	Short term (2024-2026)

03

KPI

Ensure access to necessary drugs, equipment (pumps, needles, accessories) and supplies for chelation therapy

DEFINITION (NUMERATOR/DENOMINATOR)

Number of patients requiring chelation therapy who have access to all necessary drugs, equipment (e.g., pumps, needles), and supplies / Total number of patients requiring chelation therapy

BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY
100%	100%	Patient records Drugs and equipment supply records	Annual
RESPONSIBLE		REPORTING	IMPLEMENTATION TIMELINE
Head of Thalassemia & Other Hemoglobinopathies Centre		Ministry of Health	Long term (2024-2034)

04

KPI**To develop periodic assessment of health-related quality of life (HRQoL) of thalassemia patients****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of Thalassemia patients assessed for HRQoL / The total number of Thalassemia patients.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION HRQoL assessment reports	FREQUENCY Biannual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Ministry of Health	IMPLEMENTATION TIMELINE Long term (2024-2034)

05

KPI**Collaborate and network with other regional and international centres of excellence to facilitate management of difficult thalassemia cases****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of monthly expert panel consultations conducted / The total number of planned monthly expert panel consultations

BASELINE 0%	TARGET 100% (Target - 12 per year once per month).	MEANS OF VERIFICATION Signed agreement document, referral meeting minutes	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Ministry of Health	IMPLEMENTATION TIMELINE Short term (2024-2026)

06

KPI**Develop a guideline for patient & donor selection for BMT (mechanism of prioritizing among all eligible patients) and monitoring of patients from pre BMT, during BMT and post BMT****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of completed sections of the guideline (e.g. donor selection for Bone Marrow Transplant monitoring pre-BMT, during BMT, and post-BMT stages) / The total number of sections planned for the guideline.

BASELINE 0%	TARGET 100% (formulation of BMT guideline	MEANS OF VERIFICATION Guideline report	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Ministry of Health	IMPLEMENTATION TIMELINE Short term (2024-2026)



STRATEGIC OBJECTIVE 5

DEVELOP TAILORED CARE AND SUPPORT SERVICES FOR OLDER THALASSEMIA PATIENTS (M&E)

01

KPI

Ensure that younger patients receive comprehensive health and social care to achieve normal and healthy growth and well-being

DEFINITION (NUMERATOR/DENOMINATOR)

Number of younger patients who received comprehensive health and social care services aimed at promoting normal and healthy growth and well-being / Total number of younger patients eligible for comprehensive health and social care

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Patient records	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

02

KPI

Monitor adherence to transfusion, chelation, and regular monitoring regimens during the transition period

DEFINITION (NUMERATOR/DENOMINATOR)

Number of patients in the transition period who adhered to their prescribed transfusion, chelation, and regular monitoring regimens / Total number of patients in the transition period who were prescribed transfusion, chelation, and regular monitoring regimens

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Patient records	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

03

KPI

Establish multidisciplinary care teams or link to such services including haematologists, physicians, transfusion specialists, cardiologists, endocrinologists, nutritionist and other specialists to provide coordinated care for elderly thalassemia patients

DEFINITION (NUMERATOR/DENOMINATOR)

Number of elderly thalassemia patients receiving care from a multidisciplinary team / Total number of elderly thalassemia patients requiring coordinated care.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION	FREQUENCY Annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

04

KPI

Provide access to psychological services, including counselling and support groups, to address anxiety, depression, and other issues

DEFINITION (NUMERATOR/DENOMINATOR)

The number of psychological counselling sessions conducted for elderly thalassemia patients /Total number of elderly Thalassemia patients

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Counselling records	FREQUENCY Biannual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

05

KPI

Nutritional counselling through personalized nutritional advice to help manage complications and maintain overall health

DEFINITION (NUMERATOR/DENOMINATOR)

The number of nutritional counselling sessions conducted for elderly thalassemia patients /Total number of elderly Thalassemia patients

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Counselling records	FREQUENCY Biannual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

06

KPI

Provide continuous patient education on managing thalassemia and its complications, emphasizing the importance of adherence to treatment plans

DEFINITION (NUMERATOR/DENOMINATOR)

The number of patient education programs conducted for older thalassemia patients within a year / The total number of planned patient education programs for older Thalassemia patients within a year.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION CME program records	FREQUENCY Bi annual
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

07

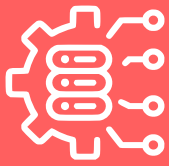
KPI

Educate family members about the specific needs and challenges of older thalassemia patients to enhance their support

DEFINITION (NUMERATOR/DENOMINATOR)

The number of education programs conducted for family members of older Thalassemia patients within a year / The total number of planned education programs for family members of older Thalassemia patients within a year.

BASELINE 0%	TARGET 100% 2 per year	MEANS OF VERIFICATION Family education program records	FREQUENCY Bi annual
RESPONSIBLE Family education team, Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)



STRATEGIC OBJECTIVE 6

DIGITALIZE THALASSEMIA CARE AND MANAGEMENT DATA INTO AN INTEGRATED HEALTH INFORMATION SYSTEM (M&E)

01

KPI

Establish a centralized, national thalassemia database to capture and analyse related data from all health facilities

DEFINITION (NUMERATOR/DENOMINATOR)

Number of health facilities that implement national thalassemia database / Total number of health facilities that needs to be implement national thalassemia database

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION System implementation documents, System Logs	FREQUENCY Biannually
RESPONSIBLE MBS, MOH-IT		REPORTING MOH	IMPLEMENTATION TIMELINE Short term (2024-2026)

02

KPI

Establish a real-time thalassemia referral system (including a tracking and timely follow up mechanism for patients)

DEFINITION (NUMERATOR/DENOMINATOR)

Number of centres that implement real-time thalassemia referral system / Total number of centres that needs to be implement real-time thalassemia referral system

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION System implementation documents, System Logs	FREQUENCY Annual
RESPONSIBLE MBS, MOH-IT		REPORTING MOH	IMPLEMENTATION TIMELINE Short term (2024-2026)

03

KPI

Conduct regular audits to ensure data quality and comprehensiveness

DEFINITION (NUMERATOR/DENOMINATOR)

Number of health care centres that conduct audits / Total number of health care centres that needs to be conduct audits

BASELINE 11%	TARGET 100%	MEANS OF VERIFICATION Audit records	FREQUENCY Annually
RESPONSIBLE MBS, MOH-IT		REPORTING MOH	IMPLEMENTATION TIMELINE Short term (2024-2026)

04

KPI

Establish a real time stock management system to optimize inventory and manage blood stocks, to reduce the high discard rate

DEFINITION (NUMERATOR/DENOMINATOR)

Number of centres that implement real time stock management system / Total number of centres that needs to be implement real time stock management system

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION System implementation documents, System Logs	FREQUENCY Biannually
RESPONSIBLE MBS, MOH-IT		REPORTING MOH	IMPLEMENTATION TIMELINE Short term (2024-2026)

05

KPI

Utilize data to monitor program performance, identify trends, and evaluate the impact of interventions

DEFINITION (NUMERATOR/DENOMINATOR)

Number of program performance reports generated using data analysis to monitor trends and evaluate the impact of interventions / Total number of scheduled program performance evaluations or reviews.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Program records	FREQUENCY Annually
RESPONSIBLE MBS, MOH-IT		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)



STRATEGIC OBJECTIVE 7

STRENGTHEN HUMAN RESOURCES AND RESEARCH CAPACITY (M&E)

01

KPI

Conduct regular in-service training (IST) programs, retraining and competency assessments about thalassemia treatment for all healthcare staff.

DEFINITION (NUMERATOR/DENOMINATOR)

The number of IST programs conducted per year for each category of health staff / The target number of training programs per year for each category of health staff.

BASELINE 0%	TARGET 100% IST- twice per year Comp assessment – annually	MEANS OF VERIFICATION Training records, CME program reports	FREQUENCY Annually
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS, MOH Medical Education Departments		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

02

KPI

Implement patient and caregivers’ education programs with regards to the importance of iron chelation and adherence to treatment protocols

DEFINITION (NUMERATOR/DENOMINATOR)

The number of education programs conducted per year / The target number of education programs to be conducted per year.

BASELINE 0	TARGET Twice a year online and onsite programs	MEANS OF VERIFICATION Education program reports	FREQUENCY Annually
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH	IMPLEMENTATION TIMELINE Long term (2024-2034)

03

KPI

Provide regular training and workshops for healthcare providers on the prenatal thalassemia management

DEFINITION (NUMERATOR/DENOMINATOR)

The number of training sessions conducted for healthcare providers / The total number of planned training sessions.

BASELINE 0	TARGET 2 session per year	MEANS OF VERIFICATION Training attendance records	FREQUENCY Annually
RESPONSIBLE Training coordinators, MOH, Head of Thalassemia & Other Hemoglobinopathies Centre /MBS.		REPORTING Head of MBS	IMPLEMENTATION TIMELINE Long term (2024-2034)

04

KPI**Integrate thalassemia education into national curriculum (medical, nursing and allied health)****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of educational institutions that have incorporated Thalassemia education into their curriculum / The total number of targeted educational institutions.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Training curriculum	FREQUENCY Annually
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre /MBS		REPORTING MOH, Ministry of education	IMPLEMENTATION TIMELINE Long term (2024-2034)

05

KPI**Facilitate participation in international training programs/workshops and seminars relevant to Thalassemia management and blood transfusion****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of healthcare professionals who have participated in international training programs / The total number of healthcare professionals targeted for international training programs.

BASELINE 0	TARGET Two individuals selected from each category of staff to take part in one international program per year	MEANS OF VERIFICATION International training participation records/ certificates	FREQUENCY Annually
RESPONSIBLE MOH, MBS		REPORTING Report to Finance Ministry	IMPLEMENTATION TIMELINE Long term (2024-2034)

06

KPI**Incorporate transfusion medicine into the curriculum of medical, nursing and allied health professionals****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of educational institutions that have incorporated transfusion medicine into their curriculum / The total number of targeted educational institutions.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Training curriculum	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MOH, Ministry of education	IMPLEMENTATION TIMELINE Long term (2024-2034)

07

KPI**Develop training and orientation programs for blood banking and transfusion services staff****DEFINITION (NUMERATOR/DENOMINATOR)**

The number of new healthcare recruits who have completed the orientation training/ The total number of new healthcare recruits.

BASELINE 0%	TARGET 100%	MEANS OF VERIFICATION Training Curriculum, Orientation program agenda	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank		REPORTING MOH - Medical Education Departments	IMPLEMENTATION TIMELINE Long term (2024-2034)

08

KPI

Promote collaborative research initiatives, incentivize funding allocation, and establish centralized data/ research repositories to support research to improve thalassemia prevention, diagnosis, treatment, and management

DEFINITION (NUMERATOR/DENOMINATOR)

Number of collaborative research initiatives & funding allocations within the year / Total number of planned research initiatives & funding allocations, targeted to be established within the year.

BASELINE 0	TARGET Target - 5 Research papers and funding allocations per year 1 centralized data / research repository	MEANS OF VERIFICATION Research collaboration agreements, Research funding records Publication records	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank / Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Head of MBS/ MOH Medical Education Departments	IMPLEMENTATION TIMELINE Long term (2024-2034)

09

KPI

Facilitate the conduction of studies/ research with regards to thalassemia patient outcomes (area of improvement)

DEFINITION (NUMERATOR/DENOMINATOR)

Number of studies or research conducted with regards to thalassemia patient outcomes / Total number of planned studies or research with regards to thalassemia patient outcomes

BASELINE 0%	TARGET 100% One study per year	MEANS OF VERIFICATION Publication records	FREQUENCY Annually
RESPONSIBLE Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Head of MBS/ MOH Medical Education Departments	IMPLEMENTATION TIMELINE Long term (2024-2034)

10

KPI

Develop a team of data analysts to support research and program evaluation

DEFINITION (NUMERATOR/DENOMINATOR)

Number of data analysts recruited and trained to support research and program evaluation / Total number of data analysts planned to be recruited and trained to support research and program evaluation

BASELINE 0%	TARGET 100% 5 new recruits	MEANS OF VERIFICATION Employment records	FREQUENCY Annually
RESPONSIBLE Head of Central Blood Bank Head of Thalassemia & Other Hemoglobinopathies Centre		REPORTING Head of MBS/ MOH Medical Education Departments	IMPLEMENTATION TIMELINE Midterm (2024-2030)

Monitoring And Evaluation Framework

STRATEGIC OBJECTIVE 1

Establish Robust Policies and Governance Framework for Thalassemia Care (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Thalassemia Act reviewed and updated	Review and update Thalassemia Act	0	Revised Act	Gazette Notification		MBS, PIIR, Legal division of MOH	Parliament through MOH	Short term (2024-2026)
Percentage of hospitals and health centres with designated focal points for thalassemia care	Number of hospitals and health centres with designated focal points / Total number of hospitals and health centres providing thalassemia care (estimated 190)	0%	100%	Hospital records, appointment letters	Annually	MBS, RAHSD	Ministry of Health	Short term (2024-2026)
Percentage of program performance indicators monitored	Number of program performance indicators monitored / Total number of identified indicators to be monitored	0%	100%		Annually	MBS	Ministry of Health	Long term (2024-2034)
Percentage of specialized positions recruited as per restructured model of MBS	Number of specialized cadres recruited / total number of specialized cadres proposed	30%	100% (87 specialized cadres)	HR records/Appointment letters	Annually	MBS, HR	Ministry of Health	Long term (2024-2034)

STRATEGIC OBJECTIVE 2

Enhance Early Detection and Prevention of Thalassemia (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Percentage coverage of carrier screening program for 18 years and above)	Number of carrier screening completed/ Total number of eligible populations for screening	34%	100%	Thalassemia screening registry	Annually	MBS	Ministry of Health	Long term (2024-2034)
Percentage coverage of school-based carrier screening program for grade 10 student	Number of carrier screening completed/ Total number of school children in grade 10	63%	100%	Thalassemia screening registry	Annually	MBS	Ministry of Health	Long term (2024-2034)
Number of health education programs for school children	Total number of health education programs conducted for school children/ Total number of education programs for school children planned.	24	100%	24 programs per year)	Annually	MBS, Ministry of Education,	Annual program reports to MOH, Ministry of Education	Long term (2024-2034)
Establish additional screening/ sample collection centres, particularly in selected islands/atolls to enhance accessibility	The number of additional screening/ sample collection centres, established in remote and underserved areas / The total number of additional screening/ sample collection centres targeted to be established.	0%	100%	Facility records	Annually	MOH, MBS, RAHS.	Ministry of Health	Mid term (2024-2030)
Strengthen pre-marital counselling services in atolls, including genetic counselling for informed decision-making, with a focus on couples at risk	The number of couples that underwent pre-marital counselling services / total number of married couples per year.	0%	100%	Counselling records	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Long term (2024-2034)
Ensure quality assurance and accreditation of genetic screening laboratories	Number of genetic screening laboratories following a quality assurance program and undergone accreditation / Total number of genetic screening laboratories	0%	100%	Accreditation certificates	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Long term (2024-2034)
Implement a referral system for specialized genetic testing, including guidelines for sample transportation to the central.	% completion of referral system & sample transportation guideline / The completed referral system & sample transportation guideline.	0%	100%	Completed Guideline	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Mid term (2024-2030)
Develop and implement standardized referral protocols to ensure consistent and timely referrals across all healthcare facilities.	% completion of referral protocol / Completed & approved referral protocol	0%	100%	Completed Protocol	Biannual	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Short term (2024-2026)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Increase the uptake of prenatal diagnosis among at-risk couples by 50% by 2034	The number of at-risk couples who actually undergo prenatal diagnosis / The total number of at-risk couples who are eligible for prenatal diagnosis	0%	50% increase from baseline	Diagnosis records	Annual	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Long term (2024-2034)
Develop and implement standardized protocols for prenatal care and management of thalassemia risk, including early foetal surveillance and management.	% completion of standardized protocols for prenatal care and management of thalassemia risk / Completed & approved standardized protocols for prenatal care and management of thalassemia risk	0%	100%	Completed Protocol	Biannual	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Short term (2024-2026)
Increase the number of accredited specialized prenatal diagnostic and treatment facilities.	Number of prenatal diagnostic and treatment facilities with accreditation/Total number of prenatal diagnostic and treatment facilities.	0%	100%	Accreditation certificates	Annual	Head of Thalassemia & Other Hemoglobinopathies Centre	MBS	Long term (2024-2034)
Develop a designated healthcare facility for comprehensive prenatal diagnostic and treatment procedures, including specialized care and support services.	% completion of Prenatal diagnostic Centres / Completed Prenatal diagnostic Centre	0%	100%	Facility records	Annual	Head of MBS / Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health, Ministry of Finance	Long term (2024-2034)
Include prenatal thalassemia diagnosis and treatment details in the maternal health education program for risk couples.	Number of couples who received maternal health education that included prenatal thalassemia diagnosis and treatment details / Total number of couples eligible for maternal health education programs	0%	100%	Programme records	Annual	Head of MBS / Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health	Long term (2024-2034)

STRATEGIC OBJECTIVE 3

Ensure the Reliability and Quality of Transfusion Services (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Establish a centralized blood bank coordination system with 5 regional blood banks in atolls and 1 centre in Greater Male' Region, to ensure availability of blood and blood products to the catchment population	% completion development of coordination system / Completed fully operational coordination system developed	0%	100%	Government circular Regional blood centre reports	Annually	Head of Central Blood Bank	MBS	Midterm (2024-2030)
Establish blood transfusion services in all government health facilities in periphery, and ensure access to blood and blood products through regional banks	Number of government health facilities with established transfusion services / Total number of government health facilities identified for transfusion services	108	100%	Government circular	Annually	Head of Central Blood Bank	MBS	Midterm (2024-2030)
Centralize component production services in 5 regional blood banks (e.g. Quadrule bags to prepare platelet concentrates)	Number of regional blood centres implementing centralized component production using efficient technologies / Total number of regional blood centres.	0%	100% Target 5	Government circular Regional blood centre reports	Annually	Head of Central Blood Bank	MBS	Midterm (2024-2030)
Ensure 100% blood component preparation from whole blood donations	Number of whole blood donations from which components have been prepared / Total number of whole blood donations collected.	50%	100%	Blood bank monthly statistics reporting form	Annually	Head of Central Blood Bank	MBS	Midterm (2024-2030)
Convert directed donations to 100% Voluntary Non-Remunerated Donors (VNRDs) by 2034 (10 years)	The number of voluntary non-remunerated donations (VNRD) achieved / The total number of blood donations	15%	100% By 2034	Blood bank monthly statistics reporting form	Annually	Head of Central Blood Bank	MBS	Long term (2024-2034)
Implement 100% TTI testing using more sensitive and quality assured methods (ELISA/ CIA) in the proposed blood banks.	Number of proposed blood banks implementing TTI testing using sensitive methods (ELISA or CIA) / Total number of proposed blood banks	16%	100%	Testing records, method validation reports, Blood bank monthly statistics reporting form	Annually	Head of Central Blood Bank	MBS	Midterm (2024-2030)
Participate in proficiency testing and accreditation programs (International Organization for Standardization (ISO)/ Association for the Advancement of Blood & Biotherapies (AABB), National Accreditation Board for Hospitals & Healthcare Providers (NABH) and any other National Accreditation Programs)	Number of laboratories taking part in proficiency testing and EQA programs / Total number of targeted laboratories to take part in proficiency testing and EQA programs.	16%	100%	Proficiency testing records, EQA report Accreditation records	Annually	Head of Central Blood Bank	MBS	Long term (2024-2034)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Establish donor, process and patient haemovigilance reporting and reviewing system to monitor adverse events.	Percentage completion of hemovigilance reporting and review system / completed hemovigilance reporting & review system.	0%	100%	Hemovigilance reports	Annually	Head of Central Blood Bank	MBS	Midterm (2024-2030)
Identify focal point from each facility for haemovigilance reporting and oversee transfusion practices.	Number of hospitals and health care centres with designated focal points for haemovigilance reporting / Total number of hospitals & health care facilities targeted for implementation.	0%	100%	Focal point identification records	Annually	Head of Central Blood Bank	MBS	Short term (2024-2026)
Establish Hospital Transfusion Committees (HTC's) and monitor transfusion practices, discards, transfusion reactions and blood stock.	Number of hospitals with established HTCs / Total number of hospitals.	0%	100%	HTC reports	Annually	Head of Central Blood Bank	MBS	Short term (2024-2026)

STRATEGIC OBJECTIVE 4 Optimize Evidence Based Thalassemia Care and Treatment (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Establishment of a thalassemia care centre with preventive, diagnostic, therapeutic and management capacity under one building	Percentage completion of thalassemia care centre / completed thalassemia care centre	0%	100%	Monthly construction progress reports.	Annually	Project Manager	Ministry of Health	Long term (2024-2034)
Appoint a multidisciplinary care team for comprehensive patient management and schedule regular follow-up appointments every 3-6 months	The number of specialized staff appointments made / The total number of required specialized staff appointments planned.	0%	100%	Staff appointment records	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health	Short term (2024-2026)
Ensure access to necessary drugs, equipment (pumps, needles, accessories) and supplies for chelation therapy	Number of patients requiring chelation therapy who have access to all necessary drugs, equipment (e.g., pumps, needles), and supplies / Total number of patients requiring chelation therapy	100%	100%	Patient records Drugs and equipment supply records	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health	Long term (2024-2034)
To develop periodic assessment of Health-Related Quality of Life (HRQoL) of thalassemia patients	The number of Thalassemia patients assessed for HRQoL / The total number of Thalassemia patients.	0%	100%	HRQoL assessment reports	Biannual	Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health	Long term (2024-2034)
Collaborate and network with other regional and international centres of excellence to facilitate management of difficult thalassemia cases	The number of monthly expert panel consultations conducted / The total number of planned monthly expert panel consultations	0%	100% (Target - 12 per year once per month).	Signed agreement document, referral meeting minutes	Annual	Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health	Short term (2024-2026)
Develop a guideline for patient & donor selection for BMT (mechanism of prioritizing among all eligible patients) and monitoring of patients from pre BMT, during BMT and post BMT	The number of completed sections of the guideline (e.g. donor selection for Bone Marrow Transplant monitoring pre-BMT, during BMT, and post-BMT stages) / The total number of sections planned for the guideline.	0%	100% (formulation of BMT guideline)	Guideline report	Annual	Head of Thalassemia & Other Hemoglobinopathies Centre	Ministry of Health	Short term (2024-2026)

STRATEGIC OBJECTIVE 5 Develop Tailored Care and Support Services for Older Thalassemia Patients (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Ensure that younger patients receive comprehensive health and social care to achieve normal and healthy growth and well-being	Number of younger patients who received comprehensive health and social care services aimed at promoting normal and healthy growth and well-being / Total number of younger patients eligible for comprehensive health and social care	0%	100%	Patient records	Annual	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Monitor adherence to transfusion, chelation, and regular monitoring regimens during the transition period	Number of patients in the transition period who adhered to their prescribed transfusion, chelation, and regular monitoring regimens / Total number of patients in the transition period who were prescribed transfusion, chelation, and regular monitoring regimens	0%	100%	Patient records	Annual	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Establish multidisciplinary care teams or link to such services including haematologists, physicians, transfusion specialists, cardiologists, endocrinologists, nutritionist and other specialists to provide coordinated care for elderly thalassemia patients	Number of elderly thalassemia patients receiving care from a multidisciplinary team / Total number of elderly thalassemia patients requiring coordinated care.	0%	100%		Annual	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Provide access to psychological services, including counselling and support groups, to address anxiety, depression, and other issues	The number of psychological counselling sessions conducted for elderly thalassemia patients / Total number of elderly Thalassemia patients	0%	100%	Counselling records	Biannual	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Nutritional counselling through personalized nutritional advice to help manage complications and maintain overall health	The number of nutritional counselling sessions conducted for elderly thalassemia patients / Total number of elderly Thalassemia patients	0%	100%	Counselling records	Biannual	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Provide continuous patient education on managing thalassemia and its complications, emphasizing the importance of adherence to treatment plans	The number of patient education programs conducted for older thalassemia patients within a year / The total number of planned patient education programs for older Thalassemia patients within a year.	0%	100%	CME program records	Bi annual	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Educate family members about the specific needs and challenges of older thalassemia patients to enhance their support	The number of education programs conducted for family members of older Thalassemia patients within a year / The total number of planned education programs for family members of older Thalassemia patients within a year.	0%	100% 2 per year	Family education program records	Bi annual	Family education team, Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)

STRATEGIC OBJECTIVE 6

Digitalize thalassemia care and management data into an integrated health information system (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Establish a centralized, national thalassemia database to capture and analyse related data from all health facilities	Number of health facilities that implement national thalassemia database / Total number of health facilities that needs to be implement national thalassemia database	0%	100%	System implementation documents System Logs	Biannually	MBS MOH-IT	MOH	Short term (2024-2026)
Establish a real-time thalassemia referral system (including a tracking and timely follow up mechanism for patients)	Number of centres that implement real-time thalassemia referral system / Total number of centres that needs to be implement real-time thalassemia referral system	0%	100%	System implementation documents System Logs	Biannually	MBS MOH-IT	MOH	Short term (2024-2026)
Conduct regular audits to ensure data quality and comprehensiveness	Number of health care centres that conduct audits / Total number of health care centres that needs to be conduct audits	11%	100%	Audit records	Annually	MBS MOH-IT	MOH	Short term (2024-2026)
Establish a real time stock management system to optimize inventory and manage blood stocks, to reduce the high discard rate	Number of centres that implement real time stock management system / Total number of centres that needs to be implement real time stock management system	0%	100%	System implementation documents System Logs	Biannually	MBS MOH-IT	MOH	Short term (2024-2026)
Utilize data to monitor program performance, identify trends, and evaluate the impact of interventions	Number of program performance reports generated using data analysis to monitor trends and evaluate the impact of interventions / Total number of scheduled program performance evaluations or reviews.	0%	100%	Program records	Annually	MBS MOH-IT	MOH	Long term (2024-2034)

STRATEGIC OBJECTIVE 7

Strengthen Human Resources and Research Capacity (M&E)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Conduct regular in-service training (IST) programs, retraining and competency assessments about thalassemia treatment for all healthcare staff.	The number of IST programs conducted per year for each category of health staff / The target number of training programs per year for each category of health staff.	0%	100% IST- twice per year Competency assessment - annually	Training records, CME program reports	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS, MOH Medical Education Departments	MOH	Long term (2024-2034)
Implement patient and caregivers' education programs with regards to the importance of iron chelation and adherence to treatment protocols	The number of education programs conducted per year / The target number of education programs to be conducted per year.	0%	Twice a year online and onsite programs	Education program reports	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH	Long term (2024-2034)
Provide regular training and workshops for healthcare providers on the prenatal thalassemia management	The number of training sessions conducted for healthcare providers / The total number of planned training sessions.	0%	2 session per year	Training attendance records	Annually	Training coordinators, MOH, Head of Thalassemia & Other Hemoglobinopathies Centre / MBS.	Head of MBS	Long term (2024-2034)
Integrate thalassemia education into national curriculum (medical, nursing and allied health)	The number of educational institutions that have incorporated Thalassemia education into their curriculum / The total number of targeted educational institutions.	0%	100%	Training curriculum	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre /MBS	MOH, Ministry of education	Long term (2024-2034)
Facilitate participation in international training programs/ workshops and seminars relevant to Thalassemia management and blood transfusion	The number of healthcare professionals who have participated in international training programs / The total number of healthcare professionals targeted for international training programs.	0	Two individuals selected from each category of staff to take part in one international program per year	International training participation records/ certificates	Annually	MOH, MBS	Report to Finance Ministry	Long term (2024-2034)

KPI	DEFINITION (NUMERATOR/DENOMINATOR)	BASELINE	TARGET	MEANS OF VERIFICATION	FREQUENCY	RESPONSIBLE	REPORTING	IMPLEMENTATION TIMELINE
Incorporate transfusion medicine into the curriculum of medical, nursing and allied health professionals	The number of educational institutions that have incorporated transfusion medicine into their curriculum / The total number of targeted educational institutions.	0%	100%	Training curriculum	Annually	Head of Central Blood Bank	MOH, Ministry of education	Long term (2024-2034)
Develop training and orientation programs for blood banking and transfusion services staff	The number of new healthcare recruits who have completed the orientation training/ The total number of new healthcare recruits.	0%	100%	Training Curriculum, Orientation program agenda	Annually	Head of Central Blood Bank	MOH - Medical Education Departments	Long term (2024-2034)
Promote collaborative research initiatives, incentivize funding allocation, and establish centralized data/research repositories to support research to improve thalassemia prevention, diagnosis, treatment, and management	Number of collaborative research initiatives & funding allocations within the year / Total number of planned research initiatives & funding allocations, targeted to be established within the year.	0%	Target - 5 Research papers and funding allocations per year 1 centralized data / research repository	Research collaboration agreements, Research funding records Publication records	Annually	Head of Central Blood Bank / Head of Thalassemia & Other Hemoglobinopathies Centre	Head of MBS/ MOH Medical Education Departments	Long term (2024-2034)
Facilitate the conduction of studies/ research with regards to thalassemia patient outcomes (area of improvement)	Number of studies or research conducted with regards to thalassemia patient outcomes / Total number of planned studies or research with regards to thalassemia patient outcomes	0%	100% One study per year	Publication records	Annually	Head of Thalassemia & Other Hemoglobinopathies Centre	Head of MBS/ MOH Medical Education Departments	Long term (2024-2034)
Develop a team of data analysts to support research and program evaluation	Number of data analysts recruited and trained to support research and program evaluation / Total number of data analysts planned to be recruited and trained to support research and program evaluation	0%	100% 5 new recruits	Employment records	Annually	Head of Central Blood Bank Head of Thalassemia & Other Hemoglobinopathies Centre	Head of MBS/ MOH Medical Education Departments	Midterm (2024-2030)

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ANNEX 1

PROPOSED MODEL FOR RESTRUCTURING MALDIVIAN BLOOD SERVICES

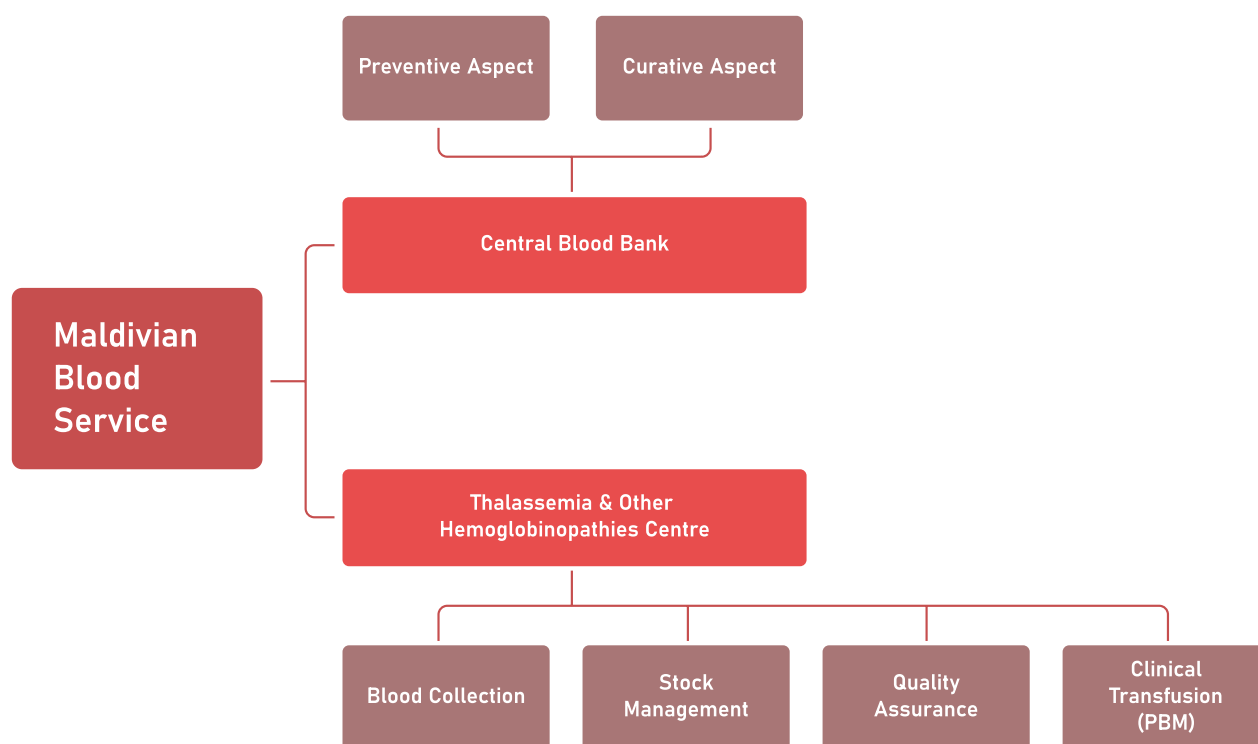


Figure 4: Suggested restructuring model of MBS

- The Maldivian Blood Service needs to clearly define the functions with regards to the Transfusion related services of the Central Blood Bank and Thalassemia related services of the Thalassemia & Other Hemoglobinopathies Centre.
- For efficient functioning and monitoring of the Transfusion Service and Thalassemia service, key personal with adequate qualifications need to be identified and recruited.
- Under the Head of the of the Central Blood Bank there would be a dedicated expert person with knowledge on transfusion medicine, to look into aspects such as National blood collection, Stock management and clinical transfusions (PBM).
- Under the Head of the Thalassemia & Other Hemoglobinopathies Centre there should be an expert person with knowledge on public health to look into the preventive and screening aspects of Thalassemia. A dedicated clinician with expertise on Thalassemia should also be appointed to manage the curative aspect.
- One or two designated Quality Managers must be assigned to cover the quality assurance portion of the Central Blood Bank and Thalassemia & Other Hemoglobinopathies Centre.
- Each identified key positions to be given job descriptions and targets to be achieved.
- The Head of the Maldivian Blood Services is the responsible person to monitor the performance of the above key personnel.

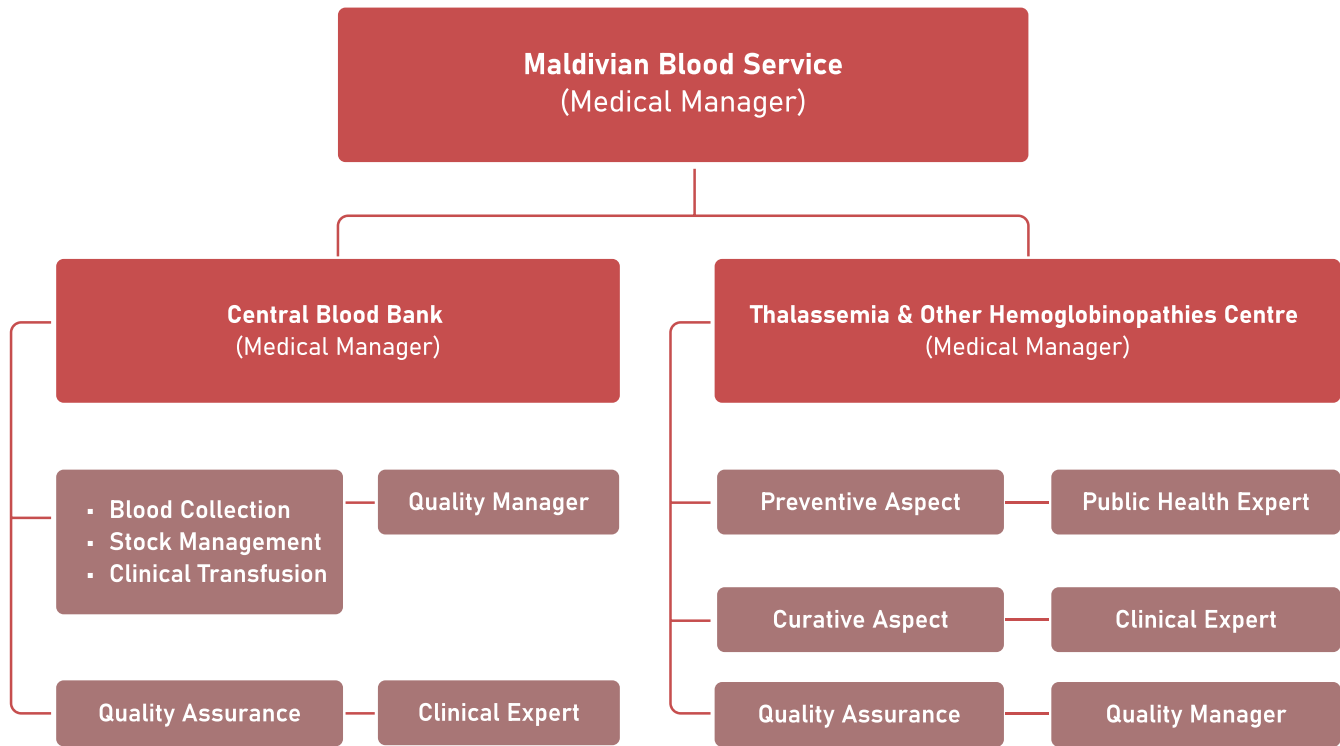


Figure 5: Suggested Administrative Structure and responsible persons

National Master Plan on Thalassemia Prevention, Control and Management (2024-2034)

