



THALASSAEMIA
INTERNATIONAL
FEDERATION

Guide to
**NAVIGATING
THE US
HEALTHCARE
SYSTEM**

for Thalassaemia
Patients & Families

A landscape analysis

August 2026

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EXECUTIVE SUMMARY

Thalassaemia is a rare, lifelong, hereditary genetic blood disorder that requires continuous access to specialized, multidisciplinary care. Although the United States has one of the world's most technologically advanced healthcare systems and the highest healthcare expenditure globally, access to care for people living with thalassaemia is often determined not only by medical need but also by insurance status, state of residence, provider availability, and the ability of patients and families to navigate a highly complex healthcare system.

This Guide examines how the US healthcare system functions in practice for individuals living with thalassaemia and identifies the factors that influence access to diagnosis, treatment, and long-term disease management. Drawing on desk research together with patient and family engagement activities, the analysis explores the structure of the healthcare system, financing and insurance arrangements, patient care pathways, the organization of thalassaemia services, geographic variation in care, and the lived experiences of patients and caregivers.

The analysis demonstrates that the decentralized nature of the US healthcare system creates significant variability in healthcare access. Insurance coverage differs considerably between employer-sponsored plans, Medicare, Medicaid, Marketplace plans, and uninsured populations, while Medicaid eligibility, reimbursement policies, and healthcare delivery vary across states. Consequently, patients with the same condition may experience very different healthcare journeys depending on where they live and the type of insurance they hold.

Specialized thalassaemia care is available through comprehensive treatment centres, primarily located within large academic hospitals. These centres provide the multidisciplinary expertise required to deliver optimal care, including transfusion management, iron chelation, monitoring of complications, genetic counselling, and transition from paediatric to adult services. However, access to these centres remains uneven because of geographic distance, provider network restrictions, referral requirements, prior authorization processes, and financial barriers. Patients living in rural areas or states with limited thalassaemia expertise frequently face additional travel burdens and fragmented care.

Patient and family experiences consistently highlight that navigating the healthcare system can be as challenging as managing the disease itself. Administrative complexity, changing insurance coverage, high out-of-pocket costs, limited awareness of thalassaemia among non-specialist healthcare professionals, and difficulties coordinating care across multiple providers all contribute to delays in diagnosis, interruptions in treatment, and increased emotional and financial burden. These challenges are often amplified for migrant families, who may also encounter language barriers, cultural differences, limited health literacy, and unfamiliarity with the US healthcare system.

Despite these challenges, the US benefits from strong clinical expertise, well-established specialist centres, comprehensive newborn screening programmes, access to modern therapies, and active patient advocacy organizations that play a critical role in supporting patients and promoting high-quality care.

Ultimately, this Guide demonstrates that successful management of thalassaemia depends not only on the availability of medical treatments but also on patients' ability to understand, access, and successfully navigate a fragmented healthcare system. By improving health literacy and providing practical information on healthcare pathways, this Guide aims to empower patients and families to make informed decisions, advocate for appropriate care, and achieve better long-term health outcomes.

INTRODUCTION

Background

Thalassaemia is a group of genetic and inherited haemoglobin disorders characterized by reduced or absent haemoglobin production, resulting in chronic anaemia and a wide spectrum of clinical complications. Depending on disease severity, individuals may require lifelong medical management, including regular blood transfusions, iron chelation therapy, disease monitoring, and access to specialized multidisciplinary care. Without appropriate diagnosis and treatment, thalassaemia can result in significant morbidity, reduced quality of life, and life-threatening complications.

Globally, thalassaemia represents a significant public health challenge. It is estimated that more than 299 million individuals carry a thalassaemia trait and that more than half a million people live with beta thalassaemia, the most severe form of the disease. However, these figures are likely underestimated due to the absence of national disease-specific registries in many countries. Historically associated with populations from malaria-endemic or previously endemic regions, including Southeast Asia, the Middle East, the Mediterranean, and parts of Africa, haemoglobin disorders are now distributed worldwide due to population migration.

In the United States (US), **thalassaemia is a rare genetic condition**, with the exact number of affected individuals unknown due to the absence of a national thalassaemia registry. The increasing diversity of the US population, including **migration from regions with high and medium thalassaemia prevalence**, has contributed to a growing population of individuals living with thalassaemia or carrying the genetic trait. In addition, milder forms of the disease, including non-transfusion-dependent thalassaemia, may remain unrecognized and underrepresented within existing estimates. The rarity and **dispersion of thalassaemia patients across the US**, combined with the wide diversity of ethnic and cultural backgrounds represented within the community, create a distinct set of challenges for patients, families, healthcare professionals and health authorities alike in ensuring consistent access to specialized expertise and comprehensive care. Patients and families experience difficulties identifying appropriate healthcare providers, understanding insurance and reimbursement systems, accessing multidisciplinary services, and coordinating lifelong disease management. These challenges may be further amplified among migrant communities due to language barriers, limited health literacy, unfamiliarity with the healthcare system, cultural differences, financial constraints, and challenges related to navigating insurance coverage.

Recognizing the distinct challenges faced by individuals living with thalassaemia and their families in the US, the Thalassaemia International Federation (TIF) has initiated the project ***Optimizing Patient Access to Healthcare – Navigating the US Healthcare System***.

Project Objectives & Deliverables

Acknowledging that improving health outcomes for people with thalassaemia requires more than access to medical treatments alone, a fact particularly pertinent for rare diseases such as thalassaemia, where fragmented care pathways and limited disease awareness among non-specialist providers may contribute to delays in diagnosis, gaps in treatment, and unequal health outcomes, the project aims to improve health equity by landscaping how the US healthcare system operates in practice, recognizing the barriers patients and parents face in accessing care, and equipping them with the knowledge needed to advocate more effectively for their own health outcomes.

Patients and families must be empowered with knowledge about their condition, healthcare rights, available services, and the practical steps required to access appropriate care. To this end, the project will deliver a:

1. Landscape analysis entitled *A Guide to navigating the US Healthcare System* (this document)
2. Short leaflet with key information from the Guide for patients and families
3. Stakeholder Network including patient organisations, healthcare providers, professional associations etc.

Purpose & Scope

This Guide constitutes a landscape analysis (hereafter referred to as the 'Guide') to provide a comprehensive understanding of the US healthcare system as it relates to thalassaemia care and to identify factors that influence patients' ability to access appropriate healthcare services.

Thus, the scope of this Guide focuses on three core aspects of healthcare delivery:

- **Access:** pathways to diagnosis, referral processes, access to specialist centres, availability of multidisciplinary care, and patient ability to engage with healthcare services.
- **Financing:** insurance coverage, reimbursement mechanisms, affordability of treatments and supportive services, and financial challenges affecting continuity of care.
- **Care delivery:** organization of thalassaemia care, access to haematologists and multidisciplinary teams, treatment pathways, supportive services, and long-term disease management.

The objectives of the Guide are to:

- Understand how individuals with thalassaemia enter, navigate, and progress through the US healthcare system, from diagnosis through lifelong disease management.
- Explore variations in healthcare delivery and access across different states and healthcare settings.
- Identify key barriers faced by patients and families in accessing appropriate care, including financial, administrative, geographic, cultural, and informational barriers.
- Identify the practical challenges experienced by patients, particularly those from migrant communities and those living in areas with limited access to thalassaemia expertise.

Given the complexity of thalassaemia as a rare, chronic condition, this Guide identifies and elaborates on the challenges faced by patients navigating a healthcare system that is not specifically designed around rare disease populations, while advocating for coordinated, lifelong care.

Methodology

The landscape analysis documented in this Guide was developed using a combination of desk research and patient/family engagement activities to provide both a system-level overview and a patient-centred understanding of healthcare access challenges.

Desk research was undertaken to examine the structure and organization of the US healthcare system, including healthcare coverage models, referral pathways, specialist care delivery, access to treatments and medications, supportive care services, and relevant financial assistance mechanisms.

Patient and family engagement activities to gather qualitative data that reflected the real-world experiences of individuals living with thalassaemia and their families. These activities included:

- In-person discussions, meetings, and interviews conducted during the 1st TIF Pan-American Conference on Thalassaemia and Other Haemoglobin Disorders & 2nd RAIN Summit, held on 11–13 July 2025 in Washington, D.C., US.
- Virtual meetings and online interactions with patients and families ensuring representation from different geographical areas across the US.
- Patient testimonials shared during the aforementioned Conference, and other TIF educational webinars and activities – particularly those associated with submission of patient journeys/stories for International Thalassaemia Day, where individuals and families highlighted their experiences, challenges, and unmet needs in relation to healthcare access, disease management, and quality of life.

The patients and families engaged through these activities represented a broad range of experiences covering three broad profiles:

- Older patients and families from historical migrant communities: Individuals and families from established migrant populations, including those of European and Mediterranean descent, providing insights into long-term experiences of living with thalassaemia within the US healthcare system.
- Patients and families from more recent migrant communities: Individuals from communities with more recent migration histories, particularly those of Asian and Latin American descent, highlighting challenges related to health literacy, language, cultural adaptation, insurance navigation, and understanding of the US healthcare system.
- Patients and families living in states with fewer thalassaemia patients: Individuals residing in areas where access to specialized thalassaemia expertise may be limited, providing insights into geographic disparities, availability of specialist care, and challenges associated with receiving coordinated multidisciplinary management.

Discussions and testimonials explored key themes including pathways to diagnosis, access to specialist care, healthcare provider awareness of thalassaemia, insurance coverage and financial barriers, treatment quality and multidisciplinary care, emerging treatment options – medicinal products and curative approaches, medication access, language and communication challenges, cultural factors, patient rights, emergency care access, and the overall ability of patients and families to navigate a complex healthcare environment.

The use of multiple engagement approaches enabled the analysis to capture a wider range of patient experiences across different demographic, cultural, and geographic contexts. However, it should be recognized that patient experiences are highly individualized and may vary according to factors such as state of residence, insurance status, socioeconomic circumstances, disease severity, and availability of specialized care.

Limitations

The research for this landscape analysis was conducted within a rapidly evolving US healthcare and policy environment as the project kicked off in January 2025. The timing was thus influenced by the 2025 US Presidential elections and the subsequent introduction of new policy priorities affecting healthcare, insurance coverage, and access to services. Given the potential impact of changes in healthcare financing, insurance frameworks, and public health programmes on individuals living with thalassaemia, additional time was required to allow these developments to emerge and to assess their possible implications for patients requiring lifelong specialized care.

Another limiting factor is the availability of published disease-specific data in the US. The absence of a national thalassaemia registry prevents accurate estimation of the total number of affected individuals, their geographic distribution, and patterns of healthcare utilization. Existing estimates are likely to underestimate the true patient population, particularly among individuals with milder or non-transfusion-dependent forms of thalassaemia and within migrant communities where diagnosis and access to specialist care may be variable.

Furthermore, healthcare access in the US differs considerably depending on state-level policies, insurance status, socioeconomic circumstances, geographic location, and availability of thalassaemia expertise. Therefore, the patient experiences captured through engagement activities may not represent all possible healthcare journeys nationwide. Although efforts were made to include diverse perspectives from older migrant communities, recent migrant populations, and individuals living in areas with limited specialist access, experiences remain influenced by individual circumstances.

Despite these limitations, the combination of desk research and patient/family insights provides an important overview of the practical challenges faced by individuals with thalassaemia in navigating the US healthcare system and supports the development of resources to improve access, health literacy, and patient empowerment.

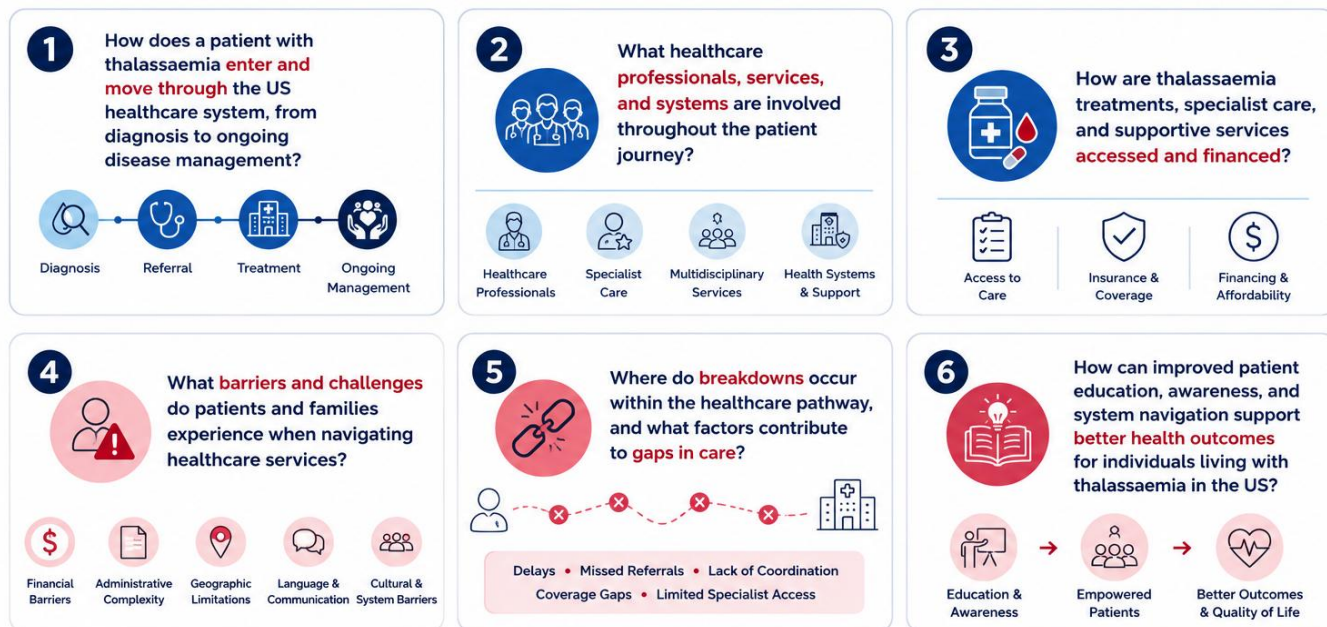
Key Questions to be answered



KEY QUESTIONS



This landscape analysis seeks to answer the following **key questions** about thalassaemia care within the US healthcare system.



Answering these questions will help identify actionable solutions to improve access, equity, and outcomes for people living with thalassaemia across the United States.



SYSTEM ARCHITECTURE: HOW THE US HEALTHCARE SYSTEM IS ORGANIZED

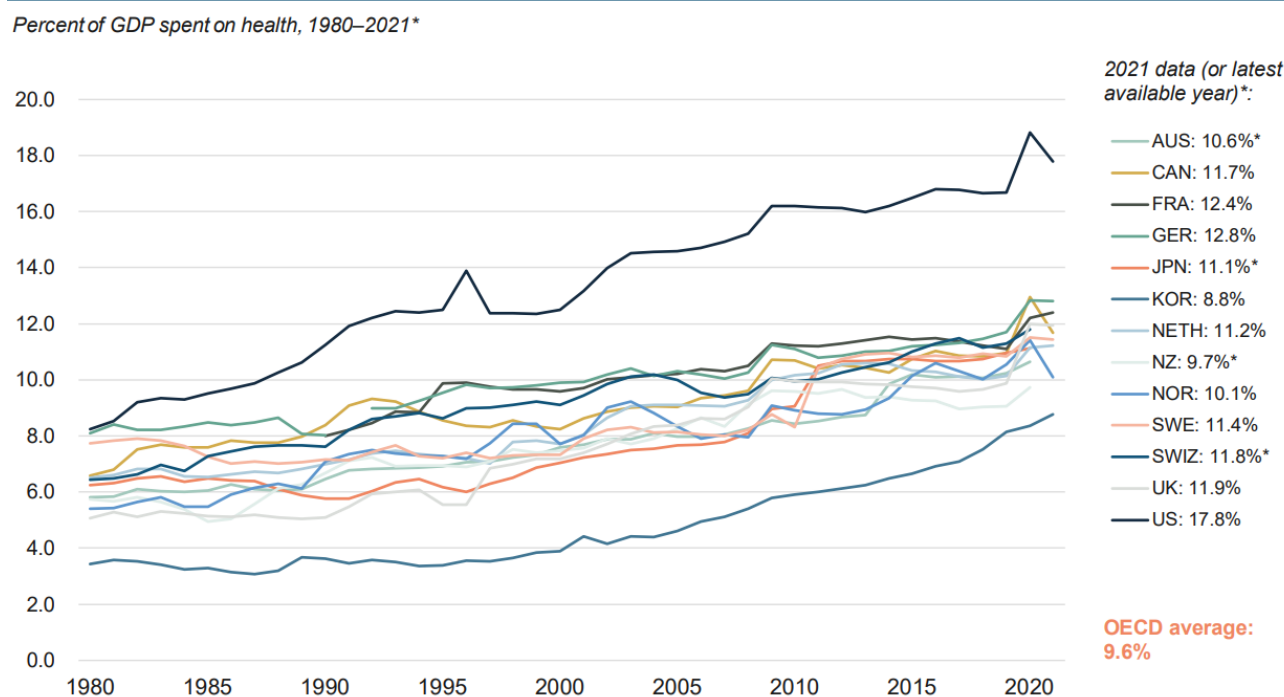
Setting the Scene: Health Indicators

Understanding key health indicators is essential for understanding each country's capacity to deliver comprehensive thalassaemia care. Measures such as HDI, under-5 mortality, Universal health coverage (UHC), and health expenditure provide insight into system performance, equity, and resource availability, helping identify structural strengths, vulnerabilities, and opportunities for targeted improvement.

Table 1 displays relevant health indicators for US, with several notable takeaways including:

- The US has very high HDI and high health spending per capital (17.3% of GDP in 2022¹) signalling to the existence of strong healthcare infrastructure and services. Healthcare expenditure in the US has been consistently higher than other countries of the Organisation for Economic Co-operation and Development (OECD) since the 1980s (Figure 1), but with worse health outcomes and lower life expectancy².

Figure 1. Percent of GDP spent on health 1980 – 2021 in 13 OECD countries



Source: Munira Z. Gunja, Evan D. Gumas, and Reginald D. Williams II, *U.S. Health Care from a Global Perspective, 2022: Accelerating Spending, Worsening Outcomes* (Commonwealth Fund, Jan. 2023). <https://doi.org/10.26099/8eiv-vc74>

- UHC service coverage index provides a general indication of essential service availability and thus an indirect indicator of the breadth of services available for long-term chronic conditions. Nonetheless it does not capture directly the existence of specialized services for specific diseases such as thalassaemia, nor their accessibility or their quality, which may be limited to geographical pockets. The

¹ 2024 Trends in the Quality of U.S. Healthcare Services. Rockville, MD: Agency for Healthcare Research and Quality; December 2025. AHRQ Pub. No. 25(26)-0009.

² U.S. Health Care from a Global Perspective, 2022: Accelerating Spending, Worsening Outcomes

US has high UHC index suggesting the existence of baseline services for the treatment of thalassaemia. However, coverage and equitable access to care is variable across the country.

- Continuity and consistency of care is connected to healthcare expenditure that in the case of thalassaemia enables maintenance of blood services, procurement of iron chelators, financially support the strengthening of existing or development of new health services.

Table 1. Health Indicators in US

COUNTRY	HDI	Under-5 mortality	UHC index	Health Expenditure (USD \$ /capita)
US	0.938	5.9	89	\$14,400

Sources: HDI: UNDP HDR: value for 2023 ; Under-5 mortality: World Bank, 2023 ; UHC Index: WHO, 2021 ; Health Expenditure: WHO, OECD, 2022-23

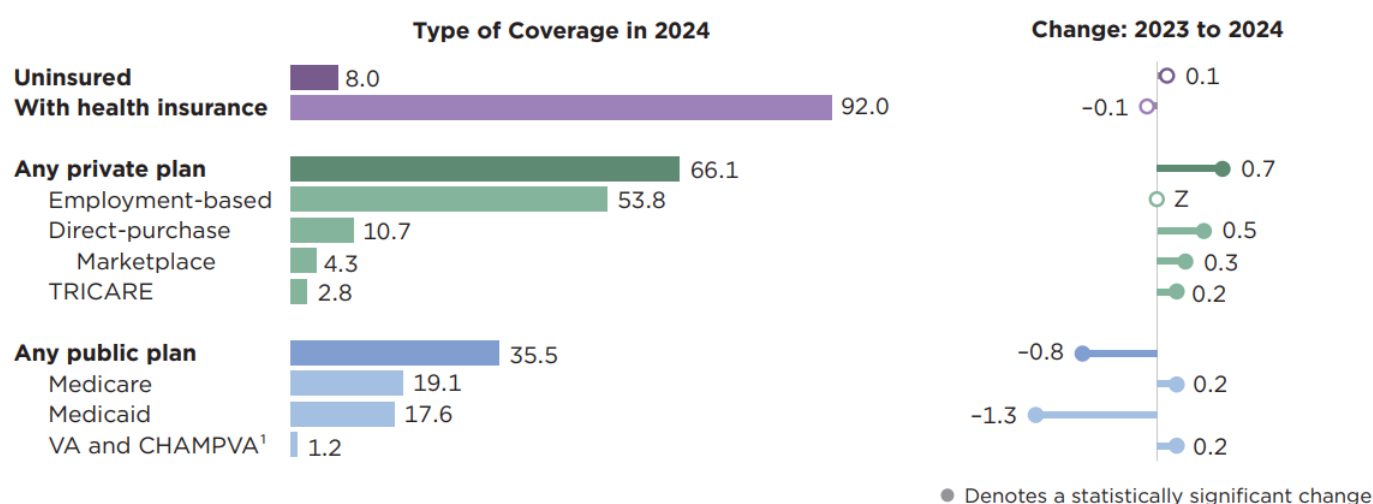
Health System

The healthcare system in the US is a mixed public–private system in which individuals obtain health coverage through a multi-layered, decentralized system of **private insurers** (employer-based, individually purchased), **public/government programs** (for eligible subpopulations such as children, elderly, low-income or disabled individuals run by federal or state governments) or **direct payments**. This leads to complexity, fragmentation and variation across States.

- In 2024, private insurance represented 66.1%, public/government programs represented 35.5%, including 19.1% for Medicare and 17.6% Medicaid respectively, and direct payments (out-of-pocket) 10.7%. Approximately 8% of the population (all ages) were uninsured for some of all of the year³.

Figure 2. Type of Health Insurance Coverage in the US⁴

Percentage of People by Type of Health Insurance Coverage and Change From 2023 to 2024



Z Rounds to zero.

¹ Includes CHAMPVA (Civilian Health and Medical Program of the Department of Veterans Affairs), as well as care provided by the Department of Veterans Affairs (VA) and the military.

Note: Population as of March of the following year. The estimates by type of coverage are not mutually exclusive; people can be covered by more than one type of health insurance during the year. Information on confidentiality protection, sampling error, nonsampling error, and definitions is available at <<https://www2.census.gov/programs-surveys/cps/techdocs/cpsmar25.pdf>>.

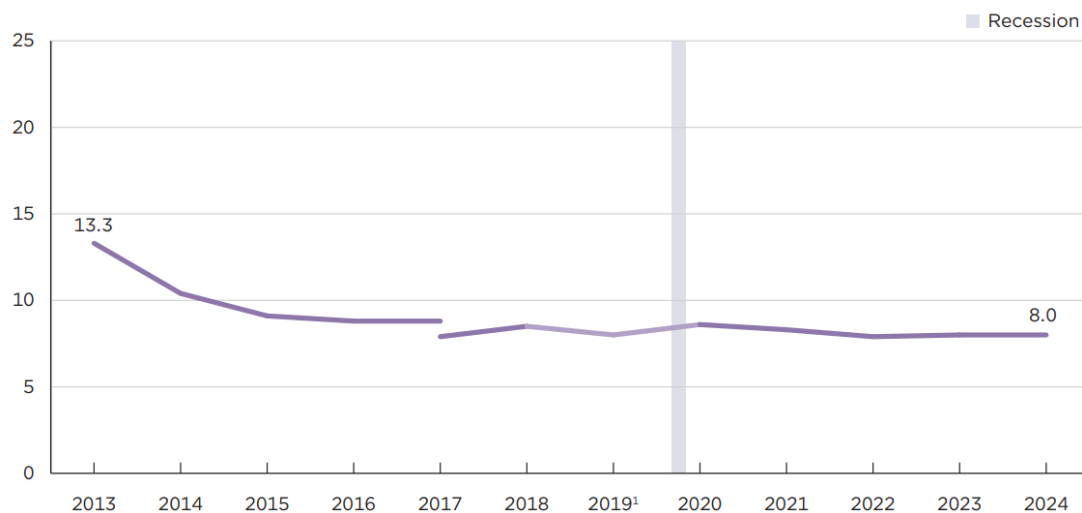
Source: U.S. Census Bureau, Current Population Survey, 2024 and 2025 Annual Social and Economic Supplements (CPS ASEC; DMS number P-7534374, DRB approval number CBDRB-FY25-0382).

³ Health Insurance Coverage in the United States: 2024

⁴ Health Insurance Coverage in the United States: 2024

Figure 3. Rate of uninsured population in the US⁵

Percentage of People Without Health Insurance Coverage: 2013 to 2024



¹ The U.S. Census Bureau recommends using caution when making comparisons between calendar year coverage in 2019 (collected in 2020) and other years: <www.census.gov/content/dam/Census/library/working-papers/2023/demo/sehsd-wp-2023-27.pdf>.

Note: Population as of March of the following year. The data for 2017 and beyond reflect the implementation of an updated processing system. The data points are placed at the midpoints of the respective years. Information on recessions is available in Appendix B. Information on confidentiality protection, sampling error, nonsampling error, and definitions is available at <<https://www2.census.gov/programs-surveys/cps/techdocs/cpsmar25.pdf>>.

Source: U.S. Census Bureau, Current Population Survey, 2018 Annual Social and Economic Supplement Bridge File and 2014 to 2025 Annual Social and Economic Supplements (CPS ASEC; DMS number P-7534374, DRB approval number CBDRB-FY25-0382).

Key Actors in the US Health System

Federal Government

- Establishes national healthcare policies, regulations, and standards.
- Funds and manages major Federal programs such as Medicare and provides oversight of the federal portions of Medicaid and Children's Health Insurance Program (CHIP), and the Health Insurance Marketplace.
- Key organisations include:
 - **Department of Health and Human Services (HHS):** Leads federal health policy and public health initiatives. Includes agencies such as:
 - **Food and Drug Administration (FDA):** Regulates drugs, medical devices, and food safety.
 - **Center for Drug Evaluation and Research (CDER):** Regulates over-the-counter and prescription drugs, including generic drugs.
 - **Center for Biologics Evaluation and Research (CBER):** Regulates biological products for human use.
 - **Centers for Medicare & Medicaid Services (CMS):** Oversees Medicare, Medicaid, and health insurance regulations.
 - **Centers for Disease Control and Prevention (CDC):** Leads disease prevention and public health activities.
 - **National Institutes of Health (NIH):** Part of the Public Health Service, supports biomedical and behavioural research within the US and abroad, conducts research in its own laboratories and clinics, trains promising young researchers, and promotes collecting and sharing medical knowledge
 - **Agency for Healthcare Research and Quality (AHRQ):** Produces evidence to make healthcare safer, higher quality, more accessible, equitable, and affordable, and to work within HHS and with other partners to make sure that the evidence is understood and used

⁵ [Health Insurance Coverage in the United States: 2024](#)

State Governments

- Play a major role in regulating insurance markets and administering Medicaid programs.
- Set eligibility rules, payment policies, and coverage requirements that may differ across states.

Private Sector

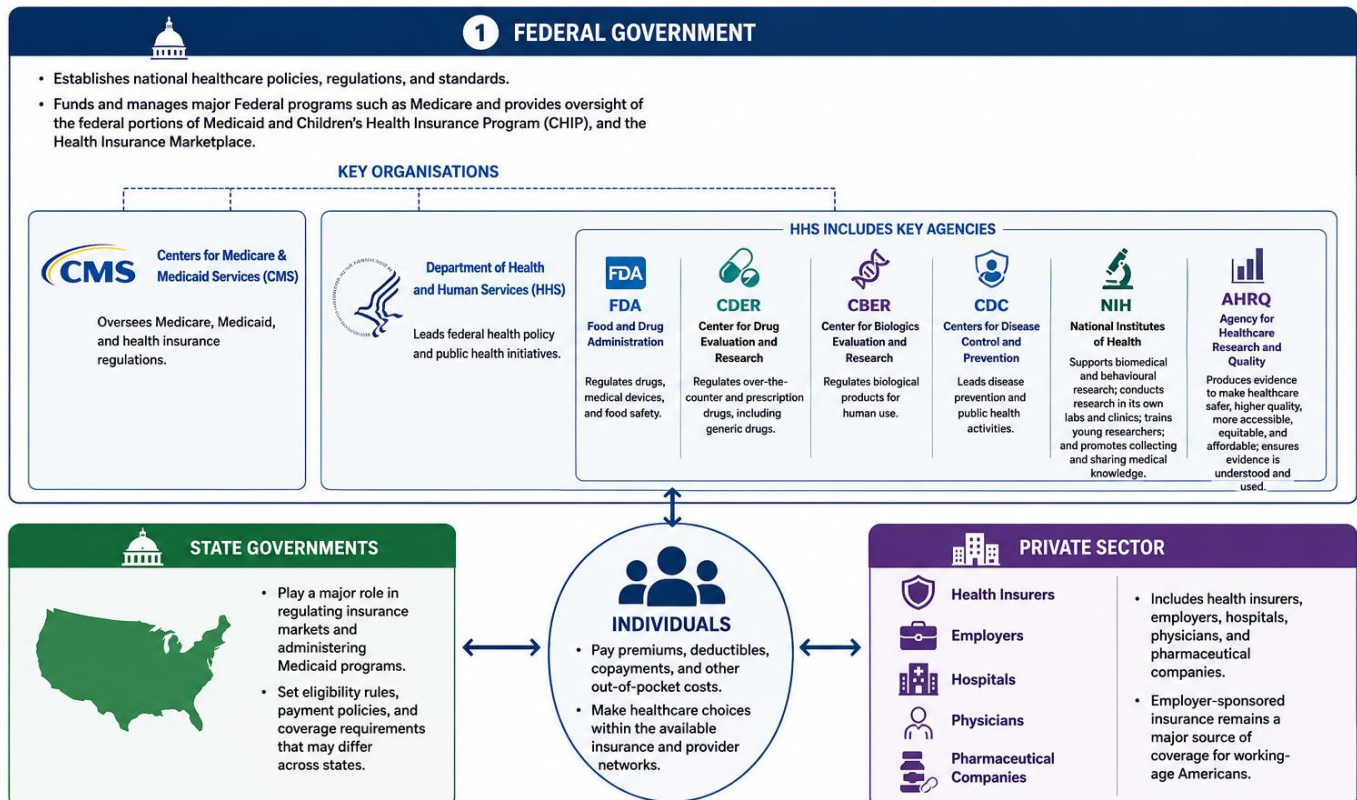
- Includes health insurers, employers, hospitals, physicians, and pharmaceutical companies.
- Employer-sponsored insurance remains a major source of coverage for working-age Americans.

Individuals

- Pay premiums, deductibles, copayments, and other out-of-pocket costs.
- Make healthcare choices within the available insurance and provider networks\

KEY ACTORS IN THE U.S. HEALTH SYSTEM

A complex system with many players working together to finance, deliver, and regulate healthcare.



Governance & Regulation

Authority is shared across federal and state governments, where the Federal Government establishes broad healthcare rules, provides funding, and manages national programs but many operational decisions are delegated to the State Governments, particularly for Medicaid administration and insurance regulation.

Thus, the different rules for insurance coverage, provider payment, and eligibility requirements contribute to:

- Differences in healthcare access between states.
- Administrative complexity.
- Challenges coordinating care across organizations.

In a nutshell

- **Federal responsibilities:**
 - Setting national standards for healthcare quality and safety.
 - Managing Medicare.
 - Regulating healthcare programs and insurance requirements.
- **State responsibilities:**
 - Administering Medicaid programs (**State Medicaid Agencies:** Manage Medicaid enrollment, benefits, and provider payments) and CHIP programs.
 - Licensing healthcare professionals and facilities.
 - Regulating insurance plans operating within the state.

Financing Structure

Healthcare financing in the US comes from a combination of public / government programs, private insurance (including employer-based) and individual payments thus relying on multiple insurance markets with different eligibility rules, benefits, and payment structures.

Public/ Government Programs

Medicare

- A federal insurance program primarily covering adults aged 65 and older, as well as some younger individuals with qualifying disabilities. See next section for more detailed information.
- Funded mainly through payroll taxes and federal government revenues.

Medicaid

- A joint federal-state program providing coverage for eligible low-income individuals and families. See next section for more detailed information.
- Eligibility requirements, benefits, and payment policies vary by state.
- Financed by federal funds managed by state governments or state funds

Children's Health Insurance Program (CHIP)

- A joint federal-state program providing coverage for children under 18 years of age in families that earn too much to qualify for Medicaid or who are not eligible for other insurance plans, including private insurance coverage.
- Eligibility requirements, benefits, and payment policies vary by state.
- All states are required to provide basic comprehensive coverage including prescriptions and doctor visits. Routine visits are free under CHIP but there may be copayments for other services.

Private Insurance

Employers

Employers are a major source of healthcare coverage for working-age Americans through employer-sponsored insurance.

- Employers typically share premium costs with employees.
- Coverage is provided through private insurance companies and varies by employer and plan design.

Individuals

Individuals contribute to healthcare costs through:

- Insurance premiums.
- Deductibles.
- Copayments and coinsurance.
- Direct payments for services not covered by insurance.

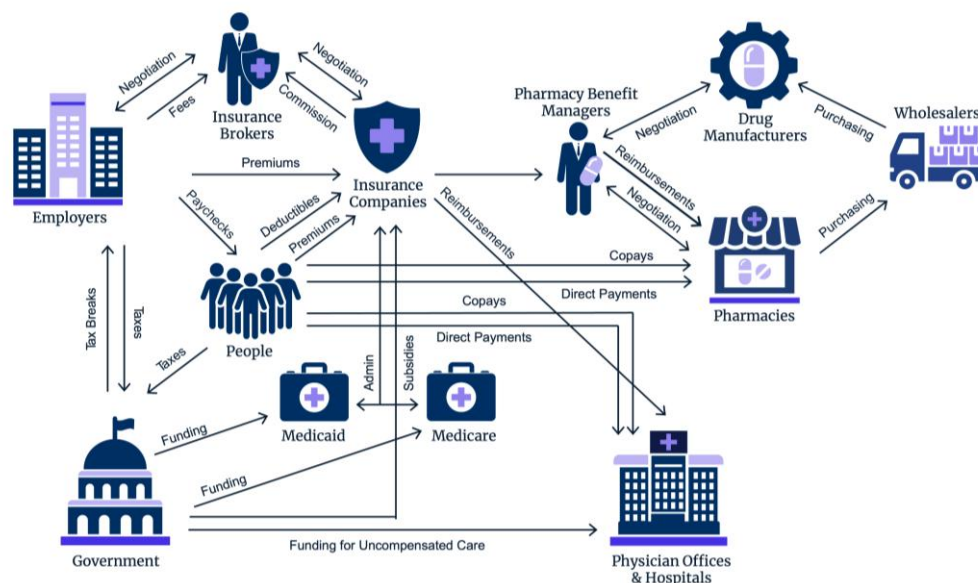
Individual payments

Even individuals with insurance coverage often face significant healthcare costs and out-of-pocket spending through:

- **Deductibles:** The amount patients must pay before insurance begins covering services.
- **Copayments:** Fixed payments for specific services, such as physician visits or prescriptions.
- **Coinsurance:** A percentage of healthcare costs paid by the patient after meeting the deductible.

High out-of-pocket costs can affect healthcare decisions and may discourage individuals from seeking preventive or necessary medical care.

Figure 4. A visual guide to payers and providers in the US Healthcare system



The Uninsured Population

Despite the availability of public and private insurance options, about **8% of the population in the US remain uninsured** and often must pay the full cost of care directly or rely on safety-net providers (i.e. organizations that deliver health care services to patients regardless of their ability to pay), such as public hospitals, community health centres (CHC), special-needs clinics, safety net hospitals etc.

Common reasons individuals remain uninsured include:

- **Cost barriers:** Insurance premiums and out-of-pocket expenses may be unaffordable.
- **Employment factors:** Some workers do not have access to employer-sponsored insurance, particularly those in part-time, temporary, or low-wage jobs.
- **Eligibility gaps:** Some individuals do not qualify for public programs such as Medicaid due to income requirements or differences in state policies.
- **Enrollment barriers:** Some eligible individuals do not enroll because of administrative complexity, lack of awareness, or personal choice.

The uninsured population creates several challenges for the healthcare system:

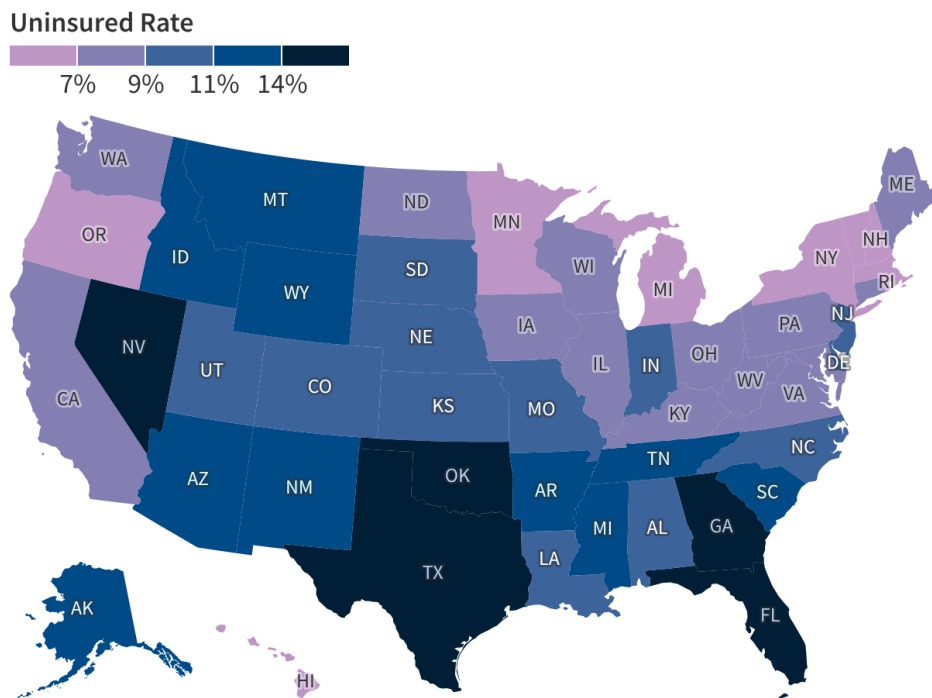
- Greater reliance on emergency departments for care.
- Delayed treatment due to concerns about cost.
- Increased uncompensated care costs for hospitals and providers.

Safety-net providers provide essential services for uninsured individuals and often serve as the front-line for low-income, immigrant and minority populations. However, access to these resources varies by location.

Most uninsured individuals (74.2%) are US citizens and 75% live in the South and West⁶ (Figure 6).

⁶ [The Uninsured Population and Health Coverage, 2025](#)

Figure 6. Uninsured rates by State, ages 0 – 64 in 2024⁷.



Note: As of March 2026, these states have not expanded Medicaid: Alabama, Florida, Georgia, Kansas, Mississippi, South Carolina, Tennessee, Texas, Wisconsin, and Wyoming.

Source: KFF analysis of 2024 American Community Survey, 1-Year Estimates, and tracking and analysis of state actions related to adoption of the ACA Medicaid expansion.

KFF

Delivery System

Healthcare in the US is delivered through a mixture of public and private providers that include hospitals, outpatient facilities, physician practices and community-based services. Unlike other healthcare systems with a nationally organized health service and funded by a single public payer, in the US, **providers are generally independent organizations that are reimbursed by multiple payers**, including Medicare, Medicaid, private insurers, and patients themselves through out-of-pocket payments. Consequently, where a patient receives care and who pays for it depend largely on their insurance coverage.

For individuals living with thalassaemia, care is lifelong, multidisciplinary, and delivered across multiple healthcare settings. Patients typically require regular blood transfusions, iron chelation therapy, laboratory monitoring, specialist consultations, and management of disease-related complications. As a result, coordinated access to specialized services and continuous insurance coverage are essential.

Specialized Comprehensive Care Centres

Optimal thalassaemia care is delivered through specialized comprehensive care centres, most of which are located within large academic medical centres or children's hospitals. These centres provide coordinated, multidisciplinary care through teams that may include haematologists, transfusion medicine specialists, nurses, pharmacists, social workers, genetic counsellors, and other allied health professionals.

Services commonly provided include:

- Regular blood transfusions
- Iron chelation management
- Laboratory and imaging monitoring
- Screening for cardiac, hepatic, and endocrine complications

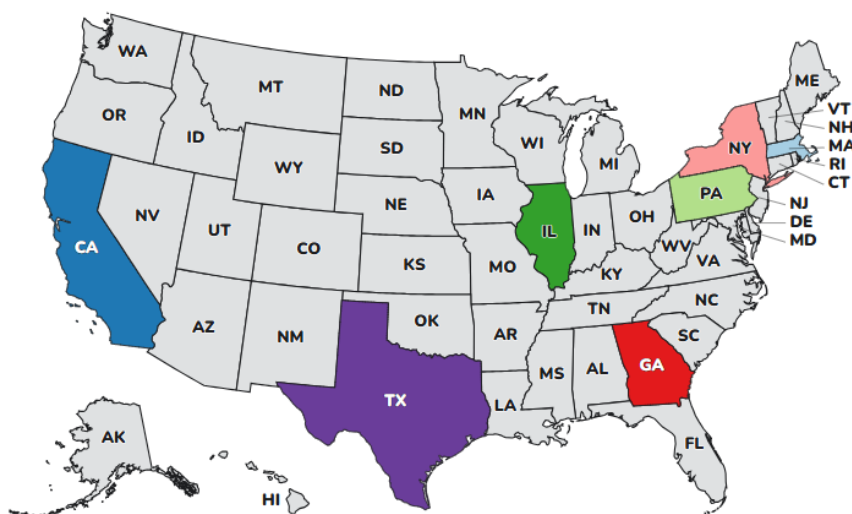
7 Key Facts about the Uninsured Population

- Genetic counselling
- Transition from paediatric to adult care

These centres are generally reimbursed through a combination of private insurance, Medicare, Medicaid, and, in some cases, hospital financial assistance programmes for uninsured patients.

The CDC has recognized **10 thalassaemia treatment centres** as reference centres (v. Children's Hospital of Boston, Children's Hospital of Los Angeles, Northern California Comprehensive Thalassaemia Center, Children's Hospital of Philadelphia (CHOP) - Pediatric Center, Penn Comprehensive Adult Thalassemia Program, Hospital of the University of Pennsylvania, Ann & Robert H. Lurie Children's Hospital of Chicago, Weill Medical College of Cornell University, Children's Healthcare of Atlanta, Children's Health Dallas) as shown in Figure 7.

Figure 7. CDC Thalassaemia Treatment Centres



Hospitals

Hospitals provide inpatient, emergency, surgical, and highly specialized services. Patients with thalassaemia may require hospital-based services for blood transfusions, management of complications, or treatment during acute illness.

Hospitals vary by ownership and mission:

Public hospitals are owned by state or local governments and often provide care regardless of a patient's ability to pay.

Non-profit hospitals are private, tax-exempt organizations that reinvest surplus revenue into patient care, education, research, and community benefit. Many academic medical centres and comprehensive thalassaemia programmes are based in non-profit hospitals.

For-profit hospitals, which are investor-owned and operate as commercial healthcare organizations.

Safety-net hospitals are defined not by ownership but by the populations they serve. They provide a substantial proportion of care to uninsured, Medicaid, and other vulnerable patients and may be public, non-profit, or, less commonly, private hospitals.

Hospital services are reimbursed by different payers depending on the patient's insurance. Medicare and Medicaid use government-defined payment systems, while private insurers negotiate reimbursement rates with hospitals. Uninsured patients may receive financial assistance but can also face substantial medical bills.

Hospitals provide major services including emergency care, surgery, specialized treatment, and inpatient care.

Outpatient and Ambulatory Care

Most routine thalassaemia care is delivered in outpatient settings, reducing the need for hospital admission while supporting ongoing disease management.

These settings include:

- Hospital outpatient clinics
- Specialist haematology practices
- Infusion centres (for blood transfusions)
- Diagnostic laboratories and imaging services

For people living with thalassaemia, much of their routine care—including regular transfusions, laboratory monitoring, iron chelation management, and follow-up with haematologists—occurs in outpatient settings of large academic or children's hospitals.

Coverage for outpatient services varies by insurance plan and may require prior authorization, provider network restrictions, or patient cost-sharing, which can affect access to specialist care.

Primary Care and Community Health Centres

Primary care providers play an important role in preventive care, routine health maintenance, vaccinations, and the management of conditions unrelated to thalassaemia. They also coordinate referrals to specialist services when needed.

Community Health Centers (CHCs), including Federally Qualified Health Centers (FQHCs), provide comprehensive primary care regardless of a patient's ability to pay. They are an important source of care for uninsured, underinsured, and Medicaid populations.

Although they do not typically provide specialized thalassaemia treatment or blood transfusions, they support patients through routine medical care, preventive services, chronic disease management, and referral to specialist centres.

Physicians

Physicians in the US generally practice independently or within hospitals and health systems. Their services are reimbursed separately from hospital services, with payment determined by the patient's insurer.

Primary care physicians (PCPs) provide preventive care, manage common medical conditions, and coordinate referrals to specialists. They often serve as the first point of contact within the healthcare system.

Specialists, including haematologists, deliver disease-specific care for patients with complex conditions such as thalassaemia. Ongoing specialist management is essential to monitor transfusion therapy, prevent complications, and coordinate multidisciplinary care.

THALASSAEMIA PATIENT IMPACT

A nationally coordinated disease-specific policy for thalassaemia does not exist, meaning that care remains variable and fragmented in terms of access, quality and continuity impacted by geographic location (urban vs rural areas), socioeconomic status of patients and healthcare provider expertise and knowledge.

Coverage for rare diseases like thalassaemia varies widely depending on a person's insurance status, plan design, and geographic location. In addition to health disparities due to socioeconomic circumstances, insurance coverage and geographic location, such systems place patients with rare and/or chronic diseases such as thalassaemia, at risk of underinsurance or financial ruin due to high out-of-pocket expenses.

Recent reports from patients followed at CDC Thalassaemia Treatment Centres showed that 29.5% of patients were on **Medicaid** and 17.8% on **Medicare** whereas a broader research in the administrative claims from US MarketScan Commercial, Medicare, and Medicaid Multi-state databases showed that 16.7% of patients were on Medicaid and 1.5% on Medicare.

For those who are **uninsured**, and not eligible for any government / public programs, safety-net organisations such as CHCs play a vital role in identifying, screening, and managing the condition. Migrants from thalassaemia high-prevalence areas can be identified as trait carriers or diagnosed in early childhood before being referred to CDC Thalassaemia Treatment Centres. In addition, organizations such as the Association of Asian Pacific Community Health Organizations (AAPCHO) and local community groups have historically helped CHCs build culturally competent genetic services for at-risk populations. NTDT patients may be managed in these settings.

Specialized care centres for thalassaemia exist (often in academic/university hospitals), but access depends on having insurance that covers hospitalizations, regular transfusions, iron chelation therapy, and long-term follow-up. Given the high cost and chronic nature of care, patients without robust insurance or with limited coverage may face high out-of-pocket burden. Therefore, coverage is highly variable.

HEALTH INSURANCE IN PRACTICE: HOW ACCESS IS ACTUALLY DETERMINED

Health Insurance Pathways

Health insurance is obtained through several different pathways, each with its own eligibility criteria, benefits, and payment arrangements.

Employer-sponsored insurance is the primary source of health coverage for working-age Americans and their families. Employers usually pay a substantial share of the premium for employee-only coverage, while employees contribute through payroll deductions. The amount paid by each side varies by employer, plan design, and whether coverage is for the employee alone or for dependents. Employer-sponsored plans often extend coverage to spouses and dependent children, although employees usually pay a higher share of the premium for family coverage than for individual coverage. Some employers also offer coverage for domestic partners or other dependents, but eligibility rules differ across plans.

Not all employers are required to offer employer-sponsored insurance. Under the Affordable Care Act (ACA), large employers with 50 or more full-time equivalent employees may face penalties if they do not offer affordable coverage that provides minimum value to full-time workers and their dependents. Affordable coverage generally means that the employee's share of the premium for self-only coverage is below a set percentage of household income, while minimum value means that the plan is expected to pay at least 60 percent of the total cost of covered services and includes substantial coverage for inpatient and physician services. Smaller employers are generally not required to provide insurance, although many do so voluntarily. When employers offer coverage under the ACA, the plans must meet certain baseline requirements and these include coverage for preventive services, emergency care, hospitalization, maternity and newborn care, mental health and substance use disorder services, prescription drugs, laboratory services, and chronic disease management. However, they do not have to cover every service or eliminate all cost-sharing.

Employer-sponsored plans usually cover a broad range of health services, including primary care visits, specialist consultations, hospital care, emergency services, preventive services, laboratory tests, imaging, prescription drugs, and maternity care. Many plans also include mental health services, rehabilitation, and some chronic disease management services. However, the exact benefits depend on the specific plan, and patients may still face deductibles, copayments, coinsurance, and limits on which providers or facilities they can use. For people with chronic conditions such as thalassaemia, access to specialized treatment centres may depend on whether those providers participate in the insurer's network.

A major feature of employer-sponsored insurance is that it cannot deny coverage or charge higher premiums because of pre-existing conditions. This means that people with conditions such as thalassaemia, diabetes, asthma, or cancer cannot be excluded from enrollment or priced out of coverage because of their medical history. In practice, this protection is especially important for individuals with long-term or high-cost conditions who need ongoing care, medications, and specialist services. Although pre-existing conditions are covered, patients may still face plan restrictions, prior authorization requirements, or network limitations that affect how easily they can access the services they need.

In some cases, people can have more than one source of coverage. For example, a person may have employer-sponsored insurance and also qualify for Medicare or Medicaid (see below). This can happen when someone is eligible for public coverage because of age, disability, or low income, while still receiving insurance through a job or a family member's job. When a person has both public and private coverage, one plan is usually the primary payer and the other acts as secondary coverage, helping to cover costs that the first plan does not fully pay.

People with employer-sponsored insurance can also sometimes have marketplace coverage (see below), but this is less common and usually occurs only in specific situations. Marketplace plans are generally used by

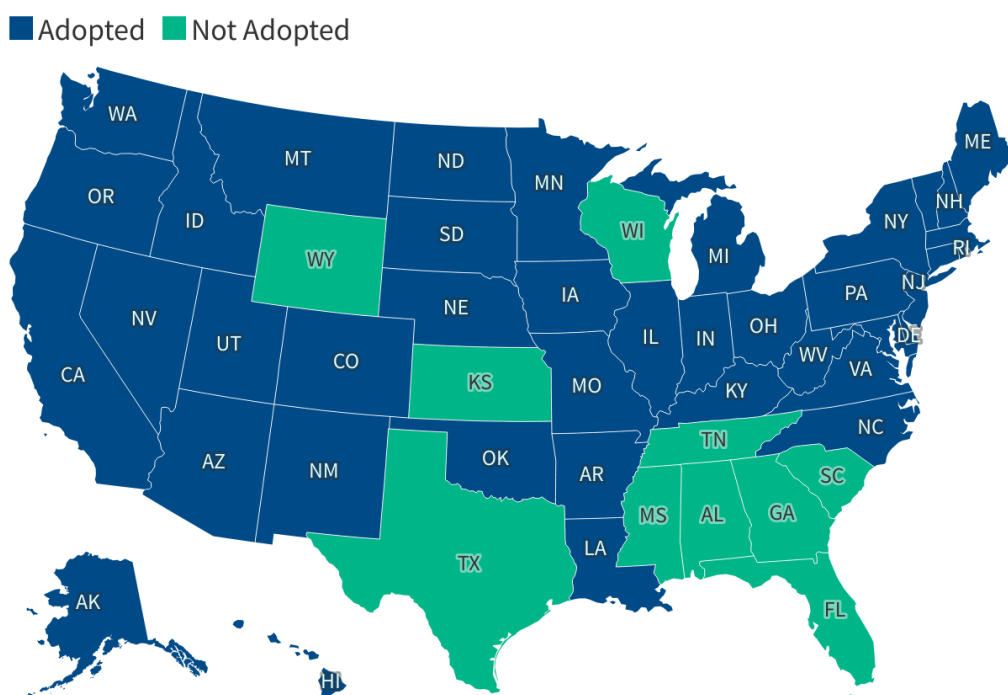
people who do not have affordable employer coverage available to them. If an employer offers coverage that meets affordability and minimum value standards, the employee usually cannot receive premium subsidies for a marketplace plan from the government. However, some individuals may still choose to buy a marketplace plan without subsidies, or they may have marketplace coverage in addition to other insurance in limited circumstances.

Medicaid is a joint federal-state program that provides health coverage for eligible low-income individuals and families. Although federal law establishes broad program requirements, **each state administers its own Medicaid program**, resulting in differences in eligibility, covered benefits, reimbursement rates, and provider participation. Eligibility is primarily based on income, household size, disability status, pregnancy, age, and, in some states, categorical rules that expand coverage to additional groups such as children, pregnant women, parents and caregivers, adults covered under the ACA Medicaid expansion, former foster youth, and individuals who need long-term care or have specific medical needs.

Medicaid is available in all 50 states and the District of Columbia (DC); as of 2025, the ACA expansion has been adopted by 40 states and DC, while Alabama, Florida, Georgia, Kansas, Mississippi, South Carolina, Tennessee, Texas, Wisconsin, and Wyoming have not (Figure 8).

Figure 8. Status of State Action on the Medicaid Expansion Decision, 2025

Status of State Action on the Medicaid Expansion Decision



Source: KFF Status of State Medicaid Expansion Decisions Tracker

KFF

Under the ACA Medicaid expansion, states that chose to expand coverage extended eligibility to many low-income adults who previously did not qualify for Medicaid, even if their income was too low to afford private insurance. This expansion has had a significant impact by reducing the number of uninsured individuals, improving access to primary and preventive care, and increasing coverage for people with chronic and complex conditions who require ongoing treatment.

Medicaid generally provides comprehensive coverage with relatively low out-of-pocket costs. However, lower reimbursement rates may limit the number of specialists willing to accept Medicaid patients, potentially affecting access to specialised haematology services.

Medicare is a **federally funded and federally administered program**, managed by the Centers for Medicare & Medicaid Services (CMS) within the US Department of Health and Human Services. Primarily for adults aged 65 years and older, as well as younger individuals who qualify through disability or certain other eligibility categories. Although Medicare offers broad access to healthcare services, beneficiaries may still be responsible for deductibles, coinsurance, and prescription drug costs unless they have supplemental coverage. Adults with thalassaemia who qualify for Medicare through disability often rely on a combination of Medicare and additional insurance to manage ongoing healthcare expenses.

Thalassaemia is not, by itself, a standard Medicare qualifying medical condition; however, individuals with severe thalassaemia may qualify for Medicare if they are first found disabled through the Social Security Administration's (SSA) disability determination process. This process generally requires the person to apply for disability benefits and provide medical evidence showing a medically determinable impairment that prevents substantial gainful activity and is expected to last at least 12 months or result in death. The SSA reviews medical records, treatment history, laboratory results, and functional limitations to decide whether the condition meets its disability criteria. In that sense, thalassaemia can be a disabling condition for some patients, but not all people with thalassaemia are considered disabled for Medicare purposes.

Health Insurance Marketplace. Individuals who do not have employer-sponsored insurance or qualify for public programs may purchase coverage through the Health Insurance Marketplace established under the ACA. The Marketplace is an online platform where individuals and families can compare private insurance plans offered by approved insurers, review premiums and benefits, and enroll during the annual open enrollment period or after a qualifying life event. Eligibility for financial assistance is based largely on household income and family size. Many enrollees receive premium tax credits that lower monthly premiums, and some lower-income individuals also qualify for cost-sharing reductions that reduce deductibles, copayments, and other out-of-pocket expenses.

Marketplace plans are organized into metal tiers—Bronze, Silver, Gold, and Platinum—which reflect how costs are shared between the insurer and the enrollee rather than the overall quality of care. Bronze plans generally have lower monthly premiums but higher deductibles and cost-sharing, while Gold and Platinum plans usually have higher premiums but lower out-of-pocket costs when care is used. In addition to price, consumers must compare provider networks, prescription drug formularies, and coverage rules such as prior authorization. These differences can have a major impact on access to specialist care and high-cost therapies. For patients with chronic conditions such as thalassaemia, a plan with a lower premium may still be less suitable if it excludes key specialists, transfusion centres, or essential medications.

All marketplace plans must cover 10 categories of essential health benefits but specific services in each category may be different based on each States requirements.



Individuals without health insurance must often pay the full cost of healthcare services out of pocket or rely on safety-net providers, CHCs, or hospital financial assistance programs. **However, certain services are available regardless of insurance status, particularly emergency screening and stabilizing treatment in hospital emergency departments under federal law. This includes care for acute illness or injury, trauma, severe pain, breathing difficulties, and emergency childbirth.**

In addition, many CHCs and public clinics provide **primary care, vaccinations, prenatal care, mental health services, and chronic disease management** with fees for services that are adjusted depending on an individual's income. Although these services remain available, lack of coverage is associated with delayed diagnosis, reduced use of preventive services, and poorer management of chronic diseases.

Key Mechanisms that shape Access

Premiums. The regular amount paid to an insurance company to keep coverage active. Premiums are usually paid monthly.

Deductibles. The amount a patient must pay out of pocket before the insurance plan begins to pay for covered services.

Copayments. A fixed amount paid by the patient for a covered service, such as a doctor visit or prescription.

Coinsurance. A percentage of the cost of a covered service that the patient must pay after meeting the deductible.

THALASSAEMIA PATIENT IMPACT

High deductibles, copayments, and coinsurance can make care less affordable even when a service is technically covered.

Provider Networks. A provider network is a list of hospitals, physicians, treatment centres, and other healthcare providers that have contracts with an insurance company. Examples include Health Maintenance Organizations (HMOs), Preferred Provider Organizations (PPOs), and Exclusive Provider Organizations (EPOs).

HMOs usually require patients to use in-network providers and often to get a referral from a primary care doctor before seeing a specialist, but they generally have lower costs. PPOs offer more flexibility and allow patients to see out-of-network providers, usually at a higher cost. EPOs are more restrictive than PPOs because they generally do not cover out-of-network care except in emergencies, but they may not require referrals. Each of these affects how patients access care and what they pay.

- **In-network providers** are part of the insurer's network and usually cost less for the patient.
- **Out-of-network providers** are not contracted with the insurer and may cost much more, or may not be covered at all.

THALASSAEMIA PATIENT IMPACT

Because specialised thalassaemia centres are often located in major academic hospitals, some patients may need to travel farther or seek special approval to receive care.

Prior Authorization. A requirement that the insurer approve certain services, medications, procedures, or specialist visits before they are provided. Prior authorization is used by insurers to control costs and review medical necessity, but it can delay treatment and create extra paperwork for patients and providers.

THALASSAEMIA PATIENT IMPACT

For chronic conditions that require regular transfusions or expensive therapies, delays can interrupt continuity of care.

Formularies. Lists of prescription drugs covered by an insurance plan. Formularies often place medicines into different cost tiers and may limit access in several ways:

- Some drugs may not be covered.
- Patients may need to try cheaper medicines first.
- Certain drugs may require prior authorization.

THALASSAEMIA PATIENT IMPACT

For patients needing iron chelation therapy or other specialised medicines, formulary rules can affect both access and affordability.

Administrative Complexity

The US healthcare system involves extensive administrative processes that affect patients, providers, and insurers.

Healthcare providers submit claims to insurers for reimbursement after services are delivered. Insurers review these claims to determine whether services are covered and whether payment will be approved.

Claims may be:

- Approved and reimbursed.
- Partially reimbursed.
- Denied because of documentation, coverage limitations, or prior authorization requirements.

When coverage is denied, patients and providers may pursue formal appeals, often requiring additional clinical documentation and multiple rounds of review before a final decision is reached.

Because different insurers maintain different billing rules, authorization requirements, and reimbursement policies, administrative complexity contributes significantly to healthcare costs and can delay access to treatment.

For certain high-cost or specialized services, insurers also require prior authorization before treatment can begin. In this process, the provider must submit clinical information explaining why a medication, procedure, test, or specialist service is medically necessary. The insurer then reviews the request and decides whether to approve, deny, or request additional information. **Prior authorization is often required for expensive drugs, specialised treatments, imaging studies, and some outpatient procedures.**

If prior authorization is denied, the treatment may be delayed, changed to a lower-cost alternative, or paid for out of pocket if the patient chooses to proceed. In some cases, the provider may submit an appeal with additional medical evidence, but this can take time and may postpone care. Denials can therefore create both financial and clinical barriers, especially for patients who need ongoing or time-sensitive treatment.

Private insurers therefore act not only as payers but also as gatekeepers, determining which services are covered, under what circumstances, and at what level of reimbursement.

Insurance coverage does not necessarily guarantee access to healthcare and access does not always mean affordability. Insurance rules determine what services are covered, where care can be received, and how much the patient must pay.

Who Influences Access

Access to healthcare in the US is shaped by a broad network of stakeholders whose decisions influence who receives care, where care is delivered, how services are financed, and which treatments are available. These stakeholders operate at different levels of the healthcare system—government, insurers, providers, industry, employers, and patient advocacy organizations—and often have different, and sometimes competing, objectives.

Federal government. The US Department of Health and Human Services (HHS) plays a central coordinating role by setting national health policy, enforcing parts of the ACA, supporting public health and research initiatives and overseeing key federal agencies, including the Centers for Medicare & Medicaid Services (CMS). CMS administers Medicare, oversees the federal aspects of Medicaid, regulates many aspects of health insurance, and establishes payment policies that influence healthcare delivery nationwide. Other federal agencies, such as the FDA, influence access by approving medicines and medical devices, while the CDC develops public health recommendations and preventive care guidance.

State governments. States play a central role in healthcare access by administering Medicaid programs, regulating private insurance markets, licensing healthcare professionals and facilities, and determining many coverage and reimbursement policies. Because states have considerable flexibility in implementing Medicaid and insurance regulations, access to healthcare can vary significantly across the country.

Private insurers and public payers. Private insurance companies, together with Medicare and Medicaid, determine which services are covered, negotiate payment rates with providers, establish provider networks, manage formularies, and implement utilization management tools such as prior authorization. As a result, they play a major role in determining both the availability and affordability of healthcare services.

Hospitals and health systems. Hospitals—including public hospitals, safety-net hospitals, non-profit hospitals, and for-profit hospitals—determine the range of services they provide, invest in specialized

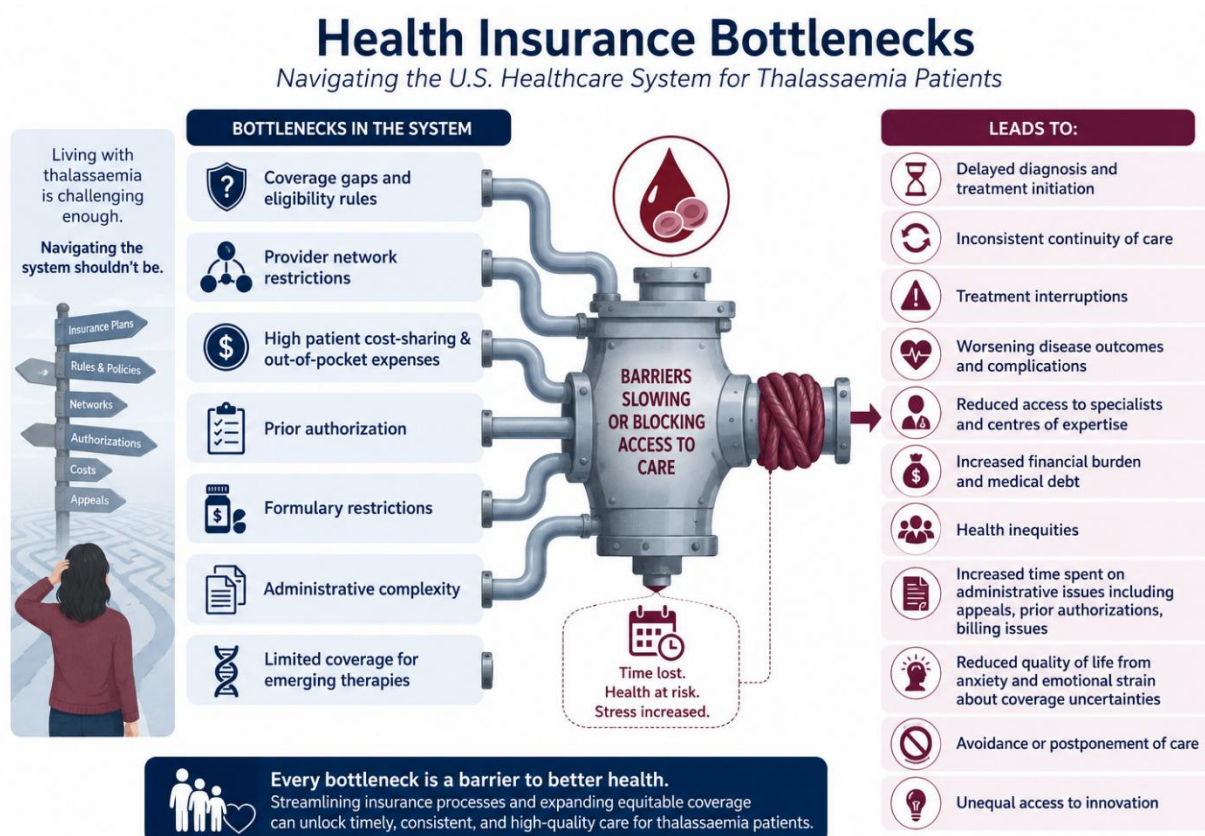
programmes, and negotiate reimbursement contracts with insurers. Academic medical centres and comprehensive treatment centres are particularly important for patients with rare diseases such as thalassaemia, as they often provide multidisciplinary expertise that is unavailable in smaller community settings.

Healthcare professionals. Primary care physicians coordinate preventive care and referrals, while specialists, such as haematologists, provide disease-specific management. Provider participation in insurance networks, willingness to accept Medicaid or other public insurance, and geographic distribution of specialists all influence patient access. Other healthcare professionals—including nurses, pharmacists, laboratory specialists, transfusion services, blood banks, and infusion centres—are also essential components of care delivery, particularly for patients requiring regular blood transfusions and ongoing monitoring.

Pharmaceutical companies and pharmacy benefit managers (PBMs). Pharmaceutical manufacturers develop new therapies and establish launch prices for medicines. Pharmacy benefit managers negotiate drug prices and rebates, manage formularies, and determine utilization management requirements such as prior authorization or step therapy. Together, these organizations influence which medicines are covered, the conditions under which they are reimbursed, and the costs borne by patients.

Patient organizations. Patient advocacy organizations work to improve access to diagnosis, treatment, and specialised care by raising awareness, supporting research, educating patients, and advocating for policy changes. For rare diseases such as thalassaemia, these organizations often play a critical role in promoting equitable access to specialised services and innovative therapies.

These stakeholders operate with different priorities—cost containment, clinical outcomes, innovation, financial sustainability, patient advocacy, and federal oversight. As a result, motives are not always aligned. While insurers focus on managing expenditures, providers prioritize patient care, manufacturers seek returns on innovation, patient organizations advocate for timely access to treatment, and HHS must balance access, affordability, quality, and program integrity across the system. Balancing these competing interests is a defining challenge of the US healthcare system and has important implications for access, affordability, and quality of care, particularly for patients requiring lifelong, high-cost treatment.



PATIENT PATHWAY: FROM SYMPTOMS TO LONG-TERM CARE

For individuals living with chronic and rare conditions such as thalassaemia, navigating the US healthcare system involves multiple entry points, providers, insurers, and administrative processes. Unlike acute conditions that may require a single episode of care, thalassaemia requires lifelong management involving regular monitoring, specialist care, transfusion services, medications, and coordination across multiple healthcare settings. Although the US healthcare system has advanced treatment capabilities, the patient experience is shaped by insurance status/coverage, availability of specialists, geographic location, and the ability to navigate a complex healthcare environment. This section describes the patient journey from initial presentation through long-term disease management, highlights the system-level factors that influence access, continuity, and quality of care and provided patient journey maps to illustrate that access is determined not only by medical need but entry point into the health system, insurance status, diagnosis status and ability to navigate the complex system.

Entry Points into the System

Emergency departments may become the first point of contact when patients experience acute complications or when access to routine care is limited because of insurance barriers, high out-of-pocket costs, difficulty obtaining appointments, or lack of nearby providers, since emergency care must be provided regardless of insurance status or copays. Emergency care provides immediate treatment regardless of insurance status, but it is generally designed for acute stabilization rather than long-term disease management.

Primary care physicians (PCPs), including paediatricians, often serve as the first healthcare contact for individuals experiencing symptoms or seeking routine care. Primary care plays an important role in recognizing symptoms and initiating diagnostic evaluation, coordinating referrals to specialists, managing general health needs alongside chronic disease care. However, PCP familiarity and experience with diagnosis and management of rare conditions is limited contributing to delayed / inappropriate referrals.

Community health centres (CHCs) and safety-net clinics provide care for individuals who may face barriers related to insurance, income, or geographic location. They may provide primary care services, preventive care, chronic disease support, referral coordination. Community-based care is an important access point, but have limited expertise in specialized care required for long-term rare conditions.

Referral and Care Coordination

Once thalassaemia is suspected or diagnosed, patients typically require referral to local specialised haematology services, which may or may not have thalassaemia experience.

Specialist services are essential for:

- Confirming diagnosis.
- Overseeing transfusion requirements.
- Monitoring iron overload.
- Multidisciplinary care coordination.
- Treatment delivery.
- Evaluating clinical / medical eligibility for advanced therapies.

However, access may be limited by:

- Few specialists with thalassaemia expertise.
- Geographic concentration of specialised centres.
- Insurance network restrictions.
- Long wait times for specialist appointments.

- Requirements for referrals or prior authorization.

Patients living in rural or underserved areas may need to travel significant distances to access expert care.

Where local haematologists are available but have limited thalassaemia expertise, **consultative arrangements** may be established with an expert centre. Routine transfusions and regular disease management may be provided locally, while the patient attends the expert centre periodically for a comprehensive evaluation and care review, typically annually or more frequently according to clinical need.

Accessing an expert centre can present additional insurance and financial barriers, particularly when the centre is located outside the patient's state of residence. **Out-of-state care** may be subject to coverage restrictions, particularly for patients enrolled in Medicaid, while patients with employer-sponsored or private insurance may require prior authorisation or face out-of-network costs. An expert centre may also not accept the patient's insurance plan.

These administrative and insurance-related barriers may be compounded by the **financial burden** associated with travelling to an expert centre. Patients and their families may incur substantial out-of-pocket costs for transportation, accommodation and other travel-related expenses, particularly when specialist services are located far from the patient's place of residence. This can make regular access to expert-centre care difficult to sustain and may affect the continuity and comprehensiveness of specialist care.

Optimal and appropriate comprehensive clinical management of thalassaemia requires an expert multidisciplinary team of healthcare professionals. However, these services may be delivered by different organizations and reimbursed by different payers making coordination challenging, so patients become responsible for coordinating their care across a fragmented system.

Chronic Disease Management

Thalassaemia is a lifelong, chronic disease that requires lifelong care rather than episodic treatment. Patients need regular follow-up, ongoing monitoring, and repeated access to specialist services throughout childhood, adulthood, and later life. Successful clinical management therefore depends on continuous access to haematology expertise, medications, transfusion services, laboratory testing, imaging, and supportive care, all of which must be coordinated over time to prevent complications, maintain health and a good quality of life.

- **Continuity of care**

Long-term disease management requires stability to ensure continuity of care. However, disruptions such as changes in insurance coverage, network restrictions, employment, Medicaid eligibility or even moving between states can be destabilizing factors affecting transfusion schedules, disease monitoring, medication access and early detection of complications.

- **Paediatric to adult care transition**

Transitioning from paediatric haematology services to adult care is a major challenge as paediatric care structures are often more coordinated than adult services thus requiring patients to take more responsibility for their care (e.g. managing appointments, medications, insurance requirements). In addition, changes in insurance coverage after adolescence and limited expertise with adult healthcare providers with thalassaemia can result in gaps in monitoring and treatment adherence.

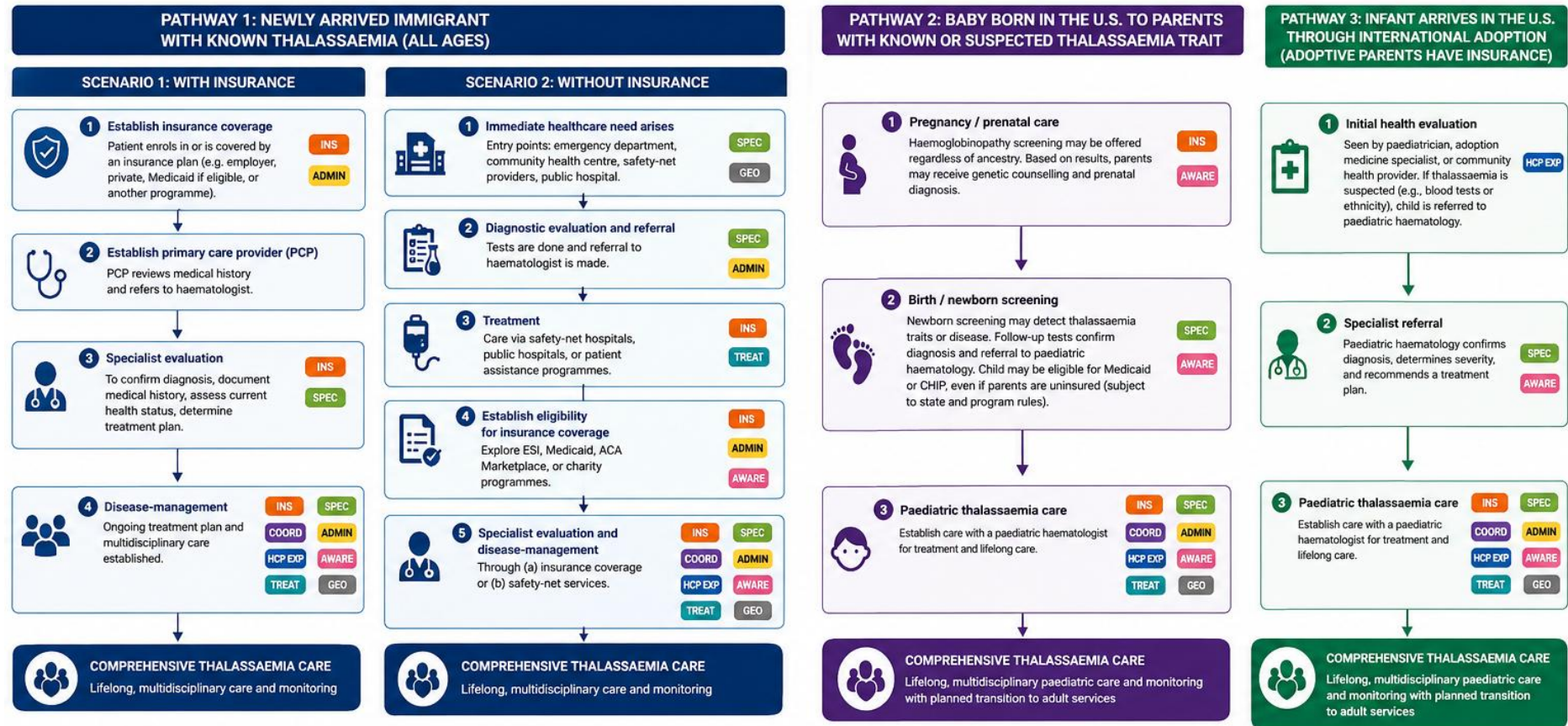
- **Long-term adherence**

Even when patients understand the importance of treatment, long-term adherence can become difficult due to barriers within the health system including challenges in accessing expert services, cost of treatment, insurance restrictions and competing personal, educational or professional responsibilities.

Table 2. Patient Journey Barriers and Potential Impact

Barrier	What it includes	Potential impact on patients
Insurance & Financial Considerations	Understanding insurance options; eligibility for Medicaid, CHIP, or Marketplace plans; premiums, deductibles, copayments, coinsurance; out-of-pocket costs; restrictions in providers and medications / formularies ; loss or changes in insurance coverage.	Delayed access to care, financial hardship, interrupted treatment, or inability to access recommended services.
Specialist Access	Limited number of thalassaemia experts; long waiting times; provider network restrictions; geographic distance to specialist centres; limited availability of multidisciplinary teams.	Delayed diagnosis, delayed treatment, increased travel burden, and reduced access to expert care.
Care Coordination & Navigation	Referral processes; communication between healthcare teams; fragmented medical records; coordination between hospitals, primary care, specialists, laboratories, pharmacies, and insurers; transition from paediatric to adult care.	Fragmented care, duplication of tests, treatment delays, and increased burden on patients and families.
Administrative & Coverage Constraints	Prior authorization; insurance approvals; formulary restrictions; claims and appeals; documentation requirements.	Delays in treatment, reduced access to medicines, and increased administrative burden for patients and healthcare providers.
HCP Expertise	Limited awareness of thalassaemia among non-specialist healthcare professionals; delayed recognition of symptoms; limited access to genetic counselling; language and health literacy challenges.	Delayed diagnosis, inappropriate referrals or treatment, and reduced patient understanding of available services.
Patient / Family Knowledge & Awareness	Understanding of disease is limited	Delayed diagnosis, treatment and monitoring adherence to avoid complications is low
Access to Treatment & Support Services	Availability of blood products; infusion services; medicines; patient assistance programmes; psychosocial support; transportation; social work services.	Interrupted treatment, reduced adherence, and increased caregiver burden.
Geographic & Social Factors	Living far from specialist centres; rural location; transportation difficulties; time away from work or school; family responsibilities; immigration-related eligibility requirements where applicable.	Missed appointments, reduced continuity of care, increased indirect costs, and unequal access to specialised services.

Scenarios of how individuals enter and navigate the U.S Healthcare system



THALASSAEMIA IN THE US

Epidemiology

Thalassaemia is a rare disease in the US due to its low prevalence (see Table 3), and predominantly occurs in communities of Middle Eastern, Asian and European origin, areas of the world with high thalassaemia prevalence (see Table 4).

Trends in population movements have evolved with those originating from South East Asia (e.g. India, China and the Philippines) and Latin America (e.g. Mexico, Brazil and Venezuela)⁸ displacing the previously predominant communities from the Middle East and Mediterranean. This has led to an increased incidence of α -thalassaemia and HbE/ β -thalassaemia (highly prevalent in South East Asia) compared to β -thalassaemia major found predominantly in populations of European and Middle Eastern descent.

Table 3. β -thalassaemia Carrier Rates & anticipated number of affected births per year in the US

COUNTRY	CARRIER RATE	EST. AFFECTED BIRTHS / YEAR
US	β -thal 0.4% HbE 0.1%	0.006/1000 live births

Table 4. Ethnic origins of populations living in US

Country	Africa	Europe	Asia	Latin American	Indigenous
US	12.6%	61%	6%	19%	1.3%

Est. Number of Patients:

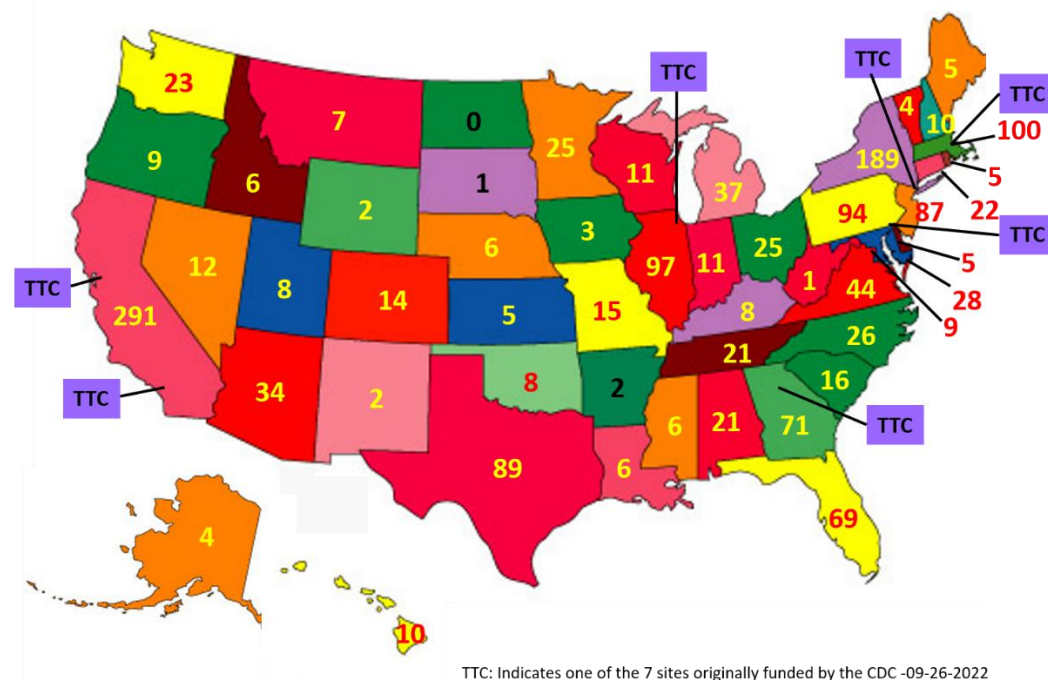
- A national registry does not exist.
- A pilot project covering 7 states (California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania) to document haemoglobinopathy prevalence ran for a 2-year period. Published results in 2016 of this Registry and Surveillance System for Hemoglobinopathies (RuSH) indicated approx. 1,037 thalassaemia patients⁹.
- More recently in 2023 an extrapolation of newborn screening data from 17 states in combination with median State birth incidence suggested an anticipated incidence rate of 1.46 / 100,000 live births and approximately 3,665 thalassaemia patients living in the US¹⁰.
- It is estimated that approximately 3,000 thalassaemia patients live in the US, of which 1,604 are voluntarily registered with Cooley’s Anemia Foundation (see Figure 9).
- The majority of patients (516, 32%) live in the Northeast, followed by South (430, 27%), West (422, 26%) and Midwest (236, 15%). As shown in Figure 9, the estimated thalassaemia patient population in 2026 is concentrated in California, New York, Massachusetts, Illinois, and Pennsylvania, which have the highest numbers of patients. At the other end of the spectrum, West Virginia and South Dakota each have an estimated one patient, while Wyoming, New Mexico, and Arkansas each have an estimated two patients.
- The number of patients in the US have overall increased by 14% between 2021 and 2026, with the largest % increase been noted in the South with 21% (comparing 2021 vs 2026 data).

⁸ <https://www.pewresearch.org/short-reads/2024/09/27/key-findings-about-us-immigrants/>

⁹ Hulihan MM, Feuchtbaum L, Jordan L, Kirby RS, Snyder A, Young W, Greene Y, Telfair J, Wang Y, Cramer W, Werner EM, Kenney K, Creary M, Grant AM. State-based surveillance for selected hemoglobinopathies. Genet Med. 2015 Feb;17(2):125-30. doi: 10.1038/gim.2014.81. Epub 2014 Jul 3. PMID: 24991875; PMCID: PMC4427044. <https://pmc.ncbi.nlm.nih.gov/articles/PMC4427044/>

¹⁰ Kasey Fu, Katherine Lawson-Michod, Michael Goodman, Cathy Lally, Jelili Ojodu; Estimated Prevalence of β -Thalassemia in the United States in 2023. Blood 2024; 144 (Supplement 1): 1098. doi: <https://doi.org/10.1182/blood-2024-200292>

Figure 9. Patients registered with Cooley's Anemia Foundation (May 2026)



Who are the Key Actors in the Ecosystem

- **Government:**
 - Federal: Department of Health and Human Services (HHS): Food and Drug Administration (FDA), Centers for Medicare & Medicaid Services (CMS), Centers for Disease Control and Prevention (CDC), National Institutes of Health (NIH), Agency for Healthcare Research and Quality (AHRQ)
 - State: Medicaid State Agencies, Children's Health Insurance Program (CHIP)
- **Healthcare providers:** Thalassaemia Treatment Centres, Hospitals, Outpatient and Ambulatory Care settings, Primary Care and Community Health Centres, Physicians (primary care physicians, specialists)
- **Payers:**
 - Health services: Private Insurers, Pharmacy Benefit Managers, Public / Government programs (Medicare, Medicaid, CHIP, GHPP), Individuals
 - Social Health Protection: Social Security Administration (SSI & SSDI)
- **Patient / Family organisations:** Cooley's Anemia Foundation
- **Professional associations:** American Society of Hematology, American Society of Pediatric Hematology/Oncology, American Society of Gene & Cell Therapy
- **Research:** Academic centres / Universities, National Institutes of Health (NIH), Agency for Healthcare Research and Quality (AHRQ), Pharmaceutical companies

Thalassaemia Services

Prevention

The low carrier rate and thus rare disease incidence of thalassaemia have resulted in efforts focusing on addressing medical needs rather than developing a full-fledged prevention programme that include the components defined by the Thalassaemia International Federation (TIF) as pivotal for the effectiveness of any thalassaemia prevention programme.

Get more information in the latest edition of [TIF's Global Thalassaemia Review](#) (Chapter 3), updated annually.

- Carrier screening is limited and voluntary with no national policy.
- The American College of Obstetricians and Gynecologists (ACOG) recommends offering hemoglobinopathy testing broadly to people planning pregnancy or at the first prenatal visit if prior results are unavailable.

- Newborn screening is, however, almost universal since 2005.

Blood

- Patients with thalassaemia and other haemoglobin disorders are anticipated to receive adequate, safe and appropriately processed/stored blood as recommended in national¹¹ and international guidelines¹². However, actual practice across treatment centers is variable¹³.
 - Results of a patient survey in the Eastern States Network¹⁴ showed that 61% of respondents noted pre-transfusion haemoglobin levels higher than 9.1g/dL.
 - A survey from 8 US thalassaemia centers found wide differences in transfusion thresholds, how often units are phenotyped (for minor antigens), and prophylactic matching (Rh, K) for patients¹⁵. This variability contributes to risks: for example, patients receiving chronic transfusions may develop alloimmunization (i.e. immune reactions to foreign RBC antigens) over time.
 - A recent study of 40 chronically transfused thalassaemia patients found an alloimmunization rate of about 32.5%¹⁶.
- The CDC contribute through many different research projects to significant improvements in blood transfusion therapy for thalassaemia.
- The diversity of populations genetic origins may contribute to challenges in identifying appropriate donors from minority populations¹⁷.
- Since January 2026, the US is no longer a member of the World Health Organization (WHO) and so observance of documents, decisions and resolutions of the WHO World Health Assembly, Executive Board and Pan-American Health Organisation (PAHO) on blood safety including but not limited to those listed below is not in effect.

While this is development is not anticipated to impact blood safety or adequacy in the US (which are governed by national law, agencies and bodies), there may be less coordination with international counterparts on the surveillance of emerging pathogens relying more on national agencies (e.g. CDC), and published scientific literature.

WORLD HEALTH ASSEMBLY & EXECUTIVE BOARD	
▪ WHA28.72 (1975) Utilization and supply of human blood and blood products	▪ WHA55.18 (2002) Quality of care: patient safety
▪ EB79.R1 (1987) Blood and blood products	▪ WHA56.30 (2003) Global health-sector strategy for HIV/AIDS
▪ WHA40.26 (1987) Global strategy for the prevention and control of AIDS	▪ WHA58.13 (2005) Blood safety: proposal to establish World Blood Donor Day
▪ WHA45.35 (1992) Global Strategy for the Prevention and Control of AIDS	▪ WHA63.12 (2010) Availability, safety and quality of blood products
▪ WHA48.27 (1995) Paris AIDS Summit	▪ WHA63.18 (2010) Viral hepatitis
▪ WHA53.14 (2000) HIV/AIDS: confronting the epidemic	▪ WHA63.20 (2010) Chagas disease: control and elimination

¹¹ <https://www.cdc.gov/thalassemia/media/pdfs/Thalassemia-Resource-for-Healthcare-Providers.pdf>

¹² TIF's Global Thalassaemia Review 2024, Chapter 4

¹³ Lal A, Wong T, Keel S, Pagano M, Chung J, Kamdar A, et al. The transfusion management of beta thalassemia in the United States. *Transfusion*. 2021; 1–13. <https://onlinelibrary.wiley.com/doi/10.1111/trf.16640>

¹⁴ Kwiatkowski, J. The role of Reference Centres and Regional Networking in enhancing patient care, 1st TIF Pan-American Conference on Thalassaemia and Other Haemoglobin Disorders, 2025

¹⁵ Goss C, Giardina P, Degtyaryova D, Kleinert D, Sheth S, Cushing M. Red blood cell transfusions for thalassemia: results of a survey assessing current practice and proposal of evidence-based guidelines. *Transfusion*. 2014 Jul;54(7):1773-81. doi: 10.1111/trf.12571. Epub 2014 Feb 24. PMID: 24611697.

¹⁶ Chang Liu, Brenda J. Grossman; Red blood cell transfusion for hematologic disorders. *Hematology Am Soc Hematol Educ Program* 2015; 2015 (1): 454–461. doi: <https://doi.org/10.1182/asheducation-2015.1.454>

¹⁷ TIF's Global Thalassaemia Review 2024, Chapter 4

WHO PAN AMERICAN HEALTH ORGANIZATION (PAHO)

- | | |
|---|--|
| ▪ CD41.R15 (1999) STRENGTHENING BLOOD BANKS IN THE REGION OF THE AMERICAS | ▪ CE 142.R5 (2008) BLOOD TRANSFUSION SAFETY: PROGRESS REPORT |
| ▪ CD41.R15 (1999) STRENGTHENING BLOOD BANKS IN THE REGION OF THE AMERICAS | ▪ CD48.R7 (2008) IMPROVING BLOOD AVAILABILITY AND TRANSFUSION SAFETY IN THE AMERICAS |
| ▪ CD46.R5 (2005) PROGRESS REPORT ON THE GLOBAL SAFE BLOOD INITIATIVE AND PLAN OF ACTION FOR 2005-2010 | ▪ CD53.R6 (2014) PLAN OF ACTION FOR UNIVERSAL ACCESS TO SAFE BLOOD |

- The availability, safety and governance of the blood ecosystem in the US is reported in the [WHO Global Status Report on Blood Safety and Availability \(2025\)](#) (see Tables 5 – 10 below) and [America's Blood Centres](#) statistics.

Important Takeaways:

- 100% of blood collected came from voluntary, non-remunerated whole blood donations.
- National donation rate of 28 whole blood donations per 1,000 people ; only 3% of the population are blood donors¹⁸.
- 98% of blood collected is separated into components.
- All donated blood is screened for HIV, Hepatitis B, Hepatitis C and syphilis; additional screening for transfusion-transmitted infections (e.g. Chagas, West Nile virus) is done on a selective basis.
- The risk of getting an infection from a blood transfusion is very small: 1 in 1 million for Hepatitis B, 1 in 2 million for Hepatitis C and 1 in 1.6 million for HIV – Types 1 and 2¹⁹.
- Nationally coordinated and high-quality standards of transfusion services / blood centres that are regulated and licensed by the FDA. The Center for Biologics Evaluation and Research (CBER) within the FDA is specifically responsible for oversight of the US blood supply²⁰. Many blood centres are also voluntarily accredited by other organizations.
- Blood establishments are inspected by the FDA at least every two years.

Table 5. Blood Donations in the US

Table 6: Blood Donations in the US

BLOOD DONATIONS								
Country	Date Year	No. Whole Blood Donations Collected (excluding autologous donations)						
		VNRD	VNRD from 1st time donors	VNRD from repeat donor	Family/replacement donations	Paid donations	Others	Total
High-Income (HIC)								
United States of America	2023	9586000	1721000	4826000	0	0	0	9586000

Blank : Not required/not applicable

/ : No response

VNRD : Voluntary non-remunerated donations

¹⁸ [America's Blood Centres Statistics, 2024](#)

¹⁹ [America's Blood Centres Statistics, 2024](#)

²⁰ U.S. Food and Drug Administration Centers for Biologics Evaluation and Research Blood & Blood Products. <https://www.fda.gov/vaccines-blood-biologics/blood-blood-products>.

Table 6. Blood Centres & Data Coverage in the US

Country	Date Year	Number of blood centres in the country			Number of blood centres covered by this report			Estimated % of Blood Donations covered by this report
		Stand-alone	Hospital-based	Total	Stand-alone	Hospital-based	Total	
High-Income (HIC)								
United States of America	2023	...	...	157	...	...	116	95

... : Not reported/not available
/ : No response

Table 7. Laboratory Test Requirements for Screening Donated Blood for Transfusion-Transmissible Infections in the US (2023)

Infections in the US (2023)

LABORATORY TEST REQUIREMENTS FOR SCREENING DONATED BLOOD FOR TRANSFUSION-TRANSMISSIBLE INFECTIONS (2023)								
Country	Date Year	Chagas disease		Malaria			HTLV-1/2	
		Ab	Others	Smear microscopy	Ag	Others	Ab	Others
High-Income (HIC)								
United States of America	2023	S					S	

USA: All donations are tested for:

- **HIV 1 +2**
- **Hepatitis B**
- **Hepatitis C**
- **Syphilis**
- **West Nile virus RNA with NAT in pools or individual donations based on seasonal activity**

Y : Required for all donations
S : Required for selected donations
Blank : Not required/not applicable
* : or antigen test

Table 8. Number & Proportion of Donations Tested Positive/Reactive for TTI Markers in the US

NUMBER & PROPORTION OF DONATIONS TESTED POSITIVE/REACTIVE FOR TTI MARKERS				
Country	Date Year	HIV 1+2		
		Positive/reactive, no.	No. donations tested	%*
High-Income (HIC)				
United States of America	2023	7839	9586000	0.0818

/ : No response

* Proportion, expressed as positive/reactive per 100 donations tested

Table 9. Clinical Use of Blood & Blood Components in the US

CLINICAL USE OF BLOOD & BLOOD COMPONENTS									
Country	Date Year	No. Hospitals Performing Blood Transfusion	No. Units of Blood Components Issued/Transfused (excluding autologous blood units)						
			Whole blood	Red cells	Whole blood derived platelets	Apheresis platelets	Fresh frozen plasma	Plasma	Cryo-precipitate
High-Income (HIC)									
United States of America	2023	3543	...***	10327000	55000	2160000	...	1182000	1171000

... : Not reported/not available
Blank : Not required/not applicable
/ : No response
* 1 unit of blood component is defined as the preparation from whole blood donations of 450 ml
** 1 unit of apheresis platelets usually contains 200 - 450 x 10 000 000 000 platelets
*** Whole blood and red cell data were combined and reported as a single figure.

Table 10. Policy, Governance, Quality Assurance and Monitoring in the US (2023)

POLICY, GOVERNANCE, QUALITY ASSURANCE AND MONITORING (2023)									
Country	Unit within MoH with responsibility for governing blood provision & transfusion activities	National Blood Policy	Multiyear national strategic plan for blood safety or equivalent	Specific Legislation Covering the Safety & Quality Of Blood And Blood Products for Transfusion	National Blood Committee (or equivalent)	Specific Government Budgetary Line Item For The NBTS/BTS	System of Cost Recovery for NBTS/BTS	National standards for the collection, testing processing, storage & distribuion of blood and blood components	National Guidelines On The Appropriate Clinical Use Of Blood
High-Income (HIC)									
United States of America	No	No	No	Yes	Yes*	No	Yes	Yes	Yes

* Governed by FDA
Some transfusion services are accredited by the Joint Commission, AABB or the College of American Pathologists.
... : Not reported/not available

Iron Overload

- All iron chelators (deferoxamine, deferiprone and deferasirox) are available but coverage and out-of-pocket cost may vary by insurer.

MRI

Magnetic resonance imaging (MRI) has been widely adopted for iron quantification in vital organs, mainly the heart and the liver. In addition to assessing the distribution and grading of iron overload, this method offers the possibility to monitor treatment response and thus guide effectively iron chelation therapy. It has been recognised as superior to biochemical methods of measuring iron overload (e.g. serum ferritin), since these can be influenced by factors such as inflammation and infection and cannot be used as surrogates of cardiac iron content.

- MRI-based iron measurement for thalassaemia patients is mostly feasible in the US where tertiary haematology centers routinely perform liver and cardiac T2*assessments as part of standard care, supported by widespread MRI availability. However maybe subject to coverage issues by payers/insurers.

Multidisciplinary Care

This section endeavours to understand the quality of care received by thalassaemia patients in the US by exploring the location, type and expertise of healthcare services provided including the aspects of multidisciplinary care, Reference Centres and networking and clinical management guidelines.

- Treatment is provided by a mixture of specialized services in States where there is a large concentration of patients, and these have developed expertise in the clinical management of thalassaemia, and paediatric/adult haematology centres in States where the number of patients are few. Subsequently, the provision of care is uneven across the country, further hindered by the rarity of thalassaemia and the long distances required to travel for expert care.
- Patients are more likely to receive care by a haematologist/oncologist than a haematologist with expertise in thalassaemia or even a dedicated thalassaemia treatment centre (see Figure 10) was

reported by a survey of patients in the Eastern States Network²¹. Moreover, patients in the same survey indicated that access to a thalassaemia centre is limited (see Figure 11).

Figure 10. Location of received care in the Eastern States

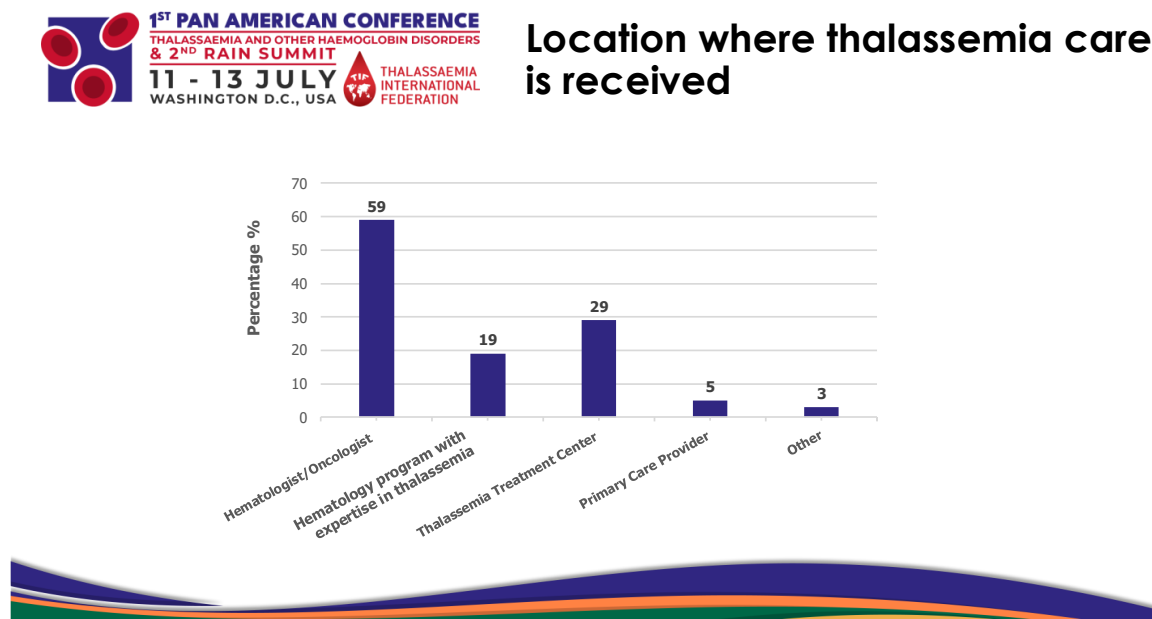
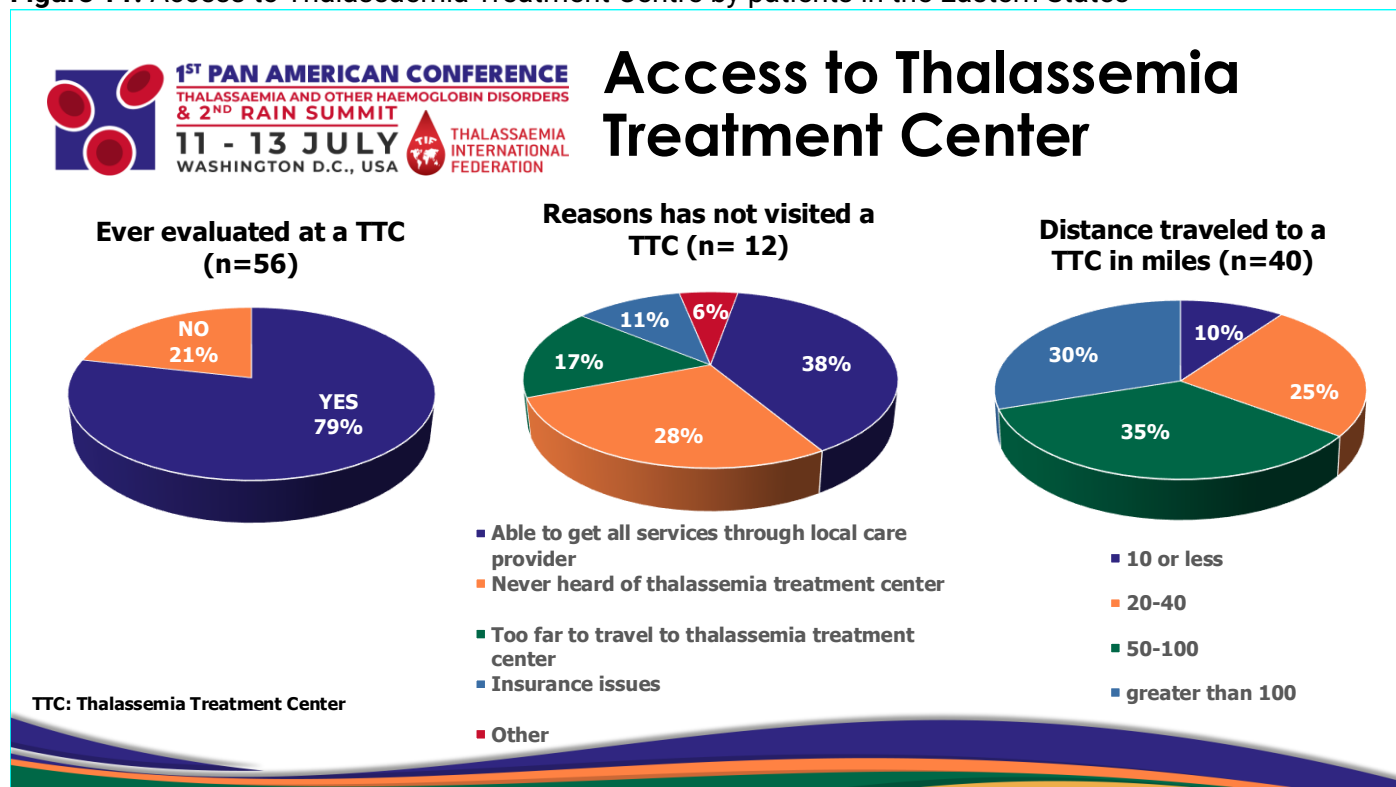


Figure 11. Access to Thalassaemia Treatment Centre by patients in the Eastern States



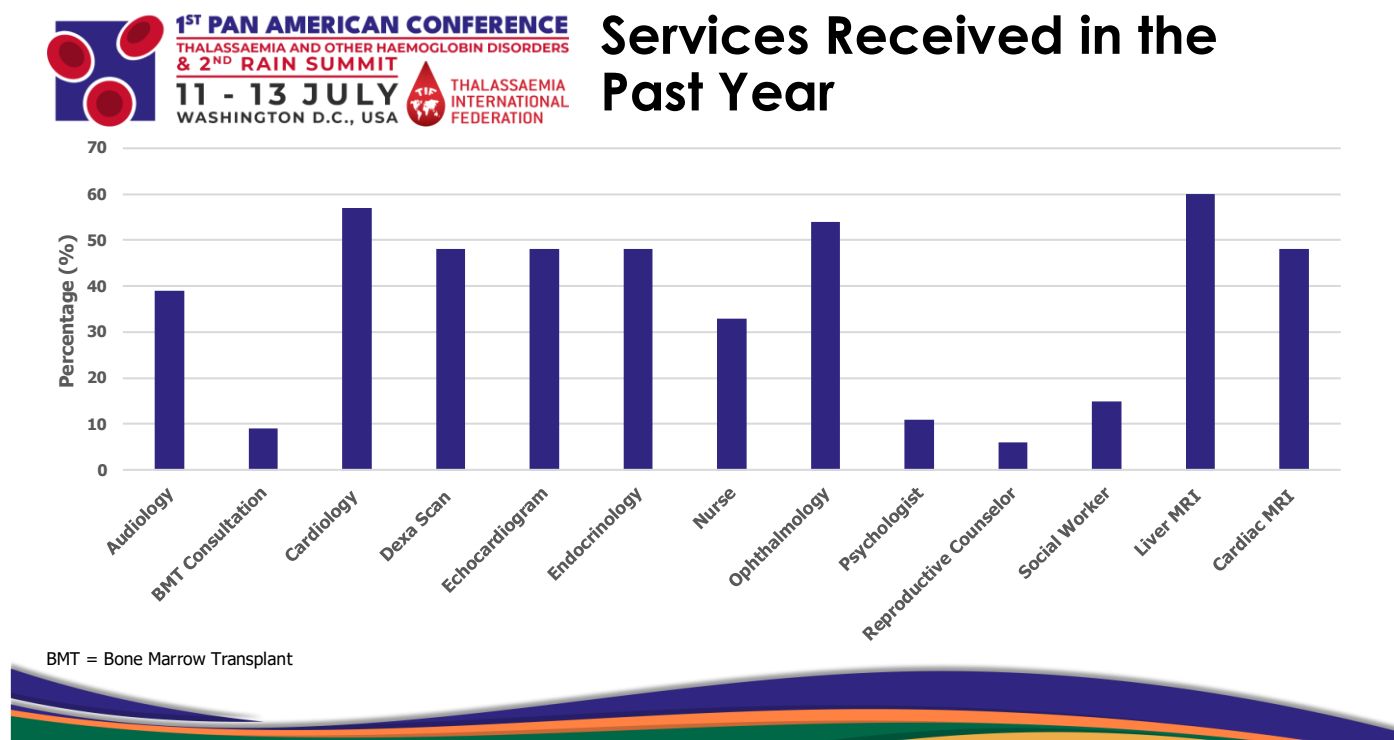
- Results of a patient survey by the Eastern States Network²² showed that:
 - Multidisciplinary care, although fragmented is pursued (see Figure 12).

²¹ Kwiatkowski, J. The role of Reference Centres and Regional Networking in enhancing patient care, 1st TIF Pan-American Conference on Thalassaemia and Other Haemoglobin Disorders, 2025

²² Kwiatkowski, J. The role of Reference Centres and Regional Networking in enhancing patient care, 1st TIF Pan-American Conference on Thalassaemia and Other Haemoglobin Disorders, 2025

- 61% of respondents noted pre-transfusion haemoglobin levels higher than 9.1g/dL.
- 24% of respondents reported LIC <5mg/g dw albeit 55% did not know their LIC!
- 31% of respondents stated their most recent cardiac T2* is >20ms however 51% did not know their T2* value!

Figure 12. Multidisciplinary care received in the past 12 months in the Eastern States



- The CDC has recognized 10 thalassaemia treatment centres as reference centres. See page 15 for more information.
- Eastern States Network²³

Coordinated by a core (Reference) center (v. Children's Hospital of Philadelphia and Weill Cornell Medical Center) it encompasses 45 Regional Sites, 110 providers and provides care for 1,324 thalassaemia patients (710 TDT, 614 NTD) with the numbers of patients at each site ranging between 2 – 179.

The Networks goals are to:

1. Increase the number of individuals with thalassaemia in the Eastern Region who receive evidence-informed comprehensive care
2. Increase the number of regional providers delivering evidence-informed comprehensive care
3. Disseminate monitoring and treatment guidelines
4. Provide education and support to local providers

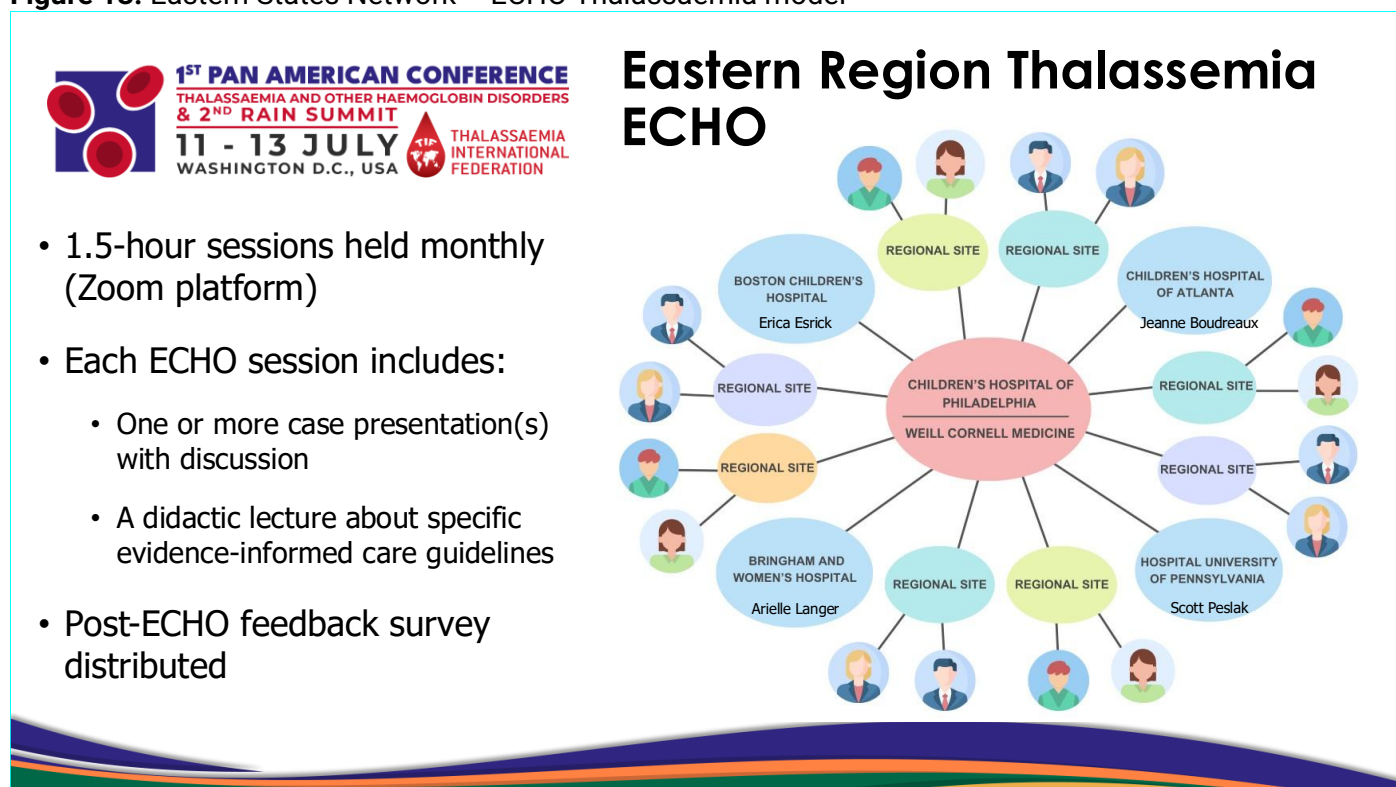
To that end, the Core Centre undertakes:

- Patient Needs Assessment to implement strategies that respond to identified needs
- Provider Monitoring Survey in order to characterize patient population and assess capacity at regional sites
- Supporting infrastructure development at local sites
- Monthly telementoring sessions (ECHO Thalassaemia) (See Figure 13)

²³ Kwiatkowski, J. The role of Reference Centres and Regional Networking in enhancing patient care, 1st TIF Pan-American Conference on Thalassaemia and Other Haemoglobin Disorders, 2025

The Network is governed by a Steering Committee that engages in quarterly meetings and is composed of patients, providers and patient organisations (CAF).

Figure 13. Eastern States Network – ECHO Thalassaemia model



- Treating physicians rely on the use of the [Thalassemia Healthcare Provider Resource Toolkit](#) (published by the CDC) which brings together a number of resources including those developed by US Reference Centres (e.g. [UCSF/Northern California Comprehensive Thalassemia Center Standards of Care](#), [Children's Hospital of Philadelphia Guidelines for Managing Transfusion Therapy for Thalassaemia](#), [Weill Cornell Medical Center Monitoring of Iron Overload](#) etc) and references TIF's Guidelines for the Clinical Management of Thalassaemia (2017, 2021).

Social Health Protection

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

- **Disease-specific benefits** are available through Social Security Administration (SSA).

More specifically, thalassaemia patients may qualify for federal disability benefits through two SSA programs: Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

Thalassemia is specifically recognized by the SSA under Section 7.05 – Hemolytic anemias, including thalassemia and its variants in the SSA Listing of Impairments. Medical eligibility may be met when the condition causes severe impairment, including beta thalassemia major requiring lifelong red blood cell transfusions at least once every six weeks to maintain life, repeated hospitalizations due to complications, or persistently severe anemia meeting SSA criteria. Meeting the medical listing does not automatically guarantee benefits; applicants must also satisfy the program's non-medical requirements.

- SSI is a needs-based federal program for individuals with disabilities who have limited income and financial resources. Eligibility does not depend on previous employment or payment of Social Security taxes. A person with transfusion-dependent thalassemia may qualify if their condition meets SSA disability criteria and they meet SSI income and resource requirements. SSI payments are generally intended to provide basic income support, and eligibility may also provide access to Medicaid depending on state rules.
 - SSDI is an insurance-based disability program for individuals who have accumulated sufficient Social Security work credits through employment in jobs covered by Social Security. A person with thalassemia must meet both the medical disability criteria and the required work-credit rules. The number of credits required depends on the person's age when disability begins. Individuals with severe thalassemia who became disabled before age 22 may also be eligible in some circumstances for *Disabled Adult Child (DAC) benefits* based on a parent's Social Security record.
- The **educational, professional and social integration** of thalassaemia patients across 7 TTCs²⁴ in the US had been reported in 2024:
 - 30.4% have a bachelor's degree
 - 38.8% are employed, full-time
 - 42.3% are not employed
 - 30.4% are married/partnered
 - 64.5% are single

Cost of Illness

Projected lifetime healthcare costs were estimated to be \$7.1 million for patients with TDT at age 50 compared to \$235,000 for matched controls. After age 36, each additional year of life added \$152,482 to the total lifetime costs for patients with TDT and \$7258 to those for matched controls. This study used administrative claims data to evaluate real-world clinical complications, treatments, Healthcare Resource Utilization, and healthcare costs in patients with TDT in the US. However, indirect healthcare costs (e.g. absenteeism, presenteeism, etc.) were not included so total cost may be even higher²⁵.

Disease Burden

The extent of morbidity or complication rates, measured by various parameters, is a reflection of the quality of clinical management as well as patient adherence.

Therefore disease burden in β -thalassaemia is a complex concept which needs several parameters to adequately define, including age distribution and complication rates.

The **age distribution** of these patients, since the needs of each age group are different. This demonstrates both the degree to which prevention of affected births is effective but also the effectiveness of clinical services provided and contributed to reduction in mortality.

Complication rates – these vary from population to population according to timely interventions and quality of care

Regrettably, systematic data collection on a national level of this data is found only in very few countries. Therefore, the information presented below is limited and warrants further exploration to obtain a deeper and truer understanding of the disease burden in the US.

²⁴ Chapin J, Cohen AR, Neufeld EJ, Vichinsky E, Giardina PJ, Boudreaux J, Le BC, Kenney K, Trimble S, Thompson AA. An update on the US adult thalassaemia population: a report from the CDC thalassaemia treatment centres. *Br J Haematol*. 2022 Jan;196(2):380-389. doi: 10.1111/bjh.17920. Epub 2021 Nov 14. PMID: 34775608; PMCID: PMC10936238.

²⁵ UDEZE C, EVANS KA, YANG Y, LILLEHAUGEN T, MANJELIEVSKAIA J, MUJUMDAR U, LI N, ANDEMARIAM B. ECONOMIC AND CLINICAL BURDEN OF MANAGING TRANSFUSION-DEPENDENT B-THALASSEMIA IN THE UNITED STATES. *J MED ECON*. 2023 JAN-DEC;26(1):924-932. DOI: 10.1080/13696998.2023.2235928

- In a recent study of thalassaemia-related deaths across the US, from 1999 to 2020, there were 2797 deaths, 74% had beta thalassaemia and 18% had alpha thalassaemia. Most deaths were attributed to cardiovascular issues but 18% had malignancies. Infection which is so common in many thalassaemia populations was the cause of death in only 3% of cases. Overall, there is a decreasing trend in thalassaemia-related mortality over the years. Weaknesses in this study include the lack of information on the comorbidity burden, or the prior interventions²⁶.
- The age distribution of patients in the databased of the Cooley's Anemia Foundation (Figure 14) and the CDC Thalassaemia Treatment Centres Consortium (Figure 15) indicate a young thalassaemia population living in the US.

Figure 14. Age distribution of patients from the Cooley's Anemia Foundation Database 2021

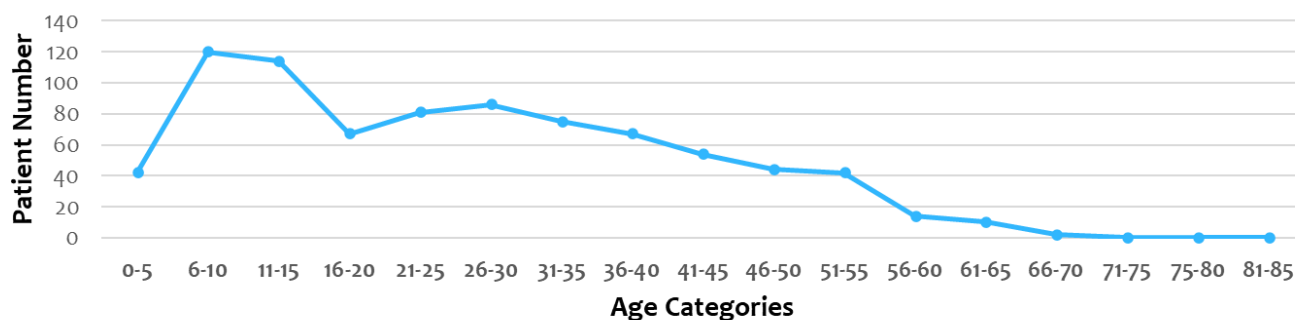
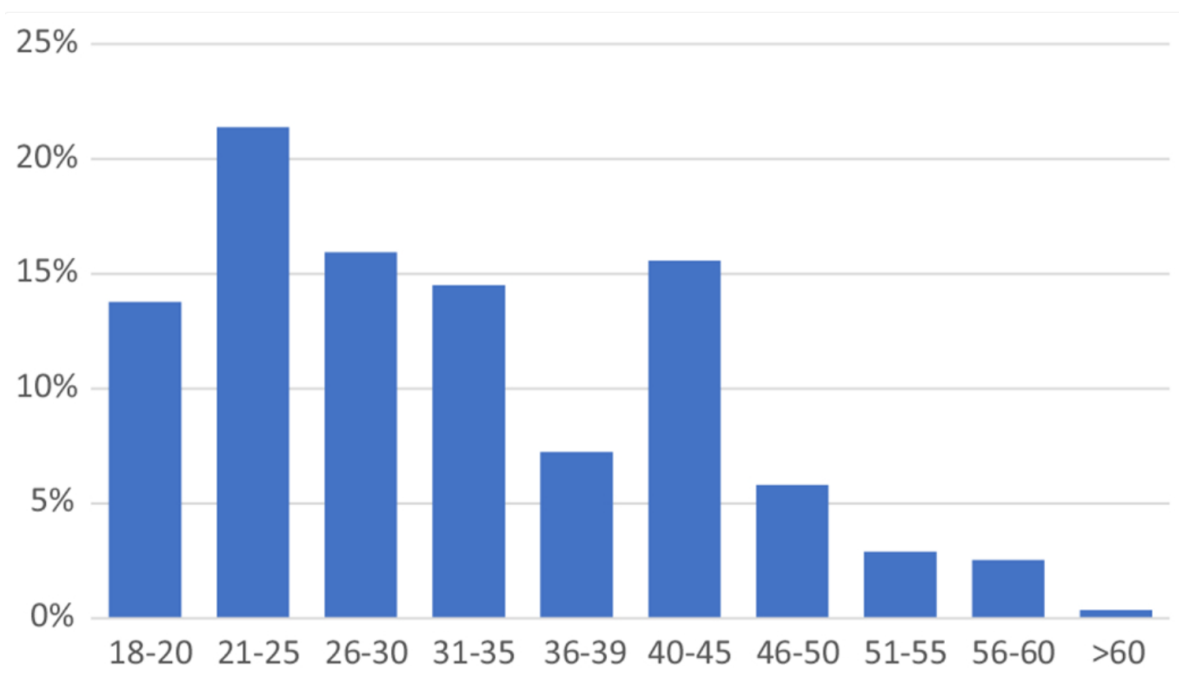


Figure 15. Age distribution of adult patients in the CDC consortium of 7 thalassaemia-treatment centers 2024²⁷



²⁶ TAN JY, YEO YH, CHAN KH, SHAABAN HS, GURON G. CAUSES OF DEATH AND MORTALITY TRENDS IN INDIVIDUALS WITH THALASSEMIA IN THE UNITED STATES, 1999-2020. J BLOOD MED. 2024 AUG 5;15:331-339. DOI: 10.2147/JBM.S470177

²⁷ Chapin J, Cohen AR, Neufeld EJ, Vichinsky E, Giardina PJ, Boudreaux J, Le BC, Kenney K, Trimble S, Thompson AA. An update on the US adult thalassaemia population: a report from the CDC thalassaemia treatment centres. Br J Haematol. 2022 Jan;196(2):380-389. doi: 10.1111/bjh.17920. Epub 2021 Nov 14. PMID: 34775608; PMCID: PMC10936238.

GEOGRAPHIC AND STATE-LEVEL VARIABILITY

Unlike healthcare systems where coverage policies, reimbursement structures, and service availability are largely standardized nationally, healthcare in the US is shaped by a combination of federal programs, state policies, private insurance markets, and local healthcare infrastructure. As a result, access to care and quality of care can differ considerably depending on where an individual lives.

Indeed, broader measures of population health demonstrate substantial variation between US states, reflecting structural factors that influence population health, including access to healthcare services, socioeconomic conditions, availability of healthcare resources (see Figure 17).

Similarly, persistent state-level variations in healthcare quality and disparities (see Figure 18) in access to care, effectiveness of treatment, patient safety, care coordination, and experiences of care demonstrate that healthcare quality is not uniformly distributed across geographic regions.

THALASSAEMIA PATIENT IMPACT

Several states with high numbers of individuals living with thalassaemia, including Massachusetts, Pennsylvania, and New York, are located within regions that demonstrate relatively strong overall healthcare quality performance. These states also have major academic medical centres and greater availability of specialized services (4 out of a total of 10 CDC thalassaemia treatment centres are located in these states), which may support access to expert thalassaemia care. However, the relationship is not uniform. California, which has one of the largest thalassaemia populations in the US (and 2 CDC thalassaemia treatment centres), is included among states with lower overall healthcare quality scores. This illustrates that although California has major centres of excellence and significant clinical expertise, the size, geographic diversity, and regional variation within the state may create disparities in access, particularly for patients living outside major metropolitan areas. At the other end of the scale, states with lower overall healthcare quality scores, including Arkansas, West Virginia, Wyoming, and New Mexico, also have among the lowest numbers of identified thalassaemia patients. The lower patient burden may reduce local demand for specialized services; however, patients living in these states may face challenges accessing expertise if local healthcare systems have limited experience with rare haemoglobin disorders.

Therefore, geographic location influences multiple aspects of the thalassaemia patient journey. A patient's state of residence can determine insurance eligibility, affordability of care, availability of specialists, access to specialized treatment centres, exposure to experienced healthcare providers, and ability to participate in clinical research. Consequently, geographic variability represents an important contributor to healthcare disparities among individuals living with thalassaemia.

Geography is not simply a matter of physical distance; it reflects the healthcare ecosystem available to patients and the extent to which that ecosystem supports high-quality, comprehensive, and equitable care.

Figure 16. Geographic distribution of patients, expert centres and Medicaid expansion status across the US

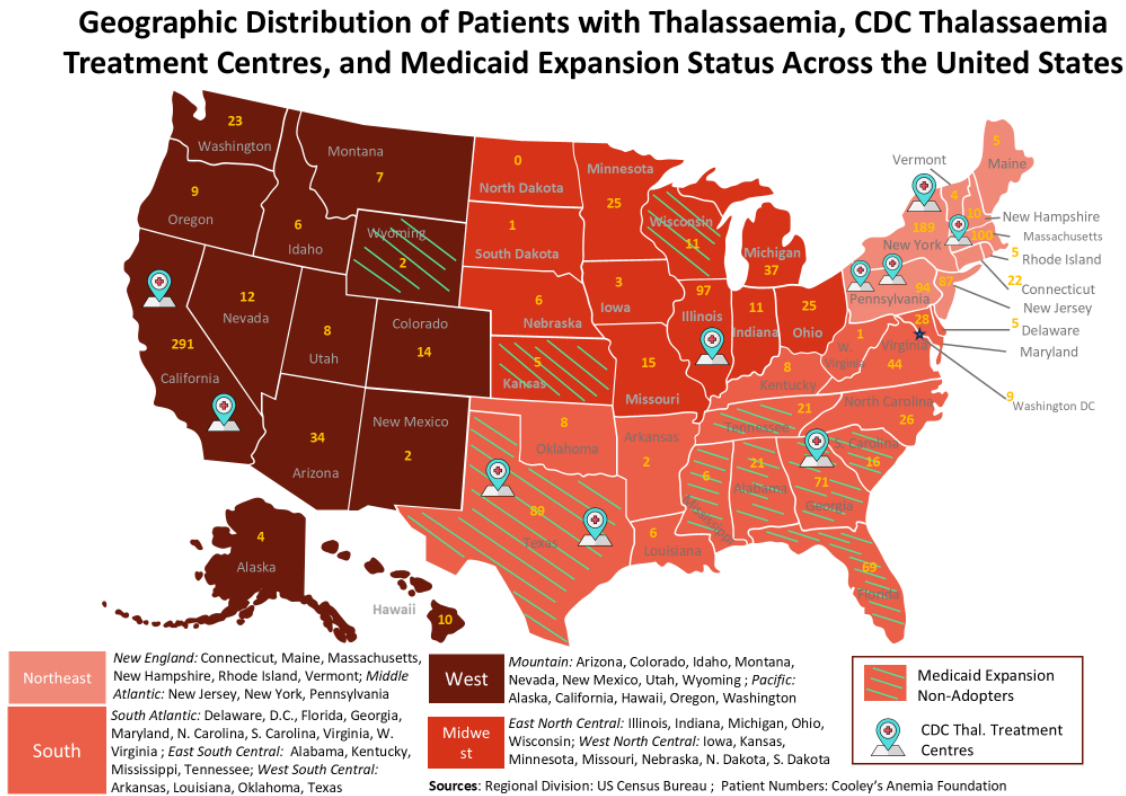
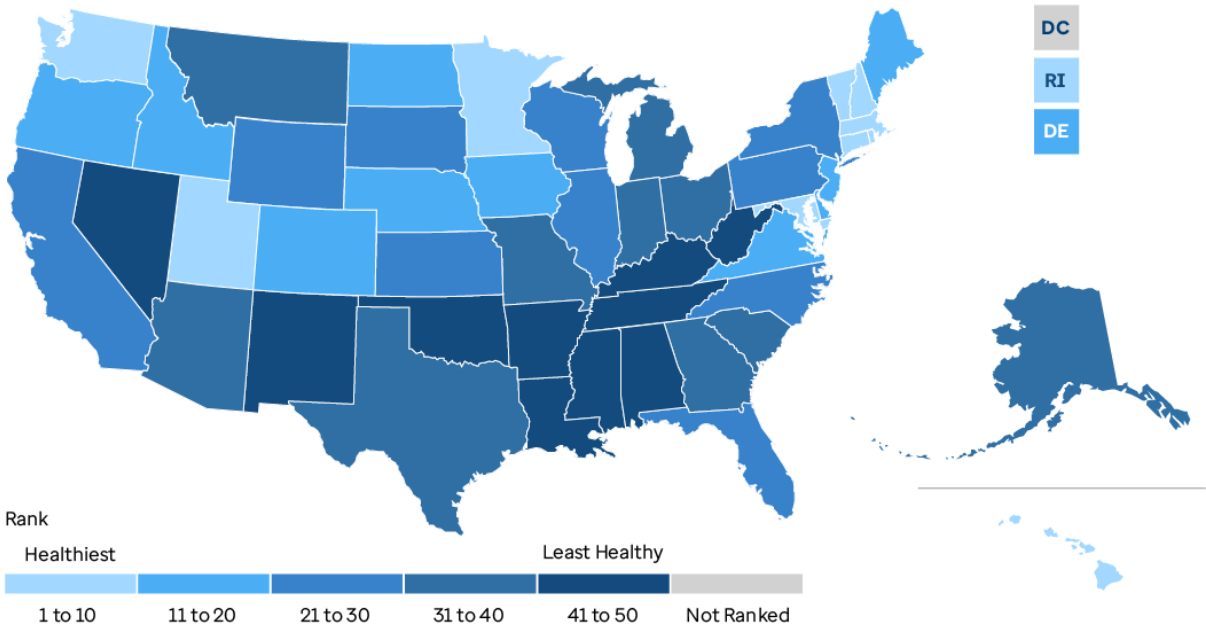


Figure 17. State Health Rankings 2025²⁸

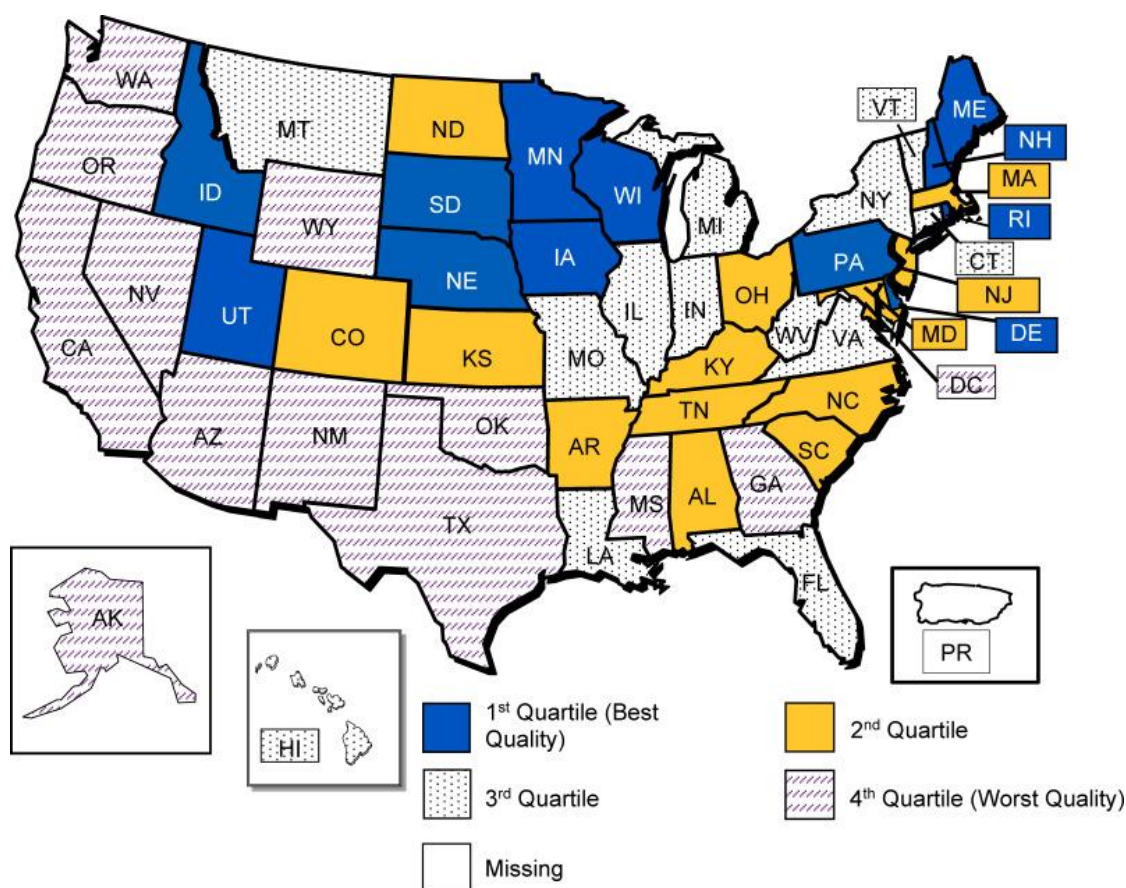
2025 Annual Report State Rankings



Source: America's Health Rankings composite measure, 2025.

²⁸ [Americas Health Rankings 2025](#)

Figure 18. State-level variability in quality of healthcare²⁹



Variation in Health Insurance Coverage

- Private insurance plans differ substantially between states and employers. Differences may include: specialist network availability; deductibles and co-payment requirements; medication coverage; reimbursement for out-of-network expertise; coverage of advanced therapies.
- Medicaid eligibility and coverage vary substantially across states as each state has considerable authority over program design. This creates variation in eligibility requirements, covered services, reimbursement approaches, managed care arrangements, and administrative processes. States that adopted Medicaid expansion generally provide broader coverage opportunities for low-income adults, while individuals living in non-expansion states may face greater challenges accessing affordable insurance. See page 19 for more information and which States have adopted the expansion.

Variation in Healthcare Infrastructure and Specialized Care Availability

- The CDC-supported thalassaemia treatment centre network has played an important role in developing expertise and improving access to specialized care. However, the geographic distribution of these centres means that many patients remain dependent on regional referral systems or must travel significant distances to access expert care.

This creates a mismatch between where patients live and where specialized knowledge is available. A state may have a significant thalassaemia population but limited specialist infrastructure, while another state may have highly developed expertise serving patients from surrounding regions.

²⁹ 2023 National Healthcare Quality and Disparities Report. Rockville (MD): Agency for Healthcare Research and Quality (US); 2023 Dec. Report No.: 23(24)-0091-EF. PMID: 38377267.

In addition, states with smaller numbers of identified patients may have limited local experience managing thalassaemia, potentially contributing to delayed diagnosis or reliance on referral to distant centres.

- Geographic disparities are particularly evident when comparing urban and rural healthcare environments. States with large urban populations and diverse immigrant communities, including California, New York, Texas, Florida, New Jersey, and Massachusetts, often have higher concentrations of thalassaemia expertise and specialized services. However, even in these states, access may not be uniform. Patients living outside major metropolitan areas may still face significant barriers related to travel distance, transportation, appointment availability, and continuity of care.

The Genetically Handicapped Persons Program (GHPP) is a California state health care program run by the California Department of Health Care Services for people with certain inherited (genetic) conditions. It is designed mainly for adults (generally age 21 and older) who are California residents (with or without US citizenship), have eligible genetic diseases,, and helps cover medically necessary services related to those conditions. **GHPP specifically lists thalassemia among its eligible conditions under blood disorders/hemoglobinopathies.**

What does GHPP provide for thalassaemia patients?

- Specialist care (such as hematology care)
- Special Care Center services (multidisciplinary genetic-condition care)
- Case management/care coordination
- Required laboratory monitoring
- Treatment-related services and supplies when authorized
- Coordination of ongoing care for complications of the genetic disorder

Consequences for Quality of Care

Geographic and state-level variability is a defining feature of the US healthcare landscape and has direct implications access to quality healthcare. Differences in insurance coverage, state policies, healthcare infrastructure, specialist availability, and population distribution collectively influence access to diagnosis, treatment, monitoring, and emerging therapies.

THALASSAEMIA PATIENT IMPACT

Variations at the State level and geographic distribution of health infrastructures for thalassaemia lead to:

- *Delayed diagnosis and referral*
- *Inconsistent disease monitoring*
- *Unequal access to therapies and innovation*
- *Increased healthcare burden*

PATIENT EXPERIENCE & BARRIERS TO ACCESS

Financial Barriers

The financial burden associated with thalassaemia extends well beyond insurance premiums and includes deductibles, co-payments, prescription costs, travel expenses, lost income, and the indirect costs of lifelong healthcare utilisation. Even individuals with comprehensive insurance may experience substantial **out-of-pocket expenses for treatment** (e.g. specialist consultations, transfusion services, iron chelation therapy, advanced imaging, fertility services, or newer disease-modifying treatments). Patients and caregivers frequently incur **additional costs associated with transportation, accommodation, childcare, and time away from work or school**, particularly when specialist care is only available at distant centres.

Financial strain may **reduce adherence to recommended monitoring or treatment**, delay medical appointments, or discourage patients from seeking preventive care until complications develop.

These challenges disproportionately affect low-income households and families with limited financial resilience, contributing to inequities in long-term health outcomes.

The Cooley's Anemia Foundation provides financial assistance to support patient travel to centres of expertise for annual comprehensive care evaluations.

Administrative Barriers

Patients with thalassaemia often encounter administrative barriers including fragmented insurance systems, prior authorisation requirements, referral restrictions, changing provider networks, and variable coverage policies between insurers and states.

Delays in obtaining approval for medications, diagnostic imaging, or specialist consultations can **interrupt continuity of care** and create unnecessary stress for patients and families. Transitions between paediatric and adult services, changes in employment, relocation between states, or changes in insurance coverage may require patients to re-establish care, repeat administrative processes, and identify new specialist providers. The cumulative administrative burden can **reduce engagement with healthcare services** and disproportionately affects individuals with limited health literacy, lower socioeconomic status, or limited social support.

Structural Inequities

Many populations disproportionately affected by thalassaemia, including individuals with ancestry from the Mediterranean, Middle East, North Africa, South Asia, and Southeast Asia, also experience broader inequities related to income, education, housing, employment, and healthcare access. **Structural racism, discrimination, and historical underinvestment in underserved communities** can limit access to preventive services, specialist care, and timely diagnosis. Mistrust of healthcare institutions, shaped by historical discrimination and unequal treatment, may further **discourage engagement with healthcare services**.

Information & Health Literacy Barriers

Effective thalassaemia management requires patients and families to understand a complex treatment regimen involving regular monitoring, medications, transfusion schedules, recognition of complications, and shared decision-making regarding emerging therapies. However, health literacy varies widely across the population, and many patients report **difficulty understanding medical information, insurance documentation, treatment options, or care pathways**.

Language barriers further compound these challenges for individuals with limited English proficiency, **reducing effective communication with healthcare providers** and increasing the risk of misunderstanding treatment recommendations.

Cultural beliefs regarding inherited conditions may also **influence perceptions** of illness, treatment adherence, or willingness to discuss reproductive health and genetic counselling.

The Thalassaemia AAC White Paper, "*Thalassemia: Enhancing Patients' Disease Understanding for Improved Outcomes*," illustrates profound gaps in community **health literacy**. It identifies a critical lack of awareness regarding the long-term impacts of chronic anemia, highlights misconceptions about treatment approaches, and advocates for tailored patient education to drive better health decisions.

The authors include patients and patient advocates from Thalassaemia International Federation, Cooley's Anemia Foundation and ABRASTA.

Read it [here](#).

Geographic Barriers

Access to specialised thalassaemia care varies considerably across the US, with comprehensive haemoglobinopathy programmes concentrated in a relatively small number of academic medical centres. Patients living in **rural areas or states without specialist services** may travel several hours to access transfusion programmes, multidisciplinary clinics, or advanced diagnostic services. Frequent travel increases financial costs, disrupts employment and education, and contributes to **treatment fatigue** for patients and caregivers. Geographic barriers may also limit access to clinical trials, novel therapies, fertility services, and transition programmes for adolescents entering adult care. Telemedicine has expanded opportunities for specialist consultation and care coordination, although access remains dependent on digital connectivity and state licensing policies.

Cultural & Social Barriers

Cultural beliefs, social norms, and community perceptions significantly influence healthcare-seeking behaviour and engagement with thalassaemia care. In some communities, inherited disorders remain poorly understood and may be associated with **stigma**, concerns regarding marriage prospects, or reluctance to discuss genetic conditions openly.

Fear of discrimination or **social isolation** may discourage individuals from seeking diagnosis, disclosing their condition, or participating in support programmes. Differences in **cultural expectations** regarding family decision-making, gender roles, and trust in healthcare professionals may also influence treatment choices. Building culturally responsive healthcare services requires meaningful engagement with affected communities, respect for cultural values, and communication that **recognises diverse beliefs while promoting evidence-based care**.

Increasing the **diversity of the healthcare workforce** is equally important. Healthcare professionals who reflect the linguistic, cultural, and ethnic diversity of the populations they serve can strengthen trust, improve communication, reduce cultural misunderstandings, and contribute to more equitable healthcare delivery.

Barriers for Migrant Populations

Migrants and refugee populations may encounter additional barriers including limited English proficiency, unfamiliarity with the US healthcare system, interrupted continuity of care, lack of medical records, uncertainty regarding insurance eligibility, and concerns related to immigration status.

Cultural differences and previous experiences with healthcare systems in their countries of origin may influence expectations of care and willingness to engage with healthcare providers. Experiences of discrimination or perceived bias may further contribute to **mistrust** and **delayed healthcare utilisation**.

These challenges underscore the importance of culturally competent healthcare services supported by professional interpretation, community outreach, patient navigation programmes, and partnerships with trusted community organisations. Expanding workforce diversity, improving **cultural competence training**, and strengthening community engagement are essential to reducing communication barriers, increasing healthcare utilisation, and ensuring equitable access to high-quality thalassaemia care for migrant and underserved populations.

CONCLUSION

This Guide demonstrates that navigating the US healthcare system is a complex and continuous process for individuals living with thalassaemia. Unlike many acute conditions, thalassaemia requires lifelong, highly coordinated care involving regular transfusions, iron chelation therapy, specialist monitoring, multidisciplinary support, and ongoing interaction with multiple healthcare providers, insurers, and administrative systems. As a result, **patients must navigate not only their disease but also a healthcare system in which access to care is influenced by insurance coverage, state policies, provider networks, and healthcare literacy.**

The US possesses considerable strengths that support high-quality thalassaemia care. These include internationally recognised specialist treatment centres, advanced diagnostic and therapeutic capabilities, comprehensive newborn screening programmes, well-regulated blood services, access to disease-modifying and emerging therapies, and a strong network of clinicians, researchers, and patient organizations committed to improving outcomes. These assets provide many patients with opportunities to receive care that reflects international standards.

However, these strengths are not experienced equally by all patients. The decentralized and insurance-based nature of the US healthcare system creates considerable variation in access to specialist services and continuity of care. Geographic location, insurance type, financial circumstances, and familiarity with the healthcare system frequently determine how quickly patients receive diagnosis, whether they can access specialist expertise, and how easily they can maintain lifelong treatment. Consequently, patients with identical clinical needs may experience markedly different healthcare journeys.

Patient engagement undertaken as part of this analysis illustrates that administrative and financial barriers often become as significant as clinical ones. Understanding insurance options, obtaining referrals, navigating provider networks, securing prior authorizations, appealing coverage decisions, and coordinating appointments across multiple providers require considerable time, knowledge, and persistence. **For many families, particularly those newly diagnosed or unfamiliar with the US healthcare system, these processes represent an additional burden alongside the daily challenges of managing a chronic disease.**

The findings also demonstrate that **disparities extend beyond financing.** Limited awareness of thalassaemia among non-specialist healthcare professionals, uneven geographic distribution of specialist expertise, fragmented coordination between providers, and the absence of nationally coordinated thalassaemia services contribute to delays in diagnosis, inconsistent management, and unequal access to comprehensive multidisciplinary care. These challenges may be particularly pronounced for individuals living outside major metropolitan areas, those from migrant communities, and patients with limited health literacy or financial resources.

This Guide has been developed to support that objective by providing information that helps patients and families better understand the US healthcare system, anticipate potential barriers, and navigate their healthcare journey with greater confidence. It also highlights the **importance of continued collaboration among healthcare professionals, patient organizations, policymakers, and the wider healthcare community to better understand the evolving needs of individuals living with thalassaemia.**

Ultimately, access to optimal thalassaemia care depends on far more than the availability of effective medical treatments. It requires patients and families to understand how the healthcare system operates, recognize their insurance rights and responsibilities, identify appropriate specialist services, and coordinate care across a fragmented landscape. Improving patients' understanding of these processes is therefore an essential component of improving access, continuity of care, and long-term health outcomes.

Key Challenges and Gaps Identified

- Limited availability of disease-specific data to accurately understand the size, distribution, and healthcare needs of the US thalassaemia population.
- Lack of a nationally coordinated thalassaemia programme or comprehensive national patient registry.
- Significant variation in healthcare access between states.
- Uneven geographic distribution of specialist thalassaemia centres and multidisciplinary expertise.
- Long travel distances for many patients to access comprehensive specialist care.
- Fragmented healthcare delivery resulting from multiple payers, providers, and administrative systems.
- Insurance network restrictions that limit access to expert treatment centres.
- High out-of-pocket costs despite insurance coverage.
- Administrative barriers, including prior authorization requirements, coverage denials, and appeals processes.
- Delays in diagnosis and referral because of limited awareness of thalassaemia among non-specialist healthcare professionals.
- Fragmented coordination between primary care, specialist services, hospitals, laboratories, pharmacies, and insurers.
- Challenges maintaining continuity of care following changes in employment, insurance coverage, or state of residence.
- Difficult transition from paediatric to adult healthcare services.
- Variable access to multidisciplinary services, including genetic counselling, psychosocial support, and specialist monitoring.
- Language, cultural, and health literacy barriers affecting many migrant and underserved communities.
- Financial and practical burdens associated with frequent travel, time away from work or school, and caregiver responsibilities.

GLOSSARY

Term	Definition
ACA (Affordable Care Act)	U.S. law expanding health insurance coverage and protecting people with pre-existing conditions.
Coinsurance	The percentage of healthcare costs a patient pays after meeting the deductible.
Copayment (copay)	A fixed amount a patient pays for a covered healthcare service or medicine.
Deductible	The amount a patient pays for covered services before insurance begins paying.
Dual eligibility	Being eligible for both Medicare and Medicaid at the same time.
Employer-sponsored insurance	Health insurance provided through an employer, usually with contributions from both employer and employee.
Exchange/Marketplace	A platform where individuals can compare and purchase health insurance plans.
Formulary	A health insurer's list of medicines it covers and the conditions for coverage.
Health insurance	Coverage that helps pay for medical services, treatments and medicines.
Health Maintenance Organization (HMO)	Insurance plan generally requiring patients to use a network and obtain referrals for specialist care.
In-network provider	A healthcare provider contracted with an insurance plan, usually costing patients less.
Medicaid	Joint federal and state health coverage for eligible people with limited income and certain other groups.
Medicare	Federal health insurance primarily for people aged 65 and older and certain younger people with disabilities.
Network	Healthcare providers and facilities contracted with an insurance plan to provide covered services.
Out-of-network provider	A provider without a contract with the patient's insurance plan, often resulting in higher costs.
Out-of-pocket costs	Healthcare expenses paid directly by the patient, including deductibles, copays and coinsurance.
Out-of-pocket maximum	The yearly limit on what a patient pays for covered services under an insurance plan.

Term	Definition
Payer	An organisation that pays or reimburses healthcare providers for covered healthcare services.
Prior authorization	Insurer approval that may be required before certain treatments, medicines or services are covered.
Preferred Provider Organization (PPO)	Insurance plan allowing patients to use in-network or out-of-network providers, usually at different costs.
Premium	The amount paid regularly to maintain health insurance coverage.
Primary care provider (PCP)	A healthcare professional who provides routine care and coordinates other healthcare services.
Public insurance	Government-funded or government-administered health coverage, such as Medicare or Medicaid.
Private insurance	Health coverage provided by private insurance companies, often through employers or individual plans.
Safety-net provider	A healthcare provider serving many patients who face financial or insurance-related barriers to care.
Specialty pharmacy	A pharmacy that provides medicines requiring special handling, monitoring or support, often for complex conditions.
Value-based care	Healthcare approach linking payment to quality, outcomes and value rather than only services provided.



Thalassaemia International Federation is a non-governmental, patient driven umbrella organisation, established in 1986, supporting the rights of patients for access to quality health, social and other care through its work with over 256 national thalassaemia associations in 69 countries across the world. Founded by a small group of doctors and patients/parents who represented National Patient Associations, mainly from Cyprus,

Greece, Italy, UK, and US i.e., countries where thalassaemia had been recognized early as a genetic, hereditary disorder with huge medical, public health, social and economic repercussions if left unaddressed in terms of both effective prevention and management.

Our Mission: The prioritisation of thalassaemia on national health agendas and the development and implementation of effective disease- specific control (prevention and clinical management) programmes within national healthcare systems based on universal coverage.

Our Vision: To support the provision of equal access of every affected patient to high quality health, social and other care in a truly patient-centred healthcare setting.

Our Work: Education | Advocacy | Collaborations/ Networking | Research | Raising Awareness

Our Partners:

World Health Organisation: In official relations since 1996

United Nations Economic and Social Council: In special consultative status since 2017

Council of Europe: Participatory status at the Conference of International Non-Governmental Organisations since 2019

European Commission: Official partners in the field of Health since 2018

TIF Resources for Policy Makers

Global Thalassaemia Review. Read 2024 edition [here](#).

Cost of Illness Model. Accessible [here](#).

Certification Programme for Reference Centres. More information [here](#).

Essential Components of a Successful National Thalassaemia Programme. A toolkit for Policymakers. Read it [here](#).

Social Health Protection for People with Thalassaemia. TIF's Disability Risk Assessment Chart. Read it [here](#).

Strengthening the Resilience of EU Health Systems. Read it [here](#).

EU Policy Recommendations for Thalassaemia and Sickle Cell Disease. Read it [here](#).

Readiness Assessment Tool for Advanced Therapies. Read it [here](#).

Position Paper on Advanced Therapeutic Medicinal Products (ATMPs) (2024). Read it [here](#).