Project brief

Addressing the burden of hemoglobinopathies with a focus on thalassemia

An integrated initiative in the states of Maharashtra and Madhya Pradesh, India

1. Background

Globally, hemoglobinopathies represent a significant and growing public health challenge. Thalassemia, one of the most common inherited blood disorders, places a disproportionate burden on low- and middle-income countries. India alone contributes nearly 25 percent of the global β-thalassemia burden, with an estimated 10,000–15,000 children born annually with thalassemia major. Despite this scale, care pathways remain fragmented, and access to early screening, diagnosis, and quality treatment is limited.

High-burden states such as Maharashtra and Madhya Pradesh face the dual challenge of large, affected populations and insufficient health infrastructure to deliver consistent, quality care.

With the Government of India's National Sickle Cell Anaemia Elimination Mission (NSCAEM) and the National Health Mission (NHM) creating strong policy momentum, the political will now exists to scale integrated hemoglobinopathy interventions. PATH's thalassemia project is designed to align closely with these national and state priorities to demonstrate high-impact, sustainable outcomes.

Addressing the burden of thalassemia in Maharashtra and Madhya Pradesh

PATH, in collaboration with the state governments of Maharashtra and Madhya Pradesh, is providing technical assistance and implementation support to address the burden of hemoglobinopathies with a focused lens on thalassemia. The project employs integrated, systems-strengthening approaches spanning prevention, early detection, treatment, and long-term care.

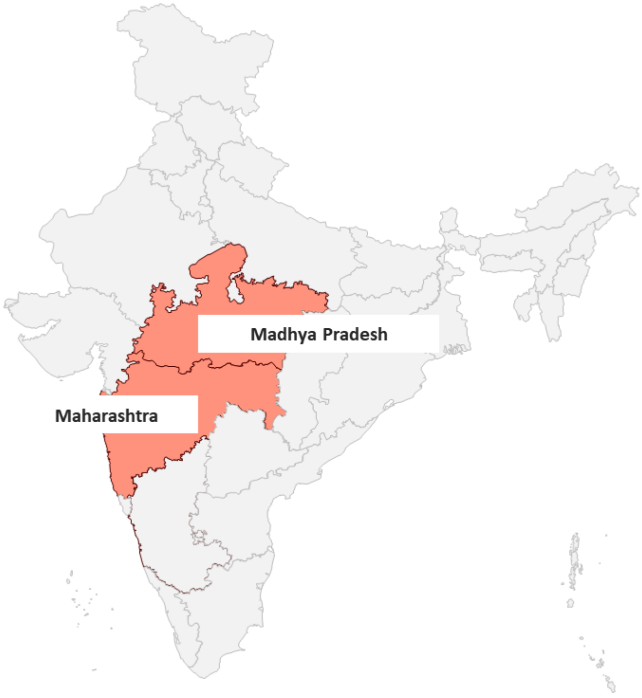

Figure 1: Map of India with Intervention States

Project implementation districts:

Nandurbar and Aurangabad in Maharashtra; and Ujjain, Ratlam, Umaria and Jabalapur in Madhya Pradesh.

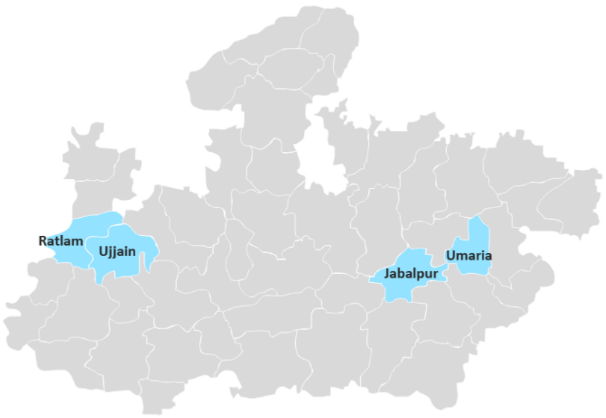

Figure 3: Map of MP with intervention districts

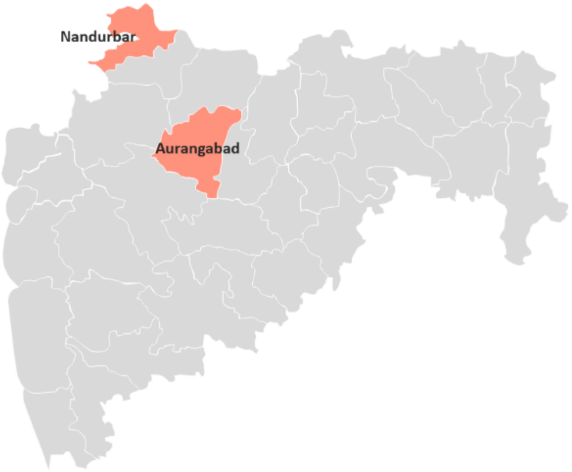

Figure 2: Map of Maharashtra with Intervention districts

2. Project goals and objectives

The primary goal is to enhance availability, accessibility, and quality of thalassemia-related services across both states. The program's four core objectives are:

Strengthening screening and prevention	**Build capacity**	**Coordinated care systems**	**Policy integration**
Scale integrated screening for pregnant women, newborns, and at-risk families in high-prevalence districts.	Equip frontline health workers with evidence-based, culturally sensitive skills for Thalassemia care.	Ensure linkage to transfusion services, iron chelation therapy, and bone marrow transplant facilities.	Aligning with national guidelines and local realities to inform evidence-based scale-up.

3. Project activities

The project provides targeted technical assistance at both state and district levels, structured around the following activity streams:

- **Screening and prevention:** Focusing on high-prevalence districts, prioritizing pregnant women, newborns, and families with known genetic risk. Intensified screening campaigns will be supported by point-of-care diagnostic pilots and community mobilization.
- **Capacity building and training:** Systematic training of frontline health workers, medical officers, and laboratory technicians to deliver timely, evidence-based, and culturally appropriate care across the continuum.

- **Coordinated care and continuum of care (CoC) models:** Establishing clear referral pathways linking primary health centres to district hospitals and specialist facilities for safe blood transfusion services, iron chelation therapy, and bone marrow transplant — ensuring no patient falls through the gaps.
- **Strengthening centres of competence (CoCs):** Enhancing the capacity of existing CoCs — initially established for Sickle Cell Disease — to serve as hubs of excellence for Thalassemia care, providing technical oversight, mentorship, and quality assurance across both states.
- **Knowledge management and IEC:** Developing guidance documents, standard operating procedures, toolkits, and information-education-communication (IEC) materials tailored to local contexts, enabling community awareness and provider readiness.
- **Supply chain strengthening:** Mapping and engaging with manufacturers of screening and diagnostic kits in India to improve supply reliability, reduce costs, and ensure uninterrupted access to essential commodities.
- **Policy integration and advocacy:** Supporting national and state-level policy alignment with global Thalassemia guidelines, using field-level learning and patient outcome data to drive evidence-informed scale-up and resource mobilization.

4. Expected impact

1.8 million+	Pregnant women, newborns, and families of affected individuals will receive integrated Thalassemia screening services during the project period across Maharashtra and Madhya Pradesh.
Improved quality of life	Enhanced capacity of healthcare providers and expanded access to evidence-based treatment - including transfusion and chelation - will improve clinical outcomes for all individuals diagnosed with Thalassemia.
Sustainable Systems	By embedding the intervention within national missions and leveraging private sector collaboration, the initiative will unlock government resources, mobilize additional investment, and institutionalize capacity for long-term sustainability.