

# National Sickle Cell Anaemia Elimination Mission

# India's Response to a Silent Genetic Crisis

June 30, 2025

"Sickle Cell Disease significantly impacts the tribal sections of our society. The government is committed to eliminate the disease before India celebrates its Amrit Kaal in 2047."

- Prime Minister Shri Narendra Modi

## **Key Takeaways**

- India launched the National Sickle Cell Anaemia Elimination Mission in 2023 to eliminate Sickle Cell Disease (SCD) by 2047, focusing on tribal and high-prevalence regions.
- Over 5.86 crore people have been screened, with 5.63 crore+ negative cases and more than 2.5 crore Sickle Cell Status Cards distributed.
- The Mission integrates screening, counselling, treatment, and digital tracking through ABHA-linked health cards and grassroots healthcare services.
- Free drugs, diagnostics, and monthly outreach camps ensure better access to care in rural and tribal areas.
- CSIR is leading scientific research with affordable molecular tests, CRISPR-based gene therapy, and preparations for clinical trials.

## Introduction

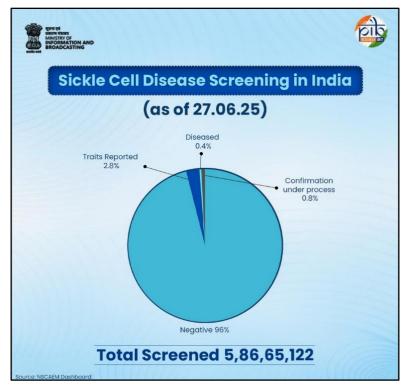
Sickle Cell Disease (SCD) is a genetic blood disorder where red blood cells become hard, sticky, and shaped like a sickle (crescent). These cells block blood flow, causing pain, weakness, and damage to organs. It is inherited from parents and can only be detected through a blood test. SCD leads to anaemia because the abnormal, sickle-shaped red blood cells are fragile and have a shorter lifespan than normal red blood cells. This means they break down faster than the body can replace them, resulting in a lower-than-normal number of red blood cells, which is anaemia.

With the aim to address the significant health challenges SCD poses, particularly among India's tribal population, the **National Sickle Cell Anaemia Elimination Mission** was introduced in the **Union Budget 2023**. This initiative was officially launched by Prime Minister Shri Narendra Modi on **July 1, 2023**, with the vision to eliminate sickle cell disease as a public health problem in India before 2047.

As per the latest report by the World Health Organisation (WHO), globally 7.74 million people are affected by SCD. Between 2000 and 2021, the global number of people living with SCD increased by 41.4%.

As of June 27, 2025, there are 2.11 lakh active patients with SCD traits in India.

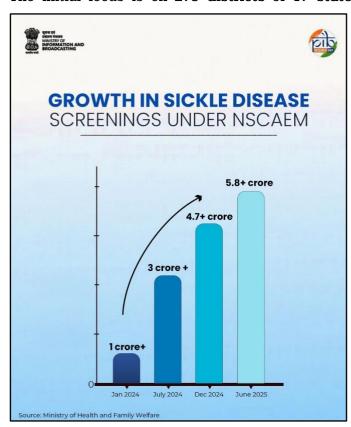
- More than 5.86 crore people have been screened so far.
- In these, more than 5.63 crore patients have successfully been screened SCD free.
- 16.46 lakh patients have been diagnosed with traces of the traits of SCD.
- **4.59 lakh** people are still awaiting the confirmation of their results.



# National Sickle Cell Anaemia Elimination Mission (NSCAEM)

The NSCAEM is implemented as a part of the National Health Mission and focuses on universal population-based screening, prevention, and management of SCD in all tribal and other highly prevalent areas of India. In its initial stage, the mission prioritizes intervention in the high-prevalence states, and the plan gradually expands to include all states/UTs in a phase-wise manner with an incremental approach.

The initial focus is on 278 districts of 17 states with higher prevalence of SCD, namely Gujarat,



Maharashtra, Rajasthan, Madhya Pradesh, Jharkhand, Chhattisgarh, West Bengal, Odisha, Tamil Nadu, Telangana, Andhra Pradesh, Karnataka, Assam, Uttar Pradesh, Kerala, Bihar, and Uttarakhand.

The National Health Mission (NHM), with its two sub-missions — National Rural Health Mission (NRHM) and National Urban Health Mission (NUHM)—is the flagship programme of the Ministry of Health and Family Welfare. It aims to provide universal access to affordable, equitable, and quality healthcare, supporting States/UTs in strengthening public health systems. The integration of the NSCAEM with NHM ensures the utilization of existing resources and minimizes duplication of efforts. For example, the established platforms of Rashtriya Bal Swasthya Karyakram (RBSK), Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA), and Anaemia Mukt Bharat are leveraged to achieve the targets of the Sickle Cell mission.

# Objectives of the NSCAEM

The objectives of the Mission are:

- Provision of affordable, accessible and quality care to all SCD patients;
- Reduction in the prevalence of SCD through awareness campaigns;
- Targeted screening of 7 crore people till FY 2025-26 in the age group of 0-40 years in affected districts of tribal areas; and
- Counselling through collaborative efforts of central ministries and state governments.

# Strategic Pillars of NSCAEM

The Mission is structured around three core strategies:

#### A. Primary Prevention

- Awareness generation through ASHAs, schools, communities.
- Pre-marital and pre-conceptional **counselling**.
- Sickle Cell Status Cards issued post-screening with a color-coded system to guide marriage and reproduction decisions.

#### **B. Secondary Prevention**

- Universal Screening of all individuals up to 40 years in a phased manner.
- Use of solubility tests, Point-of-Care (POC) tests, and HPLC/electrophoresis for confirmation.
- Target groups: newborns, children, adolescents, pregnant women, and extended family members of diagnosed individuals.
- Cascade screening and antenatal screening integrated with schemes like RBSK, PMSMA.

#### C. Holistic Management & Continuum of Care

- Treatment initiation at Primary Health Centre, Urban Primary Health Centre, and Sub-Health Centre levels with Hydroxyurea and folic acid.
- Referral system for severe complications.
- Telemedicine support via e-Sanjeevani.
- Integration with **AYUSH** for Yoga-based interventions.
- Rehabilitative care under Rights of Persons with Disabilities Act, 2016 (includes disability certification, educational and job reservation, etc.).
- Patient Support System with family tracking, ASHA follow-up, SMS reminders, community adoption, and socio-economic linkages.

This Ministry provides **technical** and **financial support** to the States/UTs for **conducting screenings** and **procurement of drugs** for sickle cell anaemia, based on the proposals received in the form of Programme Implementation Plans (PIPs) under National Health Mission (NHM).

#### Sickle Cell Status Cards

Under the NSCAEM, every individual screened for SCD is issued a Sickle Cell Status Card. This card indicates the person's status as either Normal, Carrier (Sickle Cell Trait), or Diseased (Sickle Cell Disease) and is a key tool in prevention, treatment, and counselling.

These cards are gender-coded — blue for males and pink for females — and are integrated with the individual's Ayushman Bharat Health Account (ABHA) ID for health tracking. The reverse side of the card provides a simple visual matching guide that helps in pre-marital and pre-conceptional counselling by predicting the likelihood of children being born with SCD or the trait based on the parents' status. This matching process supports informed reproductive decisions and helps prevent the transmission of the

disease, especially in high-prevalence tribal areas.

The cards are used during medical referrals, follow-ups, and are part of the broader system of integrated care and support under the mission. **More than 2.5 crore** Sickle Cell Status Cards have been distributed by **June 19, 2025**.

# Government Initiatives for Treating Sickle Cell Disease (SCD)

India is advancing a multi-pronged, technology-driven strategy to eliminate Sickle Cell Disease (SCD), which is prevalent among both tribal and non-tribal populations. Key initiatives include:

#### 1. Strengthening Access to Drugs and Diagnostics

- Hydroxyurea, a key drug used to manage SCD, has been included in the Essential Drug List under the National Health Mission (NHM) and is made available free of cost at all levels of public healthcare.
- The Free Drugs Service Initiative aims to reduce patients' out-of-pocket expenditure by ensuring that essential medicines are available in public health facilities.
- The Free Diagnostics Service Initiative provides free tests depending on the level of the health facility, ensuring accessibility to crucial blood and pathology tests for SCD patients.

#### 2. Outreach and Camp-Based Screening

- The Ministry has directed all states and union territories to conduct monthly Ayushman Arogya Shivirs—fixed-day outreach health camps—to bring diagnostic and treatment services to rural and tribal populations.
- Screening and awareness drives are organized in villages, schools, and hostels in collaboration with state governments.

#### 3. Preventive and Supportive Care at Grassroots Level

Under NSCAEM, services are being provided through Ayushman Arogya Mandirs (Sub Health Centres and Primary Health Centres) to enhance the quality of life of SCD patients. These include:

- Regular clinical follow-up
- Lifestyle and genetic counseling, especially regarding pre-marriage and prenatal decisions
- Nutritional supplementation through folic acid tablets
- Yoga and wellness sessions to promote holistic health
- Referral services for managing pain crises and complications

#### 4. Information, Education and Communication (IEC)

- Awareness and counseling materials have been developed by the Ministry of Tribal Affairs, and media-based IEC campaigns are deployed to educate communities about SCD, its symptoms, and preventive measures.
- Each screening camp includes an **awareness component**, and state governments are key implementers of these outreach activities.

In addition, the Indian Council of Medical Research (ICMR) has spent ₹4317.6 lakh since 2020 on SCD-related research initiatives.

# CSIR's Efforts in Treating Sickle Cell Disease

The Council of Scientific and Industrial Research (CSIR) has taken a leading role in India's research-based efforts to treat SCD. Through its dedicated Sickle Cell Anaemia Mission, CSIR is driving innovation in diagnostics, gene therapy, and clinical readiness to complement the public health approach under NSCAEM.

#### 1. Advanced Molecular Diagnostics

- CSIR has developed a cost-effective and high-accuracy molecular diagnostic test using Whole Blood/Dried Blood Spot-Polymerase Chain Reaction (WB/DBS-PCR).
- This test is:
  - o **Affordable** (approximately ₹100 per test)
  - Highly accurate, with 99.4% sensitivity and 100% specificity
  - o Validated by the ICMR

#### 2. Gene Editing and Therapy

CSIR has been developing a CRISPR-Cas9-based gene editing platform specifically targeted at correcting the genetic mutation responsible for SCD. The CRISPR-Cas9 technology is now patented internationally, including in the United States, and has potential applications for other haemoglobinopathies as well.

#### 3. Financial Investment in Research

CSIR has steadily allocated significant funds for SCD research under its mission mode project:

Financial Year	Funds Allocated (₹ in lakh)
2020–21	1258.01
2021–22	1110.90
2022–23	970.89
2023–24	700.00
2024–25	513.93

# Conclusion: The Road Ahead

"Sabka Saath, Sabka Prayaas can stop the spread of Sickle Cell Disease."

- Dr Mansukh Mandaviya, Union Minister for Health and Family Welfare

India's battle against SCD is a crucial public health mission that combines early diagnosis, grassroots outreach, advanced scientific research, and inter-ministerial coordination. With strong policy backing, innovative interventions like Sickle Cell Cards, integration of digital health infrastructure, and pioneering gene therapy research by CSIR, the country is poised to significantly reduce the burden of SCD, especially in tribal regions. The collective efforts under the NSCAEM represent not only a major step toward genetic disease elimination but also a powerful model of equitable and inclusive healthcare reform aligned with the vision of Amrit Kaal.

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