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स्वास्थ्य एवं
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# Advancing effective care and management of Sickle Cell Disease in India


**Presented By**

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INDIAN COUNCIL OF MEDICAL RESEARCH | NATIONAL INSTITUTE OF RESEARCH IN TRIBAL HEALTH | NATIONAL INSTITUTE OF IMMUNOHAEMATOLOGY

# Agenda

Sickle Cell Disease burden in India

Challenges in Current Model

Introducing new strategies

# Sickle Cell Prevalence in India

**Sickle Cell Belt States**

Andhra Pradesh

Chhattisgarh

Gujarat

Karnataka

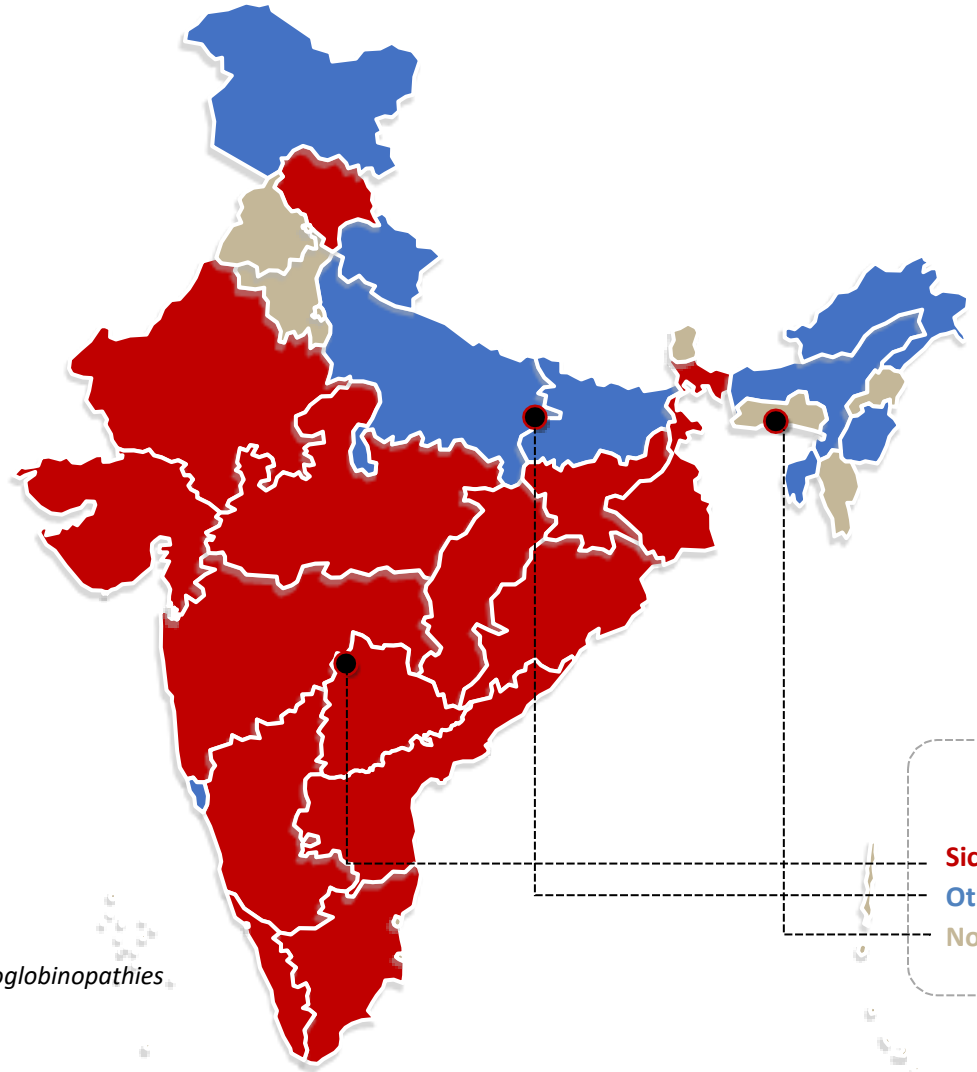
Kerala

Maharashtra

Madhya Pradesh

Telangana

Tamil Nadu




**Other Affected States**

Arunachal Pradesh

Assam

Bihar

Goa

Jammu & Kashmir

Ladakh

Manipur

Tripura

Uttarakhand

Uttar Pradesh

*Source: NHM Guidelines on Hemoglobinopathies in India, MoHFW 2016*

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**Out of the 110 million persons screened in different States, about 8.75% (996,368) tested positive**

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# Sickle Cell in India?

**Sickle Cell is particularly prevalent in scheduled tribe (ST) populations, who**

- Are the most socioeconomically disadvantaged and marginalized communities
- Located in difficult to reach rural areas
- Lack access to good education
- Mostly dependent on government for healthcare or on tribal local healers

**Tribal population in India is estimated at about 120 million people (~8.6%)**

**The Challenge**

Difficult to reach

Difficult to diagnose/treat

Difficult to counsel

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# Socio-economic impact of Sickle Cell Anemia

**In children,**

- 20% children born with SCD die before 2 years of age, as reported by ICMR and children with 30% with SCD die before reaching adulthood*
- Children with sickle cell are at risk of frequent infections. As they age, they experience delayed growth and other development problems related to vision

**In adults,**

- The average life expectancy in India < 48 years
- Patients with sickle cell disease are constantly fatigued and experience painful swelling of hands and feet.
- The major clinical manifestation among people with SCD is vaso-occlusive pain crises

**Apart from the health complications faced by people living with sickle cell disease, there is stigma associated with the disease. People with sickle cell face:**

- Racial discrimination
- Community fear/mistrust
- Inability to manage disease due to incomplete knowledge
- Occupational implications

Sources: Indian J Med Res. 2015 May; 141(5): 509–515. Sickle cell disease in tribal populations in India; Indian J Med Res. 2013 Sep; 138(3): 288–290.Morbidity pattern of sickle cell disease in India: A single centre perspective

# Identified Gaps and Challenges in Sickle Cell Prevention, Treatment and

## Awareness

- Poor understanding of the disease and large population is unaware of its cause and the need to attend screening
- Many tribals have common beliefs, traditional customs, myths, practices related to health and disease, there is need of dedicated efforts to make tribal population aware about transmission and control

## Early Screening & challenges in current diagonostics

- 1st level in Pregnant Women in 1st trimester of pregnancy: Due to lack of testing facilities at the PHC and CHC level, the early detection of Sickle Cell is frequently missed.
- 2nd level of screening is required in new-born and at school level, where the tribal children in endemic areas should be screened to find out whether they have sickle cell trait.
- Currently available test either are not accurate and those available are too expensive

## Access to Healthcare and Specialty Care

- Gaps in availability of diagnostic and treatment at PHCs and CHCs in tribal areas. Without diagnosis and comprehensive care, children suffer crippling medical problem leading to lack of education, employment opportunities and integration into the society.

## Database of Sickle Cell Patients and Carriers

- The State Governments, NGOs, Ministry of Tribal Affairs- Health have undertaken various screening programs in different pockets across country. However, there is no state level or central repository of such data.
- urgent need of create mechanism so that after screening, the data of a SCD or carrier can go to a Central Data base and can be used for the data-based planning and monitoring at district, state and national level.

## Training of Paramedical and Medical Staff

- Primary care physicians are often unable to manage a pain crisis or the typical needs of a sickle cell patient.
- When they refer patients to a district hospital, due to lack of haematologist, and a general physician instead manages the case. There is need of training of paramedical and medical staff so that they can diagnose, treat, monitor and manage the complications of Sickle Cell Disease.

## Clinical Treatment

- At present the advanced diagnostic facilities are critical even at tertiary care being cost intensive and require specialised like Chorionic Villus Sampling (CVS) during Ist Trimester of Pregnancy

# A focused approach to Sickle Cell Disease at Ministry of Tribal affairs

Ministry of Tribal Affairs (MoTA) was set up in 1999,

It is the Nodal Ministry for overall policy, planning and coordination of programmes of development for Scheduled Tribes - the most underprivileged of the Indian Society

Abhay Bhang Committee, an expert committee, in their report in 2018 on Tribal Health, has listed Sickle Cell Disease as one of the 10 special problems in tribal heath.

The Committee has suggested constitution of National Tribal Health Council, Tribal Health Cell and National Tribal Health Roadmap for dealing with tribal health issues.

MoTA under their STC component works with the MoHFW, ICMR , DST in a coordinated manner to provide maximum awareness and quality healthcare through decentralized health care delivery system

MoTA has chalked out a detailed action plan to ensure that there are no new born with sickle cell disease by 2030

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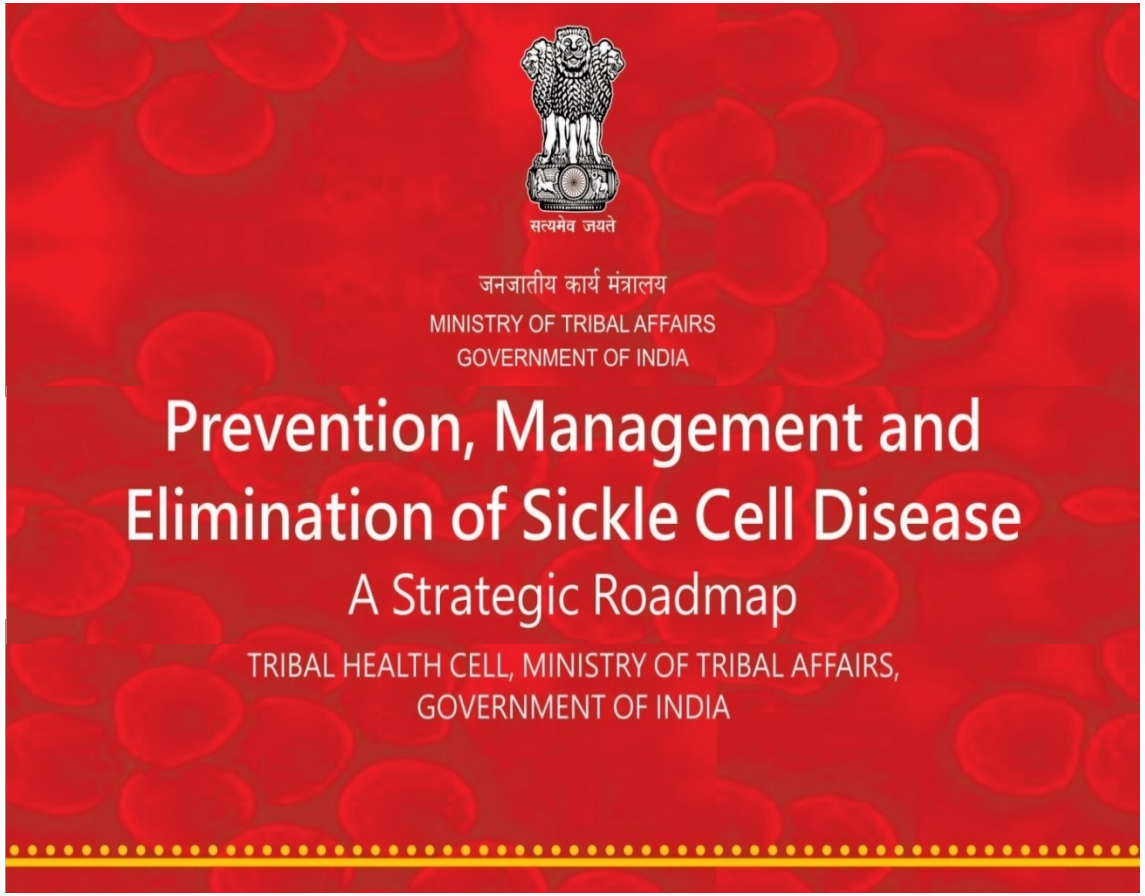
# Developed a Specific Roadmap for Sickle Cell Prevention and Management

- Awareness
- Diagnosis (targeted population screening) along with confirmatory test , data base
- Training and its modules relevant to different categories
- Work allocation of different Government departments and funding's
- Research
- Innovation
- E- Registry



# Prioritizing SCD through Targeted Interventions through Collaborative efforts of MoTA DGHS & MoHFW & others line Ministries

**Requirement**

- Awareness Program in school , colleges under adolescent Health and through school education programme , Regular IEC activities
- **Enhance knowledge building and skills of targeted audience** at each level through training
- Appropriate Guidelines, Algorithm based screenings and SOPs in place for different level of healthcare like house hold , camps , PHC/CHC district and tertiary care for referral
- Ensure availability of diagnostic facilities at each level consisting of Rapid testing (POC), at district level electrophoresis & HPLC at Tertiary care
- Strengthen diagnosis with the help of self help groups voluntary organizations, NGOs, and if possible ASHA & aganwadis
- Management of the disease at each level (District hospitals) including sickle cell competency centers at each AIIMs and Tertiary care
- **Providing** prophylaxis **Treatment of** hydroxurea , penicillin , blood transfusion, MRI , pneumococcal vaccination and other vaccination like HIB at District level and below **and at tertiary care** Prenatal diagnosis services Advance newer therapies, BMT Units at sickle cell competency centers at each AIIMs and Tertiary care
- Strengthened **Data Management System for effective Monitoring**


**Action**

- **Enhance 3 As- Availability, Accessibility and Affordability** for delivery of quality services and benefits
- **Extend Support** for innovative outreach model to connect secondary & primary care centers
- **Promote Research** on newer therapies, drugs like- and innovations for treatment & management
- **Accelerate partnership** and engagement of government agencies, private sector, pharmaceutical, research agencies, development agencies, not-for-profit organizations

**Support required**

- Collaborative efforts :
- MoTA for screening and supporting diagnostic facilities at each level specially in High prevalence areas Training and establishing sickle cell competency centers at Tertiary care
- Ministry of Health & Family Welfare for establishing treatment center at district level along with the required and essential medicines vaccination and other required treatment like surgeries of spleen and others
- Women and Child development for Awareness and Nutrition
- MoI & BC- for IEC activities
- MoE-for including chapter in class 10 and for regular awareness about the prevention
- DST for research work
- Partnerships and Collaboration

THE IMPACT

**Impact**

- Reduce SCD births , related mortality, morbidity

# 1. Enhance Awareness, Screening & Counselling

**Awareness** through school education while adding chapters in school curriculum, IEC activities through mass media mid media and social media, Awareness among pregnant woman and their spouse

**Screening of 30 million tribal, including pregnant women/year over the next 3 years, along with CSV Testing**

A. During pregnancy

- Inclusion of Testing of Sickle Cell as compulsory test during first Trimester
- Providing Kit for diagnosis of Sickle Cell using Point of Care (POC) tests
- Establishing sickle cell competency centres at tertiary care having facilities for prenatal diagnosis including
- Counselling and Medical Termination of Pregnancy

B. New Born screening

- New born to be screened in high prevalence areas at District early investigation centres (DEIC)

C. School and adolescent screening :

- Screening of population below 25 years of age and maintaining data base of sickle cell carriers and patients

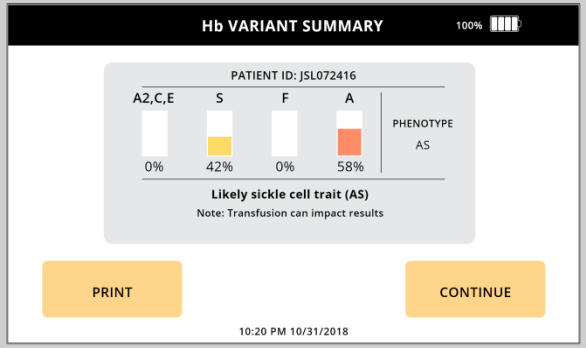
# Making accurate testing affordable and local for millions of people

## *Point of Care Tests for Sickle Cell and Thalassemia in India*

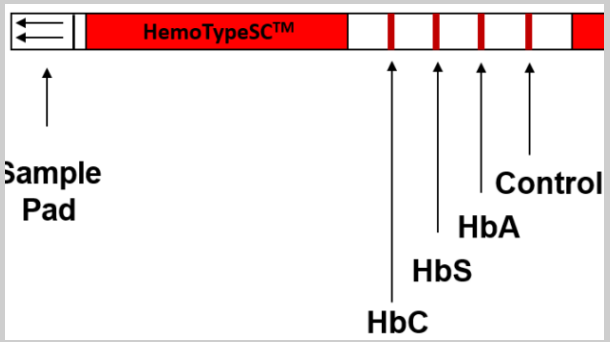
gazelle™

Sickle SCAN®

HemoTypeSC™








**Microchip Electrophoresis**

**Lateral flow immunoassay**

**Lateral flow immunoassay**

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| Feature | Gazelle | Sickle SCAN | Hemotype SC |
|---|---|---|---|
| Hb Identified | A, S, F, A2/C/E | A, S, C | A, S, C |
| Trait vs. Disease | Yes | Yes | Yes |
| Beta Thalassemia Detection | Yes | No | No |
| # Diagnostic Results | 19 | 5 | 5 |
| Sens/Spec | High | High | High |
| Newborns | Yes | Yes | Yes |
| Digital Documentation | Yes | Yes | Yes |
| Time to Result | 6-8 minutes | 5 minutes | prep time +5- 10 minutes |

# 2. Training, Advance Treatment and Rehabilitation

| |
|---|
| Preparation of Technical Training Modules |
| Designation of Nodal Institutes for training and referral mechanism (AIIMS, NIRTH and NIIH) |
| Initiation of Training of Medical and Paramedical Staff, health workers and others |
| ICHH centres at District level for Treatment including the blood bank facilities with advance technologies like ABD pad and molecular testing at the blood bank level |
| Referral mechanism @ Tertiary care( SCCC) having prenatal diagnostic services and the facilities for HSCT |
| Tele Medicine Facility |
| Inclusion in Disability act 2016 , teaching them skills to be self sustainable |

# 3. Research and Innovation

Funding for advance research (Research on gene editing) Multiple diseases- one platform for genetic correction

**CSIR IGIB, New Delhi**

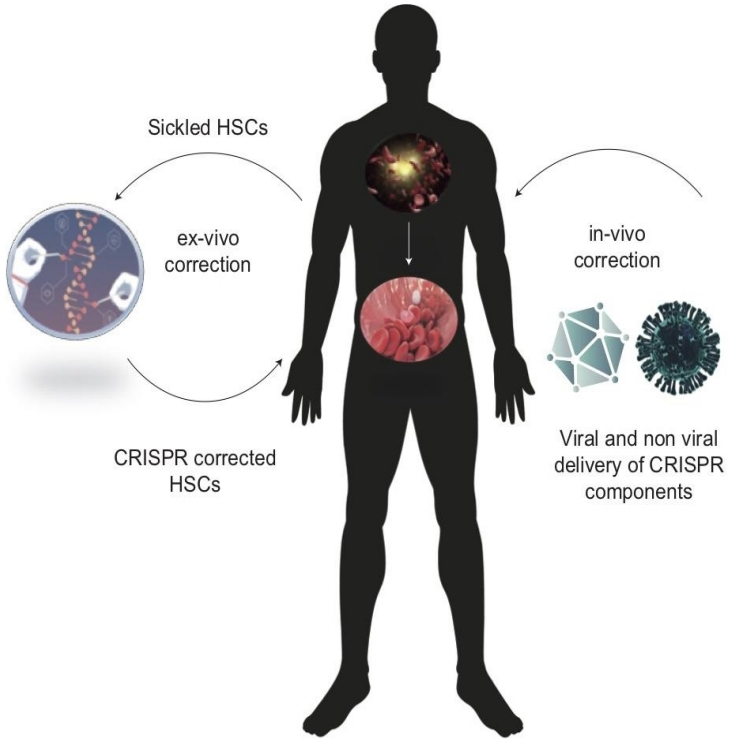
Indigenous '**Make in India**' CRISPR products

Clinical trial pipeline with AIIMS, New Delhi and other eminent clinical research institutes of India

Research in Yoga based Therapies

Introducing innovative technologies

Data generation and maintain the E- registry through mobile applications



# 4. E-Registry

### IMPACT ORIENTED

Counseling and clinical evaluation are an integral part of the testing and screening process

### ONE STOP SOLUTION

All data (patient, counselling, clinical) in a single repository, eliminating physical registers

### ON-THE-GO TRAINING

App trains health workers on the job, step by step instructions provided within the app

### OFFLINE SUPPORT

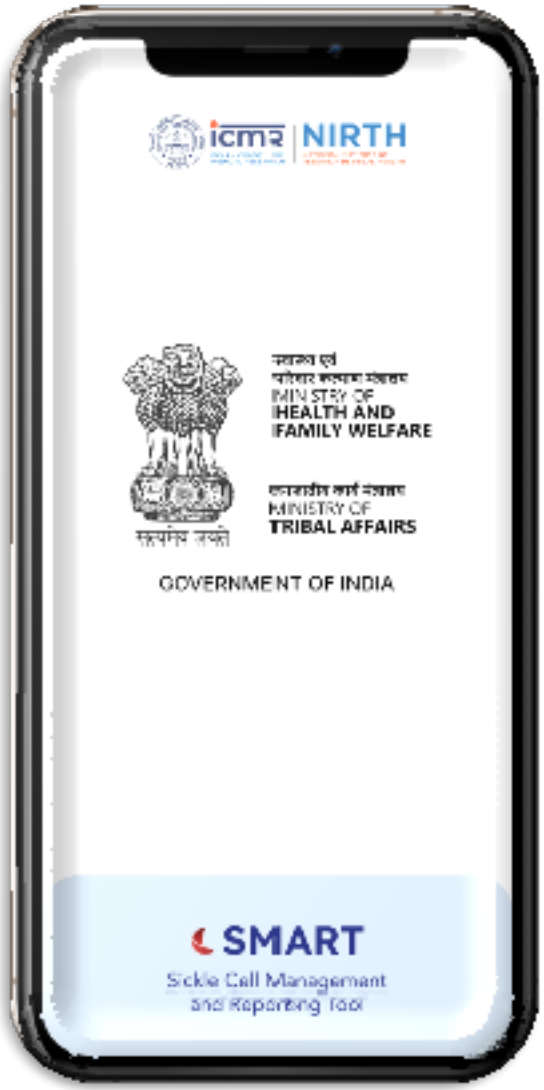
The app can work and store data offline and can sync with server later

### REALTIME CLOUD

Cloud connected real-time tracking and reporting of tests, accessible from anywhere

### MULTI-LINGUAL

The app is available in many regional languages



# Impacts

The ultimate objective is to create access to treatment and improve patients' lives in addition to

- **Reducing mortality**: Numerous studies have shown that child mortality can be reduced if early diagnosis is done and simple prophylaxis treatment is given
- **Preventing further spread of disease**: Sickle Cell Disease is a preventable disease if early diagnosis is done with good genetic counselling
- No new Born with sickle cell disease

# Thank you

The woods are lovely, dark and deep, But I have promises to keep,
and miles to go before I sleep, and miles to go before I sleep.

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