सत्यमेव जयते

Ministry of Health & Family Welfare
Government of India

National Sickle Cell Anaemia Elimination Mission 2023

Training Module for Community Health Officers







June 2023

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CHAPTER 1
INTRODUCTION TO SICKLE CELL DISEASE

Sickle Cell Disease (SCD) is a genetic disorder that requires lifelong management and contributes to infant, childhood as well as adult morbidity and mortality. It is widespread in many ethical groups in India and more common in tribal populations. About 1 in 86 births among the tribal population have SCD; the prevalence is higher in central, western, and southern India. However, now SCD is found across all ethnicities and communities.

Hemoglobin is a protein-based molecule found in the RBC that carries oxygen in our body and gives blood its red color. The person with SCD has a different kind of hemoglobin, which leads to a change in the shape of RBCs. The normal RBCs are bi-concave and smooth, with an average life span of around 120 days. Sickle cell RBCs are sticky and rigid, which causes trouble moving through the small blood vessels. These cells clog up the blood vessels, thus preventing the oxygen supply to tissues, thus causing pain and damage to those areas. The average life span of sickle cell RBCs is only 10-12 days.

1.1 Types of Sickle Cell Disease

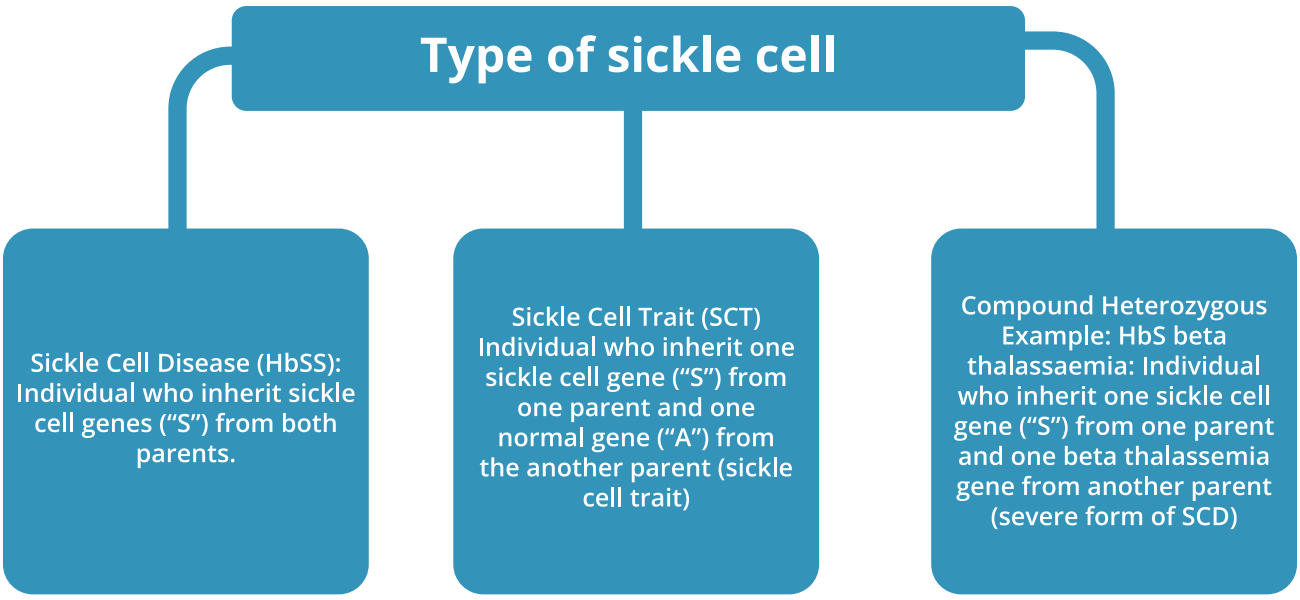
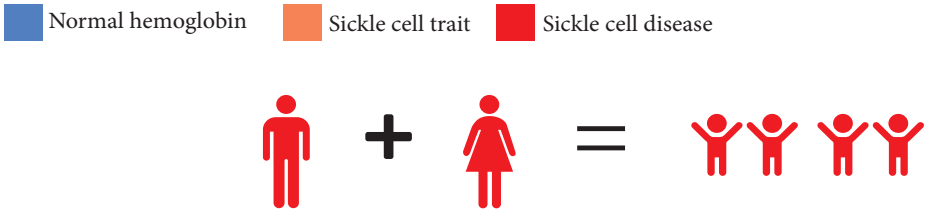


Figure 1: Most common types of sickle cell

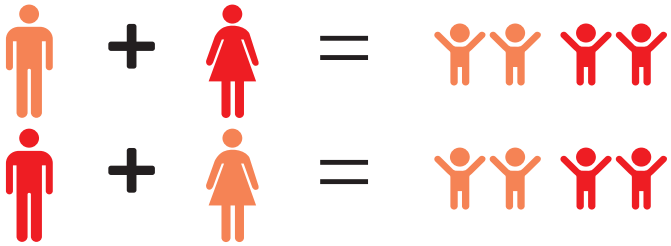
1.2 Inheritance of Sickle cell disease

As a Community Health Officer, your responsibility is to counsel the diseased and carrier or trait individual appropriately to control the transmission of the genes to the

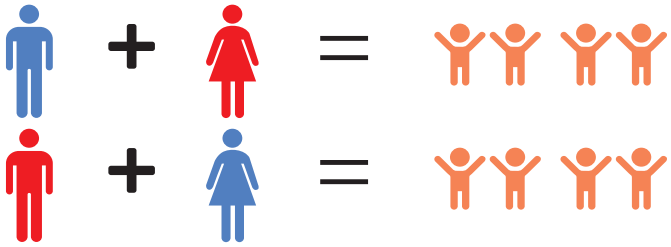
next generation. A pictorial depiction of different combinations of parent's disease status and the probability of the children getting affected is as below:



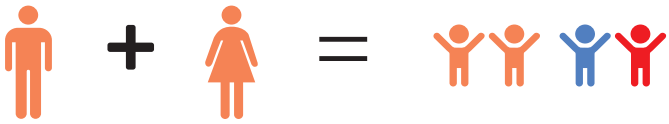
If both parents have sickle cell disease, there is a 100% chance that their children will be born with the disease



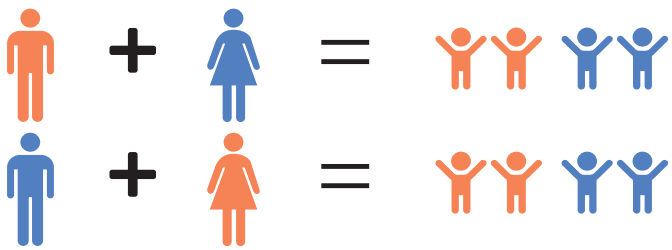
If one parent has sickle cell trait and the other has sickle cell disease, then children have a 50% chance of being diseased and 50% of being carriers



If one parent is normal and the other has sickle cell disease, then children have a 100% chance of being carriers

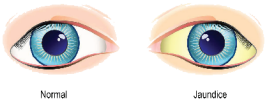
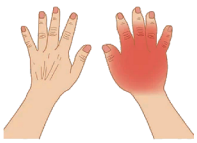
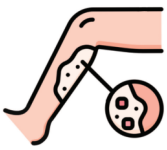


If both parents have sickle cell trait, their children have a 25% chance of being diseased, a 25% chance of being normal, and a 50% chance of being carriers



If one parent has sickle cell trait and the other is normal, then children have a 50% chance of being normal and 50% chance of being carriers

1.3 What are the signs, symptoms and complications?

Signs and symptoms	
General complain of weakness and fatigue	
Periodic episodes of pain in the joints, abdomen, and chest (Vaso-occlusive crisis)	
Pale skin and nails	
Yellow discoloration of skin and eyes (Jaundice)	
Fever and Frequent infections	
Swelling of hands and feet	
Breathlessness	
Leg ulcer	
Delayed growth or puberty	
Priapism	

Other Complications

Acute chest syndrome
Sequestration crisis
Aplastic crisis
Strokes and transient ischemic attacks
Pigmented gallstones
Osteoporosis
Bone infarction
Renal impairment
Hepatotoxicity
Seizure disorder
Diastolic dysfunction

1.4 Social and economic implications of Sickle Cell Disease (SCD)

Due to the severe complications of the disease and the need for routine and lifelong care, SCD has a significant effect on social and economic conditions. SCD causes two types of financial implications, direct and indirect costs.

Direct costs are those that are met by the healthcare system; for sickle cell disease, these include the cost of screening, primary and emergency care visits, cost of drugs, hospitalizations, blood transfusions, bone marrow transplants, and other out-of-pocket expenditures borne by the patient.

Indirect costs are those met by families and wider society. This includes loss of wages because of parents' missing work days to look after their children and students missing school due to pain crises and other SCD-related complications.

Future loss to the economy in terms of the workforce is also a concern due to early deaths of those with SCD if not identified on time and treated adequately.

CHAPTER 2
OVERVIEW OF THE NATIONAL PROGRAM FOR PREVENTION AND MANAGEMENT OF SICKLE CELL DISEASE

The government of India, in the Union Budget 2023-24, announced a mission to work towards the elimination of sickle cell disease by 2047.

2.1 Goal

Eliminate sickle cell disease as a public health problem in India before 2047

2.2 Objectives

1. To reduce the prevalence of SCD
2. Provide affordable, accessible, and quality care to all SCD patients

These objectives would be attained through strategy planning, awareness generation, strengthening of screening and testing facilities, making antenatal screening available at all levels, strengthening of laboratory services for diagnosis, facilitation of management & treatment, establishing linkages across levels of care, inter-sectoral convergence towards holistic approach and linkages with social security schemes/benefits packages.

2.3 Strategic Pillars

The three strategic pillars for SCD are:

I. Primary prevention strategies:

- Primary prevention strategies focus on awareness generation and pre-marital and pre-conceptional counselling to prevent the conception of a child with homozygous genotype.
- Prevention requires setting up genetic counselling and testing interventions in high prevalence districts to prevent sickle cell disease in the offspring. Genetic counselling and health promotion activities can lead to substantial reduction in the number of children born with the disease.
- Widespread community involvement and support are essential as there are existing diversity of cultures and opinions about a number of issues relevant to genetics, such as human reproduction issues.

II. Secondary Prevention and Screening:

Secondary prevention focuses on the following components related to early diagnosis and care of sickle cell disease.

- Screening for detection of Sickle Cell Trait to reduce the birth of children affected with Sickle Cell Disease and screening for early detection of sickle cell disease to achieve a reduction in mortality and morbidity with improvement in quality of life of the affected.

III. Holistic management and continuum of care

- Management of persons with sickle cell disease at primary, secondary, and tertiary health care levels
- Advanced diagnostic and treatment modalities at tertiary health care facilities
- Integration with AYUSH
- Patient support system
- Community Adoption
- Rehabilitation

2.4 Scope for Sickle Cell Elimination Program

The sickle cell elimination program is a part of the National Health Mission. It focuses on universal population-based screening, prevention, and management of sickle cell disease in high prevalence states of India.

The program is rolled out in a mission mode covering the entire population from zero to eighteen years of age in the first year and shall incrementally include the entire population up to forty years.

The programme would be integrated with existing mechanisms and strategies under NHM to ensure utilization of existing resources and also minimize the duplication of efforts, for example, an established platform of RBSK, Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA) and Anemia Mukt Bharat to be leveraged to achieve the targets for the Sickle Cell mission. The mission will also be further linked to the other national program for the Prevention and control of hemoglobinopathies in India.

2.5 Role of Primary Health Care Team in SCD Prevention

The primary health care team, including Community Health Officer (CHO), Auxiliary Nurse and Midwife (ANM), Accredited Social Health Activist (ASHA), Medical Officers (MO), and Staff Nurses (SN) in Ayushmann Bharat Health and Wellness Centre (AB-HWC) is associated with all aspects of SCD prevention, control, counselling, and management such as:

- Organizing community awareness events on SCD on a regular basis

- Screening people in remote tribal hamlets and family/ extended family members of those with diagnosed SCD through mobile medical units or through dedicated teams
- Conducting facility-based screening
- Conducting opportunistic screening for people attending outpatient services at the Health and Wellness Centre.
- Providing counselling services
- Referral to nearest secondary care facility (CHC/DH)

CHAPTER 3
SCREENING AND COUNSELLING FOR PREVENTION

The aim of screening is early detection of sickle cell disease and traits to reduce morbidity, mortality, and disability and to provide appropriate counselling to prevent the transmission of the disease to the off-springs.

3.1 Tools for screening and diagnosis

Screening test: Test tube-based turbidity test or solubility test for identification of HbS will be used at the SHC-HWC and mass screening camps.

For screening of SCD and SCT, the following tests are available at the SHC-HWC level. However, the availability of the tests depends on the state. The state may adopt either of the approaches for determining the status of SCD. You should screen individuals, and based on the outcome, you should provide counselling and treatment to the SCD and SCT individuals.

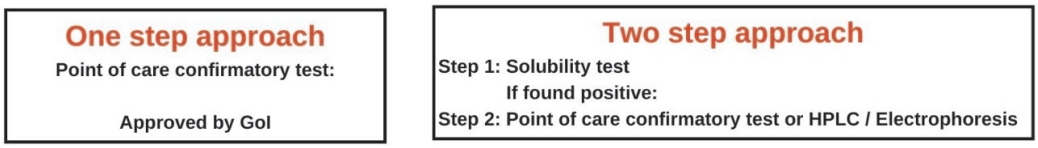


Figure 4: Approaches for screening

Confirmatory tests:

- Point of care test is a one-step confirmatory test validated by the Government of India.

3.2 Target groups

To attain a sickle cell free nation, the significant intervention is screening and early diagnosis of cases and traits. In order to cover every possible person, you should divide the population residing within your catchment area into different target groups, having a different approach for every group.

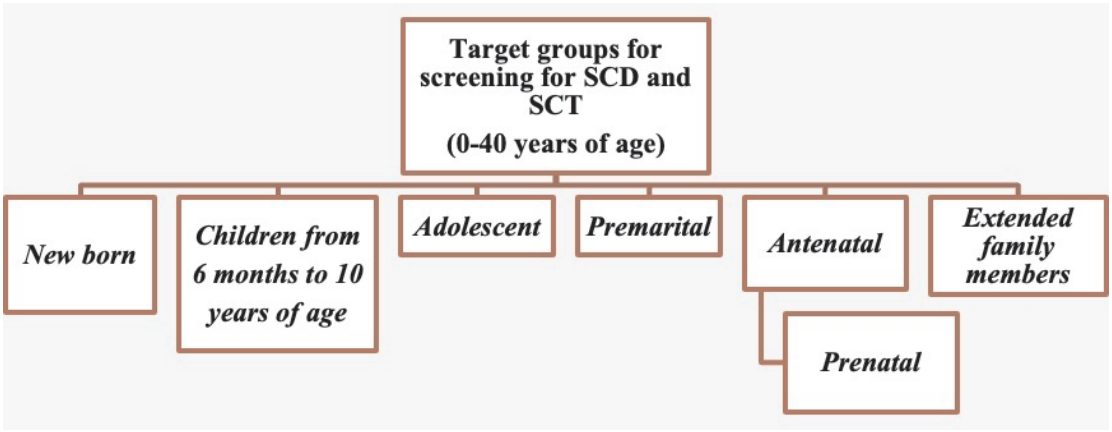


Figure 5: Target groups for screening

In high-priority areas, a mapping exercise shall be conducted to identify and grade blocks per the prevalence. Grading of blocks may be done as below:

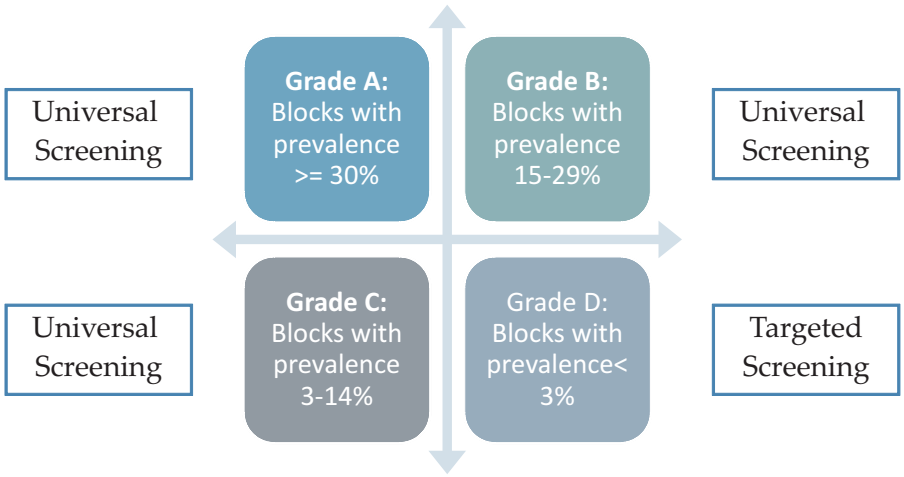


Figure 6: Grading of blocks with percentage of prevalence

Universal screening is to be initially focused on Grade A and B blocks. This may be followed by Grade C blocks. Blocks in Grade D shall require a targeted screening approach. The following table shows the various screening approaches against the target groups:

Table 1: Target groups for screening

Target groups	Setting	Role of CHO
Newborn	All public health institutions conducting institutional deliveries in sickle cell endemic areas	Counsel the pregnant women to undertake screening of the newborn after delivery. Refer and ensure all the newborns in your catchment are screened for SCD.
Children from 6 months to 10 years of age	Screening of children by RBSK teams either camp based or in Anganwadis / Schools / Ashramshalas / Eklavya Model Residential School (EMRS)	Support the RBSK team in screening children in Anganwadis/ Schools / Ashramshalas / EMRS.
Adolescent	At primary care facilities or outreach camps Rashtriya Kishore Swastya Karyakram	Support RKSK teams in screening and counselling of adolescents at Adolescent Friendly Health Clinics (AFHCs)

Premarital	At primary care facilities or outreach camps	Screen and counsel individuals of marriable age Screen and counsel all couples at the facility and during outreach camps
Antenatal Screening followed by prenatal screening	At all AB-HWC Prenatal diagnosis to be undertaken at the tertiary care facilities	Screen all pregnant women during antenatal check-ups at the facility and during outreach camps. If she found a carrier, her husband should be tested. The couple should be referred to a higher facility. The couple should be counselled on the pregnancy outcomes and its subsequent management. Refer pregnant women (8-12 weeks) with SCD to higher facilities to undertake this screening test.
Extended family screening	Outreach screening and facility-based camps	Counsel and screen family members of individuals with sickle cell at the facility and during outreach camps

Intensive screening: This will be carried out across the endemic states which will be rolled out for the period of 3 years with the target of 1 crore screening annually each year. For this mapping exercise shall be conducted throughout the endemic states to identify and grade blocks as per the prevalence. The States may screen all newborn upto 18 years of age in first year and incrementally screen all upto 40 years of age.

3.3. Facility-based screening at SHC-HWC

As a CHO, you should ensure each individual screened for sickle cell disease in your catchment area shall be registered with an ABHA ID and provided with a sickle cell card.

Post-screening individuals, should be followed up for confirmation of disease or trait status. Individuals post-screening should be registered at the respective SHC-HWC and updated on the Sickle cell portal. Every screened individual shall be provided a sickle cell card. The card includes the status of the screened individual (Normal, Carrier, Diseased).

You should conduct opportunistic screening for people attending the outpatient services at the SHC-HWC. The individuals belonging to the following categories shall be prioritized for screening to detect sickle cell diseases and sickle cell traits.

- All pregnant women should be screened for sickle cell carrier status in 1st trimester. If any pregnant woman is found to be a sickle cell carrier, then her husband should be tested. Pregnant women having sickle cell disease or trait should be referred to a higher facility.
- Screening of all newborn
- All individuals up to 40 years of age
- Cascade screening of extended family members of carriers and sickle cell positive people.

- With the help of ASHA and ANM/MPW you should organise mass screening days at AB-HWCs in collaboration with Jan Arogya Samitis (JAS) and Village Health Sanitation and Nutrition Committees (VHSNC)/Mahila Arogya Samiti (MAS), Community Arogya Samiti (CAS) and Self-Help Group (SHG).
- Provide counselling to all individuals screened for SCD
- Follow individuals for treatment adherence
- Patient's disease status, once confirmed with a solubility test or point of care test, they can be recommended to once undergo HPLC/ Electrophorosis test for confirmation at tertiary care. But the treatment can be initiated immediately after diagnosis at SHC-HWC/PHC-HWC.

3.4 Outreach screening

- Plan and organise outreach screening camps at hostels and Anganwadi centres with the help of MPW and ASHA on a monthly basis.
- Support RBSK and Mobile Medical Units or dedicated teams in conducting screening
- Priority shall be given to people under 18 years of age for screening, followed by expanded coverage to include pregnant mothers, newborn, extended family members of carriers, and sickle cell positive people
- Ensure referral of individuals to the nearest secondary care facility (CHC/DH) in case of complications.
- Disseminate IEC and BCC activities for sickle cell disease prevention using different methods such as audio-visual aids, posters, pamphlets etc.

3.5 Support to SCD and SCT cases

On identification of cases or traits, you will provide required support at the earliest. The following diagram shows the treatment and counselling approach.

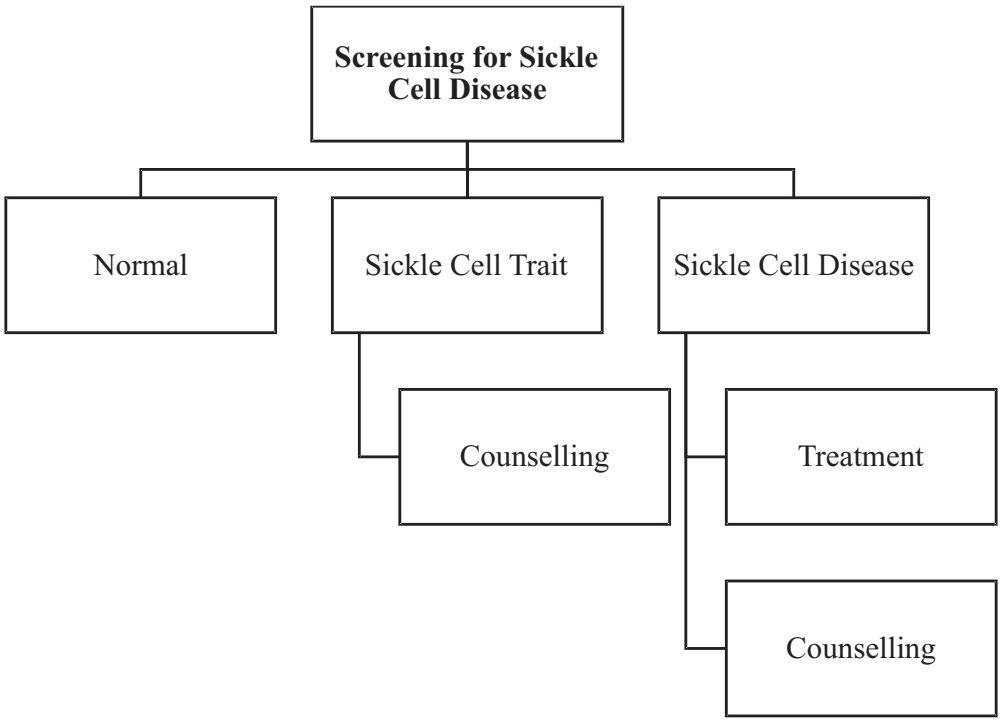


Figure 7: Screening outcomes

3.6 Genetic Counselling

Every individual who is screened for SCD should be provided a Sickle cell card. The card will show the status of the individual viz; normal, Carrier, or Diseased. Cards are colour coded as blue and pink; blue colour cards for males and pink colour cards for females. Based on the card's status, the individual will receive treatment and counselling services. The Sickle cell cards will be extensively used for the purpose of pre-marital and pre-conceptual counselling by matching the cards of prospective matches. Matching of cards will show the chances of their children being born with SCD or SCT.

Follow the steps given below for counselling about the use of sickle cell card;

- As a CHO, you should counsel and provide knowledge about the disease and its transmission. The individual or couple is free to make any decision related to marriage or conception.
- Inform the individual that blue colour cards are for male and pink colour cards are for female. And only one card would be issued for each individual.
- The card will contain details such as gender and test report (Sickle cell disease/ sickle cell carrier/ Normal) on the front side of the card. On the back of the card possibilities of having a disease in a child is explained for two individuals having sickle cell cards.

- Counsel the individual to avail of card matching from SHC-HWC before marriage.
- In each sickle cell card, there will be three holes present on the extreme left on the rear side of the card. While matching two sickle cell cards (one male and one female card) the three holes in one card will coincide with another card at two places (ⓧ). At one position, both card's holes will completely coincide, and no symbol (ⓧ) will be seen. The individual should check the statement written adjacent to that position and whether marriage is recommended or not recommended for those couple will be present on the card.

What to counsel?

Based on match the following cases should be counselled and referred for Pre-Natal diagnosis:

Table 2: Pregnancies needing Pre-Natal diagnosis

Pre Natal Diagnosis Not Required	Pre Natal Diagnosis Required.
If two individuals having sickle cell disease marry, there is a 100% chance that their children will be born with SCD	If a sickle cell disease individual and a sickle cell trait individual marry, there is a 50% chance that their children will be born with the disease and 50% chance that their children will be carriers
If a sickle cell disease individual and a normal individual marry, there is a 100% chance that their children will be born with sickle cell trait.	If two individuals having sickle cell trait marry, their children have 25% chance of being diseased, 25% of being normal and 50% chance of being carriers.
If a sickle cell disease trait and a normal individual marry, their children have 50% chance of being normal and 50% chance of being carriers.	

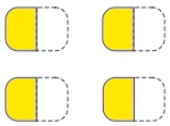
Sickle cell cards for male

Back

	Possibility of having disease in child	Marriage
⊗	All Normal	Recommended
⊗	50% Normal, 50% Carrier	Recommended
⊗	50% Normal, 50% Carrier	Recommended
⊗	All Carrier	Recommended
○	All Carrier	Recommended
⊗	25% Diseased, 50% Carrier 25% Normal	Not Recommended
⊗	50% Diseased, 50% Carrier	Not Recommended
○	50% Diseased, 50% Carrier	Not Recommended
○	All Diseased	Not Recommended

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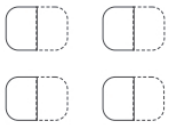
Normal
Carrier
Disease



	Possibility of having disease in child	Marriage
○	All Normal	Recommended
○	50% Normal, 50% Carrier	Recommended
⊗	50% Normal, 50% Carrier	Recommended
○	All Carrier	Recommended
⊗	All Carrier	Recommended
⊗	25% Diseased, 50% Carrier 25% Normal	Not Recommended
⊗	50% Diseased, 50% Carrier	Not Recommended
⊗	50% Diseased, 50% Carrier	Not Recommended
⊗	All Diseased	Not Recommended

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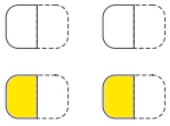
Normal
Carrier
Disease



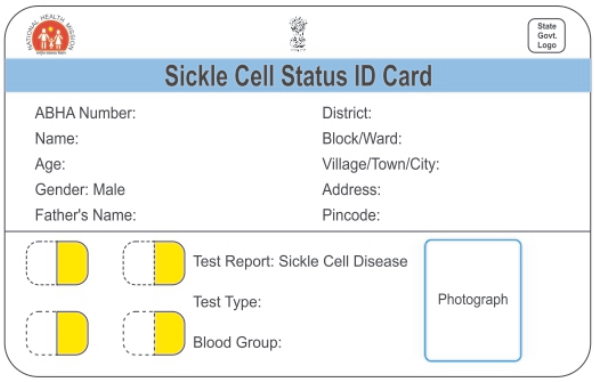
	Possibility of having disease in child	Marriage
⊗	All Normal	Recommended
⊗	50% Normal, 50% Carrier	Recommended
○	50% Normal, 50% Carrier	Recommended
⊗	All Carrier	Recommended
⊗	All Carrier	Recommended
○	25% Diseased, 50% Carrier 25% Normal	Not Recommended
○	50% Diseased, 50% Carrier	Not Recommended
⊗	50% Diseased, 50% Carrier	Not Recommended
⊗	All Diseased	Not Recommended

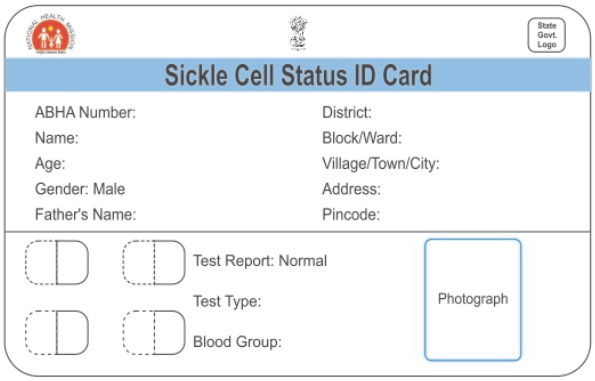
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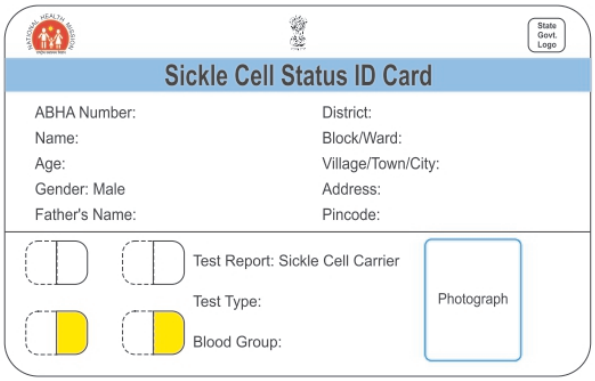
Normal
Carrier
Disease



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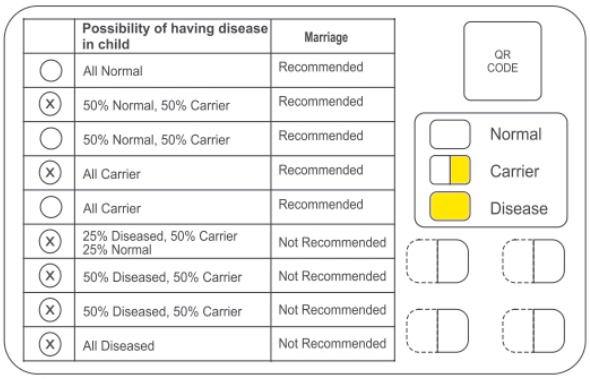


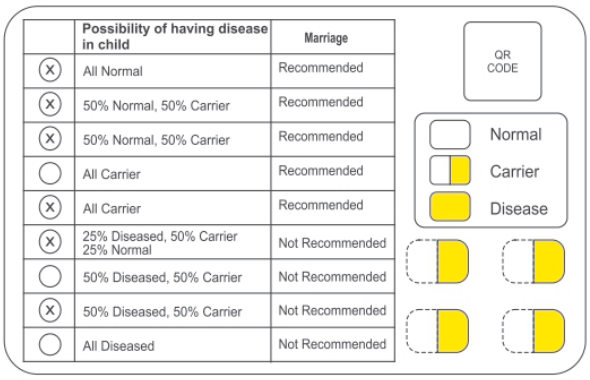


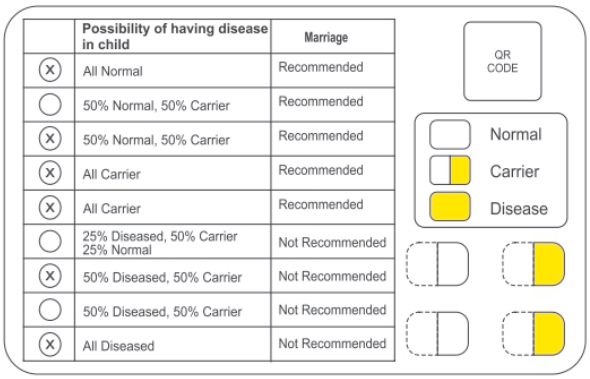


Sickle cell cards for female

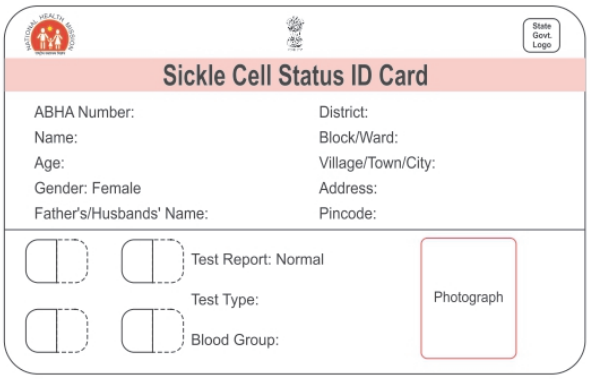
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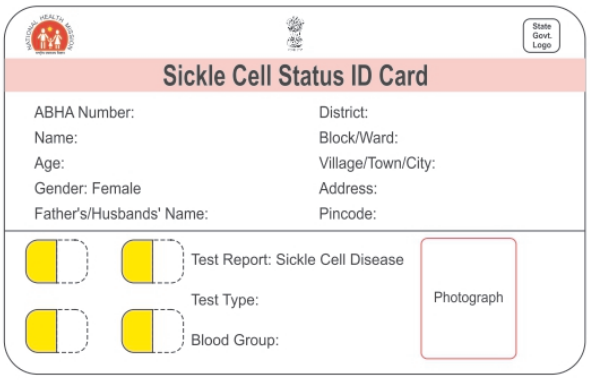


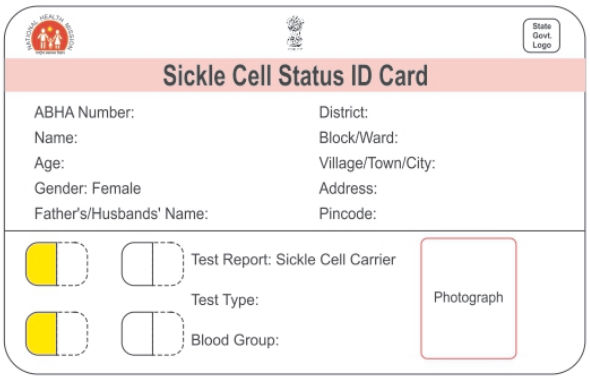




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CHAPTER 4
HOLISTIC MANAGEMENT AND CONTINUUM OF CARE

4.1 Treatment options available at AB-HWCs

The treatment of sickle cell disease usually aims at relieving the symptoms and management of crisis. The range of treatment available at SHC-HWC for individuals with sickle cell disease is as follows:

Table 3: Treatment available at AB-HWCs

Preventive	Treatment of Crisis	Rehabilitative	Therapeutic
• Increased fluid intake • Supplementation by different vitamins • Folic Acid prophylaxis • Counselling on lifestyle management • Educate parents about regular check-ups at SHC-HWC • Penicillin prophylaxis up to 5 years of age for infection prevention. • GoI approved vaccines to prevent infections • Educate and refer a patient for pneumococcus vaccination to PHC-HWC • Yoga and wellness	• Crisis episode management • Refer cases for pain management • Referral of cases to higher healthcare facilities for the management of crisis symptoms • Support patients in treatment adherence	• Registration for disability cards • Linkage to Department of Empowerment of Persons with Disabilities (Divyangjan)	• Disease modifying therapy ➢ Administration of Hydroxyurea • Referral for blood transfusion, if indicated • Refer patient to higher facilities

4.2 Preventive management

Fluid intake

Advise the patient to drink plenty of water to avoid dehydration. Dehydration increases the concentration of sickle cell hemoglobin in red blood cells along with the risk of vaso-occlusive crisis.

Vitamins and micronutrients

There is an increased need for supplementation of vitamins and micronutrients such as folic acid, calcium, vitamin D, B12, and zinc.

- Advise the patient to take protein-rich food such as pulses and legumes, eggs, meat, dairy products (milk, curd, cheese), etc
- Advise the patient to take vitamin D, B12, calcium, and zinc-rich foods.
  - Zinc-rich foods are mushrooms, garlic, wheat, watermelon seeds, pumpkin seeds, dark chocolate, cereals, nuts, meat, etc.
  - Vitamin B12-rich foods are milk, cheese, curd, paneer, egg, fish etc
  - Vitamin D-rich foods are eggs, paneer, mushroom, milk, fish, cheese, cod liver oil etc
  - Calcium-rich foods are curd, milk, drumstick leaves, banana, almonds, green leafy vegetables, soya products, etc.
  - Carbohydrate of low glycaemic index and rich in fibre- Whole cereals and grains, millets, whole pulses and legumes
  - Healthy fats used for cooking- Ground nut oil, mustard oil, coconut oil.
  - Fibre, antioxidants and micronutrients- Locally available seasonal fruits and vegetables of different colours

Table 4: The following table highlights the things to do and avoid to attain optimal nutrition:

DOs	DONTs
Water and other liquids to maintain hydration.	Bakery and confectionary
Frequent meals/ feeds at regular intervals should be offered to achieve the desired goal of nutrition.	Refined cereal and grains
Include natural rich sources of immune nutrients.	Packaged foods, sweetened Juices and carbonated beverages. Excess fat, sugar and salty food items

4.3 Prophylactic management

- Provide folic acid tablet 5mg/daily to all patients with SCD
- Provide oral Penicillin V Potassium 62.5 mg/bd for up to 1 year of age; 125mg/day for 1-2 years of age; 250 mg/day till 5 years of age
- Refer the patient to PHC-HWC/UPHC for pneumococcus and penicillin prophylaxis

- Iron supplementation should be started in case of iron deficiency anemia

  For newborn children, all vaccination as per the National Immunization schedule, shall be administered.

4.4 Rehabilitative care

- States extended support to individuals and children suffering from SCD
- Facilities under Rights for Persons with Disability act

You will make the individuals suffering from SCD aware that they can apply for Disability cards as individuals suffering from SCD are now recognized under Rights of Persons with Disability Act 2016 and amendments. As Sickle Cell Disease in one of 21 benchmark disabilities under RPWD, any SCD case will be eligible for the following:

- Free education from 6 to 18 years of age.
- 4% reservation in the education and government jobs.
- 5% reservation in higher education
- Other rights under RPWD act 2016

4.5 Management by CHO

Once the individual is confirmed positive for sickle cell disease, treatment should be initiated by MO. After treatment initiation, he/she should be referred back to the SHC-HWC closer to the residence for follow-up.

- Pain is the commonest symptom of SCD, and it may vary in intensity and frequency between patients and can last for a few hours or weeks. Dehydration, fever, temperature extremes, low oxygen, and excessive fatigue are common triggers for pain.
- For mild to moderate pain, you should provide NSAIDs/ acetaminophen/ Ibuprofen along with syndromic management unless there is any contraindication. For severe pain, immediately refer the patient to PHC-HWC.
- Patients with SCD are susceptible to both viral and bacterial infections. Any fever or infection should be considered a medical emergency.
- Pregnant women should not take any medicines by themselves and all the medicines used should be prescribed by the PHC-MO.
- The SCD women, if planning for pregnancy, then hydroxyurea drug should be discontinued three months prior to conception.
- The CHO should undertake regular check-ups of all confirmed patients every 3-6 months; the services include:

  a) Monitoring for fever, jaundice, pallor, and spleen size on each health visit

  b) Monitoring Hb level

c) Refill of medications

d) Counselling on diet, stress management, and risk reduction

e) Co-morbidity management

- In case of any complications, refer the patient to PHC-HWC/UPHC-HWC or arrange teleconsultations with specialists.
- Ensure regular home visits and supportive counselling services are provided by ASHA and MPW during treatment and to ensure treatment adherence.
- In case of severe complications in a child below two years of age, refer the child to a pediatrician/hematologist.
- Telemedicine facility: At SHC-HWC, CHO should ensure that telemedicine services availability through e-Sanjeevani-HWC to all sickle cell disease patients. The CHO would connect to the specialist or PHC-MO for the management of the disease.

4.6 Management of crisis

Table 5: Types of crisis and their precipitating factors, symptoms and treatment

Crisis	Precipitating factors	Symptoms	Treatment
Vaso-occlusive crisis	Heavy exercise, infection, dehydration, psychological stress, exposure to extreme temperature	Pain in joints like knee and elbow, vertebrae, chest, shoulder, and dactylitis (inflammation of fingers and toes giving a sausage-like appearance),	Pain relief medication Hydration Reassurance
Acute chest syndrome	Infection and overhydration	Wheezing, cough, increased breathing, and fever in children and chest pain, pain in the arms and legs, and shortness of breath in adults	Refer to PHC-HWC/UPHC-HWC
Sequestration crisis	Usually, in children aged between 3 months to 10 years of age, infection	Sudden pallor, weakness, sudden enlargement of spleen, severe anemia, and shock	Refer to PHC-HWC/UPHC-HWC
Aplastic crisis	Infection (parvovirus B19)	severe anemia	Refer to PHC-HWC/UPHC-HWC

You should know

- Hydroxyurea is contra-indicated during pregnancy and lactation
- While on Hydroxyurea therapy the following parameters are to be monitored
  - Blood pressure and oxygen saturation at every visit
  - CBC count every 2-3 months
  - Creatinine and liver function tests every 6 to 12 months
  - Urine pregnancy tests as appropriate

Indications for referral to Medical Officer At PHC:

1. Acute pain without any relief with NSAID & hydration in 1 hour
2. Pain with associated features:
   - Vomiting and unable to take medicines.
   - Pain with documented fever more than 100.4°F/38°
   - Pain with respiratory distress, either respiratory rate more than 24/min or saturation less than 95%
   - Pain with increased jaundice or cola coloured urine or brown to black urine
3. Acute abdominal pain with distension
4. Central chest pain more than 20 minutes
5. Chest pain associated with breathing difficulty or low oxygen saturation less than 95%
6. Fever documented to be more than 100.4°F/38°C
7. Haemoptysis or blood in sputum
8. Stroke- motor weakness, asymmetrical face, unable to speak coherently, confused, unresponsive to command or pain
9. Blood in urine or decreased urine output (frequency less than 4 times or subjective reduction in volume
10. Painful penile erection
11. Acute worsening of skin pallor or jaundice
12. Cold clammy skin/ impending shock
13. Fits or seizures
14. All pregnant patients
15. Swollen Feet
16. Progressive difficulty in breathing superimposed on baseline limitation or on activities of daily living

CHAPTER 5
AWARENESS GENERATION

5.1 For general population

You should create awareness among the general public living in your catchment area during home visits and camps about SCD when to refer a healthcare centre, what the symptoms are, and how to deal with someone with SCD. You should provide this information to ASHA and MPW so that they can disseminate the information to the public. IEC and BCC materials can be used to explain the details.

The required information for the public is provided below,

- Sickle cell disease does not spread through air, water, skin, food, or any other modes.
- One can acquire SCD only from parents through genes before birth
- SCD is a lifelong condition, but with proper medical interventions, it can be managed
- Sickle cell trait is not a disease, and an SCT person will not develop SCD with age
- If you or anyone known to you have these symptoms or proven family history of SCD should be recommended to get screened for SCD at SHC-HWC. The common symptoms are joint pain, frequent infections, looking pale, fatigue, breathlessness, anemia, swelling in the hands and back pain, yellow-colored eyes, and swelling in the lower part of the left chest area.
- Screening is a simple way of testing whether the individual is normal/SCT/SCD. Only a few drops of blood will be used for screening.
- If someone has SCT, he/she can lead a normal life but should avoid marrying a person with SCD or SCT to prevent the chances for their children to have SCD.
- A sickle cell card will be generated, and it is recommended to match the couple's cards before marriage.

5.2 For school teachers

As a CHO, you will provide the following information to the school teachers.

- Blood contains three types of cells, and red blood cells are one type. Red blood cell contains hemoglobin, and sickle cell disease is caused due to change in the shape of a red blood cell.
- Sickle cell disease does not spread through air, water, skin, food, or any other modes.
- One can acquire SCD only from parents through genes before birth
- SCD is a lifelong condition, but with proper medical interventions, it can be managed

- Teachers should be aware of children with SCD in their school
- Teachers should provide more care to SCD children because they require regular medication, and extra regular fluids to avoid dehydration.
- If any SCD student develops severe pain, high fever, breathing problems, or sudden weakness, the parents or doctor should be immediately informed.
- Teachers should keep the medical reports and doctors' details of the SCD children.

5.3 For parents with sickle cell disease child

- The SCD symptoms will be present from early life. Some of the signs of SCD are swelling in the hands and feet, pain in the chest and back side of the body, paleness of the body, repeated fever, weakness and tiredness, repeated infections, poor growth, jaundice, etc.
- Parents should be informed SCD can be managed with regular medication and care. Their children can also lead normal life with regular medical care.
- Parents should regularly provide medicines to their children. If the child is taking medicines by themself, then parents should monitor the regular uptake of medicines.
- Parents should share the information of the child with SCD, to school, and other places of regular contact.
- Parents should take their children for regular check-ups
- Parents should carefully monitor the health of their children. If the child is having high fever, breathing problems, pain not getting better within 24 hours, or sudden weakness or any complications should be immediately taken to a healthcare facility.
- The child should be provided with all the routine vaccines, and vaccines like Pneumococcal, Haemophilus influenza, and Meningococcal should also be administered.
- The child should be provided with plenty of water and a balanced diet, especially foods rich in protein, folic acid, calcium, vitamin D, B12, and zinc. (You should inform the locally available fruits and vegetables rich in these nutrients)
- Dehydration, infection, stress, extreme weather and temperature, high altitude, and exhaustion should be avoided
- Properly maintain the records of the treatment and test reports in a file.
- The child should be immediately taken to the doctor if he/she has any of the symptoms, repeated fever, repeated infection, repeated anemia, recurrent episodes of jaundice, repeated pain or swelling in any of the body, swelling in hands and legs, ulcers in the leg, difficulty in breathing.
- Maintain personal hygiene and hygiene at home to prevent infections. Simple steps

to avoid infection should be followed, such as washing the hands regularly, brushing the child's teeth twice a day, maintaining hygiene while preparing food, regular vaccination, and penicillin prophylaxis.

- The child should be encouraged to exercise, do yoga and meditation regularly

Sickle cell crisis

- The child can experience a pain crisis anytime, so parents should be able to identify the crisis.
- The child will have acute pain in the chest, back, legs, etc
- Other symptoms can be difficulty in breathing, enlargement at the left lower chest region (spleen enlargement), and nausea.
- Triggering factors for pain should be avoided. Pain can be triggered due to dehydration, infection, stress, extreme weather and temperature, and exhaustion.

5.4 For sickle cell disease individual

- SCD individuals should be encouraged that they can also lead a normal life with proper medical care.
- They should regularly take the medicines
- Periodically visit the doctor for check-ups and follow up at SHC-HWC
- Keep hydrated. Adults should drink 6-8 glasses of water per day
- Should avoid smoking, use of tobacco and alcohol drinking
- Should avoid traveling to high-altitude, long-distance travel in flights, extreme weather, extreme temperatures, stress, exhaustion, and dehydration.
- Take a balanced diet, especially foods rich in protein, folic acid, calcium, vitamin D, B12, and zinc (You should inform the locally available fruits and vegetables rich in these vitamins and minerals)
- The individual should be encouraged to perform regular yoga, exercise, and meditation.
- Properly maintain the records of the treatment and test reports in a file.
- Join support groups with similar disease conditions
- Check the SCD status of the spouse before planning for a family
- Maintain personal hygiene and hygiene at home to prevent infections. Simple steps to avoid infection should be followed, such as washing hands regularly, brushing the teeth twice daily, maintaining hygiene while preparing food, regular vaccination, and penicillin prophylaxis.

CHAPTER 6
COMMUNITY ADOPTION

Community adoption involves leveraging community support for people with sickle cell disease. As an SHC-HWC team leader, you should identify, orient, and motivate voluntary individuals and organizations. This initiative shall:

- Provide additional support for patients with sickle cell disease (SCD) to improve treatment outcomes
- Enhance community support in the care of sickle cell disease
- Leverage corporate social responsibility
- Organise and provide support in blood donation drives

The community adoption will enhance awareness in the public and active involvement of society about SCD, improve the nutritional status of the patients, and reduction of out-of-pocket expenditure for the family.

The identified donor can engage to support the consented individual or family of an individual or an entire geography (block/ward/ district) affected by SCD. The types of support are individuals/ families and block/ward/ district.

Table 6: Support from different levels

Individuals/ families	Block/ward/ district
• Nutritional support • Counselling for lifestyle, treatment adherence, and stress management • Mobility support for follow-up hospital visits, including for penicillin and hydroxyurea prophylaxis • Vocational support	• IEC/BCC activities for community awareness • Organising outreach screening camps • Counselling for lifestyle, treatment adherence, and stress management • Vocational support • Genetic Counselling support

6.1 Implementation Plan of Community Adoption:

Step 1: Development of integrated web portal and obtain consent from SCD patients

- Creation of ABHA ID-based e-registry for individuals with SCDs
- Integration with centralized application for developing a line listing of patients infected with SCDs
- Identification of patients through mass screening campaigns and creating a line list of all individuals with SCDs

- Mapping of individuals and families with SCDs through frontline workers.
- MO/CHO/MPW/ASHA shall approach the patients directly in person, listed from their area, and inform them about the support available under this intervention. The patient and family shall also be informed that their details shall be made available to the donor.
- Written consent should be obtained from the patient that the enrolment of the patient is his/her informed choice.
- For patients who are newly registered in the CPHC system, an OTP will be sent to the client's mobile number, and OTP will act as consent for the enrolment of beneficiaries.

Step 2: Dissemination of plan

- Use of mass media tools, SMS, digital banners, posters, leaflets, AV testimonials, social media assets, job aids, etc.
- Inter-ministerial collaboration to increase public awareness regarding the program.
- Engagement with the mass media at the national and state level.
- Newspaper and TV/radio jingle-based announcements.

Step 3: Donor identification

- A web portal should be developed for the self-registration of donors. The page should have provisions to enter the details of the donor, state wise list of districts, blocks, and cities, and the number of existing SCD patients in the block/city. The donor can choose one or more blocks/ urban wards and the intended duration for providing support. They can also enter the type of assistance that they would like to provide for the patients in the area.
- Information about the portal shall be widely disseminated through the use of mass media channels.
- District Health Society (DHS), under the chairmanship of the district collector should engage with potential donors across corporates, public sector undertakings, institutions, citizens, elected representatives, etc. DHS Chair shall approve such donations to be finally implemented for the benefit of people with SCD.

Step 4: Service delivery

- The assistance shall be provided by the identified donor to the patient, as mutually agreed with the district committee on SCD
- The donor and the district committee on SCD shall utilize existing systems or develop new systems to deliver assistance
- The donor should ensure the quality of in-kind assistance provided to the SCD patients

CHAPTER 7
MONITORING, SUPERVISION AND REPORTING

7.1 Monitoring

Sickle cell Mobile application developed by National Informatics center shall have data of every person after due generation of ABHA (unique Health ID) after being screened. The indicators pertaining to sickle cell disease intervention at SHC-HWC/UHWC and PHC-HWC/UPHC-HWC shall be updated in the Sickle cell Mobile application on a daily basis. This indicators shall be used for reviewing the status of implementation of the sickle disease prevention and care at all levels of care.

Sickle Cell Mobile application -The application has following features:

- Beneficiary registration
- Test details (solubility, HPLC/Electrophoresis or Point of Care) captured in both online and offline mode integration with ABHA ID

The application contains following details:

- Registration: To record the screened person's details.
- Screening Test Details: To record the results of solubility or POC test.
- HPLC/Electrophoresis Test Details: To record the HPLC/Electrophoresis test details.
- Syncing: To Sync offline (local database) data with the server's data

As a Community Health Officer you should

- Register your mobile number through concerned District User / State User / State Admin
- Download mobile application through https://sickle.nhm.gov.in/home or https://sickle.nhm.gov.in/home/app_download_counts
- Login using mobile number and generate MPIN
- Register the screened people through ABHA ID

7.2 Supervision and Reporting

As a Community Health Officer, you should:

- Monitor that ASHAs are conducting population enumeration and fill CBAC forms for detection of probable Sickle Cell disease and trait cases.
- Ensure monthly reporting from the facility level includes data pertaining to the screening, patients identified, and treatment persons lost to follow-up (reporting format)
- Ensure monthly data is uploaded to the portal.

- Provide technical support to MPW and ASHA for appropriate maintenance of records and reports on screening, treatment, counselling, referral, and follow-up.
- Ensure availability of logistics, diagnostics, and consumables as required for the camps for SHC-HWC.
- Train and mentor the ASHA and MPW on all aspects of SCD prevention, control, counselling, and management
- Monitor the conduction of community/village level meetings such as VHSNCs or campaigns conducted.
- Facilitate mapping of patients for community adoption
- Monitor a suggested set of indicators
    - Total number of individuals screened for sickle cell disease
    - Total number of individuals diagnosed with Sickle Cell trait
    - Total number of individuals diagnosed with Sickle Cell disease
    - Total number of individuals with Sickle Cell disease registered at the facility
    - Total number of individuals with Sickle Cell disease under community adoption scheme
- Follow-up identified cases for treatment compliance. Any referral to higher facilities should be supported through the AB-HWCs.
- Track eligible couples to provide genetic counselling and mobilize them to the nearest Ayushman Bharat Health and Wellness Centre (AB-HWC) for SCD screening, prevention, and clinical management.
- Track individuals with known or diagnosed SCDs should be encouraged to register on Sickle Cell Disease Support Corner, a Ministry of Tribal Affairs's initiative to bridge the gap between patients and health care services in tribal areas.

CHAPTER 8
ROLES AND RESPONSIBILITY

8.1 At Individual Level

- As a CHO, you should conduct opportunistic screening for people attending the outpatient services at the SHC-HWC, and pregnant women, newborns, children below 18 years of age, extended family members of carriers, and sickle cell positive people should be given high priority. Conduct solubility tests for HbS screening for all the categories of individuals who are at high priority.
- Organise mass screening days at AB-HWC.
- Undertake detailed history, and physical examination of patients to assess general signs and symptoms for identifying a disease condition.
- Referral to a higher facility and maintain a continuum of care
- Provide follow-up care to the patients when they visit AB-HWC or support ASHA and MPW when they undertake household visits.
- Counsel the patients and caregivers to understand and cope more effectively with their problems, improve health-seeking behaviour, bring about lifestyle modifications, also provide pre and post-test counselling.
- Facilitate teleconsultation for SCD patients with a specialist in case of complications
- Undertake regular check-ups of all the confirmed patients every 3-6 months, the regular check-ups include monitoring the fever, jaundice, pallor, and spleen size, monitoring hemoglobin level, refilling the medications, counsel on diet, stress management, and risk reduction.
- Refer the newborns and SCD patients to PHC-HWC for initiation of pneumococcal vaccination and penicillin prophylaxis therapy and followed up.
- Provide pain relief medications like NSAIDS, acetaminophen, etc, along with syndromic management. If pain is not relieved, refer the patient to PHC/UPHC-HWC.
- Maintain SCD patient register to ensure regular follow-up of the patients
- Provide genetic counselling to all the persons screened for SCD
- Individuals who identified as diseased or having traits should be encouraged to use Sickle Cell Cards.
- Individuals with known or detected SCDs would also be encouraged to register on Sickle Cell Disease Support Corner, which is the Ministry of Tribal Affairs's initiative to bridge the gap between patients and health care services in tribal areas.

8.2 At the Community Level:

- Support Mobile Medical Unit in conducting outreach screening
- Plan and undertake monthly community level health promotion activities, including behaviour change communication
- As a leader of the SHC-HWC team, you should ensure the communities are made aware of sickle cell disease, sickle cell traits, the necessary steps to prevent the disease, treatment, management, rehabilitation, and services available at the AB-HWCs. You should plan and organize community awareness events on SCD on a regular basis.
- As a CHO, you should support and leverage the Jan Arogya Samiti platform at AB-HWC to form a dialogue within the community to prevent SCD. You can further support the ASHAs and ANMs in raising awareness of SCD by leveraging the Village Health Sanitation and Nutrition Committee (VHSNC) meetings, Village/Urban Health Sanitation and Nutrition Days (VHSND/ UHND) meetings at Anganwadi, Arogya Sabha, Self-Help Groups (SHG), youth clubs, parent-teachers meetings in schools, Patient Support Groups. You may have a schedule to visit at least one meeting/ session once a month and ensure utilization of the above-listed platforms and groups in raising awareness against SCD. Furthermore, you should ensure engaging the tribal heads and key influential individuals among the local tribe, especially women, as champions of other community members through the regular meetings of the platforms and sessions.
- Arrange awareness generation events at the community level. Places with community gatherings in urban and rural areas, such as haat bazaars or fixed-day markets, may be included for generating awareness amongst the community. Locally relevant awareness modalities, such as street plays, wall writings, and paintings, quizzes, etc., shall be undertaken to raise community awareness on sickle cell disease and the national mission.
- You should collaborate with the NGOs working in the area in the sector of health especially tribal health, for the purpose of mobilization, awareness, and providing pre-marital and prenatal screening and counselling services.
- You can plan IEC/BCC activities in collaboration with Ministry of Tribal Affairs representatives. The identified mentees and mentors of the GOAL (Going Online as Leaders) program run by the MoTA with Facebook can be used as ambassadors for generating awareness on health issues, including Sickle cell disease.
- You should circulate audio-visual IEC/ BCC materials through local WhatsApp groups/ TV/ radio to create awareness about the facilities provided by the Government for Sickle Cell patients and the success stories of sickle cell patients.
- Educate school teachers and Anganwadi workers about the special needs of children with sickle cell disease through conducting health talks and counselling sessions.

8.3 At the facility level:

- Provide supportive supervision to ASHAs and MPW in routine population enumeration and line listing of identified SCD patients within the catchment area
- Support ASHA, MPW, community health volunteers, local NGOs to raise awareness for SCDs through home visits.
- Support ASHA and MPW in providing counselling
- Prepare micro planning for screening, diagnosis, treatment plan, and referral of the population
- Support ASHA and MPW when they undertake the household visits for follow-up care. Maintain patient records, family health folders, health risk assessment data, and treatment details for enrolled patients of HWC in a computerized database.
- Submit monthly performance reports for the HWCs to PHC MO
- Ensure availability of logistics, diagnostics, and consumables as required for sickle cell disease patients and for conducting camps

8.4 At the school level:

- Conduct health talk sessions and counselling at all schools & colleges, including tribal residential schools, tribal hostels, and Ekalvya Model Residential Schools, for early detection of SCD among school going children.
- You should coordinate with the Rashtriya Bal Swasthya Karyakram (RBSK) teams and PHC MO to leverage the platform for screening, counselling and awareness generation against Sickle cell disease at the school level.
- During the distribution of IFA tablets at schools and HWC, you shall ensure those children found to have SCD are given plain folic acid.
- In endemic areas, through biannual visits to schools, you should ensure regular reinforcement of messages/ themes through IEC/BCC activities such as interactive activities/posters/classroom and Assembly discussion at school level.

8.5 How to micro plan at SHC-HWC?

You will do the microplanning for screening activities within the catchment area. You have to follow the grading of blocks explained in chapter 3 and follow the steps below.

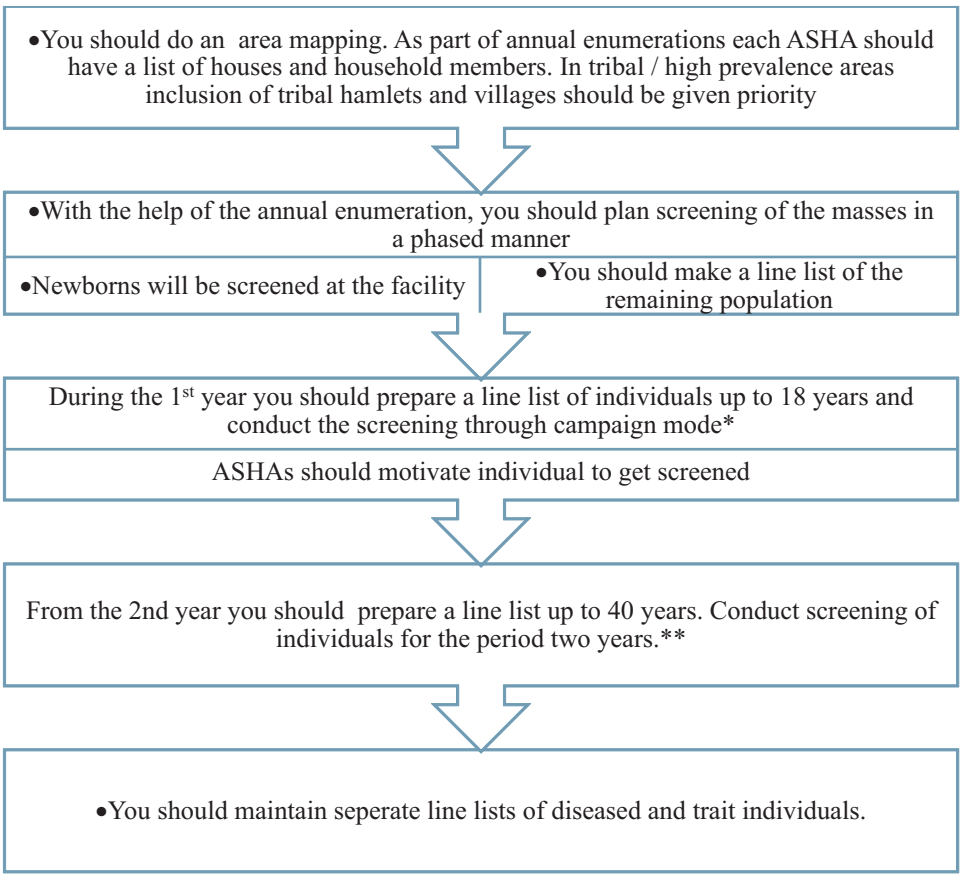


Figure 8: Steps for micro plan at SHC-HWC level

* Population up to 18 years will be covered within the 1st quarter or distributed on a monthly basis but ensure all the screening as early as possible to ensure early initiation of comprehensive healthcare for every individual.

** Population up to 40 years will be covered on a monthly basis as early as possible to ensure early initiation of comprehensive healthcare for every individual.

Annexures

Annexure 1: Solubility test

The solubility test is done to identify altered hemoglobin, either homozygous sickle cell anaemia of heterozygous sickle cell trait.

Requirements

1. Syringe
2. Blood collection vial lined with anticoagulant
3. Sickle cell buffer reagent – R1
4. Sickle cell powder reagent – R2
5. 2 Vials – one for sample one for control
6. Dropper

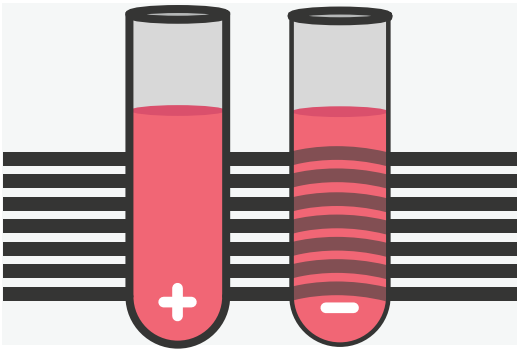


Figure 9: Outcomes of Solubility test

Precautions

1. Store reagent at room temperature
2. Discard reagent on appearance of turbidity, which will not dissolve upon mixing
3. Store the blood sample at 4-8°C
4. Severe anaemia will cause false negative. Hb concentration should be 7 g/dl or more. Cases of polycythaemia, multiple myeloma, cryoglobulinemia and other dysglobulinemia also have the chances of providing false negative results.

Preparation of working solution

1. Bring buffer and reagent powder at room temperature before mixing
2. Add one vial of powder reagent (R2) to one bottle of buffer reagent (R1). Cover the cap of R2 bottle and mix vigorously.
3. Record the reconstitution date and expiry date on the vial
4. Store the solubility buffer tightly capped at 2-8°C

   Use the buffer within 45 days.

Procedure

1. Prepare the working solution. If already prepared, bring it to room temperature
2. Collect whole blood in a vial.
3. Add 2.0 ml of working solution buffer reagent to two tubes and label the sample and control
4. Add 0.02 ml (20µl) of whole blood to the sample vial and plug it Mix by inversion.
5. Place in the test tube rack for 5 minutes.
6. Read the test in sufficient light after 5 minutes against lines placed in the background.

Inference

1. A positive result (presence of sickled hemoglobin) – If the solution turns turbid and the background lines are not visible
2. Compare the turbidity of the test solution with the negative control solution if observed, more solutions say positive
3. Heterozygous - Red-pink supernatant with a dark red band at the top.
4. Homozygous - Yellowish supernatant with a dark red band at the top.
5. A negative result (no presence of sickled hemoglobin) – If the clear or turbid solution permits the lines to be seen through the tube. Slight greyish matter on top of deep red hemolysate.

Annexure 2: How to take a dried blood spot sample

The dried blood spot (DBS) is a simple and quick test that uses the capillary blood from heel collected at the point of testing.

Steps

- Complete the details on the infant request form and blood spot card. Provide as much detail as possible to ensure timely reporting of results.
- Place the infant in a comfortable position with their barefoot. Wash and dry their hands thoroughly and wear appropriate PPE (gloves/apron) during the procedure.
- Clean the area to be used for a blood test with an alcohol wipe and allow to dry
- The best area for the heel prick is the sides of the heel. The sample should not be taken from the back of the heel.
- Remove the safety clip and place the lancet in light contact with the heel. This will ensure the incision is not too deep or too shallow. Press the trigger. The blade will create an incision and then retract. Dispose of the device in a sharps box.
- Allow the blood to flow naturally and fill three circles with blood. Fill the circles evenly with one drop of blood per circle. Ensure blood has been absorbed into the filter paper and is visible as a similar size circle at the rear of the card
- If the blood stops flowing, wipe away any congealed blood and gently massage the foot (do not squeeze). Excessive pressure reduces the density of the blood on the sample. If the infant is not bleeding, a second puncture is needed. This should be on the other foot or a different part of the same foot.
- Be careful not to contaminate the sample. Allow the blood spots to air dry for 10 minutes away from direct sunlight or heat. Once completely dry, fold the top of the card over the blood spot and place in the sealed section of the clear plastic bag with the request form in the front pocket

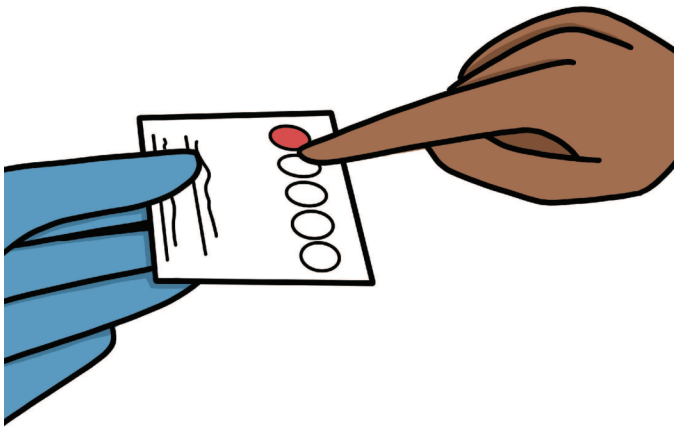


Figure 10: Blood spot card

Annexure 3: List of Abbreviations

ABHA	Ayushman Bharat Health Accounts
AB-HWC	Ayushman Bharat - Health and Wellness Centres
AFHC	Adolescent Friendly Health Clinics
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
BCC	Behaviour change Communication
CAS	Community Arogya Samiti
CHC	Community Health Centre
CHO	Community Health Officer
CPHC	Comprehensive Primary Healthcare
DEIC	District Early Intervention Centre
DH	District Hospital
DHS	District Health Society
EMRS	Eklavya Model Residential School
Hb	Haemoglobin
IEC	Information Education Communication
JAS	Jan Arogya Samiti
MAS	Mahila Arogya Samiti
MO	Medical Officer
MoTA	Ministry of Tribal Affairs
OPD	Outdoor Patient Department
PHC-HWC	Primary Health Centre– Health and Wellness Centre
PM-JAY	Pradhan Mantri - Jan Arogya Yojana
PMSMA	Pradhan Mantri Surakshit Matritva Abhiyan
PRI	Panchayat Raj Institute
PCV	Pneumococcal conjugate vaccine
RBC	Red Blood Cell
RBSK	Rashtriya Bal Swasthya Karyakram
RKSK	Rashtriya Kishore Swasthya Karyakram
RPWD	Rights of Persons with Diabaility
SCD	Sickle Cell Disease

SCT	Sickle Cell Trait
SDG	Sustainable Development Goal
SHC-HWC	Sub Health Centre - Health and Wellness Centre
SHG	Self Help Group
SMS	Short Message Service
SN	Staff Nurse
UHC	Universal Health Coverage
UHWC	Urban Health and Wellness Centre
UPHC-HWC	Urban Primary Health Centre – Health and Wellness Centre
UT	Union Territory
VHSNC	Village Health, Sanitation, and Nutrition Committees
VOC	Vaso-occlusive crises

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Namaste!

You are a valuable member of the Ayushman Bharat – Health and Wellness Centre (AB-HWC) team committed to delivering quality comprehensive primary healthcare services to the people of the country.
To reach out to community members about the services at AB-HWCs, do connect to the following social media handles:

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