सत्यमेव जयते

Ministry of Health & Family Welfare
Government of India

National Sickle Cell Anaemia Elimination Mission 2023

Training Module for Multi-Purpose Workers (M/F)/ASHAs

June 2023

CONTENT

BACKGROUND

Sickle Cell Disease (SCD) is a genetic disease in which the red blood cells have an abnormal half-moon shape. It is more common in the tribal population of India but occurs in non-tribals too. It leads to anaemia, pain, and reduced growth, and affects many organs like the lungs, heart, kidneys, eyes, bones, and brain.

The tribal health expert committee report, 2018 has listed sickle cell disease as one of the 10 priority problems in tribal health. About 1 in 86 births among the tribal population have SCD, the prevalence being higher in Central, Western, and Southern India. However, now SCD is found across all ethnicities and communities.

States with prevalence of Sickle Cell Disease include- Gujarat, Rajasthan, Uttarakhand, Maharashtra, Bihar, Jharkhand, Madhya Pradesh, Chhattisgarh, Odisha, West Bengal, Tamil Nadu, Telangana, Andhra Pradesh, Karnataka, Kerala, Uttar Pradesh & Assam. Tribal communities in India have poorer health indicators, a greater burden of morbidity and mortality, and limited access to health care services. To enable access to affordable and quality health care for all SCD patients, and to lower the prevalence, Government of India has launched a mission to eliminate sickle cell disease by 2047.

This will improve the care of all Sickle Cell Disease patients for a better future and will lower the prevalence of the disease through a multi-faced coordinated approach with focus on screening and awareness strategies.

A community health worker, MPW (M/F) / ASHA will play a pivotal role in eliminating sickle cell disease through health promotion and prevention activities in the community.

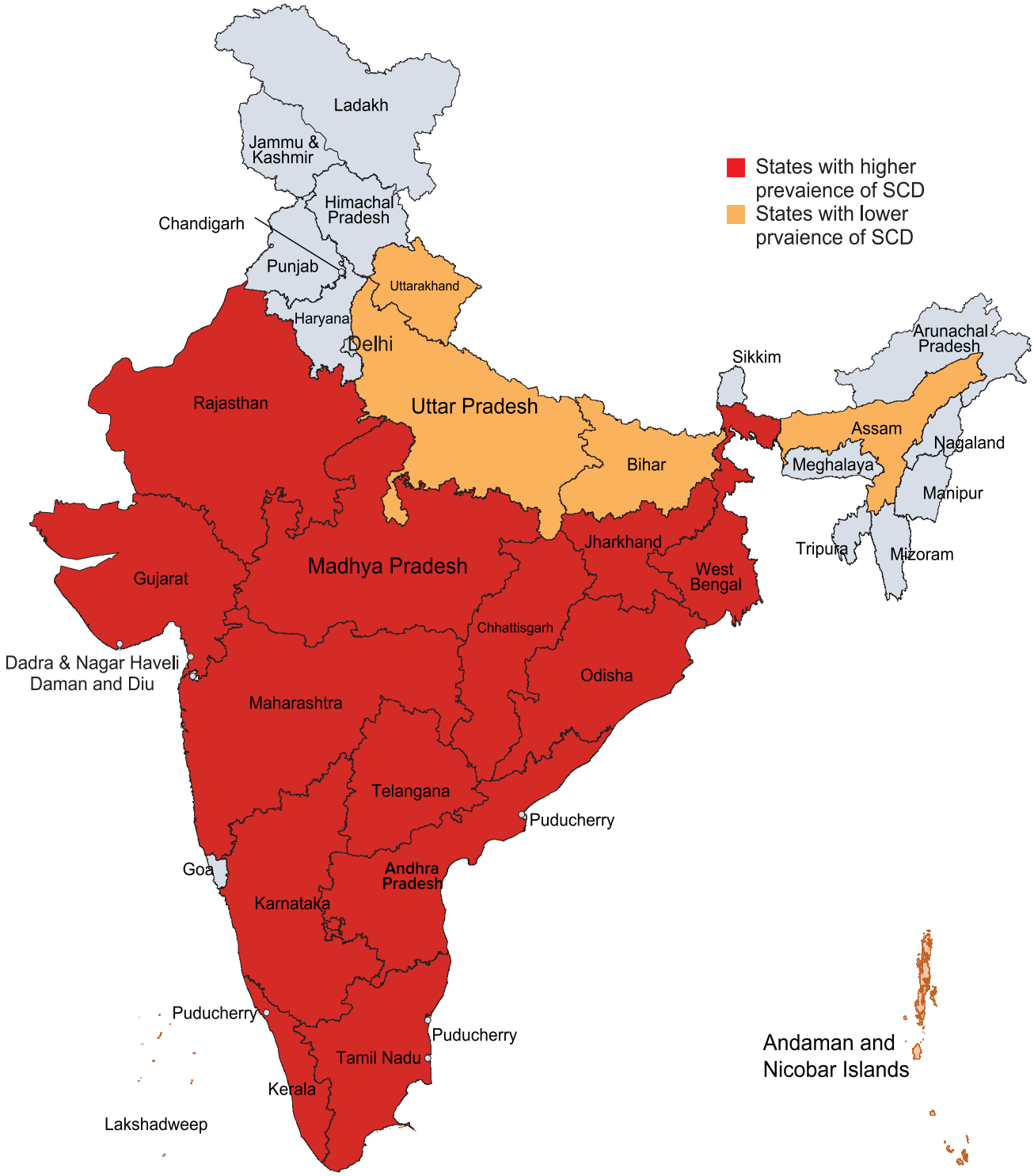


Figure 1 Prevalence of Sickle Cell Disease in India

CHAPTER 1:
UNDERSTANDING SICKLE CELL DISEASE

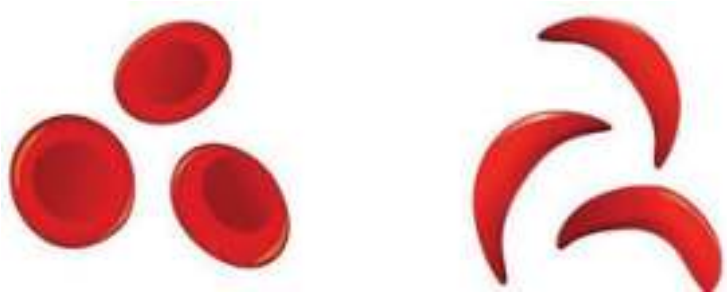
Let us first understand what Sickle cell disease is. Then we will learn about its symptoms that will help you to identify and refer the patients to AB-HWC.

1.1 What is Sickle Cell Disease?

A genetic disorder that affects red blood cells. It is passed on from parents to children.

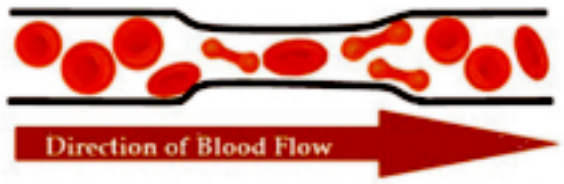
Red blood cells normally look like round discs. But in a person with sickle cell disease, they are shaped like sickles or half-moons.

lives up to 120 days



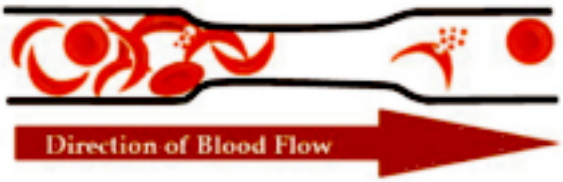
live up to 10-20 days

Figure 2 Normal and Sickled Red Blood Cells



Normal red blood cells flow freely through small blood vessels.

Figure 3 Normal Blood flow



Sickled red blood cells are rigid, and sticky cells. They get stuck in small blood vessels and slow down or block blood flow

Figure 4 Blood flow in Sickle Cell Disease

This can cause pain and other serious complications (health problems) related to the heart, lungs, kidneys, and other organs because not enough blood and oxygen are reaching the organs.

Normal red blood cells can live up to 120 days but sickle cells live for about 10 to 20 days

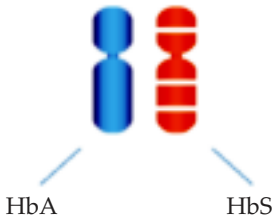
1.2 What causes sickle cell?

Sickle cell disease is not an infectious disease but rather a genetic disorder, which is carried onto families by genes. Genes are found inside cells and carry information that gets passed from parents to children.

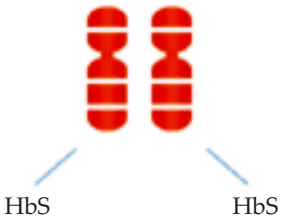
Genes carry the information that determines your features or characteristics that are passed on to a child from parents

For example, if both parents have green eyes, their child might have green eyes (where green eyes is an information which is passed)

• A child who gets a sickle cell gene from one parent and a normal hemoglobin gene from the other parent has sickle cell trait	• A child who gets two sickle cell genes, one from each parent, will have sickle cell disease.
Sickle Cell Trait	Sickle Cell Disease (HbSS)



Sickle Cell Trait

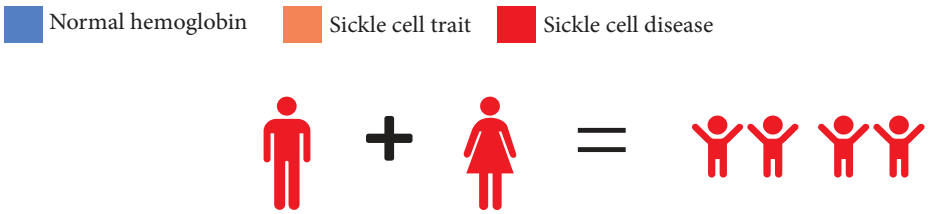


Sickle Cell Anaemia /Sickle Cell Disease

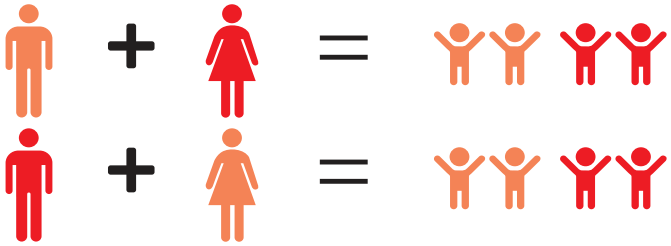
HbA – Normal Haemoglobin
HbS – Sickle Haemoglobin/ Abnormal haemoglobin

Sickle cell disease is not an infectious disease. It runs in families

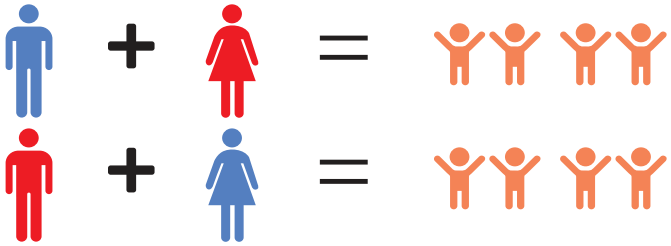
A pictorial depiction of different combinations of parents' disease status and the probability of the children getting affected is as below:



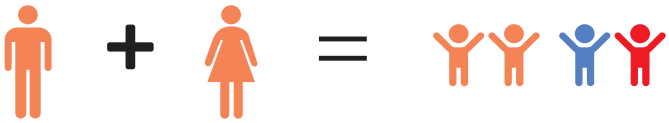
If both parents have sickle cell disease, there is a 100% chance that their children will be born with the disease



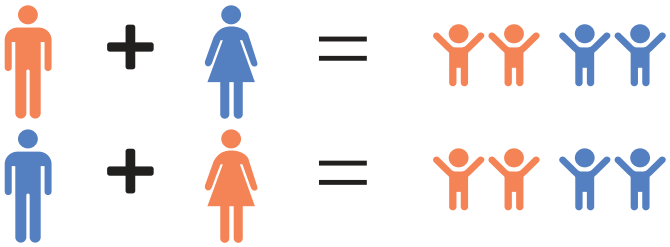
If one parent has sickle cell trait and the other has sickle cell disease, then children have a 50% chance of being diseased and 50% of being carriers



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

A person with Sickle Cell Trait is referred to as a carrier and does not always show the symptom of the disease. However, there is a possibility that his/her children will inherit the Sickle Cell Disease if he/she happens to marry a Sickle Cell Carrier or Sickle Cell Disease patient.

1.3 Clinical presentation of sickle cell disease

The signs and symptoms of sickle cell disease vary greatly from person to person. Some people are quite healthy and are diagnosed at relatively old age; some are frequently hospitalised and may have complications, while some may die at an early age from the disease and its complications.

Anaemia – People with Sickle Cell Disease have low red blood count. This makes them tired easily.

Frequent infections Children under the age of five are at the highest risk. Mainly infections can occur in the lungs, blood, and brain.

Fever - A fever may be the first sign of an infection.

Jaundice – Yellow colour usually seen in the white of the eyes. This is usually a mild and common problem.

Episodes of pain - Periodic episodes of extreme pain, called pain crises, are major symptoms of sickle cell disease. Pain occurs in Joints, Chest, Back, and Abdomen. The pain varies in intensity and can last for a few hours to a few days. Some people have only a few pain crises while some may have more.

Swelling of hands and feet - The swelling is caused by sickle-shaped red blood cells blocking blood circulation in the hands and feet.

Delayed growth or puberty - A shortage of healthy red blood cells can slow growth in infants and children and delay puberty in teenagers.

Vision problems - Tiny blood vessels that supply the eyes can become plugged with sickle cells. This can damage the retina — the portion of the eye that processes visual images — and lead to vision problems.

Leg ulcer - Leg ulcers are painful and often disabling complications of SCD.

Priapism- Prolonged painful erection of the penis without sexual arousal.

1.4 How can Sickle cell disease be treated?

Treatment for sickle cell disease is usually aimed at relieving symptoms and preventing complications. Early diagnosis and prevention of complications is critical in sickle cell disease treatment. With early intervention together with parental education and involvement, affected people live longer and survive into middle and late adulthood

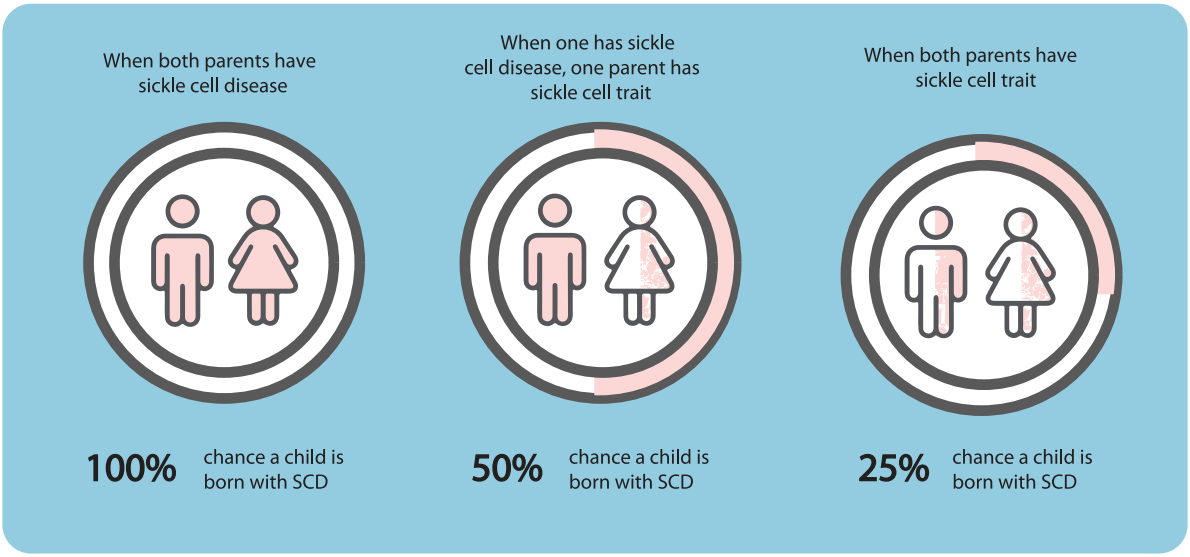
1.5 How can Sickle cell disease be prevented?

As it is a genetic condition someone is born with, the best-suited control measure of prevention is stopping the disease from passing on to the next generation. People with sickle cell trait need to be identified and counselled on marriage so that the sickle cell trait and the sickle cell disease and disease are not transmitted to future generations.

Children with sickle cell disease can lead a normal life with proper treatment and care
They can grow to be healthy and productive citizens

Let us Recap

- ✓ Sickle cell is a genetic disease affecting the red blood cells.
- ✓ SCD can only be passed on from parents to their children through genes and is not transmitted by any other means.
- ✓ The chances for a child to inherit Sickle Cell Disease in different cases are as below



✓ Common symptoms of SCD are:

Symptoms of sickle cell disease

- Looking pale
- Frequent infections/ Illness
- Yellow colored eye
- Backpain
- Enlargement of spleen
- Swelling
- Fatigue
- Breathlessness
- Aneamia/Paleness
- Joint Pain
- Low Immunity

✓ The best measure for prevention is stopping the disease from passing on to the next generation.

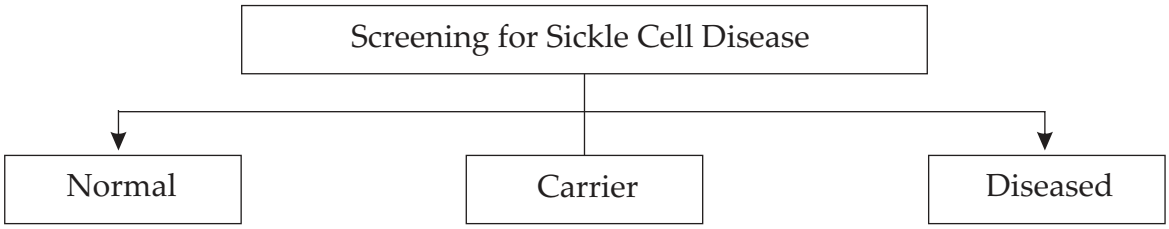
✓ Treatment for sickle cell disease is usually aimed at relieving symptoms and preventing complications

CHAPTER 2:
PREVENTION OF SICKLE CELL DISEASE AND ROLE OF MPW (M/F) / ASHA IN PREVENTION

Since you have understood what is sickle cell disease, this chapter will explain your role in prevention of the disease.

As an MPW (M/F) / ASHA your major role is in preventing the disease in your community. You should take steps to create awareness and provide information to the community about sickle cell disease prevention.

Screening is done to identify individuals with sickle cell disease or carrier. It is done at the Ayushman Bharat Health and Wellness Centre (AB-HWC) and also in the community through screening camps



There are tests which are done to screen people for sickle cell disease. Let us now learn about them.

2.1 Tools for Screening

Two types of tests are available for screening:

1. Solubility Test – This is a test tube-based test which can be used for mass screening. This is a rapid test and requires a very small blood sample. Solubility tests can be used at screening sites or at healthcare facilities. This test tells about the presence of abnormal haemoglobin in the blood. The procedure for conducting solubility test is attached as Annexure 1.

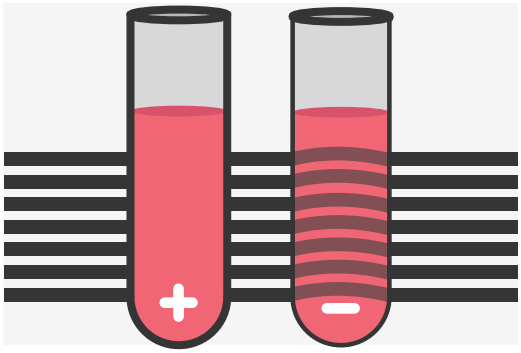


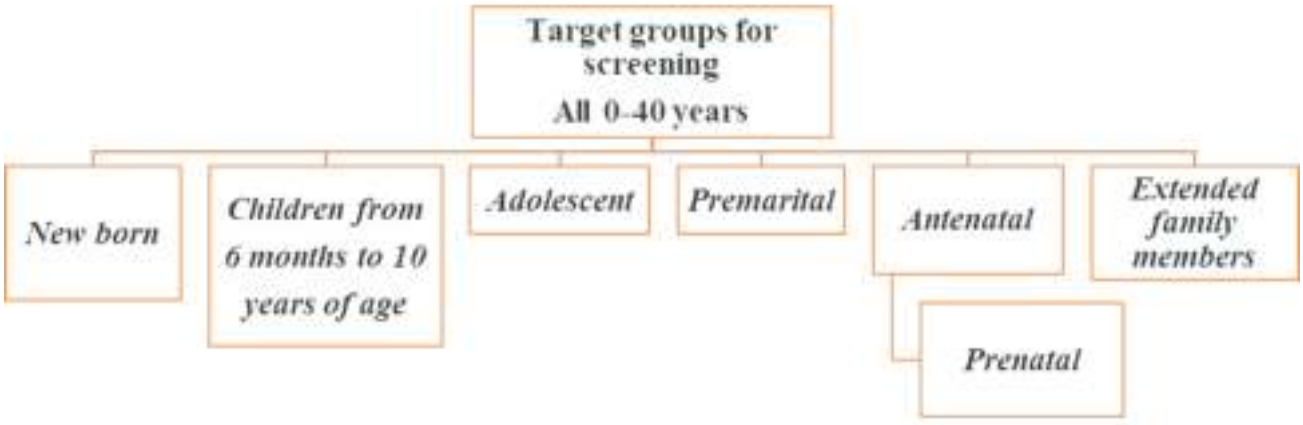
Figure 5 Solubility test

2. Point of Care Test (POC) – It is a confirmatory test. This test can be done both at the community and facility level. It distinguishes between normal, carrier and diseased individual.

Figure 6 Point of care test

Therefore, we should first identify the status of the individuals, and then proceed towards management of the disease. In sickle cell prevalent areas, universal screening of all population up to the age of 18 years is done using a mass screening approach in the first year and the entire population up to 40 years is to be screened subsequently and incrementally in three years.

Certain target groups are identified in the community for screening. These target groups are given below in the flow chart.



For prevention of Sickle Cell Disease, there are certain target groups that you should consider. The following table describes the various screening approaches and your role in each approach.

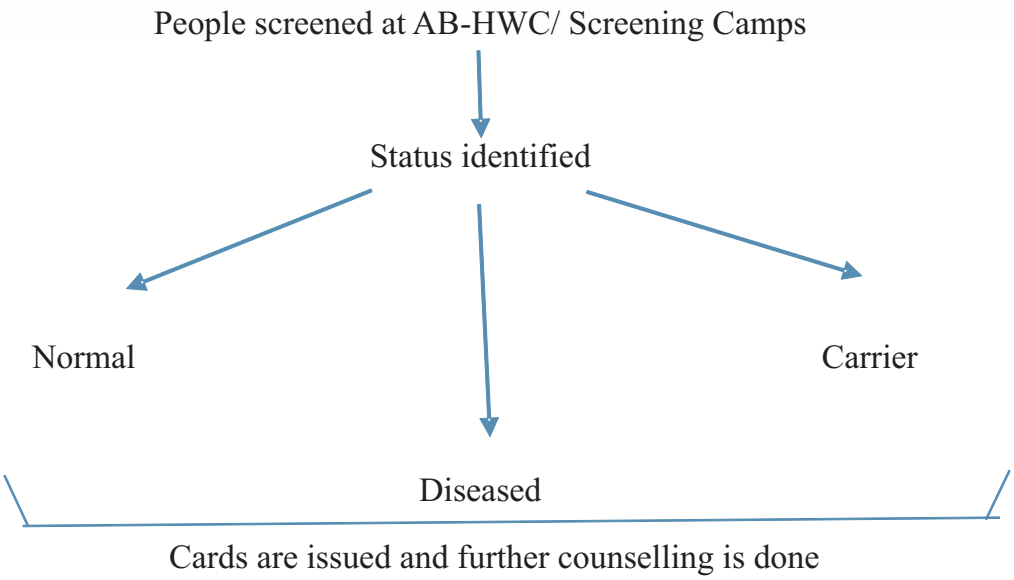
Table 1 Target groups for SCD Screening

Target groups	Setting	Your Role
Newborn	Conducted at all public health institutions conducting institutional deliveries, in sickle cell endemic areas	Motivating and counselling mothers to screen their babies.
Children from 6 months to 10 years of age	At AB-HWCs, Anganwadi centres, outreach camps, and Schools, with the help of Rashtriya Bal Swasthya Karyakram (RBSK) team.	Counselling parents to take their children to screening camps. Follow up of the positive cases for treatment adherence
Adolescent	At primary care facilities, Schools, and outreach camps. Rastriya Kishore Swasthya Karyakram (RKSK) shall be leveraged for the awareness and screening of adolescents.	Counselling parents to take their children to screening camps. Follow up of the positive cases for treatment adherence.
Premarital	At primary care facilities or outreach camps	Initial counselling of people of marital age and further motivate them to visit the nearest HWC for facility-based counselling
Antenatal	At all AB-HWCs	Initial counselling of pregnant women and further motivate them to visit nearest HWC for facility-based counselling.
Prenatal diagnosis	At the tertiary care facilities	Facilitate educating couples and motivating mothers by a specialist.
Extended family members	Outreach screening and facility-based camps.	Generating awareness in the community. Mobilising and motivating people for screening in Sickle cell disease prevalent areas.

Now, as we have understood from the above table that your role is mainly directed towards awareness generation, Mobilisation, and counselling for the prevention of sickle cell disease.

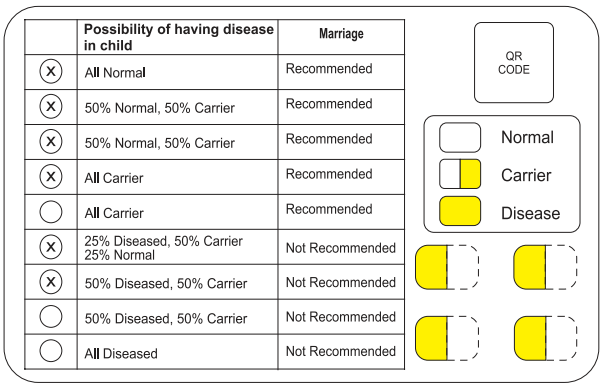
2.2 Sickle Cell Status Identity Cards

Every individual who is screened for SCD will be provided with a Sickle cell card. The card will show the status of the individual viz, Normal, Carrier or Diseased. The cards will be color coded separately for males (blue) and females (pink). Based on the card's status the individual will receive treatment and counselling services.

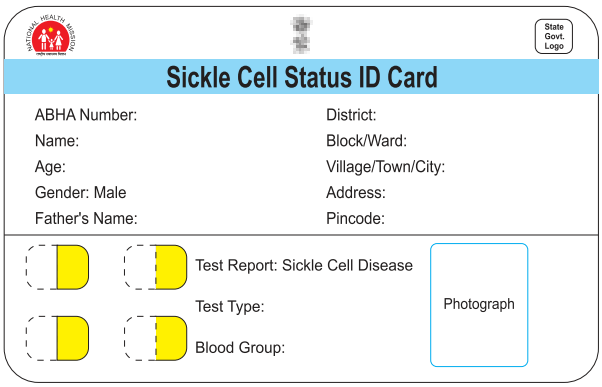


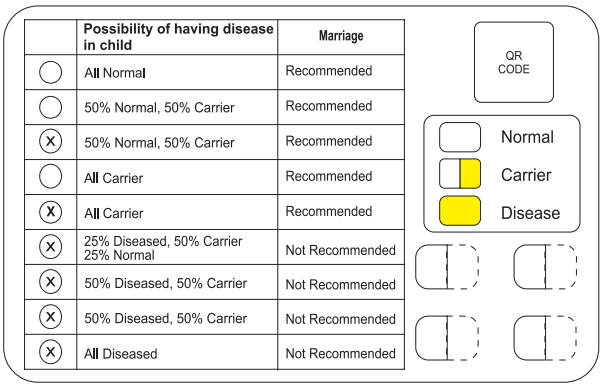
- The card contains details such as gender, and test report (Sickle cell disease/ sickle cell carrier/ Normal) on the front side of the card. On the back of the card possibility of having the disease in a child is explained for two individuals having sickle cell cards.
- In each sickle cell card, there will be three holes present on the extreme left on the back side of the card. While matching two sickle cell cards (1 male and 1 female card) the three holes in one card will coincide with the in another card at two places. At one position both card's holes will completely coincide and no ⓧ will be seen. The individual should check the statement written adjacent to that position.
- The back-side of the card contains possible outcomes of conception if any persons having sickle cell disease or carrier status marry.

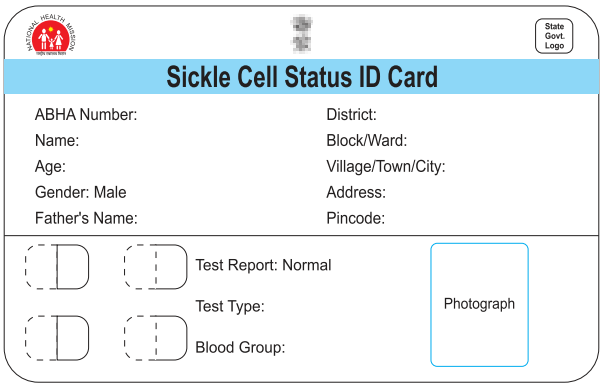
Cards distributed to males are of blue colour as depicted in the figure below:

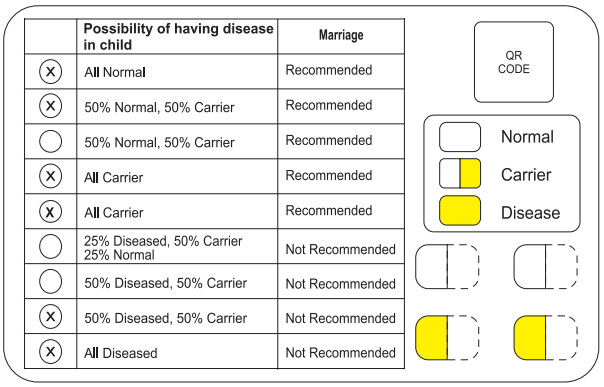


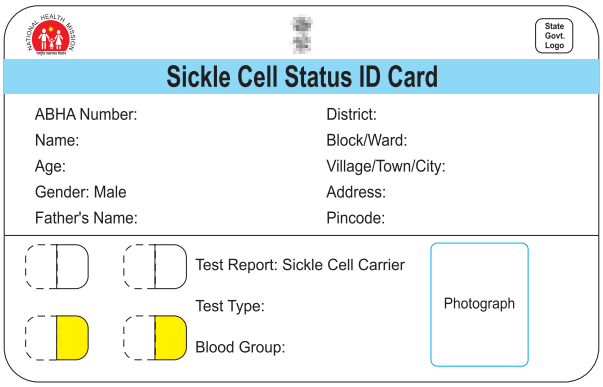
	Possibility of having disease in child	Marriage
ⓧ	All Normal	Recommended
ⓧ	50% Normal, 50% Carrier	Recommended
ⓧ	50% Normal, 50% Carrier	Recommended
ⓧ	All Carrier	Recommended
○	All Carrier	Recommended
ⓧ	25% Diseased, 50% Carrier 25% Normal	Not Recommended
ⓧ	50% Diseased, 50% Carrier	Not Recommended
○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



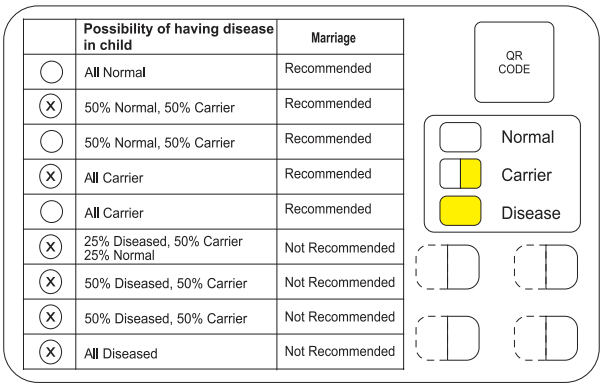


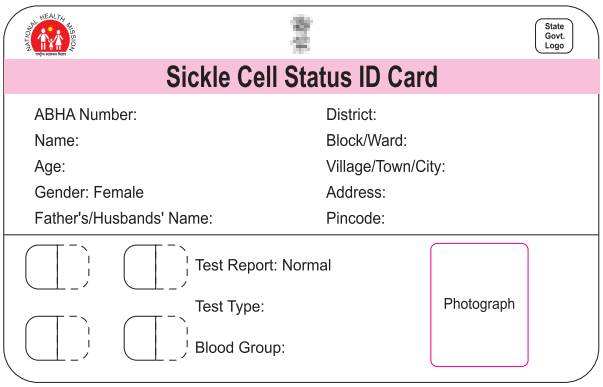


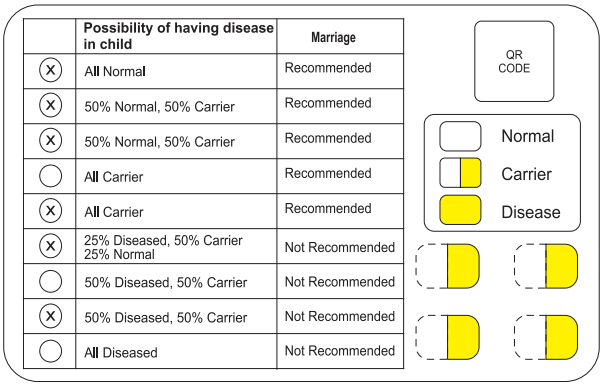


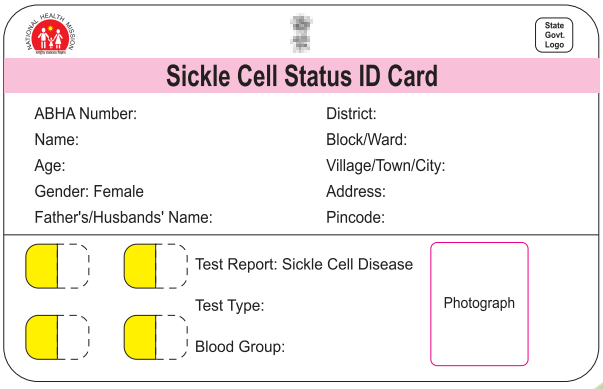


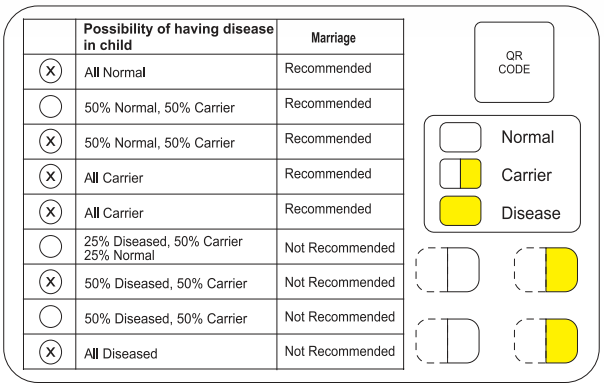
Cards distributed to females are of pink colour as depicted in the figure below:

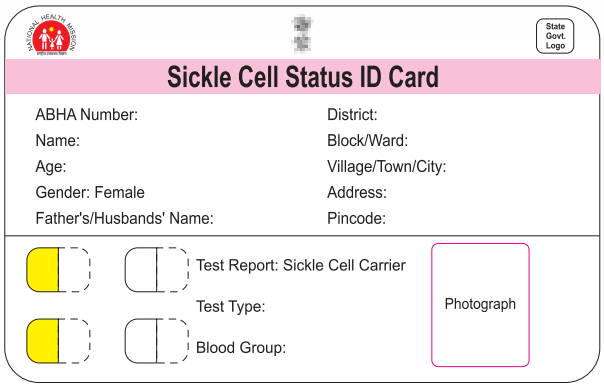












It is important for you to know about the services available at AB-HWC. This will help you to refer people to Health and Wellness Centres. You can also explain about these services at the time of counselling.

2.3 Services available for Sickle Cell Disease at Ayushman Bharat Health and Wellness Centres

A. At Sub Health Centre-Health and Wellness Centre (SHC-HWC)/ Urban Health and Wellness Centre (UHWC)

- Opportunistic outpatient-based screening of individuals at AB-HWCs
- Screening at all AB-HWCs both for outpatients and in scheduled facility-based screening camps
- Screening of referred cases from the outreach camps
- Couple/Individual counselling for families affected by SCD.
- Referral of screened cases for confirmation of diagnosis and treatment initiation at higher centres
- Teleconsultation services to higher centres
- Follow-up services for patients on SCD treatment.
- Provision of necessary drugs, diagnostic tests, and vaccinations for SCD patients.

B. At PHC-HWC/UPHC-HWC level

- Screening and confirmatory test
- Couple/Individual counselling for families affected by SCD.
- Teleconsultation services to higher centres
- Tele-counselling for nutrition, stress management and treatment adherence
- Prophylactic penicillin and vaccinations for new-borns
- Holistic management of crisis
- Mapping and Facilitation of patients for community adoption
- Provision of necessary drugs, diagnostic tests, and vaccinations for SCD patients.

2.4 Important Community Platforms to be leveraged for awareness generation:

A. Village Health and Nutrition Day (VHND) –

- Educate people about Sickle cell disease
- Generate awareness with respect to myths related to the disease.
- Educate about dietary modification for management of SCD (these are explained later in the manual)
- Follow-up care
- Ensure immunisation of children against vaccine-preventable diseases to prevent infections in sickle cell-diseased children.
- Bring together all SCD-positive people to form a peer support group.

B. Village Health and Sanitation Committee (VHSNC)

- As a member secretary of VHSNC, ASHA should draw the attention of the VHSNC/MAS to sickle cell disease prevalence, prevention, and awareness generation.
- As a member of the HWC team and VHSNC, MPW (M/F) will provide information to VHSNC regarding the services available at the AB-HWCs for Sickle Cell Disease Management.
- Conduct discussions on the formation of peer support groups.

C. Mahila Arogya Samiti (MAS) and Community Arogya Samiti (CAS)

- As a member secretary of MAS, ASHA should draw the attention of the MAS to sickle cell disease prevalence, prevention, and awareness generation.

D. Jan Arogya Samiti (JAS)

- As a member of JAS, you should brief JAS about the issues related to SCD and its status in the area and may advise on organising health promotion activities related to Sickle cell disease.

E. Health Melas

- MPW (M/F) should support CHO in organising health promotion activities.
- ASHA should mobilise people for health mela.
- Provide immunisation services in health melas
- Screen for sickle cell diseases

CHAPTER 3:
ROLE OF MPW-M/F/ASHA IN SCD PREVENTION AND COUNSELLING

Let us now read about your roles in detail.

3.1 At individual/household level:

- You should be engaged in raising awareness against SCDs through home visits
- You should make a line listing of identified SCD carrier and SCD patients within your catchment area.
- You should prepare a list of eligible couples, which may be linked with the programme to identify and provide genetic counselling and mobilize the couples to the nearest Ayushman Bharat Health and Wellness Centre (AB-HWC)
- Motivate pregnant women and their partners to screen for SCD
- Follow-up of diagnosed individuals for undergoing treatment
- Follow-up of the patients undergoing hydroxyurea therapy

3.2 At Community-level:

- You as a member of community platforms (VHSNC, JAS, MAS) should leverage these platforms to sensitize people on the importance of sickle cell disease and screening service available at AB-HWCs
- You should mobilize the eligible population for screening camps/ facility-level screening
- You should mobilise patients for Patients Support Group (PSG) meetings with support from ANM/CHO/MO.
- You should facilitate discussions for experience sharing by patients and caregivers and to enhance treatment adherence.
- You should refer all the eligible individuals and couples identified as positive or carriers either at the community level to the CHO at SHC-HWC for further advise.
- Support CHO in conducting outreach screening camps for sickle cell anaemia
- Screening of remote and inaccessible tribal hamlets through Mobile Medical Units
- Counselling and social support
- Referral of screened patients with solubility test positive
- Screening of children in Anganwadis / Schools / Ashramshalas

3.3 Key messages for Counselling

A. Dietary Modification

You must tell them about following dietary modifications

- Prefer food having carbohydrates which do not rapidly increase sugar level in blood. They should be rich in fibre to maintain a healthy gut and immunity. e.g. whole cereals and grains, millets, whole pulses and legumes
- Include vegetable and animal sources of protein in the diet, such as nuts, milk, pulses and legumes or egg, fish, meat.
- Use healthy fats for cooking e.g. fats from plant origin and nuts &seed oils e.g. Ground nut oil, mustard oil, coconut oil.
- Include locally available seasonal fruits and vegetables of different colours in the diet to meet required fibre, and nutrients.
- Consume water and other liquids to maintain hydration.
- Frequent meals/ feeds at regular intervals should be taken to achieve the desired goal of nutrition.

Restrict foods which lower immunity

- Bakery items
- Refined cereal and grains
- Packaged foods, sweetened Juices and cold drinks
- Excess fat, sugar and salty food items

B. Support for adolescents

The adolescence period is a difficult time emotionally and in patients with chronic diseases, like SCD, this leads to more stress. The adolescent may be busy with school studies and forget to take medicines, drink fluids, may become irregular with meals. Teens may be irritable and moody, with altered sleep cycles. Adolescents may rebel and become less compliant with treatment. This transitional time can be high risk for non-compliance and psycho –social problems complicating treatment compliance.

Some simple steps to assist adolescent to reach to selfcare:

- Ensure adequate knowledge about general health maintenance
- Explain why pain occur and practical things to help- fluids, diet, medicines, malaria prevention
- Introduce to peers/ support groups if not already
- Have role models from community
- Assess for inadequate coping and depression
- Community programs or SCD family programs to explain about normal teenage behaviour can be helpful

C. Patients on treatment

- Patients should be reminded that the effectiveness of medication (hydroxyurea) depends on their adherence to daily dosing
- Should be counselled not to double doses if a dose is missed
- Females of reproductive age should be counselled about consulting doctors regarding medication (hydroxyurea) prior to conceiving
- Clinical response to treatment may take 3 to 6 months

Annexure 1 - Solubility test

The solubility test is done to identify altered haemoglobin, 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

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
5. Use the buffer within 45 days

Procedure

1. Prepare the working solution. If already prepared bring 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 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. Positive result (presence of sickled haemoglobin) – If the solution turns turbid and the background lines are not visible
2. Compare the turbidity of tst solution with negative control solution if observed more solution 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. Negative result (no presence of sickled haemoglobin) – If the clear or turbid solution permits the lines to be seen through the tube. Slight greyish matter on top of deep red haemolysate.
6. If in confusion refer the case for electrophoresis

LIST OF ABBREVIATIONS

AB-HWC	Ayushman Bharat - Health and Wellness Centres
ANM	Auxiliary Nurse Midwife
ASHA	Accredited Social Health Activist
CAS	Community Arogya Samiti
CHC	Community Health Centre
CHO	Community Health Officer
CPHC	Comprehensive Primary Healthcare
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
MPW	Multipurpose Worker
OPD	Outdoor Patient Department
PHC-HWC	Primary Health Centre– Health and Wellness Centre
PoC	Point of Care
RBC	Red Blood Cell
RBSK	Rashtriya Bal Swasthya Karyakram
RKSK	Rashtriya Kishore Swasthya Karyakram
SCD	Sickle Cell Disease
SCT	Sickle Cell Trait
SHC-HWC	Sub Health Centre - Health and Wellness Centre
SDG	Sustainable Development Goal
SN	Staff Nurse
UHWC	Urban Health and Wellness Centre
UPHC-HWC	Urban Primary Health Centre – Health and Wellness Centre
VHSNC	Village Health, Sanitation, and Nutrition Committees

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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:

- https://instagram.com/ayushmanhwcs
- https://twitter.com/AyushmanHWCs
- https://www.facebook.com/AyushmanHWCs
- https://www.youtube.com/c/NHSRC_MoHFW

National Health Systems Resource Centre