REPORT

Evaluation of implementation of Sickle cell disease control program in State of Maharashtra: Comparison of performance in selected district Covered by NGOs and ASHAs

Interim Report of performance Appraisal of 9 districts covered by NGOS

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Submitted by :

Department of Community Medicine

Grant Government Medical College, Mumbai.

Central Coordinating Team

Principal Investigators

Dr.(Mrs.) Sulbha V. Akarte,
Professor & Head,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Dr.Lalit Raghunath Sankhe,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Co - Principal Investigators

Dr.Suresh Ughade,
Assistant Professor in Biostatistics,
Department of Community Medicine,
Govt. Medical College,
Nagpur.

Dr. Chhaya Rajguru (Waghmare) ,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Dr.Pallavi A. Uplap,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Co-Investigators at Partnering Institutes

Government Medical College, Nagpur

Dr. Arun Humne
Professor and Head,
Department of Community Medicine,
Government Medical College, Nagpur

Indira Gandhi Medical College, Nagpur

Dr. M. B. Khamgaonkar
Professor and Head,
Department of Community Medicine,
Indira Gandhi Medical College, Nagpur

Shri Bhausaheb Hire Government Medical College, Dhule

Dr. Muralidhar P Tambe
Professor & Head
Department of Community Medicine,
Dhule, Maharashtra

Dr. Amol R. Patil
Assistant Professor,
Department of Community Medicine,
Dhule, Maharashtra

Datta Meghe Institute of Medical Sciences, Wardha

Dr. Abhay Gaidhane,
Professor, Community Medicine, JNMC
Datta Meghe Institute of Medical Sciences,
Wardha

Dr. Quazi Syed Zahiruddin,
Professor, Community Medicine, JNMC
Datta Meghe Institute of Medical Sciences,
Wardha

Grant Government Medical College, Mumbai

Dr. Priya Warbhe
Dr. Ashwini Chikhalkar
Dr.Naresh Gill
Dr. Amandeep kaur Ratta
Dr.Shailesh Palve
Dr. Viraj Karuley

Report Writing Team Members

Dr. Chhaya Rajguru (Waghmare) ,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Dr. Pallavi A. Uplap,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Dr.Amandeep Kaur Ratta,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Dr. Viraj S. Karuley,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

Dr. Shailesh P. Palve,
Assistant Professor,
Department of Community Medicine,
Grant Govt. Medical College,
Byculla, Mumbai.

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List of Abbreviations

ASHA	:	Accredited Social Health Activist
ANM	:	Auxiliary Nursing Midwife
CS	:	Civil Surgeon
DC	:	District Coordinator
DDHS	:	Deputy Director Health Services
DHO	:	District Health Officer
DRCHO	:	District Reproductive & Child Health Officer
HA	:	Health Assistant
HPLC	:	High Performance Liquid Chromatography
IEC	:	Information, Education & Communication
MD-NRHM	:	Managing Director-National Rural Health Mission
MO	:	Medical Officer
MPW	:	Multi-Purpose Worker
MS	:	Medical Superintendent
NGO	:	Non-Governmental Organization
NRHM	:	National Rural Health Mission
PRI	:	Panchayat Raj Institutions
SCD	:	Sickle Cell Disease
SCDCP	:	Sickle Cell Disease Control Program
SHG	:	Self Help Group
SHSRC		State Health System Resource Centre
TMO	:	Taluka Medical Officer

Acknowledgment

We are very thankful to the Director of Medical Education, State of Maharashtra and Dean, Grant Government Medical College, Mumbai for entrusting us with the responsibility to conduct such an extensive study throughout the State of Maharashtra.

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The completion of this project would not have been possible without the dedicated effort of our team. The relentless pursuance and perseverance of our team has made it possible for us to conclude this extensive study.

Last but not the least our thanks to the data entry operators for their persistence and everyone in anyway associated with the project.

EXECUTIVE SUMMARY

INTRODUCTION

Sickle Cell Disease, a genetic blood disorder affects almost 2% to 35% of the tribal communities in specific districts of Maharashtra. The Disease though not curable is entirely preventable. Being the second most common haemoglobinopathy after thalassemia, it affects the quality of life of the sufferers, reduces the life expectancy and passes on to the next generation.

The Government of Maharashtra with the aim to control sickle cell disease in Maharashtra implemented the Sickle cell disease control program (SCDCP) in 20 districts of Maharashtra. The program was implemented in a phase wise manner. Initially the program was implemented in the high prevalent districts through Non-Governmental Organisation with specific focus on increasing the awareness towards Sickle Cell Disease, screening the population and counselling for preventing the occurrence of Sickle Cell Disease in future generation. In the next phase the same was implemented in other districts through the existing Health system mainly through the ASHAs.

Need of the study:

It's almost 7 yrs that the program is implemented in these districts. The Govt of Maharashtra aims to evaluate the performance of the districts. The study has been designed to evaluate the districts based on the physical, process, performance and financial indicators. This study will present a thorough assessment and situational analysis of the stakeholders, so as to provide scientific evidence to the policy makers, to decide the implementing agency for sickle cell disease control program in Maharashtra.

Objective of the study:

The present study was a process and performance evaluation of NGO and ASHA serving districts in implementation of Sickle cell disease control program in the State of Maharashtra.

Primary Objective:

- To evaluate the performance of the NGO operating Districts for the implementation of Sickle cell disease control program.
- To evaluate the performance of the ASHA operating Districts for the implementation of Sickle cell disease control program
- To compare the performances of the NGO and ASHA operating Districts and find out their strengths and weaknesses in implementation of Sickle cell disease control program
- To suggest suitable recommendations based on the findings of this evaluation exercise

Specific Objectives:

- To conduct physical assessment of the selected districts with respect to infrastructure, manpower, availability of medicines etc

- To conduct process evaluation of the above districts with respect to Various activities entrusted like- flow of funds, maintaining records, conducting meetings, Organising IEC activities, Organising Camps etc.
- To conduct performance evaluation of the above districts with respect to achieving the given targets and improvement of outcome indicators.
- To conduct financial evaluation of the above districts for appropriate utilisation of sanctioned funds.
- To identify the strengths and weaknesses in the implementation of the program through above mentioned service providers.
- To assess the awareness regarding sickle cell disease and SCDCP among the stakeholders.
- To make appropriate recommendations for better implementation of the sickle cell disease control program in Maharashtra state.

Study details:

The Study was designed to be conducted in 13 districts of Maharashtra, of which all the 9 NGO districts and 4 Districts where health system is implementing the program through ASHAs are included.

Data was collected through in-depth interviews with a range of stakeholders identified from policy makers, planners and implementers to the beneficiaries. Focus group discussions were also conducted in representative and homogeneous samples of grass root level workers and the beneficiaries, which will address areas pertaining to the study objectives.

Quantitative assessment of the performances of ASHAs and SCD assistants under NGOs was also undertaken on the basis of comparisons of defined indicators. Physical assessment of health care facilities and evaluation of financial inputs and utilization through pre-designed and pre-tested questionnaires was conducted and data quality for completeness, accuracy and reliability was periodically monitored by the team members.

Ethical clearance:

Proposed study was placed before Grant Government Medical College and Sir J.J. hospital ethics committee for approval. The letter of approval was forwarded to the partnering institute for ethical approval at the respective institutes.

The detail of the districts where the study is conducted is as follows:

Sr No	District	Service provider	Name of the NGO
1	Thane,	NGO	Navoday Gramin Sanstha, Jawhar
2	Nashik	NGO	Gauri samajik Sanstha, Nashik
3	Aurangabad	ASHAs	----
4	Bhandara	NGO	Bharatiya Aushadhi Anuisandhan Sanstha
5	Gondia	NGO	Prabuddha vinayaki kalyankari sanstha, Tirida

6	Nagpur	NGO	Aniket Bahudishiya Sanstha, Umred
7	Chandrapur	NGO	Sarvodaya yuvavikas sanstha, Chimur
8	Gadhchiroli	NGO	Arogyadham Kustharog Nirmulan Sanstha, Kurkheda, Ektal Samajik Shishan Sanstha,
9	Wardha	NGO	Shri Namdev maharaj bahuuddeshiya shikshan sanstha
10	Yavatmal	ASHAs	----
11	Amaravati	ASHAs	----
12	Dhule	ASHAs	------
13	Nandurbar	NGO	Jijau Maratha Mahila Samaj Unnati Mandal

The participating agencies:

The NRHM –Maharashtra initiated the study and State Health Society proposed the present study under the Health Department Government of Maharashtra. Department of Community Medicine, Grant Government Medical College, Mumbai was the central coordinating team and along with investigators from the following Medical Colleges has conducted the study:

Sr. No	**Participating Centres**	**Districts**	**Sickle Cell Disease Control Program Service providers**
1	Department of Community Medicine, Grant Government Medical College, Mumbai	Thane, Nashik Aurangabad	NGO NGO ASHAs
2	Department of Community Medicine, Government Medical College, Nagpur	Bhandara Gondia Nagpur	NGO NGO NGO
3	Department of Community Medicine, Indira Gandhi Medical College, Nagpur	Chandrapur Gadhchiroli	NGO NGO
4	Department of Community Medicine, Datta Meghe Institute of Medical Sciences, Wardha	Wardha Yavatmal Amravati	NGOS ASHAs ASHAs
5	Department of Community Medicine, Government Medical College, Dhule	Dhule Nandurbar	ASHAs NGO

The stakeholders interviewed were as follows:

Policy Makers	MD-NRHM
	Director Health Service
	State Programme Manager (Jt. Director Health Service)
Planners	State Program Officer
	District Project Coordinator
	Deputy Director, circle
Implementers	DHO, Civil Surgeon

	Taluka Medical Officer, Medical Officer, Medical Superintendent
	HA,ANM,MPW,ASHAs,
Beneficiaries	Sickle Cell Disease Sufferers and Carriers
	Relatives / Caregivers of Sickle Cell Disease Sufferers and Carriers
NGO Representatives	NGO In Charge
	Project Coordinator
	Supervisor
	Volunteer
Community Representatives	Self-Help Groups/Mahila Mandals /PRIs etc.

KEY STUDY FINDINGS

In all, nine NGO districts were evaluated for their performance regarding Sickle cell disease control program in the State of Maharashtra. The information was collected by a team of investigators who were faculty members and postgraduate students from Community Medicine department of selected government Medical Colleges. The information was in the form of interviews of all the stakeholders as well as the assessment of the NGO based on defined indicators to assess their infrastructure facilities and logistics management, procedure followed, performance with regards to outcome and impact of the program and financial assessment .The key findings of the study are as follows:

Opinions and perceptions of policy makers and the state level implementers:

The view point of the various stakeholders at the state level was acquired. The state level officials like Director Health Services (DHS), MD-NRHM, Joint Director-NRHM, State Program Officer, State coordinator and Deputy Directors of the concerned circles were interviewed. The aim was to get an overall view of the stakeholders specifically with regards to the implementation of the sickle cell disease control program in the state and the challenges faced by them and their opinion about better implementation of the program.

The stakeholders at the state level, more or less had the same point of view as given below:

Everyone felt that, Sickle cell disease control program is very much needed in the state. It was a known fact by all that, the disease though not curable, can be successfully prevented by increasing the awareness about sickle cell disease, screening of the susceptible population and providing supportive health services to the sufferers so as to improve their quality of life.

The sickle cell disease as compared to other disease under various national health programs is definitely not on the priority list of the state health department. The same outlook is reflected in opinions of few officials of the District as well as few of the Medical officers.

The stakeholders unanimously accepted the fact that the funding received for the sickle cell disease control program is not adequate and there is inadequate supply of solubility kits, which affects the program and its outcome. Though the manpower is adequate, the training of the manpower needs to be improved.

When mentioning about the constraints, the group felt that, the monitoring and the supervision of the NGOs is a challenge for the state level officers, as it is based on the reporting system. A few of the NGOs even after constant reminders do not submit the report on time, whereas there is inconsistency in the figures submitted by some NGOs. Direct supervision of the NGOs is not feasible as they do not directly report to the District Officials since they are not part of the system. There is a need to improve the commitment of district level officials towards the SCDCP. It was observed by almost all the officials that, the screening of the susceptible population mainly the tribal population shows progression, but the given targets are not met.

Almost all of them suggested that, there is a need for the IEC component of the program to be strengthened further.

All the stakeholders felt that the Sickle cell disease program can be implemented through ASHAs, as the ASHAs being a part of the health system and the monitoring can be done easily. Also if the cost of SCDCP implementation through the NGOs and ASHAs is compared, the cost is reduced considerably if implemented through ASHAs.

Awareness of the various stakeholders about Sickle cell Disease and Sickle cell disease control program:

- The knowledge of the higher district level officials (DHO, DRCHO, CS, and MS) and the TMO, MO (PHC) regarding sickle cell disease was adequate. In some cases however the knowledge of the Medical Officers and the Taluka Medical Officer was not adequate. It was also observed that the knowledge of the MBBS doctors regarding sickle cell disease was better as compared the AYUSH doctors. Though their knowledge about the Sickle cell disease control program was satisfactory, but they were not clear enough about their potential role and responsibility specific to the SCDCP.
- The awareness of the ANM, MPW, HA regarding SCD was adequate but limited to specifics, such as sickle cell crisis was not known. They knew about the management of sickle cell crisis and referral of the patient to higher centre. They had adequate knowledge about the SCDCP; the services provided under the program but were completely unaware about HPLC.
- The knowledge of the ASHAs was not adequate, though many were aware, of the sickle cell disease but the details about the aetiology, precautions to be taken by the patient, sickle cell crisis was not known to them. Also they were well versed with the SCDCP and the services provided under the program but were not aware of HPLC.
- The NGO In charge, Coordinator, Supervisor as well as the volunteers had good knowledge of SCD as well as the SCDCP.
- The sufferers, carriers and the caregivers being the beneficiaries of the program, almost half of them were aware of the basic facts of the disease and the SCDCP, but were not much aware about need of medical check -ups, frequency of Medical check -ups, precautions to be taken.
- The Self- Help Group and the PRI did not have adequate knowledge about the sickle cell disease as well as the SCDCP.

Overview of the training component of the program:

- Almost all the health officials were trained under the program, mostly for one day by the district training team (DTT). Except a few, almost all of those who were trained , were not satisfied with the training, and felt that the duration of the training was inadequate and also the contents were not covered in detail.
- The same findings were observed about the training of the ANM / MPW / HA / ASHA. There were no refresher sessions conducted by the concerned authorities for them.
- The training of the NGO staff was conducted by District training team, for one day or by the NGO itself at the NGO office. The NGO volunteers were periodically sensitised during monthly review meetings of the NGO staff and also by a few refresher sessions conducted by the NGO coordinator or NGO in -charge.
- The Self Help Groups or the PRI were not given any training for the same.

Service Delivery:

- The services provided under the program were increasing the awareness about the disease and the Sickle cell disease control program. The focus being on screening the target population for SCD with solubility test and confirming with electrophoresis. The patients suffering from the disease are supposed to be categorised as sufferer or carrier, based on HPLC.
- Other services, like follow up of the sufferers, so as to provide them with supportive services as well as identify the warning signs of sickle cell crisis was not adequately delivered. Many of the NGO volunteers did not strictly adhere to the no of times the sufferer has to be visited.
- Timely sending of samples for electrophoresis and HPLC with strict follow up of the results was lacking in almost all the NGOs.
- The facility of Telemedicine was not used to its full potential, due to the issues like non-availability of funds or insufficient funds provided by the funding agency for transportation of the patient from his village to the telemedicine centre, also the non-availability of the telemedicine personnel.
- The day care facilities designed specifically to deal with the sickle cell crisis patients were functional at district level, but the availability of doctors and nursing staff was inadequate. Also the day care centres were not well placed; the number of day care centres was very less, especially in case of high prevalent districts.
- Insufficient awareness about SCD in the affected as well as general population influences the utilisation of services by the community.

Reporting in Sickle cell disease control program

- According to the State level officials, the reports are received by them regularly and timely, except a few (two) districts where the NGO has to be reminded several times for timely submission of report.
- The report though submitted on time lacks the accuracy and reliability of the data provided, as discrepancy in the figures is noted in a few NGOs.

Monitoring of the program

- Proper guidelines and precise indicators at various level of monitoring were not well defined.
- Monitoring by Medical officer (PHC) and the officials at district level with less involvement was observed since the program is implemented by NGO hence they feel less accountable for the SCDCP
- The supervisory visits were found not dedicated solely to sickle cell monitoring, but taken as a combined activity with many other scheduled activities at one particular time.

Involvement and co-operation of all stakeholders

- The sickle cell disease is as a whole not given priority as compared to other national health programs like Maternal and Child Health, Vector borne disease etc.
- The lack of accountability reflects in the level of priority given to sickle cell disease program, the cooperation by the officials of health system, involvement in the activities of the program.
- Though in some instances the coordination of the NGO and the health system staff seems to be good but overall it was not up to the expected level.
- The district coordinator was doing a good job, but it was also observed that he is being involved in activities of other programs, not related to sickle cell disease, leading to diversion of his focus from SCDCP.
- The involvement of the Self-help group and the PRI was found to be inadequate.
- The involvement of health workers specifically the ANM/ MPW/HA was not adequate, again due to lack of accountability and the feeling that this was NGO's job.
- The ASHAs involvement though found at average level, but their perceptions about SCDCP showed promising results in the future.
- The community involvement regarding the SCDCP was also found average. Further, the community involvement was found to be influenced by many factors like awareness of the disease and the program, acceptability, accessibility, the feeling of belongingness to the program, their need for the services.

Comprehensive opinion of the stakeholders about the program being implemented by ASHAs or NGOs in future:

Considering the opinions of all the stake holders, there is an equal divide between those saying that NGO will implement the program better, and otherwise. The reasons cited for better NGO work being...– the NGO volunteers are focused only on the sickle cell disease and the activities under the SCDCP , ASHAs have other programs to handle , they are overburdened , as ASHA s are incentive based workforce , there is a tendency to work better in the program where the incentives are more. However, equal no of stakeholders felt that ASHA will be able to implement it in a better way, the reasons cited as – ASHA is a volunteer from the local residents itself and serves only 1000 population , so she will be more accessible and acceptable. Also she will be reporting to the health system, indirectly making the health system accountable for the program, which will improve the monitoring of the program. The performance of the program can also be closely monitored.

Infrastructure and logistics assessment:

All the NGOs assessed for infrastructure met the standards defined for space, electricity, furniture, staff requirement, except a few who did not have adequate space. Availability of vehicle for transportation was an important issue for a few of them. The IEC material was adequate and the medicines were available. But, uninterrupted supply of solubility kits and delayed release of funds were some of the major highlighted issues.

Process and performance assessment:

Based on the given indicators for process and performance all the NGOs scored well except in cases where the given target coverage was not satisfactory. Also the supervisory meetings, review meetings, meetings with the other stakeholders like ANM/ASHA/Anganwadi workers , details of the counselling sessions conducted and details of the camps organised was not well maintained. The data for some indicators was not maintained by the NGOs and was not available.

Financial assessment :

Based on the assessment indicators, all the NGOs scored good in the financial assessment .

Recommendations:

Prioritising SCDCP:

- Though the need of the program is acknowledged by all stakeholders , both Sickle cell disease and sickle cell disease control program should be given equal priority as compared to other national health programs, especially in the high prevalence districts of Maharashtra.
- There is a need to sensitise all the health system stakeholders, specifically the District level officials to the MO –PHC regarding the importance of the program.

Enhancing the Training:

- Training - the backbone of any program is also most important link for the success of the SCDCP.
- There is an urgent need to enhance the training component of the SCDCP.
- The district officials (DHO, DRCHO, MS, CS) as well as the MO –PHC along with the grass root level staff (ANM, MPW, HA) should be properly and adequately trained.
- For the district officials the training should be more to imbibe the importance of the program and administrative training regarding the monitoring and supervision of the program; however the basic details of the disease and the services provided under this program should also be stressed up on.
- There is a need to train the health system staff very rigorously about the disease as well as the program and handover the responsibility of the success of the program to the staff.
- The ASHAs should to be thoroughly trained, as they are the first contact with the community, they should not only be trained about the basics of the disease and program but also focus should be

given on enhancing their counselling skills. They should also be trained to maintain proper records and prepare accurate report.

- There should be regular training of the NGO volunteers/Supervisor scheduled throughout the year at regular intervals so as to sensitise them frequently and provide training to the newly recruited NGO volunteers.
- There is a need to periodically revise the contents of the training, so as to include more details about the disease and program and to make it more comprehensive.
- The duration of the induction training should be at least for 3 days followed by 1 day of refresher trainings. It should be made compulsory for every ANM to ASHA and NGO staff to attend at least one refreshers training in a year in addition to the initial induction training.
- More focus and efforts should be diverted towards strengthening the training component of SCDCP.

Regular Funds, Logistics supply

- Regularity and adequacy are the two important issues in any program , which predicts the success of any program
- The state level administration should ensure the regularity and adequacy of funds.
- The funding agency should ensure that there is uninterrupted supply of solubility kit, which is a must if the population has to be screened and the targets are to be met.
- In case of inadequate supply, the implementing agency should be empowered to locally purchase the kits, from the standard companies (list should be provided) .
- There is a need to increase the number of electrophoresis centres in the high prevalence districts. Or provision should be made to get the samples tested in the nearby private laboratories in case of the electrophoresis centres being very far away from the collection point and also in case of electrophoresis machines not being in working condition.
- The medicines should be regularly supplied or in case of short supply the MO –PHC should be instructed to provide for the medicines from untied funds,
- Provision of at least more HPLC centres in high prevalent districts.

Strengthening IEC:

Increasing the awareness of the affected population as well as the general population is the key objective of the program.

- Rigorous, innovative and consistent efforts to strengthen the IEC should be taken.
- New and more impressive IEC materials should be designed.
- Every opportunity of contact with the community should be explored to inform and educate them.
- Newer opportunities should be created by organising entertainment for the community so as to bring them together.
- The IEC of SCD should not be clubbed with IEC of any other program and should not be specifically restricted to a campaign mode like SC day and SC week.

Increasing the Coordination and cooperation between the stakeholders:

- There is a need to place the responsibility and accountability at every level of health care delivery system.
- The involvement of the stakeholders will increase if they are made accountable for the success of the program.
- The NGOs should be prompted to increase the communication and coordination with the health system staff.
- Steps should be taken to involve the self-help groups and PRI members and their assistance should be taken to increase the awareness in the community.
- The community should be provided with easy access to services which are acceptable to them ,and factors responsible for their active participation should be identified (like providing transportation cost to the sufferers, financial assistance to the sufferer , health insurance to the sufferer covering his medical expenses , empowering the affected population to become financially independent by providing them with self-employment or other such opportunities) which will certainly motivate the community to actively participate in the program
- Networking with other sectors for overall enhancement of the quality of life of the people affected by the disease should be the focus of the program, rather than only providing them with medicines.

Improving the service delivery:

- The services provided under this program should be acceptable and accessible
- The community should be counselled to utilise the services.
- There should be uninterrupted provision of services, so as to build trust in the community regarding the program.
- Provision of quality services is a must.

Monitoring and evaluation:

Continuous monitoring, frequent evaluations are needed for the consistent improvement of the program:

- Specific monitoring and evaluation guidelines should be formulated for SCDCP.
- Precise monitoring indicators should be identified. There is a need to revise the current monitoring indicators under SCDCP.
- Uniformity of reporting formats should be maintained, the reporting mechanism should be revised, so that all the stake holders are updated with the current status of the program.
- Inbuilt mechanism of cross checking the reports for ensuring data quality should be formulated.
- There is a need to train the health system staff as well as the NGO staff regarding the supervision and monitoring of the program.

Transferring the implementation of the program from NGO to ASHA.

Based on the above key findings, the opinion of the stakeholders and overall observations it can be proposed that the implementation of the SCDCP can be safely transferred from NGO to the Health system in few more districts where the awareness targets about Sickle cell disease and SCDCP have been achieved; and subsequently in a phased manner in remaining districts after percolation and enhancement of the knowledge of the stakeholders like ASHA, ANM, MPW.

Views of Senior Bureaucrats:

The view point of the stakeholders at the state level was acquired. The state level officials like Director Health Services (DHS), MD- NRHM, Joint Director- NRHM, State Program Officer, State coordinator and Deputy Directors of the concerned circles were interviewed. The aim was to get an overall view of the stakeholders specifically with regards to the implementation of the sickle cell disease control program in the state and the challenges faced by them and their opinion about better implementation of the program.

Stakeholders at the state level, more or less had the same point of view that is:
Everyone felt that, Sickle cell disease control program is very much needed in the state. It was a known fact by all that, the disease though not cured can be successfully prevented by increasing the awareness about sickle cell disease, screening of the susceptible population and providing supportive health services to the sufferers so as to improve their quality of life.
The sickle cell disease as compared to other disease and national health programs is definitely not on the priority list of the state health department. The same outlook is reflected in few officials of the District as well as quite a few of the Medical officers was expressed by all.
The stakeholders unanimously accepted the fact that the funding received for the sickle cell disease control program is not adequate and there is inadequate supply of solubility kits, which affects the program and its outcome. Though the manpower is adequate, the training of the manpower needs to be improved.
When mentioning about the constraints, the group felt that, the monitoring and the supervision of the NGOs is a challenge for the state level officers, as it is based on the reporting system. A few of the NGOs after constant reminders do not submit the report on time, whereas there is inconsistency in the figures submitted by some NGOs. Direct supervision of the NGOs is not feasible as they do not directly report to the District Officials as they are not part of the system. The commitment towards the SCDCP of the district level officials needs to be improved.
It was observed by all that, the screening of the susceptible population mainly the tribal population shows progression, but the given targets are not met.
Almost all of them suggested that, there is a need for the IEC component of the program to be strengthened further.
All the stakeholders felt that the Sickle cell disease program can be implemented through ASHAs, as the ASHAs being a part of the health system can be easily monitored. Also if the cost of SCDCP implementation through the NGOs and ASHAs is compared, the cost is reduced considerably if implemented through ASHAs.

Thane District

District wise findings:

Name of the District: Thane

Type of District: Tribal / NGO

Population of the District: 11,060,148

Brief of the District: As per provisional reports of 2011 census with a population of 11,060,148 Thane district is the most populous district in India which is a mix of urban, rural and tribal population .This is the third most industrialised district in Maharashtra.

Name of the NGO working in the District: Navoday Gramin Sanstha, Jawhar

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objectives of the program, the awareness levels of all the stakeholders from health functionaries, grass root level health workers, representative of panchayat raj/Self-help group as well as the beneficiaries were assessed.

The following findings are reported for Thane district about awareness of SCD and SCDCP.

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of Thane district since one month and has been implementing the Sickle cell disease control program since seven yrs in Amravati district. The knowledge of the DHO regarding the sickle cell disease is adequate.

The **District Reproductive and Child Health Officer** (DRCHO) has been in-charge of the district since three yrs and have been implementing the Sickle cell disease control program since three yrs. The knowledge of the DRCHO regarding the sickle cell disease is adequate.

Civil surgeon is a post graduate in public health with experience of working in the health system for 12 years and has been implementing SCDCP since past six years. His awareness about aetiology, clinical features complication and prevention as well as control measures was satisfactory.

Medical Superintendent of Sub District Hospital was a postgraduate in medicine working in the health system since past 8 year. His awareness about etiology, clinical features complication and prevention as well as control measures was satisfactory.

The **Taluka Medical officer** of the randomly selected Tehsil where Sickle Cell Disease Control Program is implemented was working in the health system since one & half years. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were known to the health official.

The **Medical Officer**, of the randomly selected PHCs was a BAMS graduate working in the health system since 3.5 years. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was not satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were not known to the medical officer.

The **District Co-ordinator (DC)** has been in-charge of the district and is implementing the SCDCP since three years. The knowledge of the DC regarding the sickle cell disease is adequate.

NGO In charge has been working in the health field for ten years. The NGO works in various other areas like tribal health and welfare, adolescent health. This NGO has been implementing the SCDCP in the Thane District since 5 years. His knowledge about etiology, clinical features and prevention as well as control measures of SCD including SCDCP was adequate. The services provided by the NGO under SCDCP are creating awareness, counselling and ensuring regular follow up of the patients affected with SCD.

NGO coordinator has been working in the NGO since one year. He only looks after the implementation of the SCDCP. The population served under this program is 22,29,376. The perceived role of the NGO coordinator in the SCDCP is to supervise and guide NGO volunteers, to facilitate treatment of SCD patients to higher centres, preparation and presentation of the reports to the higher authorities. The knowledge of the NGO Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. His awareness about sickle cell crisis and management, the tests to be done, cards and their significance is satisfactory.

NGO supervisor has been working in the NGO since five yrs. He only looks after the implementation of the SCDCP. The population served under this program is 22,29,376. The perceived role of the NGO supervisor in the SCDCP is to create awareness about the disease through village level meetings, organize screening camps for Sickle Cell Disease, facilitate counselling and referral services to those affected with this disease. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

ANM/MPW/ HA: The no of ANM/MPW/HA interviewed were two. Both of them have worked in the current post in the range of since three yrs. On an average the ANM/MPW/HA catered to a population of between six to seven thousand (i.e.6030 to 7500).
The ranges of services to be provided by them are counselling and provision of treatment under SCDCP program. Of the total two ANM/MPW /HA, the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	% of total (n=2)
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	50
Signs and symptoms of sickle cell disease	50
Meaning of sickle cell crisis	0
Is the disease curable	100
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	0
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	100
Test for screening of the disease,	100
Test for confirmation of the disease	50
When and where is HPLC conducted	0

This data indicates the need of training and retraining for ANM/ MPW/ HA under SCDCP periodically.

ASHA: The number of ASHAs interviewed were twenty six (26), of which all worked in the current post in the range of 1 to 6 yrs. On an average the ASHA catered to a population of 1000 to 1500.As perceived by them, the range of services to be provided by them under SCDCP are: helping organization of screening camps for SCD in the community, Counselling and distribution of FA tablets to the beneficiaries under SCD. Of the total 26 ASHAs interviewed, the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	% of total (n=26)
Meaning of sickle cell disease	53.84
Causes of sickle cell disease	53.85
Types of sickle cell disease	30.77
Signs and symptoms of sickle cell disease	88.46
Meaning of sickle cell crisis	11.53
Is the disease curable	46.15
Is the disease preventable	69.23
Precautions to be taken by sickle cell disease sufferer	76.92
Is regular health check-up necessary for sickle cell disease sufferer	96.15
How frequently is the medical check-up needed	14.61
Test for screening of the disease,	26.92
Test for confirmation of the disease	23.07
When and where is HPLC conducted	0

The above findings show that awareness about SCD among ASHAs is far from satisfactory. Training component of ASHAs regarding SCD should be strengthened as they are the first link between community and health system.

NGO Volunteer: Eleven NGO volunteers were interviewed who have worked in the current post in the range of 8 months to 6 yrs. On an average the NGO Volunteer catered to a population of 23549 to 53320.

The ranges of services to be provided by them are awareness creation in the community regarding SCD, organizing screening camps for SCD in coordination with local health services, counselling of the beneficiaries including premarital counselling, regular follow up with the SCD patients through home visits to ensure compliance towards treatment under SCDCP.

Of the total 11 NGO Volunteer the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of the total (n=11)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	81.81
Is the disease curable	90.91
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	100
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	81.82
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	100

Above table shows that knowledge of NGO volunteers was satisfactory regarding SCD.

Beneficiaries (Sufferers, Carriers and Caregivers): In the population of 934061 screened till March 2014, 370 SCD sufferers and 4169 SCD carriers were detected since inception of the SCDCP. Twenty seven SCD sufferers and 15 SCD carriers were interviewed as beneficiaries under this program while 4 caregivers of the beneficiaries were also interviewed.

The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	**% (n=46)**
Aware about Sickle cell disease	84.78
The disease is a blood disorder	76.08
The disease is a genetic condition	73.91
Children of sufferer and carrier can get this disease	56.52
The disease is not curable	52.17
The disease is preventable	63.04
Signs and symptoms of sickle cell disease	89.13
Sickle cell crisis	30.44
Precautions to be taken by sickle cell patients	93.47
Frequency of medical check up needed by sickle cell patients	89.13

Above table shows that awareness among beneficiaries regarding SCD, signs and symptoms, precautions to be taken by sickle cell disease patients and the frequency of medical check-ups needed by the sickle cell patients was quite reasonable and high.

Self-help group & PRI Members: Knowledge of SHG & PRI members were not adequate about etiology, clinical features, and prevention as well as control measures of SCD.

Awareness about the sickle cell disease control program .

District Health Officer: The district health officer when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DHO in the SCDCP is supervisory. The logistics for the program were provided by the Public Health Department of Maharashtra. The manpower required for the implementation of the program is adequate as this is an NGO district, mainly the NGO volunteers are responsible for all the activities under this program, but the MO, TMO and other existing government health staff is also supposed to actively implement the SCDCP in coordination with NGO personnel was felt by the DHO.

Implementation of the sickle cell disease control program in the district:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DHO by supervisory visits and in the monthly meetings.

The constraints faced by the DHO in implementing the SCDCP are regular availability of SCD testing kits and ensuring follow up and treatment in SCD sufferers in the tribal areas. He was of the opinion that the SCDCP should be implemented through ASHAs instead of NGO.

The following are the suggestions given by the DHO for better implementation of the SCDCP:

- Timely procurement – supply chain management is essential for achieving targets for screening of SCD. This could be possible by decentralizing purchase policy.
- Establishment of day care centres in difficult to reach areas to increase compliance towards treatment.

District Reproductive and Child Health Officer (DRCHO): The DRCHO when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DRCHO in the SCDCP is supervisory. The logistics for the program were provided by the Public Health Department of Government of Maharashtra. The manpower required for the implementation of the program is adequate as this is an NGO district; mainly the NGO volunteers are responsible for all the activities under this program, but the MO, TMO, other local health facility staff are also supposed to actively implement the activities.

Implementation of the sickle cell disease control program in the district:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.
Regular Monitoring and evaluation is done by the DRCHO by supervisory visits to screening camps, meetings with NGO officials. The progress of the SCDCP is also discussed at district level monthly meetings. No constraints were faced by the DRCHO in implementing the SCDCP.
She opined that SCDCP should be implemented through dedicated workforce of NGO as these are mainly tribal and difficult to reach areas. DRCHO suggested that financial incentives offered to NGO volunteers should be raised for better implementation of the SCDCP.

Civil Surgeon: The perceived role of the Civil Surgeon in the SCDCP is entirely supervisory. He was of opinion that adequate manpower is available as NGO personnel are dedicated for implementation of SCDCP in coordination with local government health functionary. His knowledge about services offered through this program was adequate. He did not face any difficulty regarding implementation of the SCDCP excluding irregularity of logistics. He admitted that regular monitoring is done of the activities carried out under sickle cell disease control program. However, he was of the opinion that this program should be implemented through health system.
According to him, if the program is implemented through the health system, the monitoring of the program will be good. He suggested that activities under this program should be implemented through ASHAs however their incentive should be raised.

Medical Superintendent: Role of Medical superintendent in the SCDCP was perceived as management of SCD unit, awareness and screening for SCD. He was aware of screening camps organized in his area and he has supervised all the camps taken place during last year. He knew protocol of SCD patient's management correctly. He was aware about job responsibilities of NGO and local health authority staff, logistic supply management. He has cited irregularity in the availability of screening kits due to funds insufficiency for 1-2 week duration in the last year which has been then purchased through contingency funds available with RH. He did not face any difficulty in the reporting. He received the required support from DHO regarding implementation of the SCDCP also TMO has supported by referring SCD patients under the program.
He has been monitoring supplies through SCDCP with regular meetings with laboratory technician and he has been verifying records given by laboratory technician only. His experience while working with NGO was good. He made the following suggestions to improve implementation of SCDCP.

- Uninterrupted supply of medicines and screening kits
- SCD counsellor should be available at SDH
- Pneumovac & Hib vaccine should be made available at SDH

Taluka Medical Officer: The Taluka Medical Officer when asked about the need for sickle cell disease control program expressed that certainly there is a need for this program specially in thane district, where the prevalence of sickle cell disease is high, their role in the SCDCP was perceived as to assess the disease burden in the community, create awareness and screening of SCD, further treatment of SCD affected patients. The beneficiaries are mainly identified by screening camp approach. The camps

for screening of the population are organised by the NGO in coordination with local government facility. The beneficiaries once identified are given colour coded cards by ANM & MPW and when confirmed they are further counselled to ensure compliance towards further treatment.

If the patient goes into Crisis then, these patients are given hydroxyurea and symptomatic treatment, in case of follow up of the patient's home visits are made by NGO Volunteers to ensure regular follow up.

About the resources the TMO commented that, the logistics supply was irregular in the last year, as there was no supply from district level. Therefore local purchase was done from funds available with Rogi Kalyan Samiti was done to ensure that the kits and drugs were in stock. The fund transfers under the program are regular. The reporting frequency is adequate and regular funding support and guidance for organization of camps for SCD was offered by DHO for the same.

There were no difficulties faced by TMO during implementation of the SCDCP. TMO had good experience working with NGO as NGO volunteers were working sincerely.

Medical Officer: The Medical Officer perceived that his role in the SCDCP is related to diagnosis and treatment of SCD patients. The beneficiaries are mainly identified by –screening camp approach. The camps for screening of the population are organised by NGO in coordination with local government facility The beneficiaries once identified are given colour coded cards by -supervisors in coordination with NGO staff and when confirmed they are offered counselling & treatment by NGO personnel as well as health workers from PHC. (Registered with the PHC etc.).

If the patient goes into Crisis then, these patients are managed with Intravenous fluids, antibiotics and multivitamin. In case of follow up of the patients house to house visits are provided by NGO Volunteers to ensure compliance for the visits.

About the resources the Medical officer commented that the logistics supply was irregular in the last year. The fund transfers under the program are regular. The manpower is sufficient. The reporting frequency is every monthly.

Medical Officer did not face any difficulty in the implementation of the SCDCP and there were no suggestions from him regarding improvement of implementation of SCDCP.

Medical officer and TMO did not face any difficulty in the reporting under this program. Both of them were not trained for SCDCP.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DC in the SCDCP is to supervise implementation of the program activities, in Thane district, to facilitate funds disbursal. The logistics for the program were provided by the government .The manpower required for the implementation of the program is adequate as this is an NGO district , mainly the NGO volunteers are responsible for all the activities under this program ,with cooperation from the health system functionaries. The manpower is trained adequately under the SCDCP.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DC by conducting 8-10 supervisory visits on monthly basis. During these visits, availability of drugs, testing kits and other consumables are checked and other logistics difficulties are addressed.
DC did not mention any constraints faced during implementation of SCDCP. DC suggested that SCDCP should be implemented through ASHA and also more travelling allowance should be provided to the NGO volunteers

The NGO In charge: The NGO In charge has been trained at Directorate of Health Services office, Mumbai for two days. The NGO In-charge was satisfied with the training, but it was felt that the training can be further improved by incorporating field visits.
When enquired about the logistics, funds release and other support from the health system, the response received was that there is a delay in the release of funds which delayed tendering procedure and proper supply management.
They are provided with targets to be completed in the current year by the government. The NGO In-charge monitors and supervises the implementation of the program. They have also conducted training of the volunteers in the last year.
The training of the newly recruited NGO volunteers is done by NGO personnel only.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the NGO personnel for one day at NGO office and suggested for re orientation training. When asked specifically about the implementation of the SCDCP. NGO coordinator responded that the training of many of the NGO volunteers who has recently joined has been completed through NGO coordinator for one day at NGO office.
Mass awareness activities were conducted by NGO in the community through posters, banners, leaflets, etc. On the occasion of Sickle Cell Day and Week, rallies, competitions of poster making, essay writing are organized. SCD Screening camps were conducted in schools, colleges and the days of market, medical camp or any other important events.
The flow of funds according to him was irregular. He is not satisfied with the monetary benefit also due to the delayed release of funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year four supervisory visits were conducted by him. Also all the meetings were attended by him. The reports are received every monthly basis.
The following are the suggestions by the NGO coordinator for better implementation of SCDCP:

- For better management of the referred patients there should be a NGO volunteer at Rura Hospital level
- The salary of the NGO staff should be increased and separate travelling allowance should be provided.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by District training team for three days at Rural Hospital. The NGO supervisor is satisfied with the training, but suggested that it can be improved by making it more interactive through active participation of the trainees. When asked specifically about the implementation of the SCDCP, the NGO supervisor responded that the

training of NGO volunteers was conducted by district Health team however those who have joined recently have received training by NGO coordinator.

The IEC sessions that were carried out in the community were through gram sabha, screening camps. The IEC material prepared by them was leaflets, booklets, posters. Awareness about SCD is conducted through rallies, organizing competitions of poster making and essay writing in schools, colleges. Newly wedded couples are sensitized about SCD in group meetings. The NGO supervisor has provided guidance to NGO volunteers, counselling and referral of SCD patients through numerous supervisory visits.

According to NGO Supervisor, flow of funds was not regular under this SCDCP. The NGO supervisor was not satisfied with the salary of Rupees 8235 per month.

The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. All the supervisory meetings were attended by her. The reports are received every weekly and monthly from NGO volunteers.

NGO supervisor suggested that all the required resources should be made timely available for better implementation of the program. According to her, PHC staff should be more proactively involved in the screening camps conducted by the NGO.

Observers comments based on the record verification:

All the records were complete and there was no delay in the submission of records**.**

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=2)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	0
warning signs in SCD patients	50
how to manage sickle cell disease crisis	50
treatment given to sickle cell disease patients	50
Whom to give medicines	50
Drugs used for SCD patients under the program	50
When to conduct prenatal blood test on a pregnant women for SCD	50
LOGISTICS AND TRAINING	
Regular availability of kits	100
Regular availability of medicines	100
Trained under SCDCP	0
Sensitization training conducted	0
Satisfied with the training	0

The findings indicate that there was a need to train the ANM/ MPW/ HA under SCDCP. Neither of ANM/ MPW/ HAs was aware about when SCD day and SCD week is celebrated nor the activities conducted on this occasion.

ASHA

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=26)
There is a sickle cell disease control program	80.77
Government implements the SCDCP	80.76
Services provided under SCDCP	73.07
significance of the colour cards	34.61
warning signs in SCD patients	38.46
how to manage sickle cell disease crisis	42.30
treatment given to sickle cell disease patients	38.46
Whom to give medicines	30.77
Drugs used for SCD patients under the program	34.61
When to conduct prenatal blood test on a pregnant women for SCD	23.08
LOGISTICS AND TRAINING	
Regular availability of kits	7.69
Regular availability of medicines	0
Trained under SCDCP	23.08
Sensitization training conducted	0
Satisfied with the training	23.08

These observations show that though ASHAs were aware about the SCDCP program however they did not have detailed knowledge about the services provided under the program.

All the ASHAs were not aware about when SCD Day and week is celebrated nor the activities related to it. Reporting under SCDCP was not done by ASHAs. Though ASHAs were assisting for organization of screening camps in PHCs, they suggested that they should be given training under SCDCP.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=11)
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	100
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	63.64
LOGISTICS AND TRAINING	
Regular availability of kits	54.55

Regular availability of medicines	100
Trained under SCDCP	100
Sensitization training conducted	0
Satisfied with the training	81.82

All of them (100 %) knew about the sickle cell day and SCD week celebrated and the activities conducted on these occasions.

None of them were satisfied with the financial incentives provided under the program as it was less for day to day travel and other expenses of living. According to 100 %, they are provided with targets to be completed and the frequency of reporting was every week according to 100 % of the NGO Volunteer

Based on the observations, following are the suggestions made by the NGO Volunteer:

- Monthly remuneration of Rs.8000/-
- Regular supply of test kits and medicines
- Arrangement of travelling for referred SCD patients

Beneficiaries (Sufferer, Carrier and Caregivers): The total no of beneficiaries interviewed in Thane District were 46. Of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows:

Almost 89.13 % of the beneficiaries were aware of the SCDCP. The NGO personnel followed by Public health department staff were the main source of information regarding the SCDCP. The services under SCDCP are provided by the local health authority in coordination with NGO in their local area. Among the sufferers and carriers 71.42% were tested at a camp organised for the screening of SCD, whereas 9.52% were tested at the PHC and 11.9% were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of 59.52 % Sufferers and carriers, whereas in case of 21.42% the motivation source was ANM/ MPW. In 16.66% cases the motivation source was medical officer of PHCs.

Of the total beneficiaries almost 90.47% were aware of the significance of the colour cards.

Of the sufferers and carriers who are married, only 23.8% knew about their SCD status before marriage.

According to the 66.66% beneficiaries the NGO volunteer visits them at home every month while 16.66% were paid home visits by NGO volunteers once in two months.

The services provided by the NGO volunteer during their visit to the sufferer or carrier are mainly counselling for SCD and accompanying the SCD patients for health check-up.

88.88% of SCD sufferers visit the PHC for health check-up once a month.

Seven (25.9%) SCD sufferers are going to PHC by their own and 10 (37.03%) sufferers were accompanied by their relative for the hospital visit. Seven (25.9%) SCD sufferers were accompanied by NGO volunteers while three (11.11%) were accompanied by ANM/ MPW.

Of the sufferers 5(18.52%) have had to undergo telemedicine consultation. Of the total beneficiaries 64.28% are satisfied with the services provided.

The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows:

- Concession in travelling by road
- SCD patients should be entitled for benefits of handicapped, education and housing related other government scheme

Self-Help group: Though majority of the interviewed PRI and SHG members were aware about the services provided through SCDCP and service provider, however all of them were not able to tell about the importance of colour coded cards distributed through the program. Majority of them could not tell about the number of screening camps conducted for SCD in their area. Neither did they comment on their satisfaction about services provided through the program nor made any suggestions to improve the implementation of the same.

The interviewed members of the self-help group were aware of the SCDCP and the services provided under the SCDCP. The source of their information was NGO volunteer / ASHA / Medical Officer. The services under SCDCP, in their area was provided by NGO volunteer

They did not provide any suggestions for better implementation of the SCDCP.

Evaluation based on following indicators:

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO did not have its own vehicle / hired vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. Medicines, kits and IEC material, cards are procured from local health authority. There was no regular supply of solubility kits during last one year. Since past two years NGOs are not receiving funding support for IEC from government. The case files of all the sufferers were maintained.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register, counselling register etc were well maintained and updated till date.
- Training of the human resource:
  One training session was conducted for the NGO volunteer in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by Medical Officer PHC in coordination with NGO personnel. In addition to the induction training, the NGO volunteers are periodically sensitised again, during the review meetings and their queries are addressed at the same time.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also weekly reports were obtained regularly from the NGO volunteers. NGO coordinator expressed his major time goes in compiling numerous reports.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. In the last year 12 review meetings were conducted by the

NGO coordinator. These monthly review meetings are crucial for smooth implementation of the SCDCP.

- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. Regular field visits are conducted by the NGO coordinator. Screening camps are visited by TMO twice last year.
- Organising activities under SCDCP:
  Regular IEC camps are conducted by NGO in weekly bazaar, local cultural festivals, marriages, social gatherings under Adivasi Vikas Yojana. Till February 2014, (934061) were screened for SCD in the camps while 22,44,553 were covered through various awareness activities. Celebration of sickle cell day and week gives a fair knowledge about the extent of activities conducted under SCDCP.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meeting as well as the Anganwadi worker meetings. The no of meeting attended with community leaders and mahila mandals , self-help groups on an average were more than 95%. This indicates good stakeholder involvement in the program.

Performance Indicators:

- **Outcome indicators:**

Indicator	**Figure**	**score**
Percentage of target population screened for Sickle cell disease by the NGO	**>95%**	**15**
Percentage of sufferers and carriers counselled in the last year	**>95%**	**15**
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**>70%**	**20**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**Nil**	
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**Nil**	

- **Impact Indicators:**

Indicator	**Figure**	**score**
No. of Sufferers and Carriers married to healthy partner	**>85%**	**15**
No. of married female Sufferers and Carriers currently pregnant	**Nil**	**15**
No. of married female Sufferers and Carriers gave birth within last year	**Nil**	**15**
Awareness in Target population	**>85%**	**15**

Financial Indicators:

Indicator	Figure	score
The percentage of approved budget utilised on the proposed activities	**>80%**	**8**
Organisation maintaining a separate bank account for the Sickle Cell project	**yes**	**5**
All original bills and vouchers present	**yes**	**5**
For the amount of above Rs 1000, the mode of payment is by Cheque	**Yes**	**5**
Presence of serially numbered and printed vouchers	**yes**	**3**
Cash book entry is on regular basis and updated	**yes**	**3**
All the vouchers have supportive documentary evidence	**yes**	**4**
SOEs submitted in time to SHS	**yes**	**5**
SOE s based on book of accounts	**yes**	**10**
Grand Total Score		**48**

The observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

- Targeted population of Thane district for SCD is 20,26,847 while only 9,34,061 (46%) have been screened. In order to complete the target it is very essential to make resources available timely..
- Not all existing NGO staffs as well as doctors from health services are trained at present under the program. This may affect quality of services delivered. There is an urgent need to strengthen training component under SCDCP.
- Non availability of funds on time and testing kits are the deterrent factors for keeping up motivation of the grass root level NGO volunteers working in this difficult to reach area.
- Record keeping maintained by NGO is appropriate and there is timely report submission.
- Awareness about SCD and SCDCP among PRI members and SHG was not adequate.

Based on the above findings and observations the subsequent are the recommendations for overall Better implementation of SCDCP:

- There should be sustained and uniform efforts of building of trained manpower under this program to deliver quality services to the affected population.
- Timely procurement – supply chain management of logistics is more so important in tribal and difficult to reach area. It could be possible by decentralizing purchase policy.
- Establishment of day care centres in difficult to reach areas to increase compliance towards treatment(May be at SDH level in high prevalent block) may prove effective in extending SCDCP services to the needy population.
- It is essential to involve PRI and SHG members in SCDCP who in turn can play an instrumental role in achieving compliance towards screening and treatment regarding SCD.

- There was keenness among ASHAs for receiving training under SCDCP. Capacity building along with sustainability of the activities through government health system is essential prior to handing over the program from the NGO to government health system.

Nasik District

Name of the District: Nashik

Type of District: Rural (NGO)

Population of the District: 6,109,052

Brief of the District: Nashik district has an area of 15,530 square kilometres. It is bounded by Dhule district to the north, Jalgaon district to the east, Aurangabad district to the southeast, Ahmednagar district to the south, Thane district to the southwest, Valsad and Navsari districts of Gujarat to the west, and The Dangs district to the northwest. According to the 2011 census Nashik district has a population of 6,109,052

Name of the NGO working in the District: Gauri samajik Sanstha, Nashik

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers, representative of panchayat raj/Self-help group as well as the beneficiaries were assessed.

The following are the findings about:

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of the district since 1.5yrs and implementing the Sickle cell disease control program since 1.5yrs. The knowledge of the DHO regarding the sickle cell disease was adequate.

The **District Reproductive and Child Health Officer** (DRCHO) has been in-charge of the district since 3 yrs and have been implementing the Sickle cell disease control program since 3 yrs. The knowledge of the DRCHO regarding the sickle cell disease is adequate.

Civil Surgeon: Civil Surgeon has been working in the district since 30 years and managing SCDCP as CS since past 2 years. He perceived his role in the program as supervisor. He had adequate knowledge about implementation of the program in the district.

The **Medical Superintendent** of the randomly selected sub district hospital perceived his role in the program as supervisor. He had adequate knowledge about implementation of the program in the district.

The **Taluka Medical officer** was BAMS. He was working in the health system since last 5yrs. He was not aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level

about the sickle cell traits, types, complications etc was not satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were not known to the Taluka Medical Officer.

The **Medical Officer**, of the randomly selected PHCs was MBBS graduate working in the health system 12 yrs. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were known to the health official.

The **District Co- ordinator (DC)** has been in-charge of the district and implementing the SCDCP since 2 yrs. The knowledge of the DC regarding the sickle cell disease was adequate.

NGO In charge: The NGO In charge has been working in the health field for more than 5 yrs. The NGO works in various other areas like adolescent health, self-employment for tribal etc. This NGO has been implementing the SCDCP in the Nashik District since 5 yrs. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program , it was seen that the awareness levels about the various aspects of the SCDCP was acceptable, The services provided by the NGO under SCDCP are spreading awareness in the community regarding SCD by conducting awareness campaigns, going to schools and colleges.

NGO coordinator: The NGO coordinator has been working in the NGO since 5yrs. He looks after the implementation of the SCDCP as well as Adolescent Girls' Program .The population served under this program is 11,75000. The perceived role of the NGO coordinator in the SCDCP was to manage, motivate, supervise and innovations. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken was adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since 5yrs. He looks after the implementation of the SCDCP. The population served under this program is 11 93, 000. The perceived role of the NGO supervisor in the SCDCP was to guide PHC volunteers, guidance for organization of camps, facilitating testing for SCD screening, awareness among students about the disease, SCD day observation and spread of awareness regarding the disease. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken was adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory

ANM/MPW/ HA: The no of ANM/MPW/HA interviewed were 4. They worked at the current post in the range of 3 to 26 yrs. On an average the ANM/MPW/HA catered to a population of 4500 to 15000.
The ranges of services to be provided by them are: maternal and child health services, maintenance of cold chain and vaccination, malaria eradication, family planning advise and awareness, polio eradication, leprosy diagnosis and treatment, TB treatment, organising SCD diagnostic and awareness camps under JSSK,JSY, NLEP, RNTCP, NVBDCP, Manav Vikas Yojna and SCDCP.
Of the total 4 ANM/MPW /HA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=4)**

Meaning of sickle cell disease	50
Causes of sickle cell disease	50
Types of sickle cell disease	50
Signs and symptoms of sickle cell disease	75
Meaning of sickle cell crisis	0
Is the disease curable	25
Is the disease preventable	75
Precautions to be taken by sickle cell disease sufferer	50
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	50
Test for screening of the disease,	50
Test for confirmation of the disease	0
When and where is HPLC conducted	0

The awareness of the ANM/MPW about SCD was not sufficient, as only 50% could correctly express the meaning of sickle cell disease and enumerate the causes and types of SCD. Precautions to be taken by SCD patient and frequency of medical check-up, also the screening test for SCD was known to 50% of the ANM/MPW.

The above findings suggest that the knowledge of the ANM/MPW should be increased by training them and conducting refresher sessions at regular intervals.

ASHA: The no. of ASHAs interviewed was 25. They worked at the current post in the range of 1 to 6 yrs. On an average the ASHA catered to a population of 400 to 5000.

The ranges of services to be provided by them are to update immunization, ANC check-up, maternal and child health care services, help in opening bank accounts, diet counselling of mothers of malnourished children, health education of adolescent girls, surveys in epidemics, water purification, sanitation maintenance, identification of fever patients & drug distribution, TB, leprosy patient identification under JSY, NRHM, Manav Vikas Yojna. Of the total 25 ASHA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=25)**
Meaning of sickle cell disease	34.65
Causes of sickle cell disease	0
Types of sickle cell disease	52
Signs and symptoms of sickle cell disease	28
Meaning of sickle cell crisis	0
Is the disease curable	32
Is the disease preventable	84
Precautions to be taken by sickle cell disease sufferer	24
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	4
Test for screening of the disease	4
Test for confirmation of the disease	0

When and where is HPLC conducted	0

Many ASHAs were not able tell even the meaning of the sickle cell disease and its signs and symptoms which is must for counselling people about the disease and for better implementation of the program. So, repeated training sessions are must to teach them about the disease. May be there could be assessment sessions at review meetings to check their knowledge about the disease.

NGO Volunteer: The no of NGO Volunteer interviewed were 3. They worked at the current post in the range of 4 to 5yrs. On an average the NGO Volunteer catered to a population of 16000 to 18000. The ranges of services to be provided by them are awareness about SCD and screening camps under SCDCP.
Of the total 3 NGO Volunteer the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of the total (n=3)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	100
Is the disease curable	67
Is the disease preventable	67
Precautions to be taken by sickle cell disease sufferer	100
Is regular health check up necessary for sickle cell disease sufferer	67
How frequently is the medical check up needed	33
Test for screening of the disease	100
Test for confirmation of the disease	100
When and where is HPLC conducted	0

Knowledge of the NGO volunteers about the disease was found to be satisfactory.

Beneficiaries (Sufferers, Carriers and Caregivers): Total no. of the beneficiaries interviewed were 61 out of which 20 were sufferers, 29 was carriers and 12 were caregivers.
The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	**% of the total (n=61)**
Aware about Sickle cell disease	52.46
The disease is a blood disorder	54.10
The disease is a genetic condition	36.07
The disease is due to consumption of polluted water	22.95
The disease is due to consumption of contaminated food	27.87
Mosquito bite can transmit the disease	16.40
Disease occurs more in poor people	44.26
Children of sufferer can get this disease	50.82

Children of carrier can get this disease	37.70
The disease is curable	52.46
The disease is preventable	42.62
Regular health check-up is necessary	72.13

The above finding suggests that the knowledge regarding sickle cell disease, its transmission, spread of the disease was very poor in beneficiaries. The beneficiaries though had come in contact with NGO volunteers were not having adequate knowledge of the disease and had myths about it. This could be the reflection of poor knowledge of disease among grass root level workers of the NGO and lack of creating awareness in the community about the sickle cell disease by NGO volunteer. The awareness camps for the beneficiaries as well as NGO volunteers needs to be addressed by the Medical officers and district level officials who have better knowledge about the disease.

Self-Help group: The members of the self-help group, those who were interviewed were not aware of the general information about the disease, its causes, signs and symptoms and the precautions to be taken by the sufferers.

Awareness about the sickle cell disease control program .

District Health Officer: The perceived role of the DHO in SCDCP was supervising and coordinating the program in the district. As per the DHO, the funds were provided through NRHM to the district health society and then transferred to the NGO. Funds and logistics were being provided without any delay and were sufficient. The manpower required for the implementation of the program was adequate.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. Monthly review meeting are conducted at district level and reporting from the NGO is regular regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DHO by visiting the screening camps. Performance of each PHC was evaluated based on the percentage of population screened in the village and if services were found unsatisfactory, action was taken against the responsible staff.

As per the DHO, SCDCP should be implemented through NGO because they could more closely go for screening of populations and IEC activities.

The recommendations for improvement of the current programme implementation were that district coordinators should closely monitor the activities and block level officers should be empowered to do cash purchase for solubility kits for uninterrupted supply to the NGOs.

District Reproductive and Child Health Officer (DRCHO): The DRCHO when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DRCHO in the SCDCP is mainly supervisory and monitoring. The logistics for the program were provided by the government .The manpower required for the implementation of the

program is adequate as this is an NGO district, mainly the NGO volunteers are responsible for all the activities under this program, but the MO, TMO, is supposed to provide complete assistance to the NGO for implementing the program.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC. The knowledge about the screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DRCHO by conducting supervisory visits and the reports received from the NGO.

The constraints faced by the DRCHO in implementing the SCDCP are: Interrupted supply of funds was a major concern.

The following are the suggestions given by the DRCHO for better implementation of the SCDCP:

The district coordinators should closely monitor the activities and block level officers should be empowered to do cash purchase for solubility kits for uninterrupted supply to the NGOs.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program. The perceived role of the DC in the SCDCP was supervisory and administrative. The knowledge of the DC about SCD was found to be adequate.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. The knowledge about the screening test, confirmatory test was adequate. The activities held by DC other than camps were IEC activities in public gatherings. The constraints faced by the DC in implementing the SCDCP are irregular supply of solubility kits.

The suggestions given by the DC for better implementation of the SCDCP were that counselling should be done at RH level by MSW as was done in case of HIV. He said the remuneration provided was less as compared to the administrative work being done by them which needed to be raised.

Taluka Medical Officer The Taluka Medical Officer when asked about the sickle cell disease control program, his role in the SCDCP was perceived as organisation of workshops for MOs, ANM, ASHA supervisors and in colleges. The beneficiaries are mainly identified by camp approach. The beneficiaries once identified are given colour coded cards by NGO volunteers and when confirmed the records were found in place. TMO was trained for SCDCP. But, the knowledge of the TMO about SCD was not adequate.

About the resources, TMO commented that folic acid tablets were made available according to the requirement calculated by NGOs and were distributed by NGO volunteers. The supply of solubility kits was not regular. Only 15 to 20% of the required were provided as those were not available at district level. The fund transfers under the program were not regular. The reporting frequency was monthly and there was good support and co-operation from the DHO for the same.

When asked about his experience about working with the NGOs in the field, he said that NGO volunteers worked passionately.

The difficulties faced during the implementation of the program were inadequate supply of solubility kits and irregular transfer of funds.

The suggestions given by the TMO to improve the implementation of the program were regular supply of funds and logistics. He said that there should be a district level officer for the program, the one like DTO, DMO.

Medical Officer: The MO was trained under SCDCP. The role in the SCDCP was perceived as prevention of SCD, screening and treatment of the disease and its complications. The beneficiaries are mainly identified by camp approach. The camps for screening of the population were organised by him with the help of NGO. The beneficiaries once identified were given colour coded cards by NGO volunteers.
Knowledge regarding the disease, its treatment measures and management of complications was adequate.
About the resources the Medical officer commented that the logistics supply was regular in the last year. The fund transfers under the program are regular. The manpower is insufficient as far as reporting is concerned.
Daily online reporting was done to the DHO office and there was good support and co-operation from the DHO for the same.
His experience about working with the NGOs in the field was that they were good at work.
The main constraints faced by them in implementation of the program (NGO / Health Systems) were insufficient funds because they had to spend much on travelling only.

The NGO In charge: The NGO In charge has been trained by the District Health team for 3 days at District Hospital. The NGO In-charge was satisfied with the training, but it was felt that the training can be further improved by increasing the duration of training and giving more information on SCD, also the material used for training should be more elaborative.
When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was not known. The management of the logistics in case of unavailability of sufficient funds was done by self -funding, till the release of funds.
They are provided with targets to be completed in the current year by the Government. The NGO In-charge monitors and supervises the implementation of the program. In the last year the NGO incharge conducted regular meetings, field visits and visited few camps. They have also conducted training of the volunteers in the last year. The training of the newly recruited NGO volunteers is done by the NGO itself.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the district training team doctors for 5 days in a district level institute. The NGO coordinator was not satisfied with the training and said that trainings needed to be more informative. When asked specifically about the implementation of the SCDCP, the NGO coordinator responded that : The IEC sessions that were carried out in the community were screening camps, home visits, awareness programs in schools, gram panchayats, role plays and program on radio once a month. The IEC materials prepared by them were leaflets, posters, banners and counselling booklets. . He conducts almost 2 to 3 supervisory visits every month and in those visits, he supervises stock maintenance and register maintenance.
The flow of funds according to him was not regular.

NGO coordinator suggested that for better implementation of SCDCP: there should be repeated training sessions of NGO volunteers by the government officials. TMO should conduct meetings for volunteers and supervisors. Funds should be made available without any interruption. Good works should be rewarded with incentives. NGOs should get administration charges At least transportation charges should be provided to the beneficiaries above the incentives.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the civil surgeon for 1 day at civil hospital, Nashik. The NGO supervisor is satisfied with the training and suggested that it should be conducted every year. According to him he was supposed to guide NGO volunteers for all the activities conducted under programme. When asked specifically about the implementation of the SCDCP, the NGO supervisor responded that The IEC activities that were carried out in the community were screening camps, family counselling, marriage counselling, school camps. The IEC material prepared by them was leaflets, booklets, poster and street plays. He said that his job was to supervise the work of NGO volunteers, ensure patients were getting timely treatment and ANC testing was being done and meet MO.

The flow of funds according to him was regular. He receives Rs. 8500 as salary with which he is not satisfied.

The suggestions by the NGO supervisor for better implementation of SCDCP were regular supply of solubility kits and medicines for the patients and more involvement of the PHC in implementation of the programme.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=4)**
There is a sickle cell disease control program	100
Government implements the SCDCP	50
Services provided under SCDCP	100
significance of the colour cards	0
warning signs in SCD patients	75
how to manage sickle cell disease crisis	75
treatment given to sickle cell disease patients	75
Whom to give medicines	50
Drugs used for SCD patients under the program	75
When to conduct prenatal blood test on a pregnant women for SCD	50
LOGISTICS AND TRAINING	
Regular availability of kits	50
Regular availability of medicines	75
Trained under SCDCP	25
Sensitization training conducted	25
Satisfied with the training	25

It was observed that 60% knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are awareness camps in schools, role plays at public gatherings. NGO was also trying to start mobile phone awareness SMS service in liaison with BSNL.

None of them knew about the sickle cell day and sickle cell week.

Almost all received some kind of incentives under the program, but were not satisfied with it and wanted it to be increased. None of them were provided with targets to be completed and neither of them knew frequency of reporting was weekly.

Based on the observations suggestions made by the ANM/MPW/HA: was increase in manpower at PHC for the proper implementation of program, more involvement of MPW. Media should be help in raising awareness among people about the disease and program. Beneficiaries should get help in the form of money and medicines.

ASHA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=25)**
There is a sickle cell disease control program	92
Government implements the SCDCP	78
Services provided under SCDCP	81
significance of the colour cards	20
warning signs in SCD patients	33
how to manage sickle cell disease crisis	28
treatment given to sickle cell disease patients	12
Whom to give medicines	14
Drugs used for SCD patients under the program	10
When to conduct prenatal blood test on a pregnant women for SCD	33
LOGISTICS AND TRAINING	
Regular availability of kits	11
Regular availability of medicines	0
Trained under SCDCP	7
Sensitization training conducted	3
Satisfied with the training	3

Though many of them knew about the program and services provided under the program, but their knowledge regarding the disease was not good. 44% did not even know about type of patients in SCD. None of them could exactly enumerate the drugs to be given to the SCD patients. Most of them (92%) were not even aware that they were to be trained under SCDCP. Based on observations, the IEC activities conducted under the program were awareness camps, distribution of pamphlets and role plays in public gatherings.

None of them knew about the sickle cell disease day and week and the activities conducted during these days.

They never received any kind of incentives under the program. But, they expected to be given incentives for the services they were providing under SCDCP.

Only 2 of them said that they were provided with targets to be completed. None of the ASHAs knew that frequency of reporting was weekly. They said they had never done it. All the ASHAs wanted to be trained for SCDCP.

From the above observations, it is recommended that though the program is run by NGO in the district, ASHAs being the grass root level workers and first contact with the community, they should be aware of the disease and hence they should be trained and sensitized for the sickle cell disease program.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=3)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	33
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	0
Regular availability of medicines	0
Trained under SCDCP	100
Sensitization training conducted	100
Satisfied with the training	50

Only 66% knew about the sickle cell day celebrated and the activities conducted on the day. Only 33% knew about the sickle cell week and the activities organised during the week. It's surprising since the evaluation of the NGO district was conducted just after the sickle cell week. None of them were satisfied with the incentives and wanted it to be increased. According to 66% of the interviewed NGO volunteers, they were provided with targets to be completed and the frequency of reporting was every week according to one of the NGO Volunteers. NGO volunteers suggested improving the transport facility. NGO volunteers have good orientation towards the work assigned to them. Repeated trainings must go on to keep them updated about the disease and program.

Beneficiaries (Sufferers, Carriers and Caregivers)

The total no of beneficiaries are 61. Of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows:

Almost 90% of the beneficiaries were aware of the SCDCP and most of them were informed about it by NGO volunteers. The services under SCDCP are provided by the NGO volunteers in their local area. Among the sufferers and carriers, 51.20% were tested at a camp organised for the screening of SCD, whereas 32.65% were tested at the PHC and 4.08% were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of 21 sufferers and carriers, whereas in case of 7, the motivation source was ASHA and some cases the motivation source was medical officer at PHC.
Of the total beneficiaries, almost 25 i.e. 40.98% were aware of the significance of the colour cards. Of the sufferers and carriers who were married, only 2 knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only 6 were counselled before marriage. The effect of their SCD status on their children was known to 28% only. According to the beneficiaries the NGO volunteer visits then every 15 days to every 3 months.
The services provided by the NGO volunteer during their visit to the sufferers or carriers were mainly giving folic tablets and motivation for coming to the camps. None of them were counselled about leading healthy life. The frequency at which the sufferers have to visit the primary health centre for check-up or medication is once every month only in few of them. Many of them are accompanied by NGO volunteers to the PHC during these visits. None of the sufferers had undergone telemedicine consultation. Of the total beneficiaries 46% are satisfied with the services provided.

The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows: There should be pension scheme for the patients. The money spent during sickle cell crises should be reimbursed. Free transportation services should be provided. Patients should be assured permanent government jobs.

Self-help group: The interviewed members of the self-help group were not aware of the SCDCP.

Evaluation based on following indicators:

Physical Indicators:
The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle for transportation if needed. The manpower was adequate with all the positions filled under the SCDCP. The availability of medicines was regular. The IEC material was impressive and was in the form of posters, pamphlets, booklets and banners etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were available. The solubility kits supply was uninterrupted. The case files of all the sufferers were maintained.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register, counselling register, stock register were well maintained and updated till date.
- Training of the human resource:
  The no of training sessions conducted for the NGO volunteer were 14 in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by doctors from civil hospital, NGO supervisor and NGO coordinator. In addition to the induction training, the NGO volunteers are periodically sensitised again during the monthly review meetings and their queries are addressed at the same time.
- Timely reporting:

Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly. Weekly reports were obtained regularly from the NGO volunteers and monthly reports were sent to the higher officials. Copies of 52 weekly reports by NGO volunteers and 12 monthly reports were available with the NGO.

- Frequency and adequacy of review meetings:
  Review meetings are essential part for the continuous improvement in the implementation of a program. 12 review meetings were conducted in the past one year which is an adequate number.
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO coordinator conducted about 18 field visits in last year. The district level officials conducted monthly review meetings to take update of the program and issues regarding implementation of the program.
- Organising activities under SCDCP:
  IEC activities were conducted in the screening camps, schools and public gatherings as well as SCD day and week were enthusiastically celebrated by the NGO. But, data regarding the same could not be retrieved.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meetings, as well as the Anganwadi worker meetings. The data regarding no. of meeting attended with community leaders and mahila mandals, self-help groups was not available. This indicates the stakeholder involvement in the program was average.

Performance Indicators:

Outcome indicators:

Indicator	Figure	score
Percentage of target population screened for Sickle cell disease by the NGO	**48%**	**5**
Percentage of sufferers and carriers counselled in the last year	**100%**	**15**
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**19%**	**5**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one yea	**Data not available**	
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**9%**	**5**

Impact Indicators:

Indicator	Figure	score
Percentage of Sufferers and Carriers married to healthy partner	**73%**	**10**
No. of married female Sufferers and Carriers currently pregnant	**6**	
No. of married female Sufferers and Carriers gave birth within	**8**	

last year		
Awareness in Target population	**Data not available**	**-**

Financial Indicators:

Indicator	**Figure**	**score**
The percentage of approved budget utilised on the proposed activities	**> 80%**	**8**
Organisation maintaining a separate bank account for the Sickle Cell project	**Separate bank account exists**	**5**
All original bills and vouchers present	**all present**	**5**
For the amount of above Rs 1000, the mode of payment is by Cheque	**yes**	**5**
Presence of serially numbered and printed vouchers	**Vouchers printed but not serially numbered**	**2**
Cash book entry is on regular basis and updated	**Sometimes updated**	**2**
All the vouchers have supportive documentary evidence	**yes**	**4**
SOEs submitted in time to SHS	**Yes**	**5**
SOE s based on book of accounts	**Always matched**	**10**
Grand Total Score		**46**

The observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

- The knowledge among some of the higher officials (TMO) working for SCDCP was inadequate and they are the trainees for ASHAs, ANMs and NGO volunteers.
- The grass root workers like ASHA had inadequate knowledge regarding the disease and program is concerned.
- Deficiency in knowledge of grass root workers was reflected in the awareness levels among beneficiaries also.
- ASHAs, ANMs and NGO volunteers were not satisfied with the incentives they were getting which needs to be revised by the state government.
- Supply of funds and logistics was not regular.
- Transport facilities for serious patients were not available**.**
- Telemedicine facilities were not at all used.

Based on the above findings and observations the subsequent are the recommendations for overall Better implementation of SCDCP:

- The need for complete revision of the program in the district is felt.
- State level trainings must be held for TMO, MO.
- There is utmost need for induction and sensitisation trainings of grass root workers i.e. ASHs, ANMs and NGO volunteers.
- There needs to be a system for periodic assessment of knowledge of these workers at the monthly meetings.
- State government should plan for timely dispatch of funds and assure regular supply of logistics.
- Provision of transport facility needs to be considered by the state government.
- Close monitoring by the district coordinators and block level officers is needed
- Empowering the NGO or district level officials for purchasing the solubility kits, in case of delayed release of funds so as to ensure uninterrupted supply of the same.

Nagpur District

Name of the District: Nagpur

Type of District: Rural (NGO)

Population of the District: 46, 53,171 (as per 2011 census)

Brief of the District: Nagpur is the third largest city after Mumbai, Pune in Maharashtra which is also the winter capital of the state.

Name of the NGO working in the District: Aniket Bahudishiya Sanstha, Umred

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of the district since 1 yr and has been implementing the Sickle cell disease control program since 3 yrs. The knowledge of the DHO regarding the sickle cell disease is adequate.

The **District Reproductive and Child Health Officer** (DRCHO) has been in-charge of the district since 1yr and have been implementing the Sickle cell disease control program since 4 yrs. The knowledge of the DRCHO regarding the sickle cell disease is adequate.

The **Medical Officers**, of the randomly selected PHCs were allopathic and ayurveda graduates working in the health system from 3 to 8 years. Both of them were aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc. was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health officials.

NGO In charge: The NGO In charge has been working in the health field for 11 yrs. The NGO works in various other areas like de-addiction centre and OPD services. This NGO has been implementing the SCDCP in the Nagpur District since 4 yrs. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was acceptable, The services provided by the NGO under SCDCP are creating awareness about Sickle Cell Disease and program activities, organizing screening camps for SCD, counselling of SCD sufferers and carriers to achieve compliance.

NGO coordinator: The NGO coordinator has been working in the NGO since 2 yrs. He looks after the implementation of the only SCDCP. The perceived role of the NGO coordinator in the SCDCP is to coordinate between higher authority and NGO volunteers as well as arrange the camps. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since1 yr. He looks after the implementation of the only SCDCP. The population served under this program is nearly 2 lakh. The perceived role of the NGO supervisor in the SCDCP is to monitor the work of NGO volunteers working at 4 PHC's. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

ANM/MPW/ HA: The no of ANM/MPW/HA interviewed were 14. All of them have worked in the current post in the range of 2 to 22 yrs. On an average the ANM/MPW/HA catered to a population of 2500 to 8540.

The ranges of services to be provided by them are: organizing screening camps for SCD, provision of treatment to the beneficiaries under SCDCP, counselling of the beneficiaries achieve compliance towards treatment. Of the total 14 ANM/MPW /HA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=14)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	66
Meaning of sickle cell crisis	57.26
Is the disease curable	87.14
Is the disease preventable	87.14
Precautions to be taken by sickle cell disease sufferer	66
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	78.57
Test for screening of the disease,	92.86
Test for confirmation of the disease	87.14
When and where is HPLC conducted	57.26

This table shows that though 100% of the ANM/ MPW/ HA were aware about SCD, they did not have detailed knowledge about its types, crisis indications of HPLC.

ASHA: The no of ASHA interviewed were 25. All of them worked in the current post in the range of 6 months to 5 years. On an average the ASHA catered to a population of 700 to 1500. The ranges of services to be provided by them are: assisting in the organization of SCD screening camps, counselling

and disbursing treatment to the SCD sufferers, carriers. Of the all 25 ASHA interviewed, the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=25)**
Meaning of sickle cell disease	48
Causes of sickle cell disease	88
Types of sickle cell disease	84
Signs and symptoms of sickle cell disease	64
Meaning of sickle cell crisis	16
Is the disease curable	64
Is the disease preventable	60
Precautions to be taken by sickle cell disease sufferer	64
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	68
Test for screening of the disease,	24
Test for confirmation of the disease	8
When and where is HPLC conducted	4

These findings indicate that ASHAs did not have satisfactory knowledge about SCD. There is a need to strengthen the knowledge of this grass root workers who are the first point of contact to the health system.

NGO Volunteer: The no of NGO Volunteer interviewed were two. On an average the NGO Volunteer catered to a population of 14,401 to 34,490.

The ranges of services to be provided by them are: Arrangement of camps for screening of SCD in the community, counselling and referral of the SCD screen positive patients for further diagnosis, premarital counselling, and ensuring treatment compliance through home visits to the beneficiaries Of the total 2 NGO Volunteer the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of the total**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	100
Is the disease curable	100
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	66
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	50
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	100

Beneficiaries (Sufferer, Carrier and Caregivers): In all there are 156 sufferer, carrier and caregiver (beneficiaries). Of the beneficiaries10 are sufferers, 81 are carriers and 65 are caregivers.

The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	% of the total (n=156)
Aware about Sickle cell disease	94.23
The disease is a blood disorder	59.61
The disease is a genetic condition	80.13
Children of sufferer and carrier can get this disease	87.82
The disease is not curable	83.33
The disease is preventable	64.74
Signs and symptoms of sickle cell disease	66
Sickle cell crisis	15.38
Precautions to be taken by sickle cell patients	66
Frequency of medical check-up needed by sickle cell patients	63.46

Though majority of the beneficiaries were aware about SCD, only few (59.61%) were aware that it is a blood disorder. Awareness about sickle cell crisis was least about SCD crisis (15.38%) followed by frequency of medical check-up needed by the SCD patients (63.46%). These findings clearly indicate that there is need for more focussed awareness activities in the targeted community.

Self-help group: Though SHG/ PRI members were aware about SCD however they had unsatisfactory knowledge about etiology, clinical features, prevention and control measures of SCD.

Awareness about the sickle cell disease control program .

District Health Officer: The perceived role of the DHO in the SCDCP is Monitoring and Supervision of the SCD control program. The logistics for the program were provided by the public health department of Government of Maharashtra. The manpower required for the implementation of the program is adequate as this is an NGO district, mainly the NGO volunteers are responsible for all the activities under this program , but the MO, TMO, ASHA, ANM, MPW, HA are also supposed to implement this program.

Implementation of the sickle cell disease in the district is as follows: The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DHO by supervisory visits in the field. Also the progress of the activities under SCDCP was reviewed in the monthly meetings held at district level where notices were given in case of low performance.

The constraints faced by the DHO in implementing the SCDCP are: irregular funds and non availability of SCD screening Kits

The following are the suggestions given by the DHO for better implementation of the SCDCP:

- Powers to make local purchase should be made in view of irregular supply of screening test kits
- Electrophoresis centres should be increased

District Reproductive and Child Health Officer (DRCHO): The DRCHO when enquired about the sickle cell disease control program expressed that:
There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DRCHO in the SCDCP is to ensure proper fund distribution, monitoring and evaluation of the activities under SCDCP. The logistics for the program were provided by the state public health department. The manpower required for the implementation of the program is adequate as this is an NGO district , mainly the NGO volunteers are responsible for all the activities under this program , but the MO, TMO, ASHA, ANM are also supposed to implement this program.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.
Regular Monitoring and evaluation is done by the DRCHO through surprise field visits. Review meetings taken monthly and show because notices are sent in case of low performance.
There were no constraints faced by the DRCHO in implementing the SCDCP and there were no suggestions made.

Medical Officer's: Perceived role of medical officers under SCDCP was supervision and monitoring of the program activities. The beneficiaries are mainly identified by camp approach. The camps for screening of the population are organised by NGO personnel in coordination with the PHC staff. The beneficiaries once identified are given colour coded cards by PHC staff along with NGO volunteers and when confirmed they are provided with counselling for further follow up and treatment.
If the patient goes into Crisis then, these patients are managed with pain killers, intravenous fluids, antibiotics and multivitamins. In case of follow up of the patients monthly house to house visits are provided by NGO Volunteers to ensure compliance for the visits.
About the resources the Medical officer commented that the logistics supply was irregular in the last year, the reason for the inadequate supply from the district level. The fund transfers under the program are irregular.
Of the two medical Officers interviewed, only one was trained for SCDCP.
The reporting frequency is monthly and there is a support and co-operation from the DHO for the same.
The difficulties faced during the implementation of the program are non availability of screening test kits and inadequate funds received under SCDCP. Though they had good experience about working with NGO, one of medical officer suggested that the SCDCP should be implemented entirely through health system for better monitoring purposes.
Medical officers suggested that regular funds should be made available under SCDCP. Also there should be provision of local purchase in case of non availability of logistics. One of them suggested that the blood transfusion facility should be made available at RH level as well.

The NGO In charge: The NGO In charge has been trained by the doctors from District training teams. The NGO In-charge was satisfied with the training and made no suggestions to improve the same.
When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was cited as administrative delays on the part of government. They are provided with targets to be completed in the current year by the public health department. The NGO In-charge monitors and supervises the implementation of the program. In the last year the NGO In charge conducted monthly meetings, field visits to the camps. They have also conducted training of the volunteers in the last year.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the doctors from District training team for one day at District training centre. The NGO coordinator is not completely satisfied with the training, but suggested that it can be improved by increasing duration of training to 3-4 days. Also it was suggested that the training should be conducted at slow pace by step by step approach where feedback of the participants in the training should made. When asked specifically about the implementation of the SCDCP, the NGO coordinator responded that : the training of all the NGO volunteers has been completed The IEC sessions those were carried out in the community not only during screening camps but also in weekly markets, community gatherings including prabhat pheris.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. The reports are received according to the time limits.
The flow of funds according to him was regular. He was satisfied with Rupees 10,000 as monthly remuneration under this program. He suggested that there should be volunteer capacity building through sensitization training.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the doctors from district training team for 1 day at district training centre. The NGO supervisor is satisfied with the training, but suggests that it can be further improved by step by step approach over 3-4 days. The training sessions should be made more interactive through active participation of the participants through feedback.
When asked specifically about the implementation of the SCDCP, the NGO supervisor responded that the IEC sessions that were carried out in the community were through screening camps, Gram Sabha, gat Sabha, ward Sabha, rally, poster, banner, and pamphlet. The IEC material prepared by them was leaflets, booklets, posters, counselling, book, calendar, flip charts. He has conducted almost 3-4/ months per month supervisory visits in the last year. In those visits, he meets Medical officers and paramedical staff in order to facilitate organization of screening camps for SCD. Other activities performed by him during these visits are cross checking of logistics, meetings with NGO volunteers. There was no delay in the report submission from the NGO volunteers.
The flow of funds according to him was irregular. He receives rupees 8500 as a monthly salary which included rupees 1500 as travelling allowance. He is not satisfied with the monetary benefits; also due to the delayed release of funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.

NGO supervisor suggested that there should be hike in the salary received to the NGO people. He also of opinion that more cooperation should be extended from local government authorities for implementation of the program.
All the records maintained with NGO were appropriate and updated from time to time.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=14)**
There is a sickle cell disease control program	100
Government implements the SCDCP	14.28
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	80
how to manage sickle cell disease crisis	92.86
treatment given to sickle cell disease patients	100
Whom to give medicines	92.86
Drugs used for SCD patients under the program	80
When to conduct prenatal blood test on a pregnant women for SCD	92.86
LOGISTICS AND TRAINING	
Regular availability of kits	92.86
Regular availability of medicines	85.71
Trained under SCDCP	50
Sensitization training conducted	0
Satisfied with the training	14.29

It was observed that 78.57% knew about the ideal frequency of visits to the SCD patient. Only 85.71 % knew about the sickle cell day celebrated and the activities conducted on the day. Only 85.71% knew about the sickle cell week and the activities organised during the week.
They were neither provided with the targets nor were they involved in the reporting under SCDCP. They did not receive any kind of incentive under this program.
Based on the observations the following are the suggestions made by the ANM/MPW/HA that they should be provided training to implement this program and also there should be regular supply of logistics under the SCDCP.

ASHA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=25)**
There is a sickle cell disease control program	92
Government implements the SCDCP	28
Services provided under SCDCP	80

significance of the colour cards	60
warning signs in SCD patients	76
how to manage sickle cell disease crisis	38
treatment given to sickle cell disease patients	92
Whom to give medicines	60
Drugs used for SCD patients under the program	80
When to conduct prenatal blood test on a pregnant women for SCD	64
LOGISTICS AND TRAINING	
Regular availability of kits	60
Regular availability of medicines	60
Trained under SCDCP	4
Sensitization training conducted	0
Satisfied with the training	0

It was observed that 56 % knew about the ideal frequency of visits to the SCD patient. Only 48% knew about the sickle cell day celebrated and the activities conducted on the day. Only 40 % knew about the sickle cell week and the activities organised during the week. Neither ASHAs were involved in target completion; reporting nor have they received any kind of incentive under SCDCP. There were no suggestions made by ASHAs regarding this program.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=2)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	80
Whom to give medicines	50
Drugs used for SCD patients under the program	50
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	100
Regular availability of medicines	100
Trained under SCDCP	100
Sensitization training conducted	50
Satisfied with the training	100

It was observed that 100% of NGO volunteers knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are in gram Sabha, ghat Sabha, school, anganwadi and rally in the village.
Awareness about SCD day and week and the activities conducted was 100% among NGO volunteers.
Both NGO volunteers were satisfied with the monetary incentive received under this program. Both of them said that the travelling allowance should be provided. Both of them (100%) were provided with the targets and were doing reporting on the monthly basis. Neither of them made any suggestions to improve the SCDCP.

Beneficiaries (Sufferer, Carrier and Caregiver) : The total no of beneficiaries are 156 of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows:
Almost 94.8 % of the beneficiaries were aware of the SCDCP. The NGO volunteers were the main source of information regarding the SCDCP. The services under SCDCP are provided by the NGO volunteers in their local area. Among the sufferers and carriers, 61 were tested at a camp organised for the screening of SCD, whereas 54 were tested at the PHC and 12 were tested at the private hospital.
The motivation for getting tested for SCD was given by NGO volunteer in case of 97 sufferers and carriers, whereas in case of 4 the motivation source was ASHA, IN some cases the motivation source was Medical officer.
Of the total beneficiaries almost 122 were aware of the significance of the colour cards. Of the sufferers and carriers who are married, only 8 knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only 8 were counselled before marriage.
The effect of their SCD status on their children was known to 65 of the respondents.
According to the 120 beneficiaries, the NGO volunteer visits then every month to month. The frequency at which the sufferers have to visit the primary health centre for check-up or medication is once every month.
The NGO volunteer accompanies them to the PHC during these visits in case of 24. Whereas in case of 13 the ASHA or ANM accompanies them to the health centre.
The services provided by the NGO volunteer during their visit to the sufferer or carrier are as follows: To accompany patient to the health centre for diagnosis, provide counselling, distribution of iron and folic acid tablets.
None of the sufferers have had to undergo telemedicine consultation. Of the total beneficiaries 90 are satisfied with the services provided.
The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows:

- There should be regular supply of medicines through the SCDCP
- Free travel by road and rail should be provided by the government
- Economic support should be provided by the government.

Self-help group: The interviewed members of the self-help group were aware that SCD services are provided by the government through NGO in their area. They were able to tell the number of screening camps conducted their areas. All of them were not aware about the significance of the

colour cards. Among the Self-help group members 100% were satisfied with the services under SCDCP and did not give any suggestions to improve the implementation of SCDCP.

Evaluation based on following indicators:

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. The availability of medicines and kits was irregular. The IEC material was impressive and was in the form of posters, pamphlets, booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. White cards were available. The solubility kits supply was interrupted. The case files of all the sufferers were maintained.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register, counselling register etc. were well maintained and updated till date.
- Training of the human resource:
  The no. of training sessions. Conducted for the NGO volunteer was one in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by doctors from District training team. In addition to the induction training, the NGO volunteers are periodically sensitised again during the review meetings and there queries are addressed at the same time.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also weekly reports were obtained regularly from the NGO volunteers.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. In the last year 12 review meetings conducted by the NGO coordinator regularly.
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO coordinator conducted 20 field visits in last year. The Taluka Medical officer and the district level officials conducted field visits regularly.
- Organising activities under SCDCP:
  In all the total no of IEC camps organised in the last year were 2232. The percentage of population covered in the camps was 33.73%. The percentage of population covered through other awareness activities was 497459. The celebration of sickle cell day and week gives a fair knowledge about the extent of activities conducted under SCDCP.
- Stakeholder Involvement:

The PHC volunteer attended almost all the ANM /ASHA meetings on monthly basis, as well as 48 (fortnightly) the Anganwadi worker meetings. The no of meeting attended with community leaders and mahila mandals, self-help groups on an average were 7450. This indicates the stakeholder active involvement in the program.

The data regarding performance and financial indicators was not available.

Observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

- The awareness levels of the health functionaries like the ANM/MPW/ASHA/HA was inadequate, also the awareness levels of the beneficiaries (sufferers, carriers and caregivers) were not up to the mark and needs improvement.
- The timely release of funds and availability of solubility kits was an important issue. The prioritisation, cooperation and coordination of the NGO and the health system functionaries is inadequate.
- The records though available, were not very updated and some of the important data indicating the impact of the SCDCP was not available. The reporting though on time needs improvement regarding the accuracy and the frequency.

Based on the above observations the following are the recommendations for Better implementation of SCDCP:

- Training of the implementers should be improved The NGO volunteers as well as the health system functionaries like ANM, MPW, ASHA etc need focused and quality training.
- There is a need to further increase the awareness of the population regarding SCDCP.
- The counselling component of the program should be strengthened and focused on.
- The NGO volunteers /ASHA/ANM should be trained to provide counselling in SCDCP.
- Telemedicine consultation and referral system should be strengthened and utilised properly for the benefit of the patient.
- The timely release of funds and logistics should be ensured.
- The monitoring and supervision and cooperation by the district health authorities should be improved.

Bhandara District

Name of the District: Bhandara

Type of District: Rural (NGO)

Population of the District: 2,194,262

Brief of the District: Bhandara is a district in Nagpur division of Maharashtra. According to the 2011 census Chandrapur district has a population of 2,194,262.

Name of the NGO working in the District: Sarvodaya yuvavikas sanstha, Chimur

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of the district since one and half month. He has been implementing the Sickle cell disease control program since two and half yrs, previously he was looking after the training part in SCDCP, since one and half month he is handling the post of DHO. The knowledge of the DHO regarding the sickle cell disease is adequate.

The **Medical superintendent** has been working in the current post for more than 7yrs and has been implementing the SCDCP since more than 3yrs. He had adequate knowledge about sickle cell disease. According to him , his role in SCDCP is supervisory , and to ensure that those who have tested positive for Solubility , undergo electrophoresis.

The **Civil Surgeon** has been implementing the SCDCP since a few years. He had adequate knowledge about sickle cell disease. According to him, his role in SCDCP is supervisory , and to ensure that those who have tested positive for Solubility , undergo electrophoresis.

The **District Co- ordinator (DC)** has been in-charge of the district since more than 3 yrs and has been implementing the Sickle cell disease control program since 3 yrs. The knowledge of the DC regarding the sickle cell disease is adequate. He looks after 11 lakh population (9 lakh in rural and 2 lakh in urban)

The **Taluka Medical officer** of the randomly selected taluka is a community medicine post graduates working in the health system for more than 2 yrs. And he is actively involved in the implementation of SCDCP since that time. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was

satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health official.

The **Medical Officers**, of the randomly selected PHCs were Medical (MBBS and DGO) graduates working in the health system from 3 yrs to 31 yrs. With an experience of implementing the SCDCP from 3 months to 3 years. They were aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health officials

NGO In charge: The NGO In charge has been working in the health field for 20 yrs. The NGO works in various other areas like operating a Drug De-addiction centre, Helpline-counselling centre, PPTCT counselling centre. This NGO has been implementing the SCDCP in the District since three yrs. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was acceptable.

NGO coordinator: The NGO coordinator has been working in the NGO since Seven months. He looks after the implementation of the SCDCP only .The population served under this program is 11 lakhs. The perceived role of the NGO coordinator in the SCDCP is increasing awareness about SCD, organising screening camps, send sample for HPLC , counselling the affected, and providing referral services. .The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since two yrs. He looks after the implementation of the SCDCP .The population served under this program is 1,30,000. The perceived role of the NGO supervisor in the SCDCP is visiting the sufferers, counselling of the patients and supervision of the NGO volunteers working with him. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

ANM/MPW/ HA: Nine ANM/MPW/ HA was interviewed. They had work experience from 18 months to 28 years. Population served by them was 3134 to 5220. The following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=9)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	77.77
Is the disease curable	100
Is the disease preventable	77.77

Precautions to be taken by sickle cell disease sufferer	100
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	100
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	100

ASHA: The no of ASHA interviewed were 28. They were working in the current post in the range of 2 years to 5 yrs. On an average the ASHA catered to a population of 900 to 2000.
The ranges of services to be provided by them are assisting in awareness and screening camps, providing treatment to the beneficiaries under SCDCP. Of the total 28 ASHA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=28)**
Meaning of sickle cell disease	50
Causes of sickle cell disease	92.85
Types of sickle cell disease	92.85
Signs and symptoms of sickle cell disease	92.85
Meaning of sickle cell crisis	46.42
Is the disease not curable	96.42
Is the disease preventable	67.85
Precautions to be taken by sickle cell disease sufferer	100
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	89.28
Test for screening of the disease,	82.14
Test for confirmation of the disease	82.14
When and where is HPLC conducted	50

Above findings indicate that ASHAs were aware about management of SCD patients however their basic knowledge was pathology of SCD, diagnostic tests was not satisfactory. It is essential to strengthen knowledge of these grass root workers through continued training.

NGO Volunteer: Two NGO volunteers were interviewed. They were working in the current post from 2-3 years. On an average the NGO Volunteer catered to a population of 17629 to 30910.
The ranges of services to be provided by them are: counselling, organizing screening camps, further treatment of the SCD patients, facilitating other benefits to the entitled beneficiaries under various government schemes.
Of the total two NGO Volunteers the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of the total (n=2)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100

Meaning of sickle cell crisis	100
Is the disease curable	100
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	100
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	100
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	100

Findings of table indicate that awareness about SCD among NGO volunteers was satisfactory.

Beneficiaries (Sufferer, Carrier and Caregiver):

In all there are 164 sufferer, carrier and caregiver (beneficiaries). Of the Beneficiaries 10 are sufferers, 89 are carriers and 65 are caregivers. The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	**% of the total (n=164)**
Aware about Sickle cell disease	92.07
The disease is a blood disorder	56.70
The disease is a genetic condition	78.65
Children of sufferer and carrier can get this disease	68.90
The disease is not curable	62.80
The disease is preventable	75
Signs and symptoms of sickle cell disease	85.36
Sickle cell crisis	4.26
Precautions to be taken by sickle cell patients	90.85
Frequency of medical check up needed by sickle cell patients	52.43

Though majority of the beneficiaries were aware about SCD and precautions to be taken, they had poor knowledge of SCD crisis. This clearly indicates the scope of further strengthening of the awareness activities.

Self-Help group/ PRI members: All the 8 members of the self-help group that were interviewed were well aware of the general information about the disease, its causes, signs and symptoms and the precautions to be taken by the sufferers.

<u>Awareness about the sickle cell disease control program</u>

District Health Officer: The district health officer when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district. The perceived role of the DHO in the SCDCP is disbursement of funds, performance monitoring, and liasoning with the NGO. The logistics for the program were provided by the government. The

manpower required for the implementation of the program is inadequate. According to him, there are four electrophoresis machines and all are in a working condition.

Implementation of the sickle cell disease in the district:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in coordination with the Medical officer and staff of the concerned PHC. The knowledge about the screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DHO by conducting visits during the screening camps. The review meetings are held once every month.

The constraints faced by the DHO in implementing the SCDCP are: Delay in release of funds, The ANM /ASHAs are not involved in the screening of patients.

The opinion about implementing the SCDCP through NGO or ASHA: The DHO suggested that the NGO will implement the SCDCP better than the ASHAs.

The following are the suggestions given by the DHO for better implementation of the SCDCP:

Qualified counsellors should be made available at PHC in high burden district like Bhandara. HPLC should be made available at Divisional level/ all medical colleges or HPLC can be outsourced.

Periodic review/ screening / clinical examination of sufferers should be reinforced

Neonatal screening should be made available at RH /SDH/District Hospital.

The **Medical Superintendent** when enquired about the sickle cell disease control program, said that his role was mainly a supervisory role. The no of camps organised at the Rural Hospital were two in the last and all were attended by him. According to him at the rural hospital the cards to the beneficiaries of the SCDCP were distributed by the Laboraotory technicians. There was regular supply of kits and medicines to the Rural hospital, but in case of interrupted supply , they make provision through local purchase of the consumables.

He has not been trained under the SCDCP. He monitors the program by supervisory visits to the camps organised as well as checking the NGO reports. His experience of working with an NGO is good.

He does not face any constraints in implementing the program, but following are his suggestions for better implementation of the program:

Treatment cards should be computerised and linkages should be made at all clinic and hospitals at district level , as the patients do not carry the card with them , when they come to rural hospital for crisis management and it becomes difficult to know the history of the patient.

The **Civil Surgeon** when enquired about the sickle cell disease control program said that his role was mainly a supervisory and monitory role. According to him there was regular supply of kits and medicines.

He has not been trained under the SCDCP. He monitors the program by conducting monthly review meetings. His experience of working with an NGO is good and according to him there is good coordination between the NGO volunteers and ASHAs..

He does not face any constraints in implementing the program, but following are his suggestions for better implementation of the program:

The IEC component of the program should be strengthened and genetic and Marriage counselling should be focused on , if we want to prevent the disease from occurring in the coming generation.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program expressed that:

There is certainly a felt need of this program in the district as the population of the district is as the prevalence of the SCD is very high. The perceived role of the DC in the SCDCP is NGO- supervision, supervision and monitoring of health centres, ensuring availability of kits and medicines, card distribution and reporting , monitoring the follow up of patients and conducting monthly review meetings. The logistics for the program were provided by the State .The manpower required for the implementation of the program is adequate as this is an NGO district,

Implementation of the sickle cell disease in the district:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the District coordinator by checking the registers for completeness, monthly review meetings and frequent supervisory visits.

The NGO has not developed any IEC material, but uses state govt provided IEC material

The constraints faced by the DC in implementing the SCDCP are: the issues related to delayed release of funds and irregular supply of logistics. The district coordinator is not satisfied with the monetary compensation that he receives.

The following are the suggestions given by the DC for better implementation of the SCDCP:

There is a need to increase the salaries of NGO volunteers and other stakeholders, Data entry operator should be provided exclusively for this program. Medical and Nursing staff should be made available in Day care centres.

The **Taluka Medical Officer** when asked about the need for sickle cell disease control program expressed that there is certainly a need for this program specifically in areas of high prevalence , as the awareness about this disease in very low in the tribal population , his role in the SCDCP was perceived as coordination , supervision and monitoring, training, visits and treatment follow ups .The targets for the PHCs are set by state , The beneficiaries are mainly identified by screening camp approach . The camps for screening of the population are organised by NGO volunteers with assistance from the health system staff, the beneficiaries once identified are given colour coded cards by volunteers and ASHA workers.

There was no comment made on the available telemedicine facilities

About the resources the TMO commented that, the logistics supply was regular in the last year,. The fund transfers under the program are regular. The manpower is sufficient.

The TMO is trained for SDCP. The reporting frequency is adequate and there is good support and co-operation from the DHO for the same. He monitors the program by cross checking the NGO reports through the no of kits used. His experience of working with the NGO in this Program is average, as he has to regularly visits them and advice and motivate them for better implementation of the program.

He does not face any constraint in implementing the program and following are his suggestions for better implementation:

He suggested that the program should be implemented through the NGO, the sickle cell coordinator should be a medical graduate and the IEC component of the program should be strengthened.

Medical Officer: Their role in the SCDCP was perceived as supervisory and administrative, screening the community for SCD, organising IEC activities and referring the patient in case of crisis to higher centres .The targets for the PHCs are set by the state. The beneficiaries are mainly identified by – screening camp approach. The camps for screening of the population are organised by NGO volunteers along with ANM, ASHA etc, the beneficiaries once identified are given colour coded cards by MO, HA, ANM .

About the resources the Medical officer commented that, The logistics supply was not regular _ in the last year, the reason for the irregular supply was uneven and irregular distribution to individual PHC and distribution is not according to the no of beneficiaries, the fund transfers under the program are regular. The manpower is sufficient

Of the Medical Officers, one was trained and the other was not trained for SCDCP.

The monitoring of the program is done by cross verifying with the patients.

The difficulties faced during the implementation of the program are mainly related to the irregular logistics supply.

Their experience about working with the NGOs in the field is good .

The suggestions given by the MO to improve the implementation of the program are:

The manpower should be increased and also the logistic supply chain should be improved so as to ensure uninterrupted and adequate supply of kits and medicine.

The NGO In charge: The NGO In-charge has been trained by the district training team for one day at the District training centre. The NGO In-charge was satisfied with the training .When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was not cited. In case of delay in release of funds, the NGO utilises its own resources to meet the needs. The Kits are not regularly supplied. The medicines under SCDCP are regularly supplied. The IEC is done through the display of banner, posters, and counselling sessions organised in schools, colleges etc.

They are provided with targets to be completed in the current year by the state. The NGO In-charge monitors and supervises the implementation of the program by conducting monthly review meetings.

The main constraint in implementing the SCDCP is the delayed release of funds.

The following are the suggestions given by the NGO in-charge to improve the implementation of SCDCP:

The funding to the NGO should be increased , there should be regular supply of solubility kits , increase the no of NGO volunteers , ensuring the availability of laboratory technician at the PHC level, increase the salary of NGO volunteers and supervisors and provide them separate travelling allowance.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the District team for one day at District Hospital. The NGO coordinator is satisfied with the training , When asked specifically about the implementation of the SCDCP , the NGO coordinator responded that : The IEC sessions that were carried out in the community were: screening camps ,poster display, pamphlet distribution, wall paintings , organising gram sabhas, counselling sessions in schools

The flow of funds and kits according to him was regular. He receives Rs 8500 as salary. He is satisfied with the monetary benefit The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. The reports are received every month and he has no suggestions for the better implementation of the program.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the NGO in-charge as well as the district team for one day each at NGO office as well as the District Hospital.. The NGO supervisor is satisfied with the training. When asked specifically about the implementation of the SCDCP, the NGO supervisor responded that: The IEC sessions that were carried out in the community were: screening camps, rally, poster display, pamphlet distribution, counselling session in schools and colleges. He conducts frequent supervisory visits.
The flow of funds according to him was regular. He receives Rs. 8500 as salary. He is satisfied with the monetary benefit .The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. The reports are received every month.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=9)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	100
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	55.55
Regular availability of medicines	66.66
Trained under SCDCP	88.88
Sensitization training conducted	0
Satisfied with the training	88.88

Though 100% of the ANM/ MPW/ ASHAs were aware about SCDCP activities, irregular supply of testing kits and medicines were the constraints for them. There is need to strengthen training component.
It was observed that 100 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: premarital counselling, screening camps in the community including schools and colleges, group meetings, rallies.

All of them 100% knew about the sickle cell day and week celebrated and the activities conducted on these occasions.

They were not directly involved in the target completion and reporting nor were they getting any kind if incentive through SCDCP. They have suggested for regular supply of testing kits and medicines under this program.

ASHA

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=28)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	85.71
significance of the colour cards	71.43
warning signs in SCD patients	75
how to manage sickle cell disease crisis	60.71
treatment given to sickle cell disease patients	96.43
Whom to give medicines	75
Drugs used for SCD patients under the program	96.43
When to conduct prenatal blood test on a pregnant women for SCD	92.85
LOGISTICS AND TRAINING	
Regular availability of kits	89.28
Regular availability of medicines	89.28
Trained under SCDCP	0
Sensitization training conducted	0
Satisfied with the training	0

All the ASHAs were aware that existence of SCDCP. Majority 71.43% knew correctly significance of colour coded cards. According to 60.71 % of ASHAs, SCD crisis patients should be managed by prompt referral.

It was observed that 89.28% knew about the ideal frequency of visits to the SCD patient. Majority 75% knew about the sickle cell day and week celebrated and the activities conducted on these occasions.

They did not receive any kind of incentive under the program nor were they involved in the reporting of SCDCP. They did not make any suggestions to improve the SCDCP activities.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=2)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100

warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	100
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	100
Regular availability of medicines	100
Trained under SCDCP	100
Sensitization training conducted	0
Satisfied with the training	100

It was observed that 100 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: premarital counselling, poster competitions, rallies, community group meetings, and awareness sessions in schools, colleges, etc.
There was 100% awareness about activities conducted on sickle cell day and week.
Both of them 100 % were not satisfied with the incentive and said that the incentive should be more.
They 100% were provided with the targets to be completed and had to do weekly and monthly reporting.

Beneficiaries (Sufferer, Carrier and Caregivers):

The total no of beneficiaries are 99. Of which the observed awareness level the beneficiaries regarding the sickle cell disease control program is as follows:

Almost 91.91% of the beneficiaries were aware of the SCDCP. The NGO volunteers were the main source of information regarding the SCDCP. The services under SCDCP are provided by the NGO volunteer in their local area. Among the sufferers and carriers 66.66% were tested at a camp organised for the screening of SCD, whereas 28.28% were tested at the PHC and 5.05% were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of 61.61% sufferers and carriers, whereas in case of 4.04% the motivation source was ASHA. In 34.35% cases the motivation source for getting tested was medical officer, MPW and ANM.

Of the total beneficiaries almost 95.95% were aware of the significance of the colour cards.

Of the sufferers and carriers who are married, only 11.11% knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only 8.08% were counselled before marriage.

On an average the beneficiaries are aware of their SCD status for period of 8 months to 7 yrs. Children of 43.43% beneficiaries was screened for SCD.

According to 90.9% beneficiaries the NGO volunteer visits them every monthly. The services provided by the NGO volunteer during their visit to the sufferer carrier are as follows counselling, providing treatment and accompanying them to the nearby health facility.

The frequency at which the sufferers have to visit the primary health centre for check-up or medication is once every month by 50% and according to the rest it was twice a month.

The NGO volunteer accompanies them to the PHC during these visits in case of 37.37% patients, 3.03% were accompanied by ASHA. 7.07% were accompanied by health worker to the health centre.24.24% went to PHC on their own.
Of the sufferers 4.04% had undergone telemedicine consultation for joint pain and pain in extremities. 52.52% were satisfied with the services provided under SCDCP. They suggested that other benefits apart from medical care should be provided to them on priority basis through government schemes.

Self-help group/ PRI members: The interviewed members of the self-help group were aware of the SCDCP and the services provided under the SCDCP. The source of their information was NGO volunteer (75%) followed by ASHA (25%). The services under SCDCP in their area were provided by NGO. They were able to enlist the significance of the colour cards. In all there were 4-12 camps organised in their area under SCDCP. All the Self-help group members 100% were satisfied with the services under SCDCP. They did not have any suggestions to improve the SCDCP activities, however they unanimously suggested that these SCD patients should be provided some kind of financial assistance and they should be provided free bus travel by the government.

Evaluation based on following indicators:

Physical Indicators:
The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle / hired vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. The availability of medicines and kits was not regular. The IEC material was impressive in the form of posters, pamphlets, booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were available. The solubility kits supply was interrupted / uninterrupted. The case files of all the sufferers were maintained.

Process Indicators:
The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register, counselling register etc, were well maintained and updated till date.
- Training of the human resource:
  The no of training sessions conducted for the NGO volunteer were two in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by the doctors from district training team. In addition to the induction training, the NGO volunteers are periodically sensitised again during the review meetings and there queries are addressed at the same time.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also weekly reports were obtained regularly from the NGO volunteers.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. In the last year 12 review meetings are conducted by the NGO co ordinator.

- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO co ordinator conducted 73 field visits in last year. The Taluka Medical officer and the district level officials conducted 153 and 103 field visits respectively.
- Organising activities under SCDCP:
  In all the total no of IEC camps organised in the last year were 4803. The percentage of population covered in the camps was 200.16%. The percentage of population covered through other awareness activities was 2397620. The celebration of sickle cell day and week gives a fair knowledge about the extent of activities conducted under SCDCP.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meeting on monthly basis, as well as the Anganwadi worker meeting 412. During last one year, 797 fortnightly meetings with AWWs and pregnant were attended by NGO volunteers. NGO volunteers attended 488 meetings with community leaders and stakeholders. Number of SHG and Mahil mandal group meetings attended by NGO volunteers during last one year was 3184.

Performance Indicators:

- **Outcome indicators:**

Indicator	**Figure (%)**	**score**
Percentage of target population screened for Sickle cell disease by the NGO	**92**	**10**
Percentage of sufferers and carriers counselled in the last year	**99.66**	**15**
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**98.67**	**20**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**1.32**	**NA**
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**0.66**	**NA**

- **Impact Indicators:**

Indicator	**Figure**	**score**
No. of Sufferers and Carriers married to healthy partner	**44**	**15**
No. of married female Sufferers and Carriers currently pregnant	**0**	**15**
No. of married female Sufferers and Carriers gave birth within last year	**0**	**15**
Awareness in Target population	**200 %**	**15**

Financial Indicators:

Indicator	Figure	score
The percentage of approved budget utilised on the proposed activities	**100%**	**8**
Organisation maintaining a separate bank account for the Sickle Cell project	**yes**	**5**
All original bills and vouchers present	**yes**	**5**
For the amount of above Rs 1000, the mode of payment is by Cheque		
Presence of serially numbered and printed vouchers	**yes**	**3**
Cash book entry is on regular basis and updated	**yes**	**3**
All the vouchers have supportive documentary evidence	**yes**	**4**
SOEs submitted in time to SHS	**yes**	**5**
SOE s based on book of accounts	**yes**	**10**
Grand Total Score		**48**

The all inclusive observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

- There was irregular supply of SCD testing kits and medicines under SCDCP.
- No sensitization training was conducted for almost all SCDCP program implementers.

Based on the above findings and observations the subsequent are the recommendations for overall Better implementation of SCDCP:

- It is essential to have uniform coverage of training both induction and refresher at all levels of health system for providing quality services.
- Streamlining logistics management is the key area for successful implementation.
- Reporting components of NGO should be strengthened.

Gondia District

Name of the District: Gondia

Type of District: NGO

Population of the District: 13, 22,635 (as per 2011 census)

Brief of the District: With a mix of urban, rural & tribal communities Gondia district shares its border with Madhya Pradesh, Chhattisgarh districts.

Name of the NGO working in the District: Prabuddha vinayaki kalyankari sanstha

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of the district since three months and has been implementing the Sickle cell disease control program since its inception. The knowledge of the DHO regarding the sickle cell disease is adequate.

The **District Reproductive and Child Health Officer** (DRCHO) has been in-charge of the district since 9 yrs and has been implementing the Sickle cell disease control program since 4 yrs. The knowledge of the DRCHO regarding the sickle cell disease is adequate.

Civil surgeon has been in-charge of the district hospital since 1.5 yrs and has been implementing the Sickle cell disease control program since 1.5 yrs. The knowledge of the civil surgeon regarding the sickle cell disease is adequate.

Medical Superintendent of selected Rural hospital was a medical postgraduate working in the health system since 7 years. He has been implementing SCDCP since 2 years. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health official.

The **Taluka Medical officer** of the randomly of selected Taluka was a ayurveda graduate working in the health system since five & half years. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was

satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health official.

The **Medical Officers**, of the randomly selected PHCs were MBBS and BAMS graduate working in the health system from one year to nine years respectively. Both of them were aware of the cause of sickle cell disease as well as the signs and symptoms. Their awareness level about the sickle cell traits, types, complications etc. was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were known to the health officials.

NGO In charge: The NGO In charge has been working in the health field for six yrs. The NGO works in various other areas like free coaching classes for clerical positions in banking, water conservation. This NGO has been implementing the SCDCP in the Gondia District since 3 yrs. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was adequate, The services provided by the NGO under SCDCP are creating awareness, counselling and ensuring regular follow up of the patients affected with SCD and also helping them to avail facilities offered by government under various schemes.

NGO coordinator: The NGO coordinator has been working in the NGO since one year. She looks only after the implementation of the SCDCP. The population served under this program is 13 lac. The perceived role of the NGO coordinator in the SCDCP is to pay supervisory visits to SCD camps, report preparation, monitoring and evaluation and facilitation of services under the SCDCP. Her knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since three yrs. She looks only after the implementation of the SCDCP. The perceived role of the NGO supervisor in the SCDCP is to create awareness about the disease through village level meetings, organize screening camps for Sickle Cell Disease, facilitate counselling, referral and services to those affected with this disease. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

ANM/MPW/ HA: Six ANM, three MPW and one HA were interviewed. They have worked in the current post in the range of 2 to 28 yrs. On an average the ANM/MPW/HA catered to a population of 5002 to 6786.

The ranges of services to be provided by them are counselling, performance of solubility test under SCDCP program. Of the total 10 ANM/MPW /HA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	% of total (n=10)
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	20
Is the disease curable	80
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	100
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	60
Test for screening of the disease,	100
Test for confirmation of the disease	90
When and where is HPLC conducted	0

Though awareness about etiology, clinical features, screening of SCD was 100%, however none of them were able to tell about indications of HPLC test and where it is performed. Their awareness about frequency of health check up to be done by SCD sufferers was 60%. This clearly indicate the need for training and retraining for ANM/ MPW/ HA under SCDCP.

ASHA: The no of ASHA interviewed were 27 they worked in the current post in the range of 1 to 4 yrs. On an average the ASHA catered to a population of 1000 to 1500. As perceived by them, the range of services to be provided by them under SCD control program is: creating awareness about SCD, helping in arrangement of SCD screening camps. Of the total 27 ASHA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	% of total (n=27)
Meaning of sickle cell disease	100
Causes of sickle cell disease	92.59
Types of sickle cell disease	59.26
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	0
Is the disease not curable	70.37
Is the disease preventable	29.63
Precautions to be taken by sickle cell disease sufferer	96.29
Is regular health checkup necessary for sickle cell disease sufferer	81.48
How frequently is the medical checkup needed	14.81
Test for screening of the disease,	62.96
Test for confirmation of the disease	29.62
When and where is HPLC conducted	0

Though 100% ASHAs were aware about SCD, only 59.26% were aware about its types and none of them knew about meaning of sickle cell crisis. Awareness about frequency of visits for medical check-up and tests for screening and diagnosis of SCD was not satisfactory.

NGO Volunteer: The NGO Volunteers interviewed were two. Of which both of them worked in the current post in the range of one to two yrs. On an average the NGO Volunteer catered to a population of 26719 to 29430.

The ranges of services to be provided by them are spreading the awareness about sickle cell disease control program, mobilising the community for sickle cell testing and counselling the patients about precautions to be taken by sufferers and also counselling specific to marriage under SCDCP program. Following is the awareness about sickle cell disease among them:

Question about Sickle Cell Disease	**% of the total (n=2)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	100
Is the disease curable	100
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	100
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	100
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	100

Awareness two NGO Volunteers about SCD etiology, clinical features, diagnosis & management was satisfactory.

Beneficiaries (Sufferer, Carrier and Caregivers) : In all there are 152 beneficiaries which included 12 sufferers, 78 carriers and 62 caregivers.

The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	**% of the total (n=152)**
Aware about Sickle cell disease	95.39
The disease is a blood disorder	81.57
The disease is a genetic condition	75.65
Children of sufferer and carrier can get this disease	89.47
The disease is not curable	76.31
The disease is preventable	69.73
Signs and symptoms of sickle cell disease	90.13
Sickle cell crisis	94.73

Precautions to be taken by sickle cell patients	92.10
Frequency of medical check-up needed by sickle cell patients	65.78

Awareness about SCD was satisfactory among the sufferers, carriers and caregivers. Their awareness about etiology, clinical features and management of SCD varied from 65.78% to 94.73%.

Self-help group: Awareness among the member of the self-help group that were interviewed was not satisfactory of the general information about the disease, its causes, signs and symptoms and the precautions to be taken by the sufferers.

Awareness about the sickle cell disease control program .

District Health Officer: The district health officer when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DHO in the SCDCP is supervisory. The logistics for the program were provided by the Public health Department of Maharashtra. The manpower required for the implementation of the program is not adequate as there is shortage of Laboratory technicians. As this is an NGO district, mainly the NGO volunteers are responsible for all the activities under this program, but the MO, TMO and other existing government health staffs are also supposed to actively implement the SCDCP in coordination with NGO personnel.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DHO through 1-2 supervisory visits per month to SCD screening camps. Also SCDCP program activities are discussed in the meetings held at district level once a month.

The constraints faced by the DHO in implementing the SCDCP are administrative delays in the funds distribution, shortage of laboratory technicians. He also informed that out 23 electrophoresis machines 6 are not working.

He was of opinion that this program should be implemented entirely through NGO.

The following are the suggestions given by the DHO for better implementation of the SCDCP:

- Timely funds distribution,
- Improvement of quality of counselling through appointing medical social workers as NGO volunteers.
- Screening & diagnosis of SCD should be improved by addressing issue of shortage of laboratory technicians & working electrophoresis machines.

District Reproductive and Child Health Officer (DRCHO): The DRCHO when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The

perceived role of the DRCHO in the SCDCP is supervisory as well as facilitating logistics. The logistics for the program were provided by the Public health Department of Maharashtra. The manpower required for the implementation of the program is not adequate as there is shortage of Laboratory technicians. As this is an NGO district, mainly the NGO volunteers are responsible for all the activities under this program, but the MO, TMO and other existing government health staffs are also supposed to actively implement the SCDCP in coordination with NGO personnel.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DRCHO by supervisory visits to SCD screening Camps twice a month. Also in the monthly meetings SCD activities are discussed.

The constraints faced by the DRCHO in implementing the SCDCP are:

- Irregular logistics
- Shortage of laboratory technicians
- Delay in funds disbursal
- Non working electrophoresis

He was of opinion the SCDCP should be implemented through NGO, however volunteers should be trained in counselling.

The following are the suggestions given by the DRCHO for better implementation of the SCDCP:

- Priority towards implementation of SCDCP
- More inter sectoral coordination
- Strengthening of funds, logistics and trained manpower

Civil Surgeon: The perceived role of the Civil Surgeon in the SCDCP is entirely supervisory. He was of opinion that adequate manpower is available in NGO personnel are dedicated for implementation of SCDCP in coordination with local government health functionary. His knowledge about services offered through this program was adequate. He did not face any difficulty regarding implementation of the SCDCP excluding irregularity of logistics including non availabity of HPLC. He affirmed that regular monitoring through surprise field visits to screening camps and these progress of activities under SCDCP are discussed in the monthly meetings as well. However, he was of opinion that it this program should be implemented through NGO as there is availability of separate dedicated workforce towards SCDCP. He suggested that more input should be given in terms of logistics for better implementation of the SCDCP.

Medical Superintendent: He was aware about his supervisory role in implementation of SCDCP program activities. He was aware of activities like diagnosis and treatment, crisis management of SCD patients. He was aware that this program is being implemented through NGO in coordination with local government health authority.

He has been trained under SCDCP. His perceived difficulties are coordination of NGO with local government health facility and availability of folic acid tablets. However he mentioned he has received support from higher authorities regarding this matter.

Taluka Medical Officer Role of Taluka Medical Officer in the SCDCP was perceived as a facilitator and evaluator of the activities under SCDCP. The beneficiaries are mainly identified by screening camp approach. The camps for screening of the population are organised by the NGO in coordination with local government facility. The beneficiaries once identified are given colour coded cards by ANM & ASHA. Once confirmed SCD sufferers are counselled for monthly health check up at the nearby health facility and their files were made.

If the patient goes into Crisis then, these patients are given hydroxyurea and symptomatic treatment, in case of follow up of the patients the following measures are taken their regular follow up is ensured through NGO volunteers.

About the resources the TMO commented that supply of folic acid tablets was irregular in the last year, due to no supply from district level. This issue was addressed by setting aside patient wise supply of medicines as done in treatment of tuberculosis affected patients. The fund transfers under the program are not regular.

TMO was trained for SCDCP. He has received all the required support from DHO regarding implementation of the SCDCP. The reporting frequency is done regularly under SCDCP

As per TMO there were no difficulties are faced during reporting of the SCDCP. TMO had good experience working with NGO as NGO volunteers were working sincerely

Medical Officers: Both Medical Officers felt that there is a need for a separate program for SCD control due to its prevalence in this district. Their role in the SCDCP was perceived as creating awareness and diagnosis and management of SCD patients. The beneficiaries under SCDCP once identified are given colour coded cards by PHC staff in coordination with NGO staff and when confirmed they are offered counselling & treatment by NGO personnel as well as health workers from PHC.

If the patient goes into Crisis then, these patients are managed with Intravenous fluids, antibiotics and multivitamin. In case of follow up of the patients house to house visits are provided by NGO Volunteers to ensure compliance for the visits.

About the resources the Medical officer commented that the logistics supply was irregular in the last year. However higher authorities were informed about non availability of folic acid tablets required for treatment of SCD patients and local purchase from Rogi Kalyan Samiti funds was made. The fund transfers under the program are not regular.

Both the Medical Officers were trained for SCDCP. Both of them received required support and guidance regarding implementation of SCDCP from DHO and TMO. They had a good rapport while working with NGO. Medical officers suggested that deficiency of laboratory technician & irregularity of logistics should be addressed for better implementation of the activities under SCDCP. The senior most Medical officer recommended that this program should be implemented by health system than NGO.

The NGO In charge: The NGO Incharge has been trained by the district training team for one day at district training center, Nagpur. The NGO In-charge is satisfied with the training.

When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds, testing kits, medicines by the funding agency. The reason for the delay in release of funds was cited as administrative delays. The management of the logistics in case of unavailability of sufficient funds was done by mobilizing the requirements through the district health authorities. He also mentioned that many a times laboratory technician is not available for SCD testing camps organized in other villages due to his commitment towards PHC work.

They are provided with targets to be completed in the current year by the public health department. The NGO In-charge monitors and supervises the implementation of the program. In the last year the NGO in charge conducted monthly meetings for NGO staff and also attended district health office level meetings on monthly basis.

NGO In Charge was of recommended that NGO should be given more grants for raised remuneration of NGO volunteers as well as for procurement of logistics in case of irregularity. He also suggested that more cooperation from local health authorities should be needed for better implementation of the SCDCP activities.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the district training team doctors for one day at district training center, Nagpur. The NGO coordinator is satisfied with the training and has no suggestions to improve the same.

Activities under SCDCP were implemented through trained NGO volunteers. The IEC sessions that were carried out in the community through screening camps, group meetings. The IEC material prepared by them was leaflets, booklets, posters.

She conducted 1-2 supervisory visits in the last year and in those visits, she counselled SCD patients for regular treatment and follow up along with supervision and monitoring of the NGO volunteers. Almost all the meetings were attended by her during last one year. There was no irregularity in the reporting received from NGO volunteers under SCDCP. According to her flow of funds under SCDCP was satisfactory. She receives Rupees 10,230 as a monthly salary and is satisfied with the monetary benefit. There were no suggestions by NGO coordinator for further improvement of the SCDCP.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the district training team doctors for one day at district training center, Nagpur. She is satisfied with the training and has no suggestions to improve the same.

The IEC sessions that were carried out in the community in screening camps group meetings, marriages also during home visits. The IEC material prepared by them was leaflets, booklets, posters. She has conducted almost monthly PHC wise supervisory visits in the last year. In those visits, she conducted meetings of NGO volunteers where laboratory technicians were involved, paid home visits for counselling towards noncompliant SCD patients and cross checked records maintained by them. All the reporting under SCDCP was made on timely basis.

According to NGO supervisor, the flow of funds under this program was adequate. She received rupees 8,500 per month as salary and she was satisfied with it.

Constraints faced by NGO Supervisor that many a times there was no support form Laboratory technician and ANM from PHC. She suggested that for better implementation of the program separate laboratory technician should be provided or NGO volunteers should be trained further.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=10)
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	100
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	90
Regular availability of medicines	90
Trained under SCDCP	70
Sensitization training conducted	0
Satisfied with the training	100

Though all of them were aware about details about implementation of SCDCP, 70% were only trained under SCDCP. All those who have received training were satisfied. There was no sensitization training under SCDCP conducted in this district. Though all of them admitted that IEC activities are done under SCDCP, however they could not recollect correctly about when SCD day and week is celebrated. Neither they have given any targets nor are they involved in any reporting under SCDCP. They have not received any incentive under the SCDCP. However 88% of them suggested that more information should be provided under this program.

ASHA

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=27)
There is a sickle cell disease control program	96.30
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	11.11
warning signs in SCD patients	88.88
how to manage sickle cell disease crisis	62.96
treatment given to sickle cell disease patients	66.66
Whom to give medicines	85.18
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	92.59
LOGISTICS AND TRAINING	

Regular availability of kits	37.04
Regular availability of medicines	29.63
Trained under SCDCP	0
Sensitization training conducted	0
Satisfied with the training	0

All ASHAs were aware about existence of SCDCP implemented through government, their knowledge about significance of colour coded cards distributed to the patients was only 11.11% . They had not received any formal training through SCDCP. Though ASHAs were aware about awareness conducted about SCD, none of them could tell about when the SCD day is celebrated. Only 14.81% knew about the sickle cell week and the activities organised during the week.

Nobody received any incentives under the programme. Neither they have been trained under nor have they been given some targets under SCDCP. There were no suggestions made by ASHA regarding implementation of activities under SCDCP.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	100
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	100
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	50
Regular availability of medicines	100
Trained under SCDCP	100
Sensitization training conducted	100
Satisfied with the training	100

They were enumerated rally, group meetings at villages, schools as IEC activities conducted under SCDCP. None of them were aware about when SCD Day was celebrated while one could (50%) could answer correctly SCD week celebration.
Both of them (100%) were not satisfied with incentive received under SCDCP, thought it should be more.

According to 100 % they are provided with targets to be completed and the frequency of reporting was every week according to 100 % of the NGO Volunteer.

Both of them (100%) suggested that there should be timely supply of testing kits and medicines under SCDCP.

Beneficiaries (Sufferer, Carrier and Caregiver): The total no of beneficiaries are 90. Of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows:

Almost 100% of the beneficiaries were aware of the SCDCP. The NGO volunteers (71.11%) , ANM/ ASHA (18.88%) were the main source of information regarding the SCDCP. The services under SCDCP are provided by the local health facility in coordination with NGO in their local area. Among the sufferers and carriers 30 % were tested at a camp organised for the screening of SCD, whereas 63.33 % were tested at the PHC and 5.5% were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of _64.44% sufferers and carriers, whereas in case of 22.22 % the motivation source was Medical Officer, ANM/ MPW/ ASHA.

Of the total beneficiaries almost 84.44 % were aware of the significance of the colour cards. Of the sufferers and carriers who are married, only 15.55% knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only 8.88 % were counselled before marriage. The effect of their SCD status on their children was known to 25.55%. According to the beneficiaries the NGO volunteer visits them every weekly to every monthly.. The services provided by the NGO volunteer during their visit to the sufferer or carrier are as follows counselling, accompanying them to health facility and provision of Folic acid tablets. The frequency at which the sufferers have to visit the primary health centre for check-up or medication is once every month.

The NGO volunteer accompanies them to the PHC during these visits in case of 41.67%. In case of 33 % the ANM/ MPW accompanies them to the health centre while 25% Sufferers visited to health facility on their own for health check-up. Of the sufferers 41.56% have had to undergo telemedicine consultation. Of the total beneficiaries 60% are satisfied with the services provided.

The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows:

- Financial benefits should be provided
- Benefits in the form free education, transport should be provided

Self-help group: The interviewed 60% members of the self-help group were aware of the SCDCP and the services provided under the SCDCP. The source of their information was local health authority (80%) and media (20%). The services under SCDCP in their area were provided by NGO in coordination with local health authority staff.40% was able to enlist the significance of the colour cards.

In all there were 14 camps organised in their area under SCDCP. Among the Self-help group members 80% were satisfied with the services under SCDCP. Those who were not satisfied suggested that there should more awareness activities regarding SCD.

Evaluation based on following indicators:

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. The IEC material was in the form of posters, pamphlets, booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were available. The solubility kits supply was interrupted. The case files of all the sufferers were maintained.

Process Indicators: not provided.

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:

  It was observed that all the required registers like camp register, counselling register etc were well maintained and updated till date.

Performance Indicators:

- **Outcome indicators:**

Indicator	Figure	score
Percentage of target population screened for Sickle cell disease by the NGO	**88.95**	**10**
Percentage of sufferers and carriers counselled in the last year	**100**	**15**
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**100**	**20**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**5.33**	
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**0.5**	

- **Impact Indicators:**

Indicator	Figure	score
No. of Sufferers and Carriers married to healthy partner	**100, 92**	**15**
No. of married female Sufferers and Carriers currently pregnant	**SS = 5%** **AS = 3%**	
No. of married female Sufferers and Carriers gave birth within last year	**AS = 0.7%**	
Awareness in Target population	**91.8%**	

Financial Indicators:

Indicator	Figure	score
The percentage of approved budget utilised on the proposed activities	**100**	**8**
Organisation maintaining a separate bank account for the Sickle Cell project	**Yes**	**5**
All original bills and vouchers present	**Yes**	**2**
For the amount of above Rs 1000, the mode of payment is by Cheque	**Yes**	**5**
Presence of serially numbered and printed vouchers	**Yes**	**3**
Cash book entry is on regular basis and updated	**Yes**	**3**
All the vouchers have supportive documentary evidence	**Yes**	**3**
SOEs submitted in time to SHS	**Yes**	**5**
SOE s based on book of accounts	**Yes**	**10**
Grand Total Score		**44**

The all-inclusive observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

- Training under SCDCP for all stakeholders had not taken place
- Difficulties in organizing screening camps due to shortage of laboratory technicians
- Nonworking electrophoresis machines affecting diagnosis of SCD
- Completeness of records was the important issue.

Based on the above findings and observations the subsequent are the recommendations for overall Better implementation of SCDCP:

- Capacity building of human resources through training and retraining should be done
- Logistics of screening test kits, medicines and Annual Maintenance Contract of electrophoresis machine for smoother implementation of the program activities

Gadchiroli District

Name of the District: Gadchiroli

Type of District: Tribal (NGO)

Population of the District: 1,071,795

Brief of the District: Gadchiroli District is situated in the south-eastern corner of Maharashtra, and is bounded by chandrapur district to the west, Gondia district to the north, Chhattisgarh state to the east, and Andhra Pradesh state to the south and southwest. It is the second populous district of Maharashtra. According to the 2011 census Gadchiroli district has a population of 1,071,795. Scheduled caste and scheduled tribe population in the district is 1,08,824 and 3,71,696. The tribal community population that resides in the district is 38.3%. The district is categorised as a tribal and undeveloped district.

Name of the NGOs working in the District:

A) **Arogyadham Kustharog Nirmulan Sanstha, Kurkheda,**

B) Ekta Samajik Shikshan Sanstha, Gadchiroli

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of the district since two yrs and has been implementing the Sickle cell disease control program since two yrs. The knowledge of the DHO regarding the sickle cell disease is adequate.

The **District Co- ordinator (DC)** has been in-charge of the district since three yrs and has been implementing the Sickle cell disease control program since three yrs. The knowledge of the DC regarding the sickle cell disease is adequate.

The **Medical Officers**, of the randomly selected PHCs were Ayurvedic (BAMS) graduates working in the health system from 6 to 19 Yrs. They were aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was

satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health officials

NGO – 1- Arogyadham Kustharog Nirmulan Sanstha, Kurkheda,

NGO In charge: The NGO In charge has been working in the health field for 11 yrs. The NGO works in various other areas like 1) medical mobile unit 2) De-addiction Centre. This NGO has been implementing the SCDCP in the Gadchiroli District since 1 yr only. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was acceptable, The services provided by the NGO under SCDCP are increasing awareness, screening the population with the help of solubility test, accessibility of Sanjay Gandhi Niradhar Yogna for the benefit of the sufferer.

NGO coordinator: The NGO coordinator has been working in the NGO since 11 months. He looks after the implementation of the SCDCP .The population served by the NGO under this program is **57,807.** The perceived role of the NGO coordinator in the SCDCP is Monitoring, supervision, taking, reports of camp .The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since 3 Months. He looks after the implementation of the SCDCP .The population served by him under this program is 18,000. The perceived role of the NGO supervisor, in the SCDCP is, Counselling, Camp organization. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory

NGO – 2-Ekta Samajik Shikshan Sanstha

NGO In charge: The NGO In charge has been working in the health field for 20 yrs. The NGO works in various other areas like 1) NRHM's, RCH Project as Field NGO, 2) Education Institute, 3) NGO job Portal undertakings, 4) as self-care group. This NGO has been implementing the SCDCP in the Gadchiroli District since 1 yr. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was acceptable, The services provided by the NGO under SCDCP are awareness among the public, organising Health camps, conducting rallies, training, organising blood donation camp, screening the population with solubility test, follow up of the sufferers, counselling to the sufferers and carriers.

NGO coordinator: The NGO coordinator has been working in the NGO since 2 yrs. He looks after the implementation of the SCDCP .The population served under this program is 2,03,600. The perceived role of the NGO coordinator in the SCDCP is monitoring work of volunteers; Reporting to DHO, Field Visits, coordination between the MO and Volunteers. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since 20 days. He looks after the implementation of the SCDCP. The population served by him under this program is 91,822. The perceived role of the NGO supervisor in the SCDCP is helping volunteer, reporting, Counselling, Giving information on Sanjay Gandhi Niradhar Yojana, organising screening camps. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management , the tests to be done , cards and their significance was satisfactory

ANM/MPW/ HA: The no of ANM/MPW/HA interviewed were eight. Of which all are worked in the current post in the range of 6 to 29 yrs. On an average the ANM/MPW/HA catered to a population of 1644 to 5040.
The ranges of services to be provided by them tablet under SCDP program are: screening the population with Solubility test, confirming the diagnosis with Electrophoresis test , distribution of Folic acid. Of the total 8 ANM/MPW /HA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=8)**
Meaning of sickle cell disease	25
Causes of sickle cell disease	100
Types of sickle cell disease	50
Signs and symptoms of sickle cell disease	75
Meaning of sickle cell crisis	12.5
Is the disease curable	20
Is the disease preventable	20
Precautions to be taken by sickle cell disease sufferer	60
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	60 (MONTHLY)
Test for screening of the disease,	100
Test for confirmation of the disease	62.5
When and where is HPLC conducted	00

The exact meaning of sickle cell disease was known only to 25% of the respondents, whereas causes of the SCD, was known to almost all. The type of sickle cell disease and the signs and symptoms was known to 50% and 75% respectively. 20% thought the disease to be curable, whereas 20% thought it to be preventable. The meaning of sickle cell crisis was known to only 12.5% of the respondents. The precautions to be taken by the sickle cell disease sufferer, was known to 60% of the respondents. All of them said that there is a need for regular health check-up for SCD sufferers, but only 60% knew the frequency of medical check- ups. The test for screening of SCD was known to 100% of the respondents

whereas only 62.5% knew test for confirmation of SCD. None of the respondents knew about HPLC and when and where it is conducted.
The above observations indicate that the training component of the program should be reinforced by conducting refresher training sessions for the health functionaries.

ASHA: The no of ASHA interviewed were three. Of which all , worked in the current post in the range of 3 to 7 yrs. On an average the ASHA catered to a population of 1000 to 3300.
The ranges of services to be provided by them are: ANC and PNC to pregnant females, Immunization, accompanying patients suffering serious illness or in case of emergency to the PHC. Of the total Three ASHA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=3)**
Meaning of sickle cell disease	00
Causes of sickle cell disease	66.66
Types of sickle cell disease	66.66
Signs and symptoms of sickle cell disease	66.66
Meaning of sickle cell crisis	33.33
Is the disease curable	66.66
Is the disease preventable	00
Precautions to be taken by sickle cell disease sufferer	66.66
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	66.66(monthly)
Test for screening of the disease,	100
Test for confirmation of the disease	00
When and where is HPLC conducted	00

None of the three ASHAs could tell the exact meaning of sickle cell disease. But surprisingly 66.6% of the ASHAs could correctly enumerate the causes of SCD, types of the disease, sign and symptoms of SCD. The precautions to be taken by sickle cell disease, sufferer was known by 66% of the respondents. Though all said that regular health check- ups are necessary for the sufferers only 66% knew the frequency of medical checkups. The screening test for the disease was known by all of them, but none knew about the confirmatory test like electrophoresis and HPLC.
The above findings indicate that though the knowledge of the ASHAs about sickle cell disease is acceptable, there is a need to reinforce the subject frequently by conducting refresher training sessions.

NGO Volunteer: The no of NGO Volunteer interviewed were two. Both worked in the current post in the range of 7 to 9 months. On an average the NGO Volunteer catered to a population of 1600 to 35756.
The ranges of services to be provided by them are: Organising Camps, Conducting home visits, organising group meeting, implementing IEC.

Of the total, two NGO Volunteer the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	% of the total (n=2)
Meaning of sickle cell disease	00
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	50
Meaning of sickle cell crisis	00
Is the disease curable	00
Is the disease preventable	00
Precautions to be taken by sickle cell disease sufferer	50
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	100 (monthly)
Test for screening of the disease,	50
Test for confirmation of the disease	00
When and where is HPLC conducted	00

Of the two volunteers interviewed, none knew the meaning of the sickle cell disease, but all of them knew the causes and the types of sickle cell disease. Only 50% knew the signs and symptoms of sickle cell disease. All of them said that regular health check up is necessary for SCD sufferer and the frequency of the checkups were known by all of them. Only 50% knew the screening test and none knew about the confirmation tests and HPLC.
The knowledge of the NGO volunteers is below acceptable levels, and there is an urgent need to train the volunteers. Either the training conducted was not satisfactory or there were no refresher training session conducted for a long time.

Beneficiaries (Sufferer, Carrier and Caregivers): In all there are 163 sufferer, carrier and caregiver (beneficiaries). Of the beneficiaries 17 are sufferers, 82 are carriers and 64 are caregivers.
The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	% of the total (n=163)
Aware about Sickle cell disease	63.01
The disease is a blood disorder	29.18
The disease is a genetic condition	35.13
Children of sufferer and carrier can get this disease	28.96
The disease is not curable	24.34
The disease is preventable	47.17
Precautions to be taken by sickle cell patients	32.21
Frequency of medical check up needed by sickle cell patients	14.52

Of all the 163 beneficiaries, 63% knew about sickle cell disease, but only 29% knew that it is a blood disorder and 35% knew that it was a genetic disorder. The disease is not curable was known only by 24% of the respondents whereas the disease is preventable was known by 47.1% of the respondents. The signs and symptoms of the disease and about sickle cell crisis was very poor. The precautions to

be taken by sickle cell patients were known by 32% of the beneficiaries, whereas only 14.5% knew about the frequency of medical check-ups needed by a sickle cell patient.
The above observations indicate that the awareness among the beneficiaries is inadequate. The core of the program lies in the IEC and conducting screening test. Based on the above findings, there is pressing need to strengthen the IEC.

Self-help group: The members of the self-help group that were interviewed were not so aware, of the general information about the disease, its causes, signs and symptoms and the precautions to be taken by the sufferers.

Awareness about the sickle cell disease control program.

District Health Officer: The district health officer when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DHO in the SCDCP is that of a manager. The manpower required for the implementation of the program is adequate as this is an NGO district, mainly the NGO volunteers are responsible for all the activities under this program, but the as felt by the DHO , the MO of the PHC , is also supposed to be responsible for the ensuring treatment and follow up services for the sufferers. The manpower is trained adequately under the SCDCP.
Implementation of the sickle cell disease in the district is as follows:
The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.
Regular Monitoring and evaluation is done by the DHO by conducting monthly visits.
The constraints faced by the DHO in implementing the SCDCP are: inadequate number of electrophoresis centre in the district (electrophoresis test centres are only six) . The DHO felt that the minimum electrophoresis centre should be one in each block .
The opinion about implementing the SCDCP through NGO or ASHA, when asked the DHO felt that the SCDCP should not be implemented through NGO. The government health system is very much capable of implementing the program through ASHA.
The following are the suggestions given by the DHO for better implementation of the SCDCP:
The DHO pointed out that, specific focus should be given on pre-marriage counselling, so as to prevent marriages among carriers, which is very important for the success of the program.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DC in the SCDCP is 1) Monitoring of program throughout the district, 2) Referring sickle cell patients (AS & SS) 3) NGO monitoring and evaluation 4) helping services reach to pts. e.g. day care centre 5) Timely reporting. The logistics for the program were provided by the Government. The manpower required for the implementation of the program is adequate as this is an NGO district;

mainly the NGO volunteers are responsible for all the activities under this program. The manpower is trained adequately under the SCDCP.

Implementation of the sickle cell disease in the district is as follows: The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

When asked about Monitoring and evaluation of SCDCP, the coordinator could not give a satisfactory response. Also the constraints in implementing the program could not be elaborated by him. He did not make any comment when enquired about his opinion about SCDCP being implemented by NGO or ASHA.

The following are the suggestions given by the DC for better implementation of the SCDCP:

He suggested that the ASHA and MPW may be able to work under SCDCP, but it will be difficult for them to focus on the issue, as they are involved in many other programs. There has to be a dedicated workforce for the program, but the government should recruit the people under the program , as the NGOs human resource management is not good. Also Electrophoresis testing centres should increase from the existing numbers i,e; there should be at least one electrophoresis centre in each taluka.

Medical Officer,: The Medical Officers perceived role in the SCDCP was 1) ensuring that all the people under his PHC should be screened and tested; 2) Training of the health workers 3) providing assistance in organising Health camps; 4) Focusing on target couples in sparsely population small villages., the targets for the PHCs are set by MO , The beneficiaries are mainly identified by Camp approach . The camps for screening of the population are organised by ANM, MPW, ASHA, Technician, sickle cell volunteers, the beneficiaries once identified are given colour coded cards by –technician, sickle cell volunteers,-ANM, MO and when confirmed they are registered with the PHC, ANM, ASHA record book (registered with the PHC etc.).

If the patient goes into Crisis then, refer the patient to higher centre , in case of follow up of the patients the following measures are taken treatment with FS tablets, Hb checking, monitoring of Hb.

About the resources the Medical officer commented that: The logistics supply was irregular in the last year, the reason for the it being administrative delay, less supply to the district, also supply was interrupted, but regular demand to Rural Hospital was done to ensure that the kits and drugs were in stock. The fund transfers under the program are regular. The manpower is sufficient under SCDCP.

Of the Medical Officers, both were trained for SCDCP.

The reporting frequency is monthly and there is constant support and co-operation from the DHO for the same.

The difficulties faced during the implementation of the program are: The Medical Officers did not face any difficulties worth mentioning, which they could not handle on their own.

Their experience about working with the NGOs in the field is that:

The NGO are certainly doing their work, but constant support , motivation has to be given so as to get the results from the NGOs.

The suggestions given by the MO to improve the implementation of the program are:

Funds that were given to purchase solubility test kits are stopped emergency condition need immediate action hence funds should be allowed.

NGO -1 -Arogyadham Kustharog Nirmulan Sanstha, Kurkheda

The NGO In charge The NGO In charge has been trained by the district training team for two days at district training centre, district hospital. The NGO In-charge was satisfied with the training, but it was felt that the training can be further improved by, training NGO volunteers as well as the health functionaries like ASHA, ANM, MPW, HA etc.

When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was cited as : The NGO are not given priority in the health system and also the government officials do not trust the NGOs. The management of the logistics in case of unavailability of sufficient funds was done by Purchasing the required consumables by the NGO itself.

They are provided with targets to be completed in the current year by the state. The NGO In-charge monitors and supervises the implementation of the program. In the last year the NGO in charge conducted monthly meetings. They have also conducted training of the volunteers in the last year.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the district training team doctors for one day only at district training hospitals/district hospitals. The NGO coordinator is satisfied with the training .When asked specifically about the implementation of the SCDCP, the NGO coordinator responded, various IEC activities were conducted in the community like: screening camps, group meetings. The IEC material prepared by them was leaflets, booklets, posters. Newer measures to spread awareness, about SCD were undertaken by the NGO in the form of: Pamphlet distribution, Rallies. He has conducted almost 12 supervisory visits in the last year and in those visits, he checks reports and conducts line listing.

The flow of funds according to him was irregular. He receives 10000/month as salary. He is not satisfied with the monetary benefit also due to the delayed release of funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.

The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year the supervisory visits conducted by him were 12. The reports are received every 15 days.

The following are the suggestions by the NGO coordinator for better implementation of SCDCP: There should be a dedicated doctor the sickle cell patients like -sickle cell specialist available at each PHC, provision of mobile medical team would be beneficial.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the doctor from GMC Nagpur for one day at GMC Nagpur. The NGO supervisor is satisfied with the training. When asked specifically about the implementation of the SCDCP, the NGO supervisor responded that: the training of all the NGO volunteers has been completed .The IEC sessions that were carried out in the community were: screening camps, meetings 2-3 times/month. The IEC material prepared by them was leaflets, booklets, posters. Newer measures to spread awareness about SCD were undertaken by the NGO in the form of: rallies, counselling to mother. He has conducted almost 2 supervisory visits in the last year and in those visits, monitored the activities of the volunteers by checking the registers, getting information from MO regarding the status of sickle cell disease and the work done by the volunteers, visiting technician. The flow of funds according to him was irregular. He receives 4000/month as salary. He is not satisfied with the monetary benefit; also due to the delayed release of

funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year the supervisory visits conducted by him were two .The reports are received monthly.
The following are the suggestions by the NGO supervisor for better implementation of SCDCP:
The supervisor felt that special beds should be reserved for Sickle cell patient in all hospital.

NGO -2-Ekta Samajik Shishan Sanstha

The NGO In charge: The NGO Incharge has been trained by the district training team for two days at district training centre, district hospital. The NGO In-charge was satisfied with the training, but it was felt that the training can be further improved by delivering training by experts and it should be for more duration , at least for 3 day.
When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was cited as : Delay in decision making also ,the NGO are not given priority in the health system and also the government officials do not trust the NGOs. The management of the logistics in case of unavailability of sufficient funds was done by Referring the sickle cell beneficiaries to hospitals.
The NGO In-charge monitors and supervises the implementation of the program. In the last year the NGO incharge conducted fortnightly meetings. They have also conducted training of the volunteers in the last year.

NGO coordinator: The NGO coordinator has been trained for the SCDCP by the district training team doctors for three days at district training centre/district hospitals. The NGO coordinator is satisfied with the training , but suggest that it can be improved by enforcing the technical component of the training, counselling sessions should increase. When asked specifically about the implementation of the SCDCP, the NGO coordinator responded that : the training of all the NGO volunteers has been completed .The IEC sessions that were carried out in the community were: screening camps , fortnightly group meetings . The IEC material prepared by them was leaflets, booklets, posters, flex, pamphlets. Newer measures to spread awareness about SCD, was undertaken by the NGO in the form of: Rallies, blood donation camp. He has conducted almost 24 supervisory visits in the last year and in those visits , he tried to improve the coordination with the health system, provide counselling if necessary, address the problems taking the assistance from the medical officers.
The flow of funds according to him was irregular. He receives 9000/month as salary. He is not satisfied with the monetary benefit also due to the delayed release of funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year the supervisory visits conducted by him were 24.The reports are received every month.
The following are the suggestions by the NGO coordinator for better implementation of SCDCP:

Even though camp approach is feasible, but to survey the entire population house to house survey should be done. Involvement of Panchayat Raj members should be increased, attempt to achieve good coordination with the MO should be made .

NGO supervisor: The IEC sessions that were carried out in the community were: screening camps, distribution of pamphlets every month. The IEC material prepared by them was leaflets, booklets, posters. Newer measures to spread awareness about SCD, was undertaken by the NGO in the form of: Rallies and camps. He has conducted almost 52 supervisory visits in the last year and in those visits , monitored the activities of the volunteers by checking the registers, getting information from MO regarding the status of sickle cell disease and the work done by the volunteers,.
The flow of funds according to him was not known. He receives 6500/month as salary. He is not satisfied with the monetary benefit; also due to the delayed release of funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year the supervisory visits conducted by him were 52. The reports are received every monthly.
No particular suggestion was given by the NGO supervisor.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=8)**
There is a sickle cell disease control program	100
Government implements the SCDCP	20
Services provided under SCDCP	40
significance of the colour cards	62.5
warning signs in SCD patients	60
how to manage sickle cell disease crisis	50
treatment given to sickle cell disease patients	60
Whom to give medicines	75
Drugs used for SCD patients under the program	50
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	60
Regular availability of medicines	60
Trained under SCDCP	80
Sensitization training conducted	20
Satisfied with the training	25

All of them knew about the SCDCP but the range of services provided under this program was known to 40% of the ANM/MPW and only 62.5% could enumerate the significance of the colour cards. Half of them (60%) knew about the warning signs in SCD patients, how to manage sickle cell crisis and the drugs used under this program. And 75% knew the correct time to conduct prenatal blood test on a pregnant woman for SCD.

Commenting about the logistics, 60% said there was regular availability of kits and medicine. Of all the respondents 80% were trained under the SCDCP, but only 20% were satisfied with the training whereas 60% did not respond to the question and 20% were satisfied with the training.
It was observed that 60 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: counselling and patient examination.
No one knew about the sickle cell day and the week that is celebrated and the activities conducted on the day. No one received some kind of incentive under the program.
According to 20% they are provided with targets to be completed and the frequency of reporting was every week according to 12.5 % of the ANM/MPW/HA. Based on the observations the following are the suggestions made by the ANM/MPW/HA:
The sickle cell patients should be provided with financial aid to cover the transportation expenses. The IEC should be improved to giving more information and distributing booklets or leaflets in the community. The number of screening camps organised should be increased. Provision of vehicle for, taking pts. to hospital for electrophoresis.

ASHA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=3)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	00
warning signs in SCD patients	66.66
how to manage sickle cell disease crisis	33.33
treatment given to sickle cell disease patients	33.33
Whom to give medicines	66.66
Drugs used for SCD patients under the program	33.33
When to conduct prenatal blood test on a pregnant women for SCD	66.66
LOGISTICS AND TRAINING	
Regular availability of kits	66.66
Regular availability of medicines	66.66
Trained under SCDCP	00
Sensitization training conducted	00
Satisfied with the training	00

The above findings suggest that though the ASHAs knew about the existence of SCDCP, all of them said that the government is implementing the program.
But surprisingly no one knew about the significance of the colour cards. Warning signs of sickle cell disease and whom to give medicines was known to 66.6% of the ASHAs, whereas
All of them correctly enumerated the services provided under the SCDCP. Sickle cell crisis management, treatment given to sickle cell patients and drugs used under the program was known to 33.3% of the ASHAs only.

The kits and medicines are regularly available was said by 66.6% of the ASHAs. None of the ASHAs were trained under SCDCP.

It was observed that 66.66 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: Organising Gatsabha , school function, rally, melawa .No one knew about the sickle cell day or week celebrated and the activities conducted on the day. No one received any kind of incentive under the program. They had no idea about the targets provided or the reporting system about the SCDCP.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=2)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	50
significance of the colour cards	100
warning signs in SCD patients	00
how to manage sickle cell disease crisis	00
treatment given to sickle cell disease patients	10
Whom to give medicines	100
Drugs used for SCD patients under the program	50
When to conduct prenatal blood test on a pregnant women for SCD	50
LOGISTICS AND TRAINING	
Regular availability of kits	100
Regular availability of medicines	50
Trained under SCDCP	00
Sensitization training conducted	00
Satisfied with the training	00

The NGO volunteers were working in the program for less than one year, all of them knew about SCDCP and that the program is implemented by the government. Only 50% could accurately enumerate all the services provided under the program. All of them could tell the significance of the colour cards.

No one knew about the warning signs of sickle cell disease and how to manage sickle cell crisis. The drugs used under the program, were known to 50% of the volunteers. Whereas 50% knew, about the period of prenatal testing in pregnant women.

All said that the kits were regularly available, whereas the only 50% said that the medicines were regularly available

Surprisingly all the volunteers said that they were not trained by any team of doctors under the SCDCP.

It was observed that 100% knew about the ideal frequency of visits to the SCD patient.

Based on observations, the IEC activities conducted under the program are: conducting rallies, IEC, testing of the population, organising screening camps.

Only 50 % knew about the sickle cell day celebrated and the activities conducted on the day.

100% knew about the sickle cell week and the activities organised during the week.

Almost all received some kind of incentive under the program. 50 % were not satisfied with the incentive. 100 % said that the incentive should be more.
According to 50% they are provided with targets to be completed and the frequency of reporting was not known to the NGO volunteers.
Based on the observations the following are the suggestions made by the NGO Volunteer:
According to them their monthly payment should be increased.

Beneficiaries (Sufferer, Carrier and Caregivers): The total no of beneficiaries are 163. Of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows: Only 5.72 % of the beneficiaries were aware of the SCDCP. The ANM/MPW were the main source of information regarding the SCDCP. The services under SCDCP are provided by the ANM/MPW in their local area. Among the sufferers and carriers, 9.54 %were tested at a camp organised for the screening of SCD, whereas 67.00% were tested at the PHC and 2.94% were tested at the private hospital.
The motivation for getting tested for SCD was given by NGO volunteer in case of 10.86% sufferers and carriers, whereas in case of 2.44% the motivation source was ASHA, IN some cases the motivation source was ANM/MPW and Medical officer.
Of the total beneficiaries almost 97 % were aware of the significance of the colour cards.
Of the sufferers and carriers who are married, only 2.67% knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only 2.47% were counselled before marriage. The effect of their SCD status on their children was known to 40.87%
According to the beneficiaries the NGO volunteer visits them every month. The frequency at which the sufferers have to visit the primary health centre for check- up or medication was known to 35.29%.The NGO volunteer accompanies them to the PHC during these visits according to one Sufferer only. Whereas in case of 13 sufferers, the ASHA accompanies them to the health centre. Of the sufferers none went for telemedicine consultation. Of the total beneficiaries 30.91% are satisfied with the services provided.
The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows:
Regular provision of medicines and provision of financial support ,in the form of monthly allowance to the sickle cell sufferers.

Evaluation based on following indicators:

NGO-1-Arogyadham Kustharog Nirmulan Sanstha, Kurkheda

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was inadequate with sufficient water supply and electricity. The NGO had its own vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. The availability of medicines and kits was irregular. The IEC material was impressive was in the form of posters, pamphlets, booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were

available. The solubility kits supply was interrupted. The case files of all the sufferers were maintained.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register, counselling register etc ,were well maintained and updated till date.
- Training of the human resource:
  The no of training sessions conducted for the NGO volunteer were **1** in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by district coordinator. In addition to the induction training, the NGO volunteers are periodically sensitised again during the review meetings and there queries are addressed at the same time.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also weekly reports were obtained regularly from the NGO volunteers.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. In the last year the no of review meetings conducted by the NGO coordinator are 12.
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO co coordinator conducted 7 field visits in last year. The Taluka Medical officer and the district level officials conducted zero and 12 field visits respectively.
- Stakeholder Involvement:
  The PHC volunteer did not attend a single ANM /ASHA meetings, but they attended the Anganwadi worker meetings. (12). The no of meeting attended with community leaders and mahila mandals , self-help groups on an average were **12**.

Performance Indicators:

Outcome indicators:

Indicator	Figure	score
Percentage of target population screened for Sickle cell disease by the NGO	**> 95%**	**15**
Percentage of sufferers and carriers counselled in the last year	**> 95%**	**15**
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**> 95%**	**20**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**23.8%**	**NA**
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**2.38%**	**NA**

Impact Indicators:

(The following information is not available at the NGO)

Indicator	Figure	score
No. of Sufferers and Carriers married to healthy partner	**Data not available**	**Data not available**
No. of married female Sufferers and Carriers currently pregnant	**Data not available**	**Data not available**
No. of married female Sufferers and Carriers gave birth within last year	**Data not available**	**Data not available**
Awareness in Target population	**Data not available**	**Data not available**

I. Financial Indicators:

Indicator	Figure	score
The percentage of approved budget utilised on the proposed activities	**DATA NOT AVAILABLE**	**08**
Organisation maintaining a separate bank account for the Sickle Cell project	**Separate bank account exists**	**05**
All original bills and vouchers present	**all present**	**05**
For the amount of above Rs 1000, the mode of payment is by Cheque	**yes**	**05**
Presence of serially numbered and printed vouchers	**Vouchers printed but not serially numbered**	**02**
Cash book entry is on regular basis and updated	**Sometimes updated**	**02**
All the vouchers have supportive documentary evidence	**yes**	**4**
SOEs submitted in time to SHS	**Yes**	**5**
SOE s based on book of accounts	**Always matched**	**10**
Grand Total Score		**46**

NGO – 2 Ekta Samajik Shishan Sanstha

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was inadequate with sufficient water supply and electricity. The NGO had its own vehicle / hired vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. The availability of medicines and kits was adequate. The IEC material was impressive was in

the form of posters, pamphlets , booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were available. The solubility kits supply was interrupted . The case files of all the sufferers were maintained.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register , counselling register etc ,were well maintained and updated till date.
- Training of the human resource:
  The no of training sessions conducted for the NGO volunteer were 1 in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by district coordinator. In addition to the induction training, the NGO volunteers are periodically sensitised again during the review meetings and there queries are addressed at the same time.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also weekly reports were obtained regularly from the NGO volunteers.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. in the last year the no of review meetings conducted by the NGO coordinator are 12. Comment on adequacy
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO coordinator conducted 67 field visits in last year. The Taluka Medical officer and the district level officials conducted zero and 5 field visits respectively.
- Organising activities under SCDCP:
  In all the total no of IEC camps organised in the last year were 279. The percentage of population covered in the camps was 50. The celebration of sickle cell day and week gives a fair knowledge about the extent of activities conducted under SCDCP.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meetings (10), as well as the Anganwadi worker meetings. (20). the no of meeting attended with community leaders and mahila mandals, self-help groups on an average were 6. This indicates the stakeholder fair involvement in the program.

Performance Indicators:

Outcome indicators: THE DATA IS NOT RECORDED BY THE PARTNERING INSTITUTE

Indicator	Figure	score
Percentage of target population screened for Sickle cell disease by the NGO	**>95%**	**15**
Percentage of sufferers and carriers counselled in the last year	**< 70%**	**5**
Percentage of sufferers given follow up out of total number of	**DATA NOT**	**DATA NOT**

sufferers diagnosed in the area covered under the NGO project	**AVAILABLE**	**AVAILABLE**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**DATA NOT AVAILABLE**	**DATA NOT AVAILABLE**
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**DATA NOT AVAILABLE**	**DATA NOT AVAILABLE**

Impact Indicators: THE DATA IS NOT RECORDED BY THE PARTNERING INSTITUTE

Indicator	**Figure**	**score**
No. of Sufferers and Carriers married to healthy partner	**DATA NOT AVAILABLE**	**DATA NOT AVAILABLE**
No. of married female Sufferers and Carriers currently pregnant	**DATA NOT AVAILABLE**	**DATA NOT AVAILABLE**
No. of married female Sufferers and Carriers gave birth within last year	**DATA NOT AVAILABLE**	**DATA NOT AVAILABLE**
Awareness in Target population	**DATA NOT AVAILABLE**	**DATA NOT AVAILABLE**

Financial Indicators:

Indicator	**Figure**	**score**
The percentage of approved budget utilised on the proposed activities	**DATA NOT AVAILABLE**	**-**
Organisation maintaining a separate bank account for the Sickle Cell project	**Separate bank account exists**	**5**
All original bills and vouchers present	**all present**	**5**
For the amount of above Rs 1000, the mode of payment is by Cheque	**yes**	**5**
Presence of serially numbered and printed vouchers	**Vouchers printed but not serially numbered**	**2**
Cash book entry is on regular basis and updated	**Sometimes updated**	**2**
All the vouchers have supportive documentary evidence	**Sometimes practiced**	**02**
SOEs submitted in time to SHS	**Yes**	**05**
SOE s based on book of accounts	**Always matched**	**10**
Grand Total Score		**44**

The observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

- It was observed that the NGO-1 was taking efforts in the district, but the same cannot be said about NGO-2, but there is scope for lot of improvement in the implementation of the program.
- The awareness levels of the health functionaries like the ANM/MPW/ASHA/HA were average but not adequate. Also the awareness levels of the beneficiaries (sufferers, carriers and caregivers) were not up to the mark and certainly needs improvement.
- The training of the health functionaries as well as the NGO volunteers seems to be inadequate and needs rigorous efforts.
- The timely release of funds and availability of solubility kits was an important issue identified as a constraint in the implementation of the program.
- The prioritisation, cooperation and coordination of the NGO and the health system functionaries (DHO, DRCHO,TMO, MO) regarding the implementation of sickle cell disease control program is not adequate. Also the cooperation of the ANM, MPW needs improvement.
- The inadequacy of incentives and salaries is another highlighted issue in the findings.
- As per the target achievement indicators, the performance of the NGO is average, but it does not match with the findings from the current study.
- The records though available, were not very updated and some of the important data indicating the impact of the SCDCP was not available. The reporting though on time needs improvement regarding the accuracy and the frequency.

Based on the above observations the following are the recommendations for Better implementation of SCDCP:

- The foundation of any program – training of the implementers should be improved and rigorous steps should be taken to address this issue. The NGO volunteers as well as the health system functionaries like ANM, MPW, ASHA etc. need focused and quality training.
- There is a need to further increase the awareness of the population regarding SCDCP and rigorous steps should be taken for the same.
- Along with the existing IEC material and the conventional methods of spreading awareness, new and more focused , impressive IEC material can be designed and other unconventional (out of box) methods should be used to increase the awareness about SCDCP.
- The no of screening camps conducted in a year should be increased.
- The counselling component of the program should be strengthened and focused on.
- The NGO volunteers /ASHA/ANM should be trained to provide counselling in SCDCP.
- Detailed and impressive material should be made available to the volunteer/ ASHA/ ANM to help them provide counselling.
- House to house motivation to get tested should be applied.
- Telemedicine consultation and referral system should be strengthened
- The help of younger generation, and influential community leaders should be taken.
- The timely release of funds, logistics and solubility kit as well as laboratory support is essential and should be provided.

- The monitoring and supervision and cooperation by the district health authorities should be improved.
- Even though the SCDCP is implemented through the NGO, there is a need to improve the involvement of ANM/MPW/ASHA.
- The timely reporting is important, but the importance of accuracy of the report should be stressed upon..

Chandrapur District

Name of the District: Chandrapur

Type of District: Tribal (NGO)

Population of the District: 21,94,262.

Brief of the District: Chandrapur district is located in the eastern edge of Maharashtra in Nagpur division and forms the eastern part of 'Vidharbha' region. Chandrapur district occupies an area of 11,443 km^2 which constitutes 3.72 percent of the total area of the state. Chandrapur district comprises 15 talukas, namely Chandrapur, Ballarpur, Rajura, Bhadravati, Warora, Chimur, Nagbhid (which is a railway junction too), Bramhapuri, Sindewahi, Mul, Sawali, Gondpipri, Korpana, Pombhurna and Jiwati. According to the 2011 census Chandrapur district has a population of 2,194,262. The population mainly is 64.9% rural and 35.5 % urban.

Name of the NGO working in the District: Sarvodaya Yuvavikas Sanstha, Chimur

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **District Reproductive and Child Health Officer** (DRCHO) has been in-charge of the district since 10 months and has been implementing the Sickle cell disease control program since 10 months. The knowledge of the DRCHO regarding the sickle cell disease is adequate.

The **District Co- ordinator (DC)** has been in-charge of the district since Four yrs and has been implementing the Sickle cell disease control program since Four yrs. The knowledge of the DC regarding the sickle cell disease is adequate.

The **NGO In charge** has been working in the health field for 19 yrs. The NGO works in various other areas like Incef – health micro planning, IEC programme, RCH programme. This NGO has been implementing the SCDCP in the Chandrapur District since 3 yrs . The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was acceptable. The services provided by the NGO under SCDCP are To provide diagnosis and treatment to SCD patients. To provide counselling so as to prevent occurrence of SCD in future generation, micro planning and IEC activities.

NGO supervisor: The NGO supervisor has been working in the NGO since 3 yrs. He looks after the implementation of the SCDCP .The population served under this program is 1, 60,363. The perceived role of the NGO supervisor in the SCDCP is implementing the program, organising camps, IEC activities, kits availability, supervision, results of Screening checking, referring for electrophoresis, making available Sanjay Gandhi Niradhar Yojna to sufferers, to create awareness about various govt schemes. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate .The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory

ANM/MPW/ HA: The no of ANM/MPW/HA interviewed were 3. Of which, all worked in the current post in the range of 14 to 26 yrs. On an average the ANM/MPW/HA catered to a population of 4144 to 5540.

The ranges of services to be provided by them are: Solubility test (D.s), Referral, counselling, Distribution of FA tablets under SCD control program. Of the total 3 ANM/MPW /HA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=3)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	66
Meaning of sickle cell crisis	0
Is the disease curable	66
Is the disease preventable	66
Precautions to be taken by sickle cell disease sufferer	66
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	33
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	0

Almost all the ANM/MPW/HA interviewed had correct knowledge about what sickle cell disease meant, the causes of sickle cell disease and the types of sickle cell disease. The correct signs and symptoms of sickle cell disease were enumerated by 66% of the respondents. The disease is curable was felt by 66% of the respondents and is preventable was felt by 66% of the respondents. Only 66% of the respondents knew about the precautions to be taken by sickle cell disease sufferer. None of the respondents knew about sickle cell crisis. Even though all the respondents felt that regular health check-up is necessary for sickle cell disease sufferer only 33% knew the frequency of the medical check-ups. The tests for screening and confirmation of sickle cell disease, was known to all, they had no idea about where and when HPLC is conducted.

The above findings suggest that though the health functionaries like ANM/MPW /HA were aware of many of the facts about sickle cell disease, there is need to improve the knowledge of these health functionaries. So there is a need to conduct regular sensitization workshops, so as to keep the health functionaries updated with their knowledge.

ASHA: The no of ASHA interviewed were three. Of which all worked in the current post in the range of 3 to 4 yrs. On an average the ASHA catered to a population of 1000 to 1500.
As perceived by them, the range of services to be provided by them under SCDCP is: Counselling, distribution of FA tablets, assisting in arrangement of camps. Of the total ASHA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=3)**
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	66
Meaning of sickle cell crisis	33
Is the disease curable	100
Is the disease preventable	66
Precautions to be taken by sickle cell disease sufferer	66
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	66
Test for screening of the disease,	100
Test for confirmation of the disease	66
When and where is HPLC conducted	0

Almost all the ASHA interviewed had correct knowledge about what sickle cell disease meant, the causes of sickle cell disease and the types of sickle cell disease. The correct signs and symptoms of sickle cell disease were enumerated by 66% of the respondents. The meaning of the sickle cell crisis was known to 33% of the respondents .The disease is curable was felt by all and is preventable was felt by 66% of the respondents. Only 66% of the respondents knew about the precautions to be taken by sickle cell disease sufferer. Even though all the respondents felt that regular health check-up is necessary for sickle cell disease sufferer only 66% knew the frequency of the medical check-ups. The test for screening of SCD was known to all but test for confirmation of sickle cell disease was known to 66% only. Whereas none of the ASHAs had any idea about HPLC test and where is it conducted. They had no idea about where and when HPLC is conducted.
The above findings suggest that though ASHA had knowledge about Sickle cell disease, there is certainly a need to enhance their knowledge to certain basic facts about SCD.

NGO Volunteer: The no of NGO Volunteer interviewed were two. Of which, all worked in the current post in the range of 8 months to 3 yrs. On an average the NGO Volunteer catered to a population of 25110 to 31028.
The ranges of services to be provided by them are: spreading the awareness about sickle cell disease control program, mobilising the community for sickle cell testing and counselling the patients about precautions to be taken by sufferers and also counselling specific to marriage.

Of the total two NGO Volunteers the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	% of the total (n=2)
Meaning of sickle cell disease	100
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	66
Meaning of sickle cell crisis	66
Is the disease curable	100
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	66
Is regular health checkup necessary for sickle cell disease sufferer	100
How frequently is the medical checkup needed	100
Test for screening of the disease,	100
Test for confirmation of the disease	100
When and where is HPLC conducted	100

Almost all of them knew about sickle cell disease, its causes, and types. But only 66% knew about the signs and symptoms of sickle cell disease and sickle cell crisis. It is observed that all of them felt that the disease is curable as well as preventable. The various precautions to be taken by the sufferer were known only to 66% of the respondents. Whereas regular health check-up is needed by the sufferers, the frequency of health check-ups, the screening and the confirmatory tests as well as information about HPLC was accurately known by all NGO volunteers.
The above findings show that though the knowledge of NGO volunteers about SCD seems to be adequate. There is still a need for the regular sensitization training sessions to be organised for the NGO volunteers.

Beneficiaries (Sufferer, Carrier and Caregivers): In all there are 155 sufferer, carrier and caregiver (beneficiaries). Of the beneficiaries 13 are sufferers, 80 are carriers and 62 are caregivers.
The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	% of the total (n=155)
Aware about Sickle cell disease	81.3
The disease is a blood disorder	56.77
The disease is a genetic condition	53.55
Children of sufferer and carrier can get this disease	51.61
The disease is not curable	57.42
The disease is preventable	52.90
Signs and symptoms of sickle cell disease	66
Sickle cell crisis	9.7
Precautions to be taken by sickle cell patients	66
Frequency of medical check up needed by sickle cell patients	55.50

Among the 155 beneficiaries interviewed, 81.3% knew about sickle cell disease. The disease is a blood disorder was known only by 56.8%, whereas 53.5% felt that the disease is a genetic disorder , children of sufferer and carrier can get this disease was known only by half (51.61%)of the respondents. The disease is not curable and is preventable was felt by 57.42 % and 52.9% respectively. Signs and symptoms of the sickle cell disease and precautions to be taken by sickle cell patient were known only to 66% of the beneficiaries, whereas only 9.75 beneficiaries knew about sickle cell crisis. Frequency of the medical check-up needed by the sickle cell patients was known by 55.5% of the beneficiaries.

The above observations suggest that the awareness levels of SCD among the beneficiaries, is almost average and needs to be improved. The IEC should be focussed in as the IEC strengthening is the crux of the program .

Self-Help group: The members of the self-help group that were interviewed were well aware of the general information about the disease, its causes, signs and symptoms and the precautions to be taken by the sufferers.

Awareness about the sickle cell disease control program .

District Reproductive and Child Health Officer (DRCHO): The DRCHO when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is consists of mainly tribal and SC/ST and the prevalence of the SCD is very high. The perceived role of the DRCHO in the SCDCP is to review the programme, supervision and monitoring. The logistics for the program were provided by the State as per NRHM guidelines. The manpower required for the implementation of the program is inadequate as this is an NGO district , mainly the NGO volunteers are responsible for all the activities under this program , but the MO, TMO, ASHA, ANM are also supposed to provide supportive services. The manpower is trained adequately under the SCDCP.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test and confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DRCHO by targets given and achieved or not, facility available, medicines availability, IEC materials referred.

The constraints faced by the DRCHO in implementing the SCDCP are: Inadequacy of Staff for SCDCP, There should be a regular and uninterrupted supply of Laboratory consumables & medicine

The opinion about implementing the SCDCP through NGO or ASHA?

Though NGO is working well in the district, the program can be implemented through ASHAs by giving them appropriate incentives.

The following are the suggestions given by the DRCHO for better implementation of the SCDCP: For better implementation of the SCDCP, there is an urgent need for the screening of the whole district. The para medical staff like the ANM, MPW etc. are required. Also counsellors should be appointed for the same.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly tribal and the prevalence of the SCD is very high. The perceived role of the DC in the SCDCP is Monitoring, Reporting, Provide facilities, and Grant distribution. The logistics for the program were provided by the State. The manpower required for the implementation of the program is adequate as this is an NGO district; mainly the NGO volunteers are responsible for all the activities under this program. He did not comment on the role of health functionaries like ANM and MPW, ASHA. Implementation of the sickle cell disease in the district is as follows:
The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.
When enquired about Regular Monitoring and evaluation of the District, the District coordinator
Regularly checks the reports that are sent by the NGO and cross checks with the patients and other records and also checks with the usage of the testing kits.
The constraints faced by the DC in implementing the SCDCP are the timely availability of kits, also coordination between the NGO and the District officials.
The following are the suggestions given by the DC for better implementation of the SCDCP: there is a need that a focused team of doctors for training and treatment should be available. Also a focused team for testing is necessary.

The NGO In charge: The NGO Incharge has been trained by the district training team doctors for 2 days at district training centre. The NGO In-charge was satisfied with the training.
When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was cited as Renewal letter is not given on time, Grant letter is not given on time. The management of the logistics in case of unavailability of sufficient funds was done by ensuring the use of buffer solution instead of solubility kits.
With regards to the challenges faced by the NGO in- charge in implementing the SCDCP, There are issues mainly with the funding of the program, because of delay of funds, The PHC level support is not adequate, the solubility kits are not adequately provided and not on time. The electrophoresis samples are not taken on time

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the district training team doctors for 1 day at district training centre. The NGO supervisor is satisfied with the training, but suggests that it can be improved by increasing duration of training and it should be given slowly. When asked specifically about the implementation of the SCDCP, the NGO supervisor responded that: the training of all the NGO volunteers has been completed. The IEC sessions that were carried out in the community were, organising screening camps, spreading awareness through Gram sabha, gat sabha, ward sabha , conducting rallies, poster, displaying banners /posters , and distributing pamphlet. The IEC material prepared by them was leaflets, booklets, posters, counselling book, calendar, flip charts. He has conducted almost 3-4/ months supervisory visits in the last year and in those visits , he does meeting MO at PHC, Check solubility kits swabs, EDTA etc, Prepare indent,

Attend meeting with ANM,MPW regarding camps arrangement, Give Targets to ANM,MPW & volunteer as suitable to them.

The flow of funds according to him was irregular. He receives 7000/month+1500 for T.A. = 8500 per month as salary. He is not satisfied with the monetary benefit , also due to the delayed release of funds they do not get any salary for months together.

The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers..

The following are the suggestions by the NGO supervisor for better implementation of SCDCP:

The monetary benefit / salary received by the NGO volunteer and the supervisor are not adequate and should be increased. Also the funds release should not be delayed so as to ensure regular salaries, the PHC staff and other government health officials should co-operate with the NGO for better implementation of the program. The involvement of the district officials like the distribute load equally (not only in NGO), PNC, govt, should help as well top govt officials like CS should intervene.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=3)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	100
significance of the colour cards	77.34
warning signs in SCD patients	66
how to manage sickle cell disease crisis	33
treatment given to sickle cell disease patients	77.34
Whom to give medicines	66
Drugs used for SCD patients under the program	66
When to conduct prenatal blood test on a pregnant women for SCD	66
LOGISTICS AND TRAINING	
Regular availability of kits	100
Regular availability of medicines	100
Trained under SCDCP	66
Sensitization training conducted	0
Satisfied with the training	33

All the respondents knew about the sickle cell disease program, and the services provided under the program. The warning signs in SCD patients, how to manage sickle cell crisis, whom to give medicines, drugs used under the program and when to conduct prenatal blood test on a pregnant women, was known only to 66% of the respondents. The significance of the colour cards and the treatment given to sickle cell disease patients was 77.34%.

All of the respondents said that the availability of kits and medicines was regular. Only 66% were trained under the SCDCP. , Whereas only 33% were satisfied with the training.

The above finding clearly indicates that the training component should be strengthened.

It was observed that 66 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: awareness of the School children, spreading awareness through Gram Sabha (monthly 1 day) and at anganwadis, conducting home visits ,

Only 33 % knew about the sickle cell day and sickle cell disease week celebrated and the activities conducted on the day.

According to 33 % they are provided with targets to be completed and none of them knew that the frequency of reporting for SCDP was every week .

Based on the observations the following are the suggestions made by the ANM/MPW/HA: Training of ANM should be done repeatedly, Electrophoresis should be done at PHC level. Social knowledge should be increased.

ASHA

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=3)**
There is a sickle cell disease control program	100
Government implements the SCDCP	66
Services provided under SCDCP	88.67
significance of the colour cards	55.33
warning signs in SCD patients	66
how to manage sickle cell disease crisis	33
treatment given to sickle cell disease patients	66
Whom to give medicines	100
Drugs used for SCD patients under the program	66
When to conduct prenatal blood test on a pregnant women for SCD	100
LOGISTICS AND TRAINING	
Regular availability of kits	100
Regular availability of medicines	100
Trained under SCDCP	66
Sensitization training conducted	0
Satisfied with the training	33

All the ASHAs knew about the SCDCP, whereas only 88% actually knew about the services provided under the program. Warning signs in SCD patients, treatment given and drugs used under SCDCP was known to 66% of the ASHAs. Half of them (55%) knew about the significance of colour cards. Almost all of them knew about the time of conducting prenatal blood test on a pregnant women for SCD.

All of them commented that there was regular availability of kits and medicines, whereas only 66% of the ASHAs were trained under SCDCP and only b33% of them were satisfied with the training received

It was observed that, 100 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: conducting sessions in gram Sabha to spread awareness about SCD.

Only 33 % knew about the sickle cell day celebrated and the activities conducted on the day, whereas no one knew about the sickle cell week

Almost all did not receive any kind of incentive under the program.
According to 33 % they are provided with targets to be completed and the frequency of reporting was not known to any of the ASHA
Based on the observations the following are the suggestions made by the ASHA: More camps should be held for Diagnosis & awareness

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=3)**
There is a sickle cell disease control program	100
Government implements the SCDCP	0
Services provided under SCDCP	88.67
significance of the colour cards	100
warning signs in SCD patients	88.67
how to manage sickle cell disease crisis	50
treatment given to sickle cell disease patients	88.67
Whom to give medicines	75
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	50
LOGISTICS AND TRAINING	
Regular availability of kits	0
Regular availability of medicines	50
Trained under SCDCP	50
Sensitization training conducted	0
Satisfied with the training	50

The findings suggest that all of them were aware of SCDCP. Whereas only 88% , could accurately enumerate the services provided under the program. Warning signs and treatment provided were known to 88% of the NGO volunteer only 50% knew the management of Sickle cell crisis and 100% knew about the drugs used for SCD patients under the program.
Only 50% knew about the time to conduct prenatal blood test on a pregnant woman for SCD.
Only 50% were trained under SCDCP, none of them commented about the regularity of kits, whereas 50% said that the medicines were regularly available.
It was observed that 100 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: awareness Program in gram Sabha, displaying poster & banners in the villages.
All (100) % knew about the sickle cell day and the week celebrated and the activities conducted .
Almost all received incentive under the program, 100 % were not satisfied with the incentive. All of them said that the incentive should be more (Rs 7000/month).
According to 100 % they are provided with targets to be completed and the frequency of reporting was every week according to 50 % of the NGO Volunteer
Based on the observations the following are the suggestions made by the NGO Volunteer: Pre-marriage counselling should be done, financial help should be provided to all patient, there should be provision of travel expenditure.

Beneficiaries (Sufferer, Carrier and Caregivers): The total no of beneficiaries are 155. Of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows:

Almost 81.29 % of the beneficiaries were aware of the SCDCP. The NGO volunteers were the main source of information regarding the SCDCP. The services under SCDCP are provided by the NGO volunteers in their local area. Among the sufferers and carriers, 19 were tested at a camp organised for the screening of SCD, whereas 91 were tested at the PHC and 10 were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of 75 sufferers and carriers, whereas in case of 12 the motivation source was ASHA, in some cases the motivation source was Medical officer. Of the total beneficiaries almost 97 were aware of the significance of the colour cards. Of the sufferers and carriers who are married, only 2 knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only 3 were counselled before marriage. On an average the beneficiaries are aware of their SCD status since 1 to 15 yrs. The effect of their SCD status on their children was known to 65 beneficiaries. According to the beneficiaries the NGO volunteer visits them every month.

The services provided by the NGO volunteer during their visit to the sufferer or carrier are as follows: To accompany patient to the health centre for diagnosis, provide counselling, distribution of iron and folic acid tablets.

The frequency at which the sufferers have to visit the primary health centre for check up or medication is once every month.

The NGO volunteer accompanies them to the PHC during these visits in case of 24 beneficiaries only. Whereas in case of 13 the ASHA or ANM accompanies them to the health centre. Of the sufferers none have had to undergo telemedicine consultation. Of the total beneficiaries 90 are satisfied with the services provided.

The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows: there should be regular supply of medicines, provision of proper counselling, provision of free pass of train and bus to students, free blood transfusion, more camps should be organised, economic support to the family of SCD patient.

Self-Help group: The interviewed members of the self-help group were aware of the SCDCP and the services provided under the SCDCP. The source of their information was ANM. The services under SCDCP in their area were provided by NGO volunteer. They were able to enlist the significance of the colour cards. In all there were 3 camps organised in their area under SCDCP. Among the Self-help group members all were satisfied with the services under SCDCP. The suggestions given by them for better implementation of the SCDCP are as follows: More camps should be held to increase awareness regarding disease, diagnosis & counselling.

Evaluation based on following indicators:

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP .The

availability of medicines was arranged at the PHC The IEC material was not so impressive and was in the form of posters, pamphlets, booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were available. The solubility kits supply was interrupted. The case files of all the sufferers were not available.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register , counselling register etc ,were well maintained and updated till date. But referral register , laboratory register and stock register were not available at the time of visit.
- Training of the human resource:
  The no of training sessions conducted for the NGO volunteer were two in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by District Coordinator. In addition to the induction training, there were no refresher training organised for the NGO volunteers.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also reports were obtained regularly from the NGO volunteers.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. In the last year the no of review meetings conducted by the NGO coordinator are 14 (at least one /month, which is adequate).
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO coordinator and the Taluka Medical officer did not have any record of the field visits conducted in last year. District level officials conducted around 10 field visits.
- Organising activities under SCDCP: The details of the activities organised was not available at the time of visit.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meetings (12 in last year), they did not attend any Anganwadi worker meetings. The no of meeting attended with community leaders and mahila mandals, self help groups on an average were 96 meetings in last year. The total no of home visits conducted by the NGO volunteers was 42 home visits in a year, which do not meet the ideal no of times the sufferer should be given home visit.

Performance Indicators:

Outcome indicators:

Indicator	Figure	Score
Percentage of target population screened for Sickle cell disease by the NGO	**85%**	**10**
Percentage of sufferers and carriers counselled in the last year	**100%**	**15**
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**100%**	**20**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**13%**	**NA**
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**5%**	**NA**

- **Impact Indicators:**

Indicator	Figure	Score
No. of Sufferers and Carriers married to healthy partner	**96%**	**15**
No. of married female Sufferers and Carriers currently pregnant	**Data not available**	
No. of married female Sufferers and Carriers gave birth within last year	**Data not available**	
Awareness in Target population	**Data not available**	

II. Financial Indicators:

Indicator	Figure	Score
The percentage of approved budget utilised on the proposed activities	**More than 80% utilised**	**8**
Organisation maintaining a separate bank account for the Sickle Cell project	**Separate bank account exists**	**5**
All original bills and vouchers present	**all present**	**5**
For the amount of above Rs 1000, the mode of payment is by Cheque	**yes**	**5**
Presence of serially numbered and printed vouchers	**Vouchers printed but not serially numbered**	**2**
Cash book entry is on regular basis and updated	**Sometimes updated**	**2**
All the vouchers have supportive documentary evidence	**yes**	**4**
SOEs submitted in time to SHS	**Yes**	**5**
SOE s based on book of accounts	**Always matched**	**10**
Grand Total Score		**46**

The overall observations of the interviewer team regarding all the aspects of the implementation of the SCDCP are as follows:

- It was observed that the NGO was taking efforts in the district, but there is scope for lot of improvement in the implementation of the program.
- The awareness levels of the health functionaries like the ANM/MPW/ASHA/HA were average. Also the awareness levels of the beneficiaries (sufferers, carriers and caregivers) were not up to the mark and certainly needs improvement.
- The timely release of funds and availability of solubility kits was an important issue identified as a constraint in the implementation of the program.
- The prioritisation, cooperation and coordination of the NGO and the health system functionaries (DHO, DRCHO, TMO, MO) regarding the implementation of sickle cell disease control program is not adequate. Also the cooperation of the ANM, MPW needs improvement.
- The inadequacy of incentives and salaries is another highlighted issue in the findings.
- As per the target achievement indicators, the performance of the NGO is average, but it does not match with the findings from the current study. The records though available, were not very updated and some of the important data indicating the impact of the SCDCP was not available.
- The reporting though on time needs improvement regarding the accuracy and the frequency.

Based on the above findings following are the recommendations for Better implementation of SCDCP:

- There is a need to further increase the awareness of the population regarding SCDCP and rigorous steps should be taken for the same.
- Along with the existing IEC material and the conventional methods of spreading awareness, new and more focused , impressive IEC material can be designed and other unconventional (out of box) methods should be used to increase the awareness about SCDCP.
- The counselling component of the program should be strengthened and focused on.
- The NGO volunteers /ASHA/ANM should be trained to provide counselling in SCDCP.
- Detailed and impressive material should be made available to the volunteer/ ASHA/ ANM to help them provide counselling.
- The screening of the population for SCD should be improved.
- The No. Of camps or the house to house motivation to get tested should be increased.
- Telemedicine consultation and referral system should be strengthened
- The help of younger generation, and influential community leaders should be taken.
- The timely release of funds, logistics and solubility kit as well as laboratory support is essential and should be provided.
- The monitoring and supervision and cooperation by the district health authorities should be improved.
- Even though the SCDCP is implemented through the NGO, there is a need to improve the involvement of ANM/MPW/ASHA.
- The timely reporting is important, but the importance of accuracy of the report should be stressed upon.

Nandurbar District

Name of the District: Nandurbar

Type of District: Rural (NGO)

Population of the District: 13,00,000

Brief of the District: The district occupies an area of 5035 km^2 and has a population of 1,311,709 of which 15.45% were urban (as of 2001). Nandurbar is primarily a tribal (Adiwasi) district.

Name of the NGO working in the District: Jijau Maratha Mahila Samaj Unnati Mandal

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objectives of the program, the awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **District Health Officer** has been in-charge of the district since 6yrs and has been implementing the Sickle cell disease control program since 7yrs. The knowledge of the DHO regarding the sickle cell disease was adequate.

District Reproductive and Child Health Officers (DRCHO) post in the district has been vacant.

The **Taluka Medical officer** was randomly selected from the district. His qualification was MBBS. He was working in the health system since last 11yrs. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc. was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were known to the health official.

The **Medical Officer**, of the randomly selected PHCs was BAMS graduate working in the health system 30yrs. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc. was not satisfactory. The tests to be performed for screening was known but for confirmation was not.
Overall, it appeared that he had very little role in Sickle Cell Disease Control activities.

NGO In charge: The NGO In charge has been working in the health field for 15yrs. The NGO works in various other areas like mobile medical services under NRHM, women counselling centre and blood on call to civil hospital, Nandurbar. This NGO has been implementing the SCDCP in the Nandurbar District since 4.5 yrs. The NGO In charge has sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures is adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program , it was seen that

the awareness levels about the various aspects of the SCDCP was acceptable, The services provided by the NGO under SCDCP are organising screening camps, counselling, treatment, regular health check-ups and provision of IEC material. These activities are done with the help of NGO volunteers.

NGO coordinator: The NGO coordinator has been working in the NGO since 6 months. He looks after the implementation of the SCDCP only. The population served under this program is 16,48,295. The perceived role of the NGO coordinator in the SCDCP was to guide and coordinate the field activities done with help of NGO volunteers. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken was adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: He looks after the implementation of the SCDCP only. The population served under this program is 2,46, 812. The perceived role of the NGO supervisor in the SCDCP was to monitor the activities going on under the program. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken was found to be adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

ANM/MPW/ HA: The no of ANM/MPW/HA interviewed were 6. They worked at the current post in the range of 2 to 26yrs. On an average, ANMs catered to a population of 2000 to 5000 and HA served the population of approximately 15000.
The ranges of services to be provided by them were immunization, survey of malaria surveillance, family planning, case finding and drugs distribution to patients of TB, malaria & leprosy, ANC registration, ANC check-up, counselling, delivery services, sickle cell disease management under pulse polio immunization, RNTCP, filaria control program, malaria control program, janani suraksha yojana, family welfare program and SCDCP.
Of the total 6 ANM/MPW /HA the following is information regarding awareness about the sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=6)**
Meaning of sickle cell disease	67
Causes of sickle cell disease	100
Types of sickle cell disease	100
Signs and symptoms of sickle cell disease	100
Meaning of sickle cell crisis	67
Is the disease curable	100
Is the disease preventable	100
Precautions to be taken by sickle cell disease sufferer	100
Is regular health check up necessary for sickle cell disease sufferer	83
How frequently is the medical check-up needed	67
Test for screening of the disease,	100
Test for confirmation of the disease	83
When and where is HPLC conducted	0

Most of the ANMs and HA were aware of the cause of disease and preventive measures to be taken for it.

ASHA: Total of 13 ASHAs were interviewed in Nandurbar district. They worked at the current post in the range of 1.5 to 7yrs. On an average the ASHA catered to a population of 700 to 1500.
The ranges of services to be provided by them are ANC and PNC visits, take pts for delivery testing, immunization DOTS to TB patients, MDT to leprosy patients, drug delivery to ANC pts bringing general pts to PHC, RH birth and death registration, kishori sabha under MCH program, JSY, RNTCP, Leprosy control program and pulse polio immunization. Following is the awareness of ASHAs about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=13)**
Meaning of sickle cell disease	31
Causes of sickle cell disease	69
Types of sickle cell disease	54
Signs and symptoms of sickle cell disease	64
Meaning of sickle cell crisis	62
Is the disease curable	54
Is the disease preventable	85
Precautions to be taken by sickle cell disease sufferer	77
Is regular health check-up necessary for sickle cell disease sufferer	100
How frequently is the medical check-up needed	62
Test for screening of the disease,	77
Test for confirmation of the disease	31
When and where is HPLC conducted	0

NGO Volunteer: The no of NGO Volunteer interviewed were 23. They were working at the current post in the range of 1 to 6yrs. On an average the NGO Volunteer catered to a population of 1000 to 36000.
The ranges of services they were providing were awareness and counselling about SCD, Health education, testing and reporting for SCD and card distribution, group meeting programs for carrier & sufferer pts , counselling and referring patients to civil hosp and make arrangements for transport under SCDCP.
Of the total 23 NGO Volunteer, the following is the information regarding awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of the total (n=23)**
Meaning of sickle cell disease	96
Causes of sickle cell disease	83
Types of sickle cell disease	87
Signs and symptoms of sickle cell disease	43
Meaning of sickle cell crisis	30
Is the disease curable	56
Is the disease preventable	83
Precautions to be taken by sickle cell disease sufferer	78
Is regular health check-up necessary for sickle cell disease sufferer	100

How frequently is the medical check-up needed	65
Test for screening of the disease,	100
Test for confirmation of the disease	91
When and where is HPLC conducted	4

Though most NGO volunteers knew about the disease, its cause and types, knowledge regarding signs and symptoms of the disease and crisis was not satisfactory. Also, though almost all of them knew about the screening and confirmatory tests to be done, only one of the volunteers could tell about HPLC.

Beneficiaries (Sufferer, Carrier and Caregiver): In all there were 154 beneficiaries i.e. sufferers, carriers and caregivers interviewed. 11of them were sufferers, 80 were carriers and 63 were caregivers.
The knowledge of the beneficiaries regarding the Sickle Cell disease was as follows:

Questions about sickle cell disease	**% of the total (n=154)**
Aware about Sickle cell disease	82
The disease is a blood disorder	66
The disease is a genetic condition	51
Children of sufferer and carrier can get this disease	62
The disease is not curable	33
The disease is preventable	52
Signs and symptoms of sickle cell disease	44
Sickle cell crisis	16
Precautions to be taken by sickle cell patients	60
Frequency of medical check up needed by sickle cell patients	57

Self-help group/ PRI: 6 members of the PRI were interviewed and found to be aware of the general information about the disease, its causes, signs and symptoms and the precautions to be taken by the sufferers.

<u>Awareness about the sickle cell disease control program .</u>

District Health Officer: The district health officer when enquired about the sickle cell disease control program expressed that there was certainly a felt need of this program in the district as the population of the district was mainly tribal and the prevalence of the SCD was very high. The perceived role of the DHO in the SCDCP was to distribute funds to NGO and monitor for smooth running of the program in the district.

Implementation of the sickle cell disease control program in the district is as follows: The implementation of the SCDCP in the district is through the NGO. There was regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC.

Regular Monitoring and evaluation was done by the DHO by regularly checking the monthly report sent by NGO.
The constraints faced by the DHO in implementing the SCDCP were low literacy rates of the people which made counselling and IEC activities difficult.
DHO said the program could be implemented through ASHA by strengthening them by giving them honorarium. Also monitoring was not possible with NGOs.
The suggestions given by the DHO for better implementation of the SCDCP were training of the medical officers about the SCDCP and improvement of the counselling part of the program.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program expressed that there was certainly a felt need of this program in the district as the population of the district was mainly tribal and the prevalence of the SCD was very high. The perceived role of the DC in the SCDCP was to coordinate the project. The manpower required for the implementation of the program was adequate as this was a NGO district; mainly the NGO volunteers were responsible for all the activities under this program.
Implementation of the sickle cell disease in the district is as follows: There was regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.
Regular Monitoring and evaluation is done by the DPM by visiting the screening camps and checking the monthly reports.
No major constraints were faced by the DC in implementing the SCDCP.
DC suggested that for better implementation of the SCDCP, the NGO volunteers should be regularised.

Taluka Medical Officer Role of the TMO in SCDCP was perceived as to assure screening of the population for SCD, regular supply of medicines to sufferers and carriers and marriage counselling of the patients. The beneficiaries are mainly identified by camp approach and in OPD . The camps for screening of the population are organised by NGO. The beneficiaries once identified are given colour coded cards by NGO volunteers, ASHAs and ANMs. When confirmed they were registered they were given visits by NGO volunteers and ASHAs. Counselling was also done by them.
If the patient goes into Crisis the it was managed on the basis of symptoms and in case of follow up of the patients were counselled to take healthy diet and regular check ups.
Telemedicine facilities were never used for consultation with specialists.TMO was trained for SCDCP
About the resources the TMO commented that the logistics supply was not regular in the last year, the reason for it was unavailability of drugs but folic acid tablets were taken from rogi kalyan samiti to ensure that the patients got regular medicines.
Records were submitted by NGO volunteers directly to NGO, so were not verified. There was cooperation from DHO for identifying the sensitive areas and proper implementation of the program in those areas.
The difficulties faced during the implementation of the program were non-cooperation and no mobilization of community in NGO camps. Also results of electrophoresis were not informed on time which would lead to delayed categorization of the patients. There was overall lack of coordination and no supervision list was prepared by the district's NGO supervisor.

Their experience about working with the NGOs in the field was that the work was not coordinated. They were not giving updates to the MO.
The suggestions given by the TMO to improve the implementation of the program were that ASHAs should be strengthened by providing more training and more incentives and the program should be implemented through them rather than NGOs because they were more close to the community and better counselling of the people would be done.

Medical Officer: The Medical Officer when asked about the need for sickle cell disease control program expressed that it was much needed program as prevalence of the disease was high in this district being it a tribal area. His role in the SCDCP was perceived as detection and treatment of SCD patients. The beneficiaries are mainly identified by camp approach. The camps for screening of the population are organised by NGO volunteers. The beneficiaries once identified are given colour coded cards by lab technicians and when confirmed they are registered with the PHC.
Knowledge regarding management of sickle cell crisis was not satisfactory. Telemedicine facilities were never used.
About the resources the Medical officer commented that the logistics supply was not in the last year, the supplies were inadequate but purchase was done with rogi kalian samiti funds to ensure that the kits and drugs were in stock. The fund transfers under the program were regular.
Medical Officer was trained for SCDCP. The reporting frequency was monthly and regular.
The difficulties faced during the implementation of the program were inadequate supply of drugs n kits. Their experience about working with the NGOs in the field was good. NGO volunteers were helpful in organising the camps and mobilising people for testing and patients for treatment.
No constraints were mentioned by MO in implementation of the program.
The suggestions given by the MO to improve the implementation of the program were to increase the number of camps. Since, he had very little role in the implementation of sickle cell disease control activities and also lack of a favourable attitude towards the same.

The NGO In charge The NGO In charge has been trained by the UNICEF team for 2 days at district hospital Nandurbar and reorientation training was done for 2 times. The NGO In-charge was satisfied with the training, but it was felt that the training can be further improved by frequent training sessions and in depth information regarding the disease should be imparted.
When enquired about the logistics, funds release and other support from the health system, the response received was that there is delay in the release of funds by the funding agency. The reason for the delay in release of funds was cited as delay by the CEO in release of fund.
The NGO In-charge monitors and supervises the implementation of the program.

NGO coordinator: The NGO coordinator has not been trained for the SCDCP. The IEC sessions that were carried out in the community were screening camps. The IEC material prepared by them was leaflets, booklets, posters. He gives supervisory visits every 15 days in the field to look for smooth functioning of the program.
The flow of funds according to him was not regular. He receives no incentives.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year the supervisory visits conducted by him were 24. Also 12 meetings were attended by him.

The reports are received from NGO volunteers every week.
The following are the suggestions by the NGO coordinator for better implementation of SCDCP were to regularise the posts of NGO volunteers and supervisors.
The NGO coordinator was found wanting in knowledge, coordination, application and leadership skills. The supervision activities also are not satisfactory.

NGO supervisor: The NGO supervisor has been trained for the SCDCP by the NGO for 3 days at district hospital. The NGO supervisor was satisfied with the training.
The IEC sessions that were carried out in the community were screening camps, counselling sessions at PHC, gram panchayat and schools. The IEC material prepared by them was leaflets, booklets, posters. He used to conduct supervisory visits every 15 days.
The flow of funds according to him was not regular and he did not receive any incentives for this job.
The monitoring and supervision was done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. No data was available regarding number of visits conducted.

ANM/MPW/HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=6)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	83
significance of the colour cards	83
warning signs in SCD patients	100
how to manage sickle cell disease crisis	100
treatment given to sickle cell disease patients	100
Whom to give medicines	0
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	83
LOGISTICS AND TRAINING	
Regular availability of kits	83
Regular availability of medicines	100
Trained under SCDCP	33
Sensitization training conducted	33
Satisfied with the training	100

It was observed that all of them knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program were counselling in schools and gram panchayats.

None of them knew about the sickle cell day and the activities conducted on the day. Only 67% knew about the sickle cell week and the activities organised during the week. They did not get any kind of incentive under the program. Only one ANM said that target to be completed was given and none of them said that frequency of reporting was every week.
Based on the observations the following are the suggestions made by the ANM/MPW/HA that patients should be given monetary help. More awareness needs to be spread so that more people know about the disease and number of sufferers can be reduced.

ASHA

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total (n=13)**
There is a sickle cell disease control program	100
Government implements the SCDCP	100
Services provided under SCDCP	69
significance of the colour cards	84
warning signs in SCD patients	92
how to manage sickle cell disease crisis	69
treatment given to sickle cell disease patients	61
Whom to give medicines	0
Drugs used for SCD patients under the program	100
When to conduct prenatal blood test on a pregnant women for SCD	0
LOGISTICS AND TRAINING	
Regular availability of kits	23
Regular availability of medicines	100
Trained under SCDCP	69
Sensitization training conducted	69
Satisfied with the training	100

It was observed that only 38% knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program were awareness sessions during monthly immunization programs.
None of them knew about the sickle cell day and week dates. Only 2 of them could tell about the activities conducted during these days. Only one of them said that she received incentive under the program. Only one of them said they were provided with targets to be completed and the frequency of none of them knew about the correct frequency of reporting.
Based on the observations the following are the suggestions made by the ASHA:
Free travelling facilities and free blood transfusion to the patients. Training should be made more elaborative. Incentives should be increased.

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=23)
There is a sickle cell disease control program	100
Government implements the SCDCP	56
Services provided under SCDCP	74
significance of the colour cards	100
warning signs in SCD patients	61
how to manage sickle cell disease crisis	91
treatment given to sickle cell disease patients	61
Whom to give medicines	25
Drugs used for SCD patients under the program	96
When to conduct prenatal blood test on a pregnant women for SCD	42
LOGISTICS AND TRAINING	
Regular availability of kits	69
Regular availability of medicines	82
Trained under SCDCP	91
Sensitization training conducted	74
Satisfied with the training	85

It was observed that 43% knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: awareness sessions at panchayat youth gathering, schools, ashrams and creating awareness by personal visits to houses.
Only 39% knew about the sickle cell day celebrated and the activities conducted on the day.
Only 56% knew about the sickle cell week and the activities organised during the week.
Almost all received some kind of incentive under the program. 42% were not satisfied with the incentive. 50% said that the incentive should be more as the workload was more.
According to 22 out of 23, they are provided with targets to be completed and the frequency of reporting was every week according to only 2 NGO Volunteers.
Based on the observations the following are the suggestions made by the NGO Volunteers: raise incentives due to heavy work, SCDCP should be transferred under NRHM

Beneficiaries (Sufferer, Carrier and Caregiver): The total no of beneficiaries were 154 beneficiaries i.e. sufferers, carriers and caregivers interviewed. 11of them were sufferers, 80 were carriers and 63 were caregivers.
Of which the observed awareness levels of the beneficiaries regarding the sickle cell disease control program is as follows:
Almost 56% of the beneficiaries were aware of the SCDCP. The ASHA were the main source of information regarding the SCDCP. The services under SCDCP were provided by the ASHA and NGO volunteers in their local area. Among the sufferers and carriers, 67were tested at a camp organised for the screening of SCD, whereas 11 were tested at the PHC and 3 were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of 17 sufferers and carrier, whereas in case of 38 the motivation source was ASHA, IN some cases the motivation source was ANM and MO.
According to the beneficiaries the NGO volunteers visited them every 15 days to 3 months. But this was told by only 7% of the beneficiaries.
The services provided by the NGO volunteer during their visits to the sufferer or carrier were giving folic acid tablets, counselling and taking to health check-up.
The frequency at which the sufferers have to visit the primary health centre for check-up or medication is once to twice every month.
The NGO volunteer accompanies them to the PHC during these visits in case of 17 beneficiaries. Whereas in case of 20, the ASHA accompanies them to the health centre. Many of them go by themselves.
None of them have had to undergo telemedicine consultation. Of the total beneficiaries only 48% were satisfied with the services provided.
The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows

- Health education in school for students to create awareness about SCD and motivate them.
- Regular health check-up, drugs distribution and counselling of the patients.
- Camps should be regular.
- Information should be published in newspapers.
- More detailed information about disease should be given.
- NGO volunteer should be strengthened to provide services.
- Blood transfusion for children should be easily available.

Self-help group: The interviewed members of the self-help group were aware of the SCDCP and the services provided under the SCDCP. The source of their information was NGO volunteer and ASHA. The services under SCDCP in their area were provided by NGO. They were not able to enlist the significance of the colour cards. Self-help group members were satisfied with the services under SCDCP. The suggestions given by them for better implementation of the SCDCP were as follows.

- Availability of blood for transfusion easily
- Loan facility should be provided for treatment
- Increased awareness among community members

Evaluation based on following indicators:

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle / hired vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP

Process Indicators:
The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register , counselling register etc ,were well maintained and updated till date.
- Training of the human resource:
  The training register and records were not produced.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly also weekly reports were obtained regularly from the NGO volunteers.
- Frequency and adequacy of review meetings:
  Review meetings are an essential part for the continuous improvement in the implementation of the program. In the last year the no of review meetings conducted by the NGO coordinator were 12. At every meeting 50 to 60% of the staff would be present. Though the number of meetings conducted was sufficient, attendance of the staff was not satisfactory.
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO coordinator conducted 15 -20 field visits in last year. The Taluka Medical officer and the district level officials conducted 4 and 1 field visits respectively.
- Organising activities under SCDCP:
  In all the total no of IEC camps organised in the last year were 3033. The percentage of population covered in the camps was 95. The percentage of population covered through other awareness activities was 1678879. The celebration of sickle cell day and week gives a fair knowledge about the extent of activities conducted under SCDCP.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meetings (4/ year), as well as the Anganwadi worker meetings. (12/ year). The no of meeting attended with community leaders and mahila mandals, self help groups on an average were 10-14/ year. This indicates the stakeholder' good involvement in the program.

Performance Indicators:

Outcome indicators:

Indicator	Figure	score
Percentage of target population screened for Sickle cell disease by the NGO	**25**	**5**
Percentage of sufferers and carriers counselled in the last year	**100**	**15**
Percentage of sufferers given followup out of total number of sufferers diagnosed in the area covered under the NGO project	**100**	**20**
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**3.4**	
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**0.01**	

Impact Indicators:

Indicator	Figure	score
No. of Sufferers and Carriers married to healthy partner	**93**	
No. of married female Sufferers and Carriers currently pregnant	**NA**	
No. of married female Sufferers and Carriers gave birth within last year	**NA**	
Awareness in Target population	**95%**	

The all inclusive observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

Observations:

- Knowledge of the higher officials was satisfactory about the disease as well as program.
- Knowledge of the MO about the disease was not satisfactory.
- NGO incharge, supervisor and coordinator had adequate knowledge about the disease as well as program. They were aware of their roles in the program.
- Among grass root workers, knowledge of the ANM, HA and NGO volunteers were adequate but ASHAs were not adequately trained for SCD and program.
- No innovative methods were being used as far as IEC is concerned.
- Awareness levels among beneficiaries were not good which could be the reflection of poor knowledge among ASHAs.
- Many higher officials as well as beneficiaries suggested that program could be implemented through ASHAs as they were more close to the community.
- Supply of the funds and logistics was not regular.
- Beneficiaries wanted to be given monetary benefits.

Recommendations:

- State level and district level training need to be held for higher officials especially for MOs. They need to be trained rigorously because they are they trainers for grass root workers.
- There needs to be a quality check system for trainings as many of the workers though trained, did not have sufficient knowledge.
- More measures must be taken to raise awareness among general population about the disease.
- Regular supply of Funds and logistics must be ensured for smooth running of the program.

Wardha District

Name of the District: Wardha

Type of District: **Rural (NGO)**

Population of the District: 13,14,690

Brief of the District: **Wardha district** is one of the 35 districts in Maharashtra state in western India. This district is a part of Nagpur Division. The city of Wardha is the administrative headquarters of the district.

Name of the NGO working in the District: Shri Namdev maharaj bahuuddeshiya shikshan sanstha

Results:

As sensitisation and increasing awareness of sickle cell disease control program is one of the important objective of the program. The awareness levels of all the stakeholders from health functionaries, grass root level health workers as well as the beneficiaries were assessed. The following are the findings of the same:

Awareness about the sickle cell disease

The **Civil Surgeon** has been in-charge of the district since 2 yrs and has been implementing the Sickle cell disease control program since 2 yrs. The knowledge of the Civil surgeon regarding the sickle cell disease was adequate.

The **District Reproductive and Child Health Officer** (DRCHO) has been in-charge of the district since 2 yrs 9 months and have been implementing the Sickle cell disease control program since 2 yrs 9 months. The knowledge of the DRCHO regarding the sickle cell disease was adequate.

The **Medical Superintendent** randomly selected Sub District Hospital was M.B.B.S, M.D., DCH graduates working in the health system from last 10 yrs 6 months. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health official.

The **Taluka Medical officer** of randomly selected Taluka of Wardha District was M.B.B.S. graduates working in the health system from 17 yrs. He was aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc. were satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease, was known to the health official.

The **Medical Officers**, of the randomly selected PHCs were M.B.B.S and B.A.M.S. graduates working in the health system from last 1 year. Both of them were aware of the cause of sickle cell disease as well as the signs and symptoms. The awareness level about the sickle cell traits, types, complications etc

was satisfactory. The tests to be performed for screening and confirmation of the sickle cell disease were not known to the both of them.

The **District Sickle Cell Co- ordinator (DC)** was been in-charge of the district since 3 years and had been implementing the Sickle cell disease control program since 3 years. The knowledge of the DC regarding the sickle cell disease was adequate.

NGO In charge: The NGO In charge was working in the health field for 12 yrs. The NGO was working in various other areas like social welfare programme, blood camp, rehabilitation programme, customer awareness programme and HIV awareness programme. This NGO had been implementing the SCDCP in the Wardha District since 3 years 6 months. The services provided by the NGO under SCDCP were testing, counselling, and regular health check up, crisis management. The NGO In charge had sufficient knowledge of the sickle cell disease; the awareness about the causes, signs and symptoms, preventive measures was adequate. The NGO In charge was assessed for the awareness about the sickle cell disease control program, it was seen that the awareness levels about the various aspects of the SCDCP was acceptable.

NGO coordinator: The NGO coordinator had been working in the NGO since three and half yrs. He was looking after the implementation of the SCDCP. The population served under this program was 8.5 lacs. The perceived role of the NGO coordinator in the SCDCP was to arrange report and manage the camps related to the projects, to fill the limitations of on-going programme. The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken was adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory.

NGO supervisor: The NGO supervisor has been working in the NGO since 4 yrs. He looks after the implementation of the SCDCP .The population served under this program is 1,12,928. The perceived role of the NGO supervisor in the SCDCP is arrange camps, testing and management .The knowledge of the Coordinator regarding the aetiology of the SCD as well as preventive measures to be taken is adequate. The awareness about sickle cell crisis and management, the tests to be done, cards and their significance was satisfactory

ANM/MPW/ HA:

The no of ANM/MPW/HA interviewed were three. All worked in the current post in the range of 2 to 25 yrs. On an average the ANM/HA catered to a population of 4948 to 7200.

The ranges of services to be provided by them are: under all national programs. Of the total 3 ANM/HA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=3)**
Meaning of sickle cell disease	100%
Causes of sickle cell disease	100%
Types of sickle cell disease	100%
Signs and symptoms of sickle cell disease	100%
Meaning of sickle cell crisis	0%

Is the disease curable	100%
Is the disease preventable	100%
Precautions to be taken by sickle cell disease sufferer	100%
Is regular health checkup necessary for sickle cell disease sufferer	100%
How frequently is the medical checkup needed	0%
Test for screening of the disease,	100%
Test for confirmation of the disease	33.33%
When and where is HPLC conducted	0%

Findings of above table indicate that even though all the ANM/ MPW/ HA were aware about meaning, causes, types and clinical features of SCD, they had no knowledge regarding its management including SCD crisis, frequency of medical check-up. Also their knowledge regarding confirmatory test for SCD including HPLC was poor. These findings clearly indicate need for training and retraining under SCDCP.

ASHA: The no of ASHA interviewed were 26. All worked in the current post in the range of one to fourteen yrs. On an average the ASHA catered to a population of 625 to 1500.
The ranges of services to be provided by them are: Guidance to pregnant mothers to give services like janani suraksha yojana and immunization, under RCH program. Of the total 26 ASHA the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of total (n=26)**
Meaning of sickle cell disease	30.76%
Causes of sickle cell disease	80.76%
Types of sickle cell disease	92.30%
Signs and symptoms of sickle cell disease	96.15%
Meaning of sickle cell crisis	7.69%
Is the disease curable	53.84%
Is the disease preventable	46.15%
Precautions to be taken by sickle cell disease sufferer	88.46%
Is regular health checkup necessary for sickle cell disease sufferer	88.46%
How frequently is the medical checkup needed	15.38%
Test for screening of the disease,	57.69%
Test for confirmation of the disease	30.76%
When and where is HPLC conducted	3.84%

Though majority of ASHAs were aware about causes, types and clinical features of SCD, however there was poor awareness regarding SCD crisis, tests for confirmation SCD including HPLC. Variable awareness regarding SCD was clearly indicative for need of strengthen the training component under SCDCP.

NGO Volunteer:

The no of NGO Volunteer interviewed were 26. Of which all worked in the current post in the range of 11 months to 4 yrs. On an average the NGO Volunteer catered to a population of around 17000.

The ranges of services to be provided by them are: Counselling, Health education, arrangement of screening camps and provision of treatment to SCD sufferers, facilitating benefits under various government schemes to the eligible SCD sufferers. All NGO Volunteer, the following is the awareness about sickle cell disease:

Question about Sickle Cell Disease	**% of the total (n=26)**
Meaning of sickle cell disease	76.92%
Causes of sickle cell disease	100%
Types of sickle cell disease	100%
Signs and symptoms of sickle cell disease	100%
Meaning of sickle cell crisis	100%
Is the disease curable	76.92%
Is the disease preventable	92.30%
Precautions to be taken by sickle cell disease sufferer	100%
Is regular health checkup necessary for sickle cell disease sufferer	100%
How frequently is the medical checkup needed	100%
Test for screening of the disease,	80.76%
Test for confirmation of the disease	100%
When and where is HPLC conducted	84.61%

Findings indicate that awareness among NGO volunteers regarding SCD was satisfactory.

Beneficiaries (Sufferer, Carrier and Caregiver):

In all there are 159 sufferer, carrier and caregiver (beneficiaries). Of the beneficiaries 10 are sufferers, 82 are carriers and 67 are caregivers. The knowledge of the beneficiaries regarding the Sickle Cell disease is as follows:

Questions about sickle cell disease	**% of the total (n=159)**
Aware about Sickle cell disease	67.79%
The disease is a blood disorder	49.28%
The disease is a genetic condition	52.01%
Children of sufferer and carrier can get this disease	56.90%
The disease is not curable	35.28%
The disease is preventable	44.60%
Signs and symptoms of sickle cell disease	80.17%
Sickle cell crisis	0.62%
Precautions to be taken by sickle cell patients	74.75%
Frequency of medical check up needed by sickle cell patients	23.18%

Though 67.79% of the beneficiaries were aware about SCD, only 44.60% though that the disease is preventable. Awareness regarding SCD crisis was least (0.62%) followed by frequency of medical check up needed by SCD patients (23.18%).

Awareness about the sickle cell disease control program .

Civil Surgeon: The perceived role of the CS in the SCDCP was monitoring, supervision and evaluation. The logistics for the program were provided by the state government. According to him manpower required for smooth implementation of the SCDCP was not sufficient.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district was through the NGO. There was regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation was done by the CS by monthly visits to SCD screening camps.

No constraints were faced by the CS in implementing the SCDCP.

When asked to opinion about implementing the SCDCP through NGO or ASHA, he expressed SCDCP can be implemented effectively by public health workers, i.e.by ASHA.

The following are the suggestions given by the CS for better implementation of the SCDCP:

- Contractual appointment of medical officer or physician should be made for day care centre
- HPLC should be provided at district level

District Reproductive and Child Health Officer (DRCHO):

The perceived role of the DRCHO was the SCDCP is implementation of SCDCP in the district according to the government guidelines. The logistics for the program were provided by the government. The manpower required for the implementation of the program was adequate as this is an NGO district , mainly the NGO volunteers are responsible for all the activities under this program , but the MO, TMO, ANM, MPW, are also supposed to be responsible for the same.

Implementation of the sickle cell disease in the district is as follows:

The implementation of the SCDCP in the district was through the NGO. There was regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co-ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate. Regular Monitoring and evaluation is done by the DRCHO every monthly.

The constraints faced by the DRCHO in implementing the SCDCP were: motivating PHC medical officers for proper implementation of the SCDCP activities.

He expressed that the NGO was doing well in implementation of the SCDCP and did not make any recommendations for improvement of SCDCP activities.

District Coordinator (DC): The District Coordinator when enquired about the sickle cell disease control program expressed that: There is certainly a felt need of this program in the district as the population of the district is mainly rural and the prevalence of the SCD is very high. The perceived role of the DC in the SCDCP is monitoring, logistics, grant distribution to district and NGO, reporting. The logistics for the program were provided by the government. The manpower required for the implementation of the program is adequate as this is an NGO district , mainly the NGO volunteers are responsible for all the activities under this program , but the MO, TMO, paramedical workers are also

supposed to be responsible. The manpower is trained adequately under the SCDCP at D.D office Nagpur.

Implementation of the sickle cell disease in the district is as follows: The implementation of the SCDCP in the district is through the NGO. There is regular reporting from the NGO office regarding the status of the project. The camps were organised by the NGO volunteers in co- ordination with the Medical officer and staff of the concerned PHC. The knowledge about the exact screening test, confirmatory test was adequate.

Regular Monitoring and evaluation is done by the DPM by 10 visits/month. The DC suggested that there is a need for involvement of MO and health staff in implementing the SCDCP.

Medical superintendent: Role of Medical Superintendent in the SCDCP was perceived as to create awareness in society about SCD, ensure adequate logistic supply, facilitation of screening camps, counselling and further treatment completion. He was trained under SCDCP.

The beneficiaries were mainly identified by camp approach. The camps for screening of the population were organised by NGO in collaboration with local health system. The beneficiaries once identified are given colour coded cards by laboratory technicians designated for SCDCP and when confirmed they are registered with the nearby PHC. He was aware about SCD crisis management. About the resources the MS commented that the logistics supply was irregular in the last year. The fund transfers under the program were regular.

Medical superintendent did not face any difficulty in the monthly reporting. TMO/ DHO provided all the required support during implementation of the program. He did not face any difficulty during implementation of the SCDCP.

His experience about working with the NGOs in the field was that: they were least interested in the field work, would rarely communicate with staff and doctors, rarely accompany with patient in crisis and helped the patient to get rid of their difficulties.

Following suggestions were made by Medical Superintendent for better implementation of the SCDCP:

- Adequate support for implementation of the SCDCP in terms of funding, trained laboratory technician, logistics should be provided
- PCR test should be made available for prevention of HIV during blood transfusion
- Pure RBC pack should be made available for blood transfusion.

Taluka Medical Officer: Role of Taluka Medical Officer in SCDCP was planning for solubility test camps, facilitation of further diagnosis of solubility positive patients. He was aware about further management of the SCD positive patients including follow up. He was trained under SCDCP.

TMO was of opinion that SCD crisis patients should be hospitalized for further management. They should be advised to drink plenty of water and folic acid on regular basis.

About the resources the TMO commented that there was regularity in the logistics and funds supply under SCDCP.

According to TMO, it was essential to have designated person who is responsible for implementation of the SCDCP activities. There was support received by him from DHO level in terms of IEC and trained manpower. He had a good experience about working with the NGOs in the field.

The suggestions given by the TMO to improve the implementation of the program are:

- training should be strengthened under SCDCP

- More coordination is needed from all levels of health system

Medical Officer: Both of the Medical officers interviewed perceived that their role is to supervise awareness and screening activities and treatment provider to the beneficiaries under SCDCP. Both of them were aware about management protocol for the SCD screen positive patients including job responsibilities of the health workers. Of the Medical Officers, Both were trained for SCDCP.
About the resources both the Medical officers commented that the logistics supply was regular however there was irregularity in the funds supply in the last year.
There were no difficulties by them while reporting of SCDCP. They had received the required support form TMO, DHO level regarding the program.
They did not comment about experience while working with NGO however they suggested that more awareness should created at mass level.

District Sickle Cell Coordinator: District Sickle Cell Coordinator had received training under SCDCP for two days at from district training team from Nagpur. He was satisfied with the training provided. He suggested that induction training should be given to the newly joined staff including medical officers to NGO members at the earliest possible to impart the quality services under this program. He emphasized that special attention should be given in relation to report preparation as well during training.
He said that apart from celebration of SCD day and week, IEC activities are also done in the form of group meetings on regular basis. IEC material in the form of booklets, pamphlets, rallies was developed under this program.
He used to conduct 10 supervisory visits under this program where his role was to monitor logistics flow, cross checking reporting done and facilitate fund disbursal under SCDCP.
He was not satisfied with the financial remuneration received under this program.
Suggestions of District Sickle Cell Coordinator to improve the SCDCP activities were as below:

- There is need for more active involvement from PHC Medical Officers to Health workers
- Contingency funds should be made available under SCDCP

The NGO In charge: The NGO Incharge has been trained by the district training team doctors for one day at district training centre/district hospitals. The NGO In-charge was satisfied with the training, but it was felt that the training could be further improved by giving training through expert doctors at least every 6 months.
When enquired about the logistics, funds release and other support from the health system, the response received was that there was delay in the release of funds by the funding agency. The reason for the delay in release of funds was cited as lack of fund at higher authority. The management of the logistics in case of unavailability of sufficient funds was done by providing the most required from other sources.
They were provided with targets to be completed in the current year by the government. Role of NGO Incharge was mainly monitoring and supervision of the SCDCP activities in the district. In the last year the NGO Incharge had conducted 12 meetings, 12 field visits and visited all camps. They had also conducted training of the volunteers in the last year.

Following suggestions were given by NGO Incharge about SCDCP:

- More funds should be made available

- Regular supply of logistics should be made
- More attention is needed to be paid by the government for better implementation of the program

NGO coordinator: The NGO coordinator had been trained for the SCDCP by the district training team doctors for one day at district training centre/district hospitals. The NGO coordinator was satisfied with the training , but suggested that it could be improved by increasing duration of training up to 2 days . When asked specifically about the implementation of the SCDCP, the NGO coordinator responded that : the training of all the NGO volunteers was conducted at district training centre for one day by district training medical officer. The IEC sessions that were carried out in the community thorugh screening camps, posters, rallies. The IEC material prepared by them were leaflets, booklets , posters. Newer measures to spread awareness about SCD were undertaken by the NGO in the form of: flex banners, pamphlets, camp, role plays, counselling. The flow of funds according to him was not regular. He receives 1000/month for camps as a salary. He was not satisfied with the monetary benefit also due to the delayed release of funds they do not get any salary for months together. As a sole earning member of the family it becomes difficult for survival.
The monitoring and supervision is done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. He had conducted almost 60 supervisory visits in the last year and in those visits, he used to counsel the SCD patients through home visits whenever needed, conduct meetings with NGO volunteers and check the report generated. . In the last year he had conducted 12 meetings in the field.
The following are the suggestions by the NGO coordinator for better implementation of SCDCP:

- Salary received should be raised
- More publicity should be done in the community about SCD though celebration of SCD day and week.

NGO supervisor: The NGO supervisor had been trained for the SCDCP by the district training team doctors for 2 days at a rural hospital. The NGO supervisor was satisfied with the training. The IEC sessions that were carried out in the community were: screening camps, posters, rallies. The IEC material prepared by them was leaflets, booklets , posters. Newer measures to spread awareness about SCD was undertaken by the NGO in the form of: banner, scroll board.
The flow of funds according to him was regular. The monitoring and supervision was done by conducting supervisory visits as well as regular meetings and reporting from the NGO volunteers. In the last year he has conducted 12 supervisory visits. In those visits he was facilitating SCD screening camps in the community, counselling of the beneficiaries and reporting. He had conducted monthly meetings on regular basis in the community and reporting was done regularly on monthly basis. NGO supervisor suggested that some financial support should be extended to SCD carriers from poor families. He had no other suggestions to improve the SCDCP program activities.

Observers comments based on the record verification:

All the records were complete and updated on time to time.

ANM/MPW/ HA:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=3)

There is a sickle cell disease control program	100%
Government implements the SCDCP	33.33%
Services provided under SCDCP	100%
significance of the colour cards	33.33%
warning signs in SCD patients	100%
how to manage sickle cell disease crisis	00%
treatment given to sickle cell disease patients	100%
Whom to give medicines	100%
Drugs used for SCD patients under the program	100%
When to conduct prenatal blood test on a pregnant women for SCD	100%
LOGISTICS AND TRAINING	
Regular availability of kits	100%
Regular availability of medicines	100%
Trained under SCDCP	66.66%
Sensitization training conducted	0%
Satisfied with the training	33.33%

Though awareness regarding SCDCP was high among ANM/ MPW/ HA, only 33.33% were aware about disease the program is implemented through government. Only 33.33% could tell significance of colour coded cards under the program.

It was observed that 100 % knew about the ideal frequency of visits to the SCD patient. Based on observations, the IEC activities conducted under the program are: health education, counselling and home visits

No one knew about the sickle cell day celebrated and the activities conducted on the day. Only 33.33% knew about the sickle cell week and the activities organised during the week.

Neither they were involved in the target completion nor in the reporting under SCDCP. No one had received some kind of incentive under the program. They have suggested that repeated training should be provided regarding SCDCP.

ASHA

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	**% of total(n=26)**
There is a sickle cell disease control program	84.61%
Government implements the SCDCP	76.92%
Services provided under SCDCP	80.76%
significance of the colour cards	34.61%
warning signs in SCD patients	69.23%
how to manage sickle cell disease crisis	0%
treatment given to sickle cell disease patients	73.07%
Whom to give medicines	73.07%
Drugs used for SCD patients under the program	69.23%
When to conduct prenatal blood test on a pregnant women for SCD	38.48%

LOGISTICS AND TRAINING	
Regular availability of kits	53.84%
Regular availability of medicines	57.69%
Trained under SCDCP	3.84%
Sensitization training conducted	0%
Satisfied with the training	0%

Neither ASHAs were not trained under SCDCP nor were they had satisfactory knowledge about SCDCP. There is need to train all the cadres of health system for better implementation of SCDCP.
It was observed that 38.46 % knew about the ideal frequency of visits to the SCD patient.
Only 84.61% knew about the sickle cell day celebrated and the activities conducted on the day.
Only 84.61% knew about the sickle cell week and the activities organised during the week.
All the ASHAs interviewed were not involved in the reporting and target completion under SCDCP. They did not receive any kind if incentive under this program.
ASHAs suggested that they should be provided with training under the program

NGO Volunteer:

Awareness about Sickle Cell Disease Control Program:

Question about Sickle Cell Disease Control Program	% of total (n=26)
There is a sickle cell disease control program	100%
Government implements the SCDCP	100%
Services provided under SCDCP	92.30%
significance of the colour cards	96.15%
warning signs in SCD patients	100%
how to manage sickle cell disease crisis	80.76%
treatment given to sickle cell disease patients	100%
Whom to give medicines	100%
Drugs used for SCD patients under the program	100%
When to conduct prenatal blood test on a pregnant women for SCD	100%
LOGISTICS AND TRAINING	
Regular availability of kits	88.46%
Regular availability of medicines	96.15%
Trained under SCDCP	100%
Sensitization training conducted	69.23%
Satisfied with the training	88.46%

Awareness of NGO volunteers regarding SCD was satisfactory. This should be maintained by retraining periodically throughout the SCDCP.

It was observed that 61.53% knew about the ideal frequency of visits to the SCD patient. Based on servations, the IEC activities conducted under the program are: Weekly village camp programme, counselling, programme meeting prabhatpheri etc.

All the NGO volunteers (100%) knew about SCD day and week celebrated and details of the activities conducted on these occasions.

Almost all received some kind of incentive under the program. 88.46 % were not satisfied with the incentive. 76.92% said that the incentive should be more. All the NGO volunteers were provided with the targets and there was 100% monthly reporting by them.

Major constraints were faced by NGO volunteers during implementation of SCDCP were cooperation difficulties from nearby health facility and inadequate transport facility

Based on the observations the following were the suggestions made by the NGO Volunteers:

- Transport facility should be made available under this program
- Salary of NGO volunteers should be raised; separate Travelling and Dearness Allowance should be provided.
- There should be dedicated laboratory assistant under this program
- More cooperation is needed from local health facility.

Sufferer and Carrier: The total no of beneficiaries are 159. Of which the observed awareness levels of the benefeciaries regarding the sickle cell disease control program is as follows:

Almost 64.61 % of the beneficiaries were aware of the SCDCP. The NGO volunteers were the main source of information regarding the SCDCP. The services under SCDCP are provided by the NGO volunteer in their local area. Among the sufferers and carriers, 35% were tested at a camp organised for the screening of SCD, whereas 30.97% were tested at the PHC and 11.22% were tested at the private hospital.

The motivation for getting tested for SCD was given by NGO volunteer in case of 21.94% sufferers and carriers, whereas in case of 0.74% the motivation source was ASHA, IN some cases the motivation source was Medical officer, ANM and MPW.

Of the total beneficiaries interviewed, no one were aware of the significance of the colour cards. Of the sufferers and carriers who are married, only 12.44% knew about their SCD status before marriage. Among the sufferers and carriers above adolescent age, only one were counselled before marriage.

On an average the beneficiaries are aware of their SCD status since 5 to 30 yrs. The effect of their SCD status on their children was known to 8.53%.

According to the beneficiaries the NGO volunteer visits then every 15 days to every month.

The services provided by the NGO volunteer during their visit to the sufferer or carrier are as follows: treatment, counselling for good health, provide medicines.

The frequency at which the sufferers have to visit the primary health centre for check up or medication is once every month.

The NGO volunteer accompanies them to the PHC during these visits in case of 20.49%, whereas in case of 20% the ASHA or medical officer accompanies them to the health centre. Of the sufferers no one had to undergo telemedicine consultation. Of the total beneficiaries 22.19% are satisfied with the services provided.

The recommendations suggested by the beneficiaries for better implementation of the SCDCP in their area are as follows:

- More awareness about SCD should be done
- All the family members should be screened for SCD and they should be cards with the cards
- Medicines should be provided

Most of the carriers were aware about their disease status. They did not know about the benefits of the programme. Also cards were not provided to the carriers.

Evaluation based on following indicators:

Physical Indicators:

The infrastructure of the office of the NGO was assessed and it was observed that the space was adequate with sufficient water supply and electricity. The NGO had its own vehicle / hired vehicle for transportation if needed. The human resource was adequate with all the positions filled under the SCDCP. The availability of medicines and kits was adequate. The IEC material was impressive and was in the form of posters, pamphlets, booklets, etc. The message in the IEC material was loud and clear. An attempt was made by the NGO to display the IEC material so as to catch attention. The cards were available. The solubility kits supply was uninterrupted. The case files of all the sufferers were maintained.

Process Indicators:

The process of implementation of SCDCP was assessed under the following headings:

- Maintaining updated records:
  It was observed that all the required registers like camp register , counselling register etc ,were well maintained and updated till date.
- Training of the human resource:
  The no of training sessions conducted for the NGO volunteer were two in the last year. All the NGO volunteers were trained under SCDCP. The training was conducted by doctors form government health services.
  In addition to the induction training , the NGO volunteers were periodically sensitised again during the review meetings and there queries were addressed at the same time.
- Timely reporting:
  Timely reporting being a key to the success of any program is equally essential for SCDCP also. It was observed that the reporting by the NGO was done regularly on weekly basis.
- Frequency and adequacy of review meetings:
  Review meetings is an essential part for the continuous improvement in the implementation of the program . In the last year 12 review meetings were conducted by the NGO coordinator. Attendance for meetings was almost 100%.
- Monitoring and evaluation:
  Monitoring and evaluation is an integral part of any program. The NGO co ordinator conducted 70 field visits in last year.
- Organising activities under SCDCP:
  In all the total no of IEC camps organised in the last year were 4650. The percentage of population covered in the camps was 53.57%. The percentage of population covered through other awareness activities was 100%. The celebration of sickle cell day and week gives a fair knowledge about the extent of activities conducted under SCDCP.
- Stakeholder Involvement:
  The PHC volunteer attended almost all the ANM /ASHA meetings (12) , as well as the Anganwadi worker meetings. (24). The no of meeting attended with community leaders

and mahila mandals , self help groups on an average were 5 meetings per month. This indicates the stakeholder fully involve in the program.

Performance Indicators:

Outcome indicators:

Indicator	Figure	score
Percentage of target population screened for Sickle cell disease by the NGO	**Data Not available**	
Percentage of sufferers and carriers counselled in the last year		
Percentage of sufferers given follow up out of total number of sufferers diagnosed in the area covered under the NGO project	**Data Not available**	
Percentage of sufferers facing crises events out of the total number of sufferer diagnosed in last one year	**Data Not available**	
Percentage of sufferers who died out of the total number of sufferer diagnosed in last one year	**Data Not available**	

Impact Indicators:

Indicator	Figure	score
No. of Sufferers and Carriers married to healthy partner	**Data Not available**	
No. of married female Sufferers and Carriers currently pregnant	**Data Not available**	
No. of married female Sufferers and Carriers gave birth within last year	**Data Not available**	
Awareness in Target population	**Data Not available**	

Financial Indicators:

Indicator	Figure	score

The percentage of approved budget utilised on the proposed activities	**98.40%**	**8**
Organisation maintaining a separate bank account for the Sickle Cell project	**ICICI bank**	**5**
All original bills and vouchers present	**yes**	**5**
For the amount of above Rs 1000, the mode of payment is by Cheque	**yes**	**5**
Presence of serially numbered and printed vouchers	**yes**	**3**
Cash book entry is on regular basis and updated	**yes**	**3**
All the vouchers have supportive documentary evidence	**yes**	**4**
SOEs submitted in time to SHS	**yes**	**5**
SOE s based on book of accounts	**yes**	**10**
Grand Total Score		**48**

The all inclusive observations of the interviewers regarding all the aspects of the implementation of the SCDCP are as follows:

Observations:

- Need of retaining regarding SCD was reflected in the awareness levels of SCDCP implementers and beneficiaries
- There was irregularity of screening test kits and fund flow was noted.
- Less priority from both NGO and health system side was reported
- There was a demand by SCDCP beneficiaries regarding more awareness activities, need for other family members' screening.
- Cards were not distributed to all the beneficiaries under SCDCP

Recommendations:

- Well placed training and retraining activity with some mechanism of assessment should be incorporated for uniform coverage.
- Logistics including funds flow should be streamlined.
- Demand for provision of cards as well as screening of other family members clearly indicate deficiency in the quality services offered by the NGO. This issue needs to be addressed urgently.