

**GOVERNMENT OF INDIA
MINISTRY OF HEALTH AND FAMILY WELFARE
DEPARTMENT OF HEALTH AND FAMILY WELFARE**

**LOK SABHA
UNSTARRED QUESTION NO. 2736
TO BE ANSWERED ON 04.08.2023**

“LANCET COMMISSION REPORT ON SICKLE CELL DISEASE”

2736. SHRI KARTI P. CHIDAMBARAM:

Will the Minister of **HEALTH AND FAMILY WELFARE** be pleased to state:

- a. whether the Government is aware of the recent report released by Lancet Commission on sickle cell disease which found that reducing sickle cell disease is beyond the reach of most individuals in the country and the highest burden of disability caused by sickle cell disease is found in the country and if so, the details thereof, State/UT-wise;
- b. whether the Government has taken cognizance of the fact that there is a shortage of healthcare and scientific professionals, who have expertise in treating sickle cell disease and if so, the details thereof;
- c. whether the Government has taken/proposed to take any steps to develop trials aimed at developing novel treatment and if so, the details thereof and if not, the reasons therefor; and
- d. whether the Government has taken into account the fact that the exclusion of disability data from the 6th installment of the National Family Health Survey will adversely impact the data-collection on disability caused by sickle cell disease?

ANSWER

**THE MINISTER OF STATE IN THE MINISTRY OF HEALTH AND FAMILY
WELFARE**

(PROF. SATYA PAL SINGH BAGHEL)

(a) The Government is aware of the recent report of Lancet Commission. However, the Commission Report does not state the efforts of Government of India through the recently launched National Sickle Cell Anaemia Elimination Mission (NSCEM). The suggestions in the report are already in place in the country through this mission. There are many Point Of Care tests (POC) available and in use in India including indigenous ones. Further, all efforts of the country are not indicated in the report. It is not true that the country has the highest burden of disability caused by sickle cell disease, as the data presented in the report pertains to African countries only. It is also to be noted in the report that the data on SCD of India is an estimate based on probabilistic birth projection by country by 2023. Projected number is based

on regional limited data source from high prevalent areas, which increases the chance of over-estimation and will not reflect true % of the country.

The Objectives of the National Sickle Cell Anaemia Elimination Mission are provision of affordable and accessible care to all Sickle Cell Diseased patients, quality of care for diseased and reduction in the prevalence of Sickle Cell Disease through awareness creation, universal screening of 7 crore people in the age group of 0-40 years in affected 278 districts of tribal areas, and counseling through collaborative efforts of central ministries and state governments.

(b) Rural Health Statistics (RHS) is an annual publication, based on Health care administrative data reported by States/UTs. As per RHS 2021-22, State/UT-wise details of healthcare professionals along with detail of healthcare professionals may be seen at the following link of RHS 2021-22:

<https://hmis.mohfw.gov.in/downloadfile?filepath=publications/Rural-Health-Statistics/RHS%202021-22.pdf>

Training modules for primary care of Medical Officers, Community Health Officers (CHOs), Staff Nurses and Multi-Purpose Workers (M/F)/ASHAs has been launched under National Sickle Cell Anaemia Elimination Mission which can be accessed at : <https://sickle.nhm.gov.in/home/guidelines>

(c) Council of Scientific & Industrial Research (CSIR), through its constituent laboratories namely, CSIR-Institute of Genomics and Integrative Biology (CSIR-IGIB), Delhi and CSIR-Indian Institute of Chemical Technology (CSIR-IICT), Kolkata has engaged in Research & Development for gene editing approaches for sickle cell anemia therapy under CSIR Sickle Cell Anemia Mission. Under this Mission, CSIR-IGIB along with CSIR-IICB has provided proof-of-concept correction of sickle cell anaemia mutation in patient-derived cells and the increase in Fetal hemoglobin (HbF) production through Hereditary Persistence of Fetal Hemoglobin (HPFH) editing [publication in Proceedings of the National Academy of Sciences, 2019]. CSIR leads are now taken forward towards a dedicated Phase-I clinical trial with funding from Department of Science and Technology and the Ministry of Tribal Affairs.

(d) Questions on disability were included for the first time in NFHS-5, however, there was no question on disability caused by sickle cell disease. Further, the selection of questions to be included in NFHS-6 questionnaire is based on recommendations of a Technical Advisory Committee and other high-level Committees comprising of representatives from concerned Central Ministries such as M/o Social Justice and Empowerment, M/o Statistics and Programme Implementation, M/o Women and Child Development, NITI Aayog etc., development partners and domain knowledge experts, constituted for smooth functioning of the survey. After detailed discussions and deliberations, the Committees decided for non-inclusion of disability-related questions in NFHS-6 on the following grounds:

(i) Most of the data related to disability are already available in the survey report of National Sample Survey (NSS) 76th round namely “Survey of Persons with Disabilities”,

which was a dedicated survey conducted by Ministry of Statistics and Programme Implementation (MoSPI) during July-December 2018 to collect detailed information on this specific aspect.

(ii) The primary focus of NFHS is maternal and child health and other associated questions. The dedicated survey of NSS, gives a better coverage of disability prevalence, having wider indicators on disability as compared to NFHS-5. Based on data collection for a few parameters on disability in NFHS, it is not possible to adequately capture the all-India extent of disability and will significantly underestimate the prevalence of disability.

(iii) The multiple sources of information on one particular indicator creates confusion as the figures are often different.

(iv) Further, types of disability have several medical terminologies, which may result in inappropriate responses as the respondents might not be aware of the specific disabilities.