



सत्यमेव जयते

**NATIONAL ACADEMY OF MEDICAL SCIENCES (INDIA)**

**DIRECTORATE GENERAL OF HEALTH SERVICES**

**MINISTRY OF HEALTH & FAMILY WELFARE**

**GOVERNMENT OF INDIA**

**REPORT OF TASK FORCE**

*ON*

**Tribal Health**



**2024**



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*ON*  
**Tribal Health**



## **ACNOWLEDGEMENT**

We gratefully acknowledge the invaluable contributions of the experts in the Tribal Health from across the country for their unwavering support throughout the drafting of this Task Force report. It would not have been possible without the guidance and help of all these experts, who in one way or another contributed and extended their valuable time and assistance in its preparation and completion.

We are extremely grateful to NAMS to give us this opportunity, which made us interact with the diverse group of members, without whose collaboration, this report would not have been completed. Their calm and positive encouragements made this work all the more enjoyable. A big thanks to all the coordinators of the thematic areas of tribal health for their genuine and continued support despite their busy schedules.

To all those who were a part of this journey, our deepest and sincere gratitude for extending your hands.



## **PREFACE**







The tribal communities in India constitute a major portion of the population residing in the remote and underdeveloped areas, despite their significant contributions to the country's rich cultural heritage. These people in India face significant health challenges including limited access to health care facilities, nutritional problems, high maternal and child morbidity and mortality. They are having a dual burden of both communicable and non-communicable diseases like cardiovascular diseases and cancers.








The inadequate health infrastructure, limited access and lack of awareness often hinder the delivery of essential health services to tribal population. The report of the NAMS Task Force on "Health Problems among Tribal Communities in India" has identified the major gaps and challenges in attaining Health for All among tribal people. It also provides a roadmap and recommendations to improve upon the health parameters of the tribals in India.












## **TASK FORCE MEMBERS**

<b>S.No.</b>	<b>Task Force Member</b>
1.	<p><b>Prof. (Dr.) Saurabh Varshney</b>  <b>Chairman of Task Force</b>  Executive Director &amp; CEO  All India Institute of Medical Sciences (AIIMS)  Deoghar, Jharkhand, India</p> 
2.	<p><b>Dr. Aparup Das</b>  ICMR, New Delhi</p> 
3.	<p><b>Dr. (Mrs.) Sanghamitra Pati</b>  Director &amp; Scientist G  ICMR-RMRC  (Regional Medical Research Centre)  Chandrashekharpur, Bhubaneswar, Orissa</p> 
4.	<p><b>Dr. K. Rekha Devi</b>  Scientist-F  ICMR-RMCR  (Regional Medical Research Centre)  Dibrugarh, Assam</p> 
5.	<p><b>Dr. Pradeep Dwivedi</b>  Additional Professor  Department of Pharmacology  All India Institute of Medical Sciences (AIIMS)  Jodhpur, Rajasthan</p> 
6.	<p><b>Prof. (Dr.) G. Jahnavi</b>  Professor &amp; Head  Department of Community &amp; Family Medicine  All India Institute of Medical Sciences (AIIMS)  Deoghar, Jharkhand, India</p> 

7.	<b>Dr. N. Arlappa</b> Scientist G ICMR- National Institute of Nutrition Hyderabad	
8.	<b>Dr. Tapas Chakma</b> Scientist G ICMR NIRTH (National Institute of Research in Tribal Health) NIRTH Complex, Nagpur Road P.O.Garha, Jabalpur (MP)	
9.	<b>Dr. Dheeraj Kattula</b> Associate Professor Department of Psychiatry CMC, Vellore	
10.	<b>Prof. (Dr.) Rajkumar Lenin Singh</b> Professor Department of Psychiatry RIMS Imphal, Manipur	
11.	<b>Dr. Satish Gogulwar</b> Convenor and Founder Trustee Amhi Amchya Arogyasathi Gadchirolli, Maharashtra	
12.	<b>Dr. GVL Narasimha</b> Assistant Professor Centre for Addiction Medicine Department of Psychiatry NIMHANS, Bengaluru	
13.	<b>Dr. Dewesh Kumar</b> Associate Professor Department of Community & Family Medicine RIMS, Ranchi	

14.	<b>Dr. Subarna Roy</b> Director National Institute of Traditional Medicine	
<b>Co-opted Members</b>		
15.	<b>Dr. Rajesh Kumar</b> Associate Professor Department of General Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	
16.	<b>Dr. Richa</b> Associate Professor Department of Community and Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	
17.	<b>Dr. Santanu Nath</b> Associate Professor Department of Psychiatry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	
18.	<b>Dr. Arshad Ayub</b> Assistant Professor Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	
19.	<b>Dr. Adity Bansal</b> Assistant Professor Department of Dentistry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	
20.	<b>Dr. Indranil Das</b> Assistant Professor Department of Transfusion Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	



## **LIST OF ABBREVIATIONS**

ST: Scheduled Tribes

ASHAs: Accredited Social Health Activists

CoE: Center of Excellence

CoC: Center of Competence

PVTGs: Particularly Vulnerable Tribal Groups

NAMS: National Academy of Medical Sciences

VC: Video-conferencing

SDGs: Sustainable Development Goals

NNMB: National Nutrition Monitoring Bureau

RDAs: Recommended Dietary Allowances

NFHS: National Family Health Survey

ITDA: Integrated Tribal Development Areas

MAD: Minimum Acceptability of Diet

ICDS: Integrated Child Development Services

ANC: Antenatal Care

PNC: Postnatal Care

OOPE: Out-of-Pocket Expenditures

PHC: Primary Health Centre

CHC: Community Health Centre (CHCs)

ICMR: Indian Council of Medical Research

ICMR-NIIH: Indian Council of Medical Research-National Institute of Immunohaematology

ICMR-NIRTH: Indian Council of Medical Research-National Institute of Research in Tribal Health

CVD: Cardiovascular Diseases

CI: Confidence Interval

BMI: Body Mass Index

NCRP: National Cancer Registry Programme

DALYs: Disability-adjusted Life Years

NNMS: National NCD Monitoring Survey

APJCP: Asian Pacific Journal of Cancer Prevention

NHSRC: National Health Systems Resource Centre

PBCRs: Population-Based Cancer Registries (PBCRs)

AAR: Age-adjusted Rate

ASIR: Age Standardized Incidence Rate

NER: North East Region

NPCDCS: National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke

IIPS: Indian Institute for Population Sciences

IEC: Information, Education, and Communication

BCC: Behavioural Change Communication

WHO: World Health Organization

CMI: Common Mental Illness

SMI: Severe Mental Illnesses

ADHD: Attention Deficit Hyperactivity Disorder

SUD: Substance Use Disorder

GATS: Global Adult Tobacco Survey

IDU: Injectable Drug Users

SDGs: Sustainable Development Goals

UN: United Nation

OCD: Obsessive Compulsive Disorder

Tele-MANAS: Tele Mental Health and Networking Across States

MMR: Maternal Mortality Rate

TECHO: Technology for Community Health Operations

OHIP: Oral Health Impact Profile

DMFT Index: Decayed, Missing, Filled Teeth Index

FDGs: Focus Group Discussions

OHI-S Index: Oral Health Index- Simplified

OHI-M: Oral Health Index- Modified

HNSCC: Head and Neck squamous cell carcinoma

GLOBOCAN: Global Cancer Statistics

SLT: Smokeless Tobacco

HPV: Human papilloma Virus

CME: Continuous Medical Education

TSNAs: Tobacco-specific Nitrosamines

SCA: Sickie Cell Anemia

HbS: Hemoglobin S

HbE: Hemoglobin E

HbD: Hemoglobin D

MBD: Mother's Brother's Daughter

FSD: Father's Sister's Daughter

DFCC: Double First Cross-Cousins

ANM: Auxiliary Nurse Midwifery

POC tests: Point of Care tests

HPLC: High-performance Liquid Chromatography

MoHFW: Ministry of Health and Family Welfare

NGO: Non-governmental Organization

HCW's: Health Care Workers

HiB: Haemophilus Influenza Type-b

AIIMS: All India Institute of Medical Sciences

TIF: Thalassemia International Federation

HLEG: High Level Expert Group

HSCs: Health Sub-Centres

IMPACT: Innovative Models Promoting Access-to-Care Transformation

MHUs: Mobile Health Units

CHWs: Community Health Workers

PPPs: Public-Private Partnerships

AED: Automated External Defibrillator

CAELUS project: Care & Equity-Healthcare Logistics UAS Scotland

OPD: Out-patient Departments

ORMS: Online referral management system

MBBS: Bachelor of Medicine, Bachelor of Surgery

MRHRU: Model Rural Health Research Unit

NSCEM: National Sickle cell Anaemia Elimination Mission

INI: Institutions of National Importance

SHC-HWC: Sub Health Centre-Health and Wellness Centre

PHC-HWC: Primary Health Centre-Health and Wellness Centre

AI: Artificial Intelligence



## **OPERATIONAL DEFINITIONS OF TERMS USED IN THE REPORT**

**Non-communicable Diseases (NCDs):** Non-communicable diseases (NCDs), also known as chronic diseases, tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors.

**Out-of-pocket expenditure:** Any direct outlay by households, including gratuities and in-kind payments, to health practitioners and suppliers of pharmaceuticals, therapeutic appliances, and other goods and services whose primary intent is to contribute to the restoration or enhancement of the health status of individuals or population groups. It is a part of private health expenditure.

**Cardiovascular Diseases:** A group of disorders of the heart and blood vessels.

**Chronic respiratory diseases:** Diseases of the airways and other structures of the lung. Some of the most common are asthma, chronic obstructive pulmonary disease (COPD), occupational lung diseases and pulmonary hypertension.

**Lean Diabetes:** Diabetes characterized by reduced insulin secretion and less insulin resistance compared with diabetes among the obese population, and lean diabetes may be a result of different underlying factors, such as malnutrition.

**Cancer:** Cancer is a large group of diseases that can start in almost any organ or tissue of the body when abnormal cells grow uncontrollably, go beyond their usual boundaries to invade adjoining parts of the body and/or spread to other organs.

**DALY:** One DALY represents the loss of the equivalent of one year of full health. DALYs for a disease or health condition are the sum of the years of life lost to due to premature mortality (YLLs) and the years lived with a disability (YLDs) due to prevalent cases of the disease or health condition in a population.

**Center of Excellence:** A center of excellence (COE or CoE), also called an excellence center, is a team, a shared facility or an entity that provides leadership, best practices, research, support, or training for a focus area.

**Center of Competence:** A center of competence focuses on strategic research agendas, support strong interactions between science and industry, and provides truly collaborative research with a medium to long-term perspective.

**National Rural Health Mission:** It is dedicated to delivering quality healthcare to rural populations, with a special focus on vulnerable groups and states such as the Empowered Action Group (EAG) States, North-eastern States, Jammu & Kashmir, and Himachal Pradesh.

**Sickle Cell Disease:** It is an inherited disorder that affects haemoglobin, the protein that carries oxygen through the body.

**Substance Use Disorder:** It is a treatable mental disorder that affects a person's brain and behaviour, leading to their inability to control use of substances like legal or illegal drugs, alcohol, or medications.

**mHealth:** It is general term for the use of mobile phones and other wireless technology in medical care.

**Traditional Healers:** It refers to those practitioners who provide any health and health related healing services using their indigenous knowledge, and who are registered with an appropriate body.

**WHO Oral Health assessment form:** The standard form for oral health assessment designed for collection of all the information needed for planning oral care services.

## **TERMS OF REFERENCE**

The National Academy of Medical Sciences (NAMS), Ministry of Health of family welfare assigned specific terms of reference to the National Task Force constituted vide Ref. NAMS/Task Force/Tribal Health/dated 21.03.2024 which are enlisted as below:

1. To identify the current status of Tribal Health in the country.
2. Identify the deficiencies and challenges which need to be addressed.
3. To recommend measures for improving the interventions in the area of Tribal Health.



## **EXECUTIVE SUMMARY**

### **Background**

India's tribal population, comprising over 104 million people across 705 distinct tribes, faces unique health challenges. These tribes are distributed across various regions, with concentrations in central states like Madhya Pradesh, Chhattisgarh, and Jharkhand, as well as the North-Eastern states. Andaman and Nicobar islands host five Particularly Vulnerable Tribal Groups (PVTGs), namely Great Andamanese of Strait island, Onges of Little Andaman, Jarawa's of South and Middle Andaman, Sentinelese of Sentinel island and Shompens of Great Nicobar. Despite this diversity, tribal communities share common health disparities, including limited access to quality healthcare. The Expert Committee on Tribal Health, formed in 2013, aims to address these issues. Key health concerns among tribal populations include maternal and child health, communicable diseases, non-communicable diseases (NCDs), nutritional deficiencies, and mental health issues. Substance abuse and hemoglobinopathies further impact tribal health outcomes.

Hence, this report aims to identify and address the key health concerns among tribal populations, including nutritional deficiencies, mental health issues, maternal and child health, non-communicable diseases (NCDs), Oral health, hemoglobinopathies and access to healthcare.

### **Methodology**

The process of developing the white paper on Tribal Health followed structured steps. It commenced with an initial meeting chaired by Prof. (Dr.) Saurabh Varshney, during which the theme and purpose of the Task Force were introduced. Subsequent video-conferencing meetings were scheduled with Task Force members. Communication channels, including a WhatsApp group and a dedicated email address, facilitated collaboration. Members were organized into smaller groups and assigned different thematic areas to contribute their expertise in tribal health research. After receiving individual thematic reports, these were cross-checked by other groups, and suggested changes were adopted. The final report was compiled and reviewed by the core group.

## Findings

India's tribal and indigenous populations face significant health disparities driven by socio-cultural factors and limited access to healthcare. A crucial concern is the nutritional status of these communities, with a reported decrease in nutrient intake, particularly micronutrients, across all age groups. The absence of recent data highlights the need for updated assessments to revise interventions and policies addressing undernutrition and non-communicable diseases (NCDs). Tribal populations are notably burdened by NCDs, with cardiovascular diseases being a leading cause of mortality, especially among older members. These health issues are exacerbated by limited healthcare access, poverty, and cultural disparities, necessitating urgent interventions such as the integration of traditional healing practices, the strengthening of public health systems, and the empowerment of health workers like ASHA.

Mental health challenges, including depression, anxiety, and addiction, are also prevalent among specific tribal groups, with traditional healing practices and inadequate infrastructure compounding these issues. Achieving sustainable development goals for these communities requires culturally sensitive interventions and community-based strategies, prioritizing mental health services to ensure equitable healthcare. Furthermore, tribal populations face high maternal and child mortality rates due to socio-economic disadvantages, harmful traditional practices, inadequate nutrition, and neglected women's health. Limited access to medical care and hereditary diseases further exacerbate these adverse outcomes, calling for focused research, accessible healthcare, nutritional support programs, and evidence-based awareness campaigns.

Oral health presents another significant challenge for tribal communities, driven by limited healthcare access, low awareness, illiteracy, and poverty. Efforts to improve oral health must consider regional behaviours, socio-economic status, and historical trends, employing targeted community-based approaches to raise awareness about oral pre-cancerous lesions and cancers. Additionally, addressing hemoglobinopathies in tribal India requires a comprehensive approach, including early detection, genetic counselling, improved healthcare delivery, and community involvement. Establishing Center of Excellence (CoE) or Center of Care (CoC) in AIIMS across states can facilitate comprehensive management and training for healthcare staff, promoting prevention and control at all levels.

Access to healthcare for tribal populations in India faces significant challenges, resulting in disparities in health outcomes and services. Key issues include inadequate infrastructure, social stigma, reliance on traditional healing practices, and a shortage of health workers. To address these gaps, strategies such as the IMPACT Model, Hub-and-Spoke Design, and culturally sensitive care are recommended. Policymakers should prioritize a National Plan of Action for tribal health, ethical data collection, and training and retention of tribal health workers. Services should focus on cultural sensitization, tele-education, and expanding healthcare availability, with health literacy and awareness initiatives being crucial for improving tribal health. Comprehensive, culturally sensitive approaches are essential to address these multifaceted health challenges and ensure equitable healthcare access and outcomes for these vulnerable communities.

## **Way Forward**

To improve the health of India's tribal populations, it is crucial to enhance healthcare infrastructure, integrate traditional practices, and empower local health workers through continuous training and support. Regular, region-specific health surveys and focused research on non-communicable diseases and mental health are needed to inform targeted interventions. Implementing comprehensive, culturally sensitive health programs, alongside poverty alleviation and education initiatives, will address the socio-economic determinants of health. Establishing Centers of Excellence and utilizing telemedicine and tele-education can bridge healthcare gaps, ensuring equitable access and better health outcomes for these communities.





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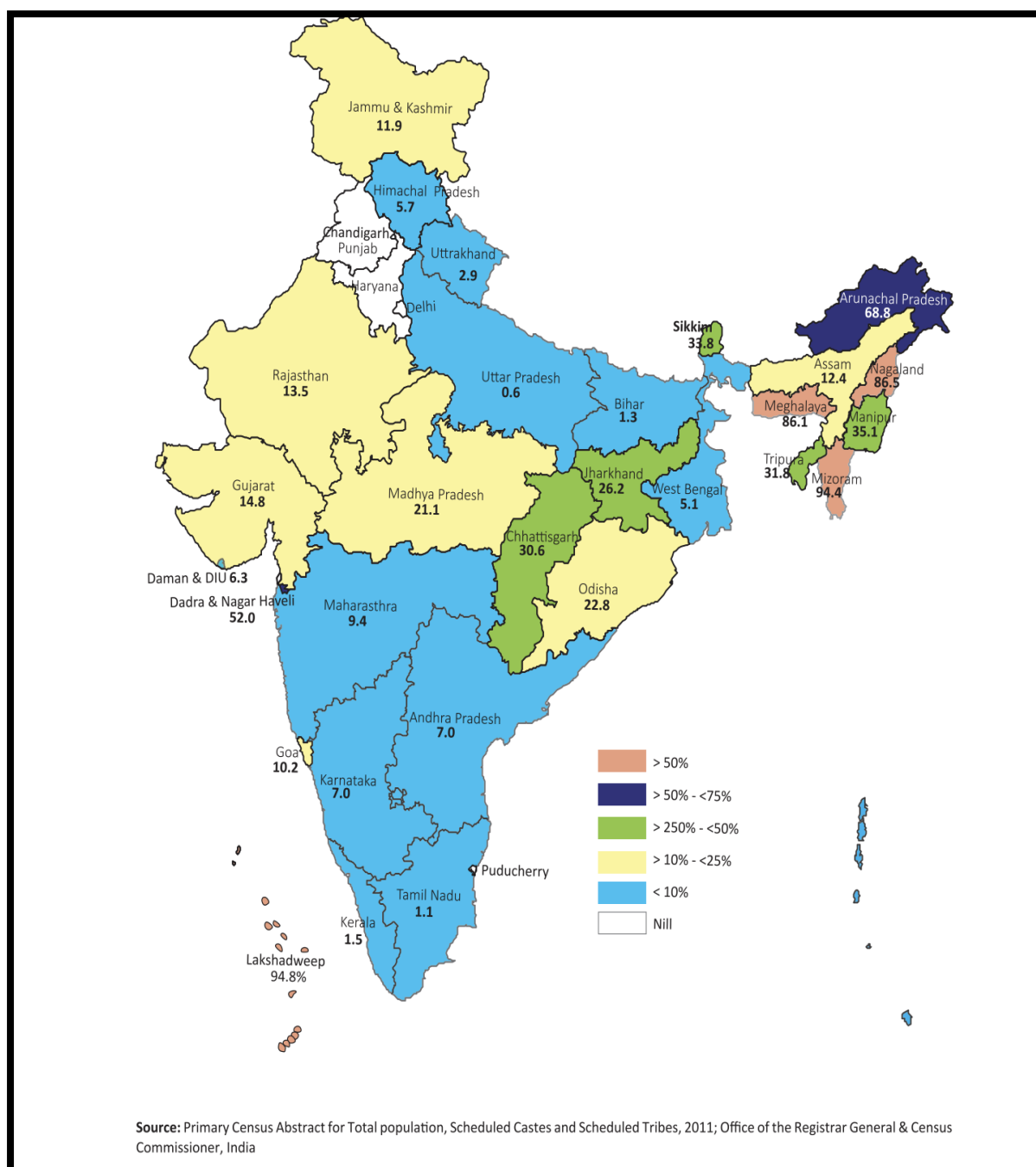
## **INTRODUCTION**

Article 342 of the Indian Constitution defines 'Scheduled Tribes' as "tribes or tribal communities or parts of or groups within tribal communities which the President of India may specify by public notification." India is home to more than 104 million tribal people, distributed across 705 distinct tribes, making it the country with the second-largest tribal population worldwide. They constitute approximately 8.6% of India's total population and inhabit various regions across the country. These 705 tribes can be categorized into four groups based on their locations:

1. Those residing in Scheduled V areas and tribal-dominated blocks and districts.
2. Tribes from North-East India.
3. Particularly Vulnerable Tribal Groups (PVTGs).
4. Tribal communities living outside Scheduled areas.

In this vast subcontinent, over two-thirds of the tribal population resides in seven central states: Madhya Pradesh, Chhattisgarh, Jharkhand, Odisha, Maharashtra, Gujarat, and Rajasthan. The North-Eastern states, however, have the highest density of tribal populations in rural areas, often in challenging terrains such as dense forests and hilly regions (Figure-1). Some tribes have also integrated into urban areas, blending with non-tribal populations in cities and towns. This socio-cultural, economic, and health diversity places them in a vulnerable position amid rapid urbanization, posing challenges across various aspects of their lives, including healthcare, nutrition, and economics.

Healthcare remains a significant challenge for tribal communities in India, who face disparities in access to quality healthcare compared to non-tribal populations, a common issue globally. Despite the diversity among tribal populations, poorer health indicators, higher morbidity and mortality rates, and limited healthcare access are prevalent across all tribal communities. Research on tribal health remains limited. Recently, the Ministry of Tribal Affairs collaborated with the Ministry of Health and Family Welfare to address tribal health issues, forming the 'Expert Committee on Tribal Health' in 2013, chaired by Dr. Abhay Bang. This committee includes healthcare experts, academics, civil society members, and policymakers dedicated to improving tribal health.



**Figure-1: Distribution of Tribal population in India from the Report of Expert Committee on Tribal Health**

Tribal populations in India experience a quadruple burden of diseases encompassing physical, mental, social, and cultural challenges. Major health concerns include reproductive, maternal, new-born, child, and adolescent health; communicable diseases like malaria, tuberculosis, and sexually transmitted infections; non-communicable diseases (NCDs); genetic disorders; nutritional deficiencies; and mental health issues and addiction. India records the highest infant

and maternal mortality rates among tribal populations globally. Despite national nutrition interventions, undernutrition remains prevalent among tribal populations. Epidemiological transitions have also led to an increasing burden of NCDs such as cardiovascular diseases, diabetes, hypertension, and cancers among tribal communities. Substance abuse is higher among tribal populations compared to the general population, contributing to oral precancerous lesions and cancers, particularly linked to tobacco use. Hemoglobinopathies such as Haemoglobin-S & E and  $\beta$ -thalassemia pose significant challenges to tribal health, increasing morbidity and mortality rates.

The reliance on traditional healers and beliefs in spirits and demons contribute to health problems and poorer outcomes among tribal communities. Low literacy rates, especially in health, coupled with socio-economic disadvantages, exacerbate these issues. While grassroots healthcare workers like ASHAs and Anganwadi workers play crucial roles in health education and managing common ailments among tribes, tertiary healthcare centres also play a vital role in addressing complex health needs.

Acknowledging the myriad health challenges faced by tribal populations, the taskforce established by the National Academy of Medical Sciences (NAMS) aims to bring together experts from various health disciplines to develop a comprehensive roadmap for tribal health. The taskforce focuses on key areas such as tribal nutrition, non-communicable diseases, mental health and addiction, healthcare access, maternal and child health, oral health and hygiene, and hemoglobinopathies and sickle cell anaemia. The report synthesizes existing literature, identifies knowledge gaps concerning tribal populations, and proposes actionable recommendations for stakeholders. It serves as a foundational document for future research and policy initiatives in tribal health. Happy reading!

## **METHODOLOGY**

With reference to the allocated terms of reference by the National Academy of Medical Sciences, a structured methodology was constructed to develop a white paper to be submitted to the Government of India, for improving the interventions in the area of Tribal Health.

The first meeting was held with the Internal committee members on 26<sup>th</sup> April 2024, under the chairmanship of Prof. (Dr.) Saurabh Varshney, where the theme and idea for the Task Force was introduced. It was decided that a series of video-conferencing (VC) meetings will be scheduled with the Task Force members. A WhatsApp group entitled “NAMS Tribal Task Force” was created for smooth functioning of the force. An email address dedicated to this task force was created i.e “[nams.taskforce.tribal@gmail.com](mailto:nams.taskforce.tribal@gmail.com)”. All the members were intimated for the scheduled meetings (Table-1) through this email id, asking them to share their major contributions in the field of tribal health.

**Table-1:** Scheduled meetings with the NAMS Task Force members

Meeting/Platform	Date & time	Key points
1 <sup>st</sup> Videoconference meet/Zoom Zoom link is as follows: <a href="https://zoom.us/j/99609002612?pwd=RTNqSXVtOFMrd25SdktlSlhKRFlZz09">https://zoom.us/j/99609002612?pwd=RTNqSXVtOFMrd25SdktlSlhKRFlZz09</a>	06.05.2024 3:00pm-4:00pm	Brief introduction of all task force members nominated by NAMS.  The Chairperson co-opted five new members.  Thematic areas related to tribal health discussed upon.  Seven sub-topics finalized.  All members were divided into seven sub-groups and one coordinator of each group was identified.  A structured format for the drafting of report was discussed.

		Members were asked to post relevant articles/literature on WhatsApp group.
2 <sup>nd</sup> Videoconference meet/Zoom Zoom link is as follows: <a href="https://zoom.us/j/95211141585?pwd=SE9EQk01aUJkUXVaRG9xdDF3Z2NpUT09">https://zoom.us/j/95211141585?pwd=SE9EQk01aUJkUXVaRG9xdDF3Z2NpUT09</a>	13.05.2024 3:00pm-4:00pm	The seven subgroups presented their preliminary search and data.  Views/ inputs taken from each member.  Chairperson suggested to create a pre-final draft.
3 <sup>rd</sup> Videoconference meet/Zoom Zoom link is as follows: <a href="https://zoom.us/j/95459346268?pwd=WUJsSm8zTDdiS2x1TDZqN1ptNFR2dz09">https://zoom.us/j/95459346268?pwd=WUJsSm8zTDdiS2x1TDZqN1ptNFR2dz09</a>	28.05.2024 3:00pm-3:45pm	Pre final draft of all subgroups presented by coordinators.  The deadline for version 1 of the subgroup draft report was decided to be 31 <sup>st</sup> may 2024, following which it would be put on open forum for discussion till 4 <sup>th</sup> June 2024.  Subsequent to inputs from all members, Version 2 would be finalized by 10 <sup>th</sup> June 2024.
4 <sup>th</sup> Videoconference meet/Zoom Zoom link is as follows: <a href="https://zoom.us/j/95429216809?pwd=LmMlYcK0qV89Ga6bO1mFWaxF8au0Fb.1">https://zoom.us/j/95429216809?pwd=LmMlYcK0qV89Ga6bO1mFWaxF8au0Fb.1</a>	13.06.2024 3:00pm-3:30pm	Dr. Indranil Das was co-opted as member of the Task force for his contribution to subtopic  Hemoglobinopathies and Sickle Cell Anaemia.  All members were asked to submit their respective drafts by 15 <sup>th</sup> June 2024.  It was decided that internal committee members will work on compilation of all drafts till 25 <sup>th</sup> June 2024, which would be considered as Version 3.

		The draft would be put on open forum till 27 <sup>th</sup> June 2024 and the comments to be compiled by 30 <sup>th</sup> June 2024.
5 <sup>th</sup> Internal committee members meet/Offline	15.06.2024 1:00pm-1:30pm	<p>The Chairperson decided that all the internal members to review the report submitted by other members among themselves and give the feedback.</p> <p>Work distributed among the drafting committee members.</p>
6 <sup>th</sup> Internal committee members meet/Offline	02.07.2024 9:40am-10:45am	<p>Drafts of sub-topics to be shared with respective group members to take their approval.</p> <p>An undertaking to be taken from all the task force members to maintain the confidentiality of this report.</p> <p>Final soft copy of the report to be submitted to NAMS by 10.07.2024.</p>

The NAMS task force members shows representation from all over India as shown below (Figure-2):



**Figure-2: Representation of our Task force members nominated by NAMS**

## **HEALTH ISSUES IN TRIBAL COMMUNITIES**

The health problems faced in the tribal population have been divided into seven main thematic areas (Figure-3):

1. Nutritional problems
2. Non-communicable Diseases
3. Mental Health & Addiction
4. Maternal & Child Health
5. Oral Hygiene & Health
6. Hemoglobinopathies & Sickle Cell Anaemia
7. Access to Healthcare



**Figure-3: Depicts the main health issues among Tribal communities**



# **Theme-I**

## **Nutrition Problems**



## Introduction

Proper nutrition is a basic human right, and the nutritional well-being of a population is a reflection of the performance of national social and economic sectors and it is an indicator of the efficiency of national resource allocation. Similarly, nutritional status is a measure of an individual's health condition as affected primarily by the intake of food and utilisation of nutrients.(1) Despite the several national nutrition intervention programmes in operation for more than five decades, the persistent problem of undernutrition among vulnerable groups, particularly among the tribal population, continues to be a serious public health concern in India. Though there was a decline in the overall prevalence of undernutrition, its magnitude is still very high in India, and there are no signs of meeting the targeted nutritional goals, i.e. Sustainable Development Goals (SDGs) by 2030 or in the near future. The National Nutrition Monitoring Bauru (NNMB) periodic surveys carried out in tribal, rural and urban areas of different states in India revealed that the dietary pattern of the population residing in different regions of India varies significantly as the nutrition of the population is influenced by their culture, customs, religion etc.(2-4)

Tribal communities are socially and economically disadvantaged as they are isolated from the general population and reside in hilly and forest areas. They constitute 8.2% of the total population of India (Census 2011).(2) There are 705 tribal groups in India, of which 75 are Particularly Vulnerable Tribal Groups (PVTG), numbering 28 lakh. More than two-thirds of the Schedule Tribes live in the seven states of Madhya Pradesh, Chhattisgarh, Jharkhand, Odisha, Maharashtra, Gujarat and Rajasthan.(3) A general feature of the tribal population of the country is their exclusive geographical habitat. In view of their habitat and dietary habits, they often distinguish themselves from other population groups. Geographical isolation, primitive agricultural practices, socio-cultural taboos, poor health-seeking behaviour, poverty, etc., lead to a higher risk of malnutrition as well as the development of various morbidities.

Socio-economic conditions, such as agricultural patterns and occupation profiles, vary among different tribes and are determined by the ecosystem they live in.(4) Several studies have shown a close relationship between tribal ecosystems and nutritional status.(5) Tribal populations are at risk of undernutrition because of their dependence on primitive agricultural practices and the uncertainty of food supply.

## **Present scenario**

The periodic nutrition surveys carried out by the National Nutrition Monitoring Bureau (NNMB) periodic surveys undernutrition is a major concern among the tribal population. The time trends revealed that the dietary intakes marginally declined over a period of time and it was reflected in the intakes of various nutrients, where the gaps between the actual intakes and recommended dietary allowances (RDAs) were high with respect to micronutrients such as vitamin A, iron, folic acid, riboflavin etc. Nutrition and Health Survey was conducted by Andaman and Nicobar Tribal and Research Institute in 2019 on PVTGs of the islands which revealed that malnutrition was still present among them. Among the Great Andamanese, there were 3 preschool children of which 2 were stunted, and among the school children, 10.5% were undernourished and 26% were obese. Among Onge preschool children 90.5% were stunted and among school children 35% were undernourished. Among Shompen preschool children 25% were stunted and among school children 47% were stunted. Among Jarawa preschool children 12.5% were undernourished and among school children 9.2% were wasted.(6) Similarly, the nutritional indicators reported by the National Family Health Surveys were also poor among the tribal population. As per the recent report of NFHS-5, the prevalence of malnutrition among tribal children in the country has shown a declining trend, viz., the prevalence of stunting, wasting and underweight has reduced from 43.8%, 27.4% and 45.3%, respectively in NFHS-4 to 40.9%, 23.2% and 39.5% respectively under NFHS-5. Though there seems to be an overall improvement from NFHS-4 to NFHS-5 data, there are still gaps like anaemia, mild to moderate malnutrition and other micronutrient deficiencies which need to be addressed.

## **Justification**

Despite the several national nutrition intervention programmes in operation for more than five decades, the persistent problem of undernutrition continues to be a public health concern among the tribal population in India. The NNMB has carried out three rounds (1985-87, 1998-99 and 2008-09) of Nutrition surveys in ITDA areas of 10 states such as Andhra Pradesh, Karnataka, Kerala, Tamil Nadu, Maharashtra, Gujarat, Odisha, Madhya Pradesh, Uttar Pradesh and West Bengal revealed that the tribal population was subsisting on inadequate diets in terms both quality and quantity and the same was reflected in poor nutritional status of both children and adult population. The dietary diversity among the tribal population was very poor,

and the minimum acceptability of diet (MAD) among tribal children aged below 2 years was extremely poor. Similarly, children's diets are poor in micronutrients, resulting in multiple micronutrient deficiencies, also known as hidden hunger, resulting from prolonged consumption of diets with poor dietary diversity and a lack of micronutrients and their absorption.

## **Challenges**

There are a various number of National Nutrition Programs implemented in our country over a period of five decades but still undernutrition continues to be a major concern among the tribal population in India. Children under 5 years and pregnant women are at risk of malnutrition. These include poverty, food insecurity, inadequate access to quality food, limited utilisation of milk and milk products among certain tribes, declining availability of forest-based animal and plant foods, insufficient and unsafe water sources, inadequate sanitation facilities, limited knowledge about hygiene, health, breastfeeding, and complementary feeding practices, time constraints hindering frequent feeding of children, high prevalence of infections like malaria, diarrhoea, respiratory, and skin infections, delayed healthcare-seeking behaviour, and inadequate healthcare infrastructure.

In addition to this consumption of packed and processed food had penetrated in the tribal areas as it became easily available, affordable and accessible. The rise of television, mobile phones, and internet access in tribal areas has exposed these communities to aggressive advertising for junk food and processed snacks. Advertisements often glamorize these products, making them seem attractive and aspirational. Younger generations, in particular, are often influenced by the lifestyle portrayed in media, leading them to adopt more urban and processed food choices over traditional diets. As traditional food systems based on local agriculture, hunting, and gathering started to decline due to land encroachment, deforestation, and changes in lifestyle, many tribal communities found it easier to buy processed foods rather than produce their own. The widespread availability and affordability of processed food have had significant impacts on the health and culture of tribal communities, contributing to shifts in diet-related diseases like diabetes, obesity, and malnutrition, which were previously rare in these populations. In a study conducted by Suparna Ghosh et al on women of indigenous community of Munda tribes of Jharkhand it was observed that the women were consuming packaged foods like biscuits, chips,

namkeen, chowmein etc twice a week.(7) In another study conducted by Suparna Ghosh et al on Dietary Diversity among farmers of Sauria Paharia Tribal Community it was observed that 32% of the households were consuming biscuits, sweets and savory snacks regularly and 1/4<sup>th</sup> of the households were consuming twice a week.(8) Consumption of junk food which is rich in sugar frequently leads to calcium and magnesium deficiency as it interferes with its absorption. Junk food also contains Phytates, oxalates, and lectins which bind to minerals like calcium, iron, and zinc, making it harder to absorb them. In a study conducted by Alka Jain on Assessment of Nutritional Status & Fast Food Trends in College going Tribal Girls of Ambikapur, District Surguja, Chhattisgarh it was observed that 76.67% of the surveyed subjects consumes fast food two times in a day.(9) In a study conducted by Chakma et al on the Health and Nutrition Profile of Tribals of Madhya Pradesh and Chhattisgarh it was observed that the diet of the primitive tribes namely Abujhmara, Baiga, Bharia, Birhor, Hill Korwa, Kamar, Maria Gond (Maharashtra) was mainly cereal based. Consumption of pulses was low in all the tribes except Bharias. Similarly, the green leafy vegetables (GLV) consumption was very low  $13.5 \pm 2.7$  gm/day among Abujhmaras and low in other tribes too. Consumption of other vegetables, roots and tubers were also not up to the mark. Consumption of Iron, Calcium, Vitamin A and all other micronutrients were lower than RDA. This was affecting the overall health of the tribes as more than half of the preschool children of all the tribes were suffering from mild, moderate to severe malnourishment.(10)

Addressing these issues remains crucial in combating malnutrition among tribal populations.

### **Gaps/Lacunae**

The diets of the tribal population were poor in terms of both quantity and quality. Dietary diversity was poor, and the micronutrient-rich foods were very low. Recent data on the diet and nutritional status of tribal people in India are not readily available. The last NNMB survey was carried out in 2008-09. Hence, to understand the magnitude of undernutrition, a Pan-India comprehensive nutrition survey should be undertaken among the tribal communities as early as possible.

### **Intervention strategies**

Integrating nutrition interventions with tribal health initiatives holds the promise of fostering holistic well-being within indigenous communities by leveraging traditional knowledge and

local resources to address prevalent nutritional challenges. Through a multifaceted approach encompassing the promotion of backyard kitchen gardens, utilization of forest vegetables and fruits, revival of local traditional foods, integration of forest foods, and enhancements in the Integrated Child Development Services (ICDS), this intervention seeks to not only improve dietary diversity and nutritional intake but also preserve cultural heritage and empower community members to take ownership of their health. By highlighting the nutritional value of indigenous foods such as millets, brown rice, Mahua flowers, Tendu fruits, Jamun, and eggs, alongside practical steps for implementation and monitoring, this comprehensive plan aims to catalyse sustainable change and enhance the health outcomes of tribal populations across generations.

## **1. Promotion of Backyard Kitchen Garden**

### **Objective**

Improve access to fresh vegetables and herbs, enhance food security, and promote nutritional diversity.

### **Steps**

- **Assessment:** Conduct a thorough survey to identify households with suitable space for kitchen gardens and assess their existing knowledge and resources.
- **Training:** Organize comprehensive workshops covering various aspects of gardening, including soil preparation, seed selection, planting techniques, irrigation methods, natural pest control, and composting.
- **Seeds and Tools Distribution:** Provide households with starter kits containing a variety of seeds such as spinach, kale, tomatoes, carrots, and herbs, along with essential gardening tools and organic fertilizers.
- **Support Systems:** Establish a network of trained community volunteers who can offer ongoing guidance, troubleshooting assistance, and periodic workshops to address specific challenges.

- **Monitoring and Evaluation:** Implement a robust monitoring system to track garden progress, including regular visits to assess plant growth, record harvest yields, and conduct dietary surveys to measure the impact on household nutrition.
- **Community Engagement:** Organize monthly gatherings where participants can share experiences, exchange produce, and learn new recipes that incorporate homegrown vegetables and herbs.

### Nutritional Value

- **Spinach and Kale:** Rich sources of vitamins A, C, and K, as well as minerals like iron, calcium, and magnesium.
- **Tomatoes:** Packed with vitamin C, potassium, folate, and the antioxidant lycopene.
- **Carrots:** High in beta-carotene, fibre, vitamin K1, potassium, and antioxidants.
- **Herbs (e.g., basil, cilantro):** Provide flavour and essential nutrients such as vitamins A and K, and minerals like calcium and potassium.

## 2. Promotion of Forest Vegetables and Fruits (Organic)

### Objective

Utilize local forest resources to enhance dietary diversity and nutrition.

### Steps

- **Resource Mapping:** Conduct an extensive survey of nearby forests to identify edible plants and fruits, considering seasonal availability and sustainability.
- **Training:** Organize workshops led by local forest experts to educate community members on responsible foraging practices, including species identification, ethical harvesting, and conservation efforts.
- **Cooking Demonstrations:** Host cooking demonstrations where traditional recipes incorporating forest vegetables and fruits are showcased, emphasizing their nutritional value and culinary versatility.



- **Preservation Techniques:** Provide training on various preservation methods such as drying, pickling, and fermenting to extend the shelf life of forest produce and ensure year round availability.
- **Documentation:** Develop a comprehensive guidebook documenting the nutritional profiles, medicinal properties, and cultural significance of different forest foods, accompanied by recipes and cooking tips.

### Nutritional Value

- **Forest Vegetables (e.g., wild greens, mushrooms):** Rich sources of vitamins, minerals, and antioxidants, including vitamin C, calcium, and beta-carotene.
- **Forest Fruits (e.g., berries, wild figs):** Packed with vitamins, fibre, and phytochemicals, offering immune-boosting and anti-inflammatory benefits (Annexure-D).

## 3. Promotion of Local Traditional Foods (Millets, Brown Rice)

### Objective

Revive and incorporate traditional foods into daily diets to improve nutrition and preserve cultural heritage.

### Steps

- **Awareness Campaign:** Launch an extensive awareness campaign highlighting the nutritional superiority of traditional foods like millets and brown rice compared to refined grains, emphasizing their role in preventing malnutrition and chronic diseases.
- **Distribution:** Collaborate with local farmers and cooperatives to ensure the availability of high-quality millets, brown rice, and other traditional grains at affordable prices through community markets and mobile vans.
- **Recipe Development:** Partner with nutritionists and local chefs to develop innovative recipes that showcase the versatility and deliciousness of traditional dishes, catering to diverse tastes and dietary preferences.

- **Cooking Classes:** Conduct hands-on cooking classes in community kitchens, schools, and women's self-help groups to teach participants how to prepare nutritious meals using traditional ingredients, with a focus on balanced nutrition and portion control.
- **Incentives:** Offer incentives such as cooking utensils, recipe booklets, and subsidized grain packages to encourage households to adopt traditional foods as staple ingredients in their daily meals.

#### **Nutritional Value (Annexure-II & III)**

- **Millets (e.g., finger millet, pearl millet):** Excellent sources of complex carbohydrates, dietary fibre, protein, and essential micronutrients like iron, zinc, and magnesium.
- **Brown Rice:** Rich in fibre, vitamins (especially B vitamins), minerals (such as magnesium and selenium), and antioxidants, with a lower glycaemic index compared to white rice.

#### **4. Promotion of Forest Foods (Mahua Flower, Tendu Fruits, Jamun)**

##### **Objective**

Integrate highly nutritious and culturally significant forest foods into regular diets.

##### **Steps**

- **Education:** Conduct community workshops and storytelling sessions led by elder members to revive traditional knowledge about the nutritional and medicinal properties of forest foods like Mahua flowers, Tendu fruits, and Jamun.
- **Harvesting Training:** Train community members, particularly women and youth, on sustainable harvesting techniques that promote biodiversity conservation and respect indigenous cultural practices.
- **Processing:** Establish decentralized processing units equipped with solar dryers, grinding mills, and fermentation tanks to facilitate the preservation and value addition of forest foods, creating marketable products like jams, syrups, and flour blends.

- **Recipe Sharing:** Organize cooking competitions and recipe exchange events where community members can showcase their creativity in incorporating forest foods into everyday dishes, fostering a sense of pride and ownership in traditional cuisine.
- **Cultural Events:** Celebrate seasonal harvest festivals and rituals that center around forest foods, promoting cultural resilience and intergenerational knowledge transfer within the community.

#### **Nutritional Value (Annexure-IV & V)**

- **Mahua Flower:** Rich in carbohydrates, proteins, and essential fatty acids, with therapeutic properties for digestive health and immunity.
- **Tendu Fruits:** High in vitamin C, calcium, and antioxidants, known for their cooling effect on the body and potential anti-inflammatory benefits.
- **Jamun (Indian Blackberry):** Excellent source of vitamin C, iron, potassium, and phytochemicals like anthocyanins, which have anti-diabetic and anti-cancer properties.

### **5. ICDS (Integrated Child Development Services) Enhancements**

#### **Objective**

Improve nutritional status of mothers and children through targeted interventions at ICDS centres. In Maharashtra state, started a scheme for tribal area known as Late Abdul Kalam Amrut Aahar Yojana from 2015. In this scheme one-time free lunch (with rich protein including eggs and pulses) at Anganwadi centre for all ANC Mother up to 6 months PNC Mother (The free lunch started from 3 month of ANC up to 6 months after delivery)

#### **Steps**

##### **A. One Lunch to ANC/PNC Mothers**

- **Meal Planning:** Develop a rotating menu of balanced meals that meet the nutritional needs of pregnant and lactating mothers, incorporating locally available ingredients such as pulses, green leafy vegetables, whole grains, and seasonal fruits.

- **Infrastructure:** Upgrade existing kitchen facilities at ICDS centres to meet food safety standards, including proper storage, cooking, and serving equipment, as well as hygiene protocols for food preparation and sanitation.
- **Training:** Provide comprehensive training to ICDS staff, including cooks, caregivers, and health workers, on meal planning, portion control, food safety, and hygiene practices, emphasizing the importance of maternal nutrition for foetal and infant development.
- **Monitoring:** Implement a robust monitoring and evaluation system to track the quantity and quality of meals served to ANC/PNC mothers, as well as their dietary intake and nutritional status through regular anthropometric measurements and haemoglobin testing.
- **Community Involvement:** Establish partnerships with local women's self-help groups and community health volunteers to involve mothers in menu planning, meal preparation, and nutrition education sessions, empowering them to make informed choices about their dietary intake and feeding practices.

### **Nutritional Value**

- **Balanced Meals:** Ensure that each meal includes a combination of macronutrients (carbohydrates, proteins, fats), as well as micronutrients (vitamins and minerals) essential for maternal health and foetal development.
- **Examples:** Lentils and beans provide plant-based proteins, iron, and folate; green leafy vegetables like spinach and fenugreek are rich in vitamins A, C, and K, as well as calcium and iron; whole grains like brown rice and millets offer complex carbohydrates, fibre, and B vitamins.

### **B. Eggs 4 Days a Week to 0-6 Years Children**

- **Supply Chain:** Establish a reliable procurement system for sourcing fresh eggs from

local poultry farms or cooperative societies, ensuring regular and sufficient supply to meet the dietary requirements of children aged 0-6 years.

- **Storage:** Invest in appropriate storage facilities such as refrigerators or coolers to maintain egg freshness and safety during transportation and distribution to ICDS centres.
- **Meal Integration:** Incorporate eggs into the daily menu of ICDS centres, offering them in various forms such as boiled, scrambled, or as part of nutritious dishes like vegetable omelettes, egg muffins, or egg-fried rice, to cater to children's preferences and encourage regular consumption.
- **Monitoring:** Implement a monitoring system to track egg consumption among children, as well as any adverse reactions or allergies, and periodically assess their growth and developmental milestones to evaluate the impact of egg supplementation on nutritional outcomes.
- **Parental Education:** Conduct interactive nutrition education sessions for caregivers and parents of young children, highlighting the importance of eggs as a nutrient-dense food source rich in high-quality proteins, essential amino acids, vitamins (A, D, E, B12), and minerals (iron, zinc), critical for supporting growth, brain development, and immune function during the early years of life.

A Pan-India comprehensive nutrition survey should be undertaken among the tribal population in terms of anthropometry, dietary intake through diet surveys, biomarkers for micronutrients like Vitamin A, iron, folic acid, B 12, Vitamin D, diet related non-communicable diseases.

## Way forward

1. To understand the dietary behaviors in terms of cultural context.
2. To design a recipe book for local communities, including the local fruits, tubers and vegetables.



## **Theme-II**

# **Non-communicable Diseases**





## **Introduction**

Non-communicable diseases (NCDs) have emerged as a significant public health challenge globally, with a particularly high burden among tribal populations in India. This review delves into the prevalent NCDs affecting tribal communities in India, shedding light on the common diseases that afflict these populations, such as diabetes, hypertension, and cardiovascular diseases. The inadequate access to healthcare facilities further exacerbates the management of NCDs in tribal areas, leading to delayed diagnosis, poor treatment outcomes, and increased mortality rates. Moreover, socio-economic factors play a crucial role in contributing to the heightened burden of NCDs among tribal populations, including poverty, limited education, and cultural disparities. By exploring these complexities, this section of the report aims to provide insights into the challenges faced by tribal communities in dealing with NCDs and offers potential strategies for improving healthcare delivery and outcomes in these marginalized populations.

## **Burden**

Non-communicable diseases (NCDs) have become a pressing issue among tribal populations in India, as evidenced by recent studies highlighting the prevalence of NCD risk factors and associated health complications. These studies indicate a significant burden of NCDs in tribal regions, leading to a high proportion of mortality due to lifestyle diseases. For instance, cardiovascular diseases (CVDs) have emerged as a prominent cause of NCD-related deaths in India, showcasing the diverse prevalence and impact of NCDs across different regions of the country.(9,10) Moreover, the burden of multi-morbidity, where individuals suffer from multiple chronic conditions simultaneously, has been on the rise among tribal communities, with an estimated prevalence of around 50% among older participants.(11) This increase in NCD prevalence poses a substantial challenge to the healthcare system, as evidenced by studies focusing on the economic burden of out-of-pocket expenditures (OOPE) associated with NCD treatment among tribal households.(12) Despite the alarming statistics, there is a lack of comprehensive data on the exact prevalence and impact of NCDs among tribal populations, emphasizing the urgent need for further research and targeted healthcare interventions to address this growing health crisis.

## **Indian scenario**

A comprehensive report led by Dr. Abhay Bang, commissioned by the ministries of health and tribal affairs, highlights that despite constituting 8% of the population, tribal communities account for 30% of malaria cases, 60% of *P. Falciparum* cases, and 50% of malaria mortality.(13) The prevalence of cardiovascular disease among tribals is nearly the same as non-tribals in seven out of ten states with significant tribal populations and higher in Maharashtra and the Andaman and Nicobar Islands. Hypertension prevalence among tribal adults is comparable to the national rate, with specific figures reported for the Baiga and Bharia tribes in Madhya Pradesh. Mental stress among tribals is exacerbated by conflict, displacement, and loss of livelihood. Health infrastructure in tribal areas is inadequate, with significant shortfalls in primary health centers (PHCs) and community health centers (CHCs) in states like Jharkhand, Madhya Pradesh, and Maharashtra.(13) There is also a substantial manpower shortage, with an 82% shortfall in specialist doctors, 33% in lab technicians, and 28% in staff nurses. The panel recommends integrating traditional healing practices with modern medicine, strengthening public health systems, and leveraging the role of health workers like ASHA to address these health disparities.(13)

### **1. Tamil Nadu**

A study by Dsouza et al. in the tribals of Nilgiri, Tamil Nadu, revealed that 78% of participants were aware of common noncommunicable diseases (NCDs) in their community, with 67% receiving information primarily from ASHWINI and other healthcare facilities.(14) While 72% recognized an unhealthy diet as a risk factor and 25% acknowledged family history, understanding of other risk factors was low: lack of physical activity (7%), old age (2%), and environmental factors (3%). Awareness of alcohol (10%) and tobacco (4%) as risk factors was also limited, and 41% had misconceptions about NCDs being transmissible. Despite 72% understanding the importance of screening, 93% had their blood pressure checked at least once, 74% had their blood sugar checked, but only 33% attended screening camps.(14) These findings highlight significant gaps in awareness and understanding of NCDs among the tribal population, emphasizing the need for targeted health education and intervention strategies to improve health outcomes in these communities.

## **2. Karnataka**

The study by Mallikarjuna Majgi S found that among the study population, the prevalence of diabetes, hypertension, and dyslipidemia were 4.6%, 28.8%, and 85.7%, respectively.(15) Between tribal and non-tribal populations living in forest-dwelling areas, significant differences were found in diabetes and HDL abnormality, but not in hypertension, dyslipidemia, LDL abnormality, TGA abnormality, TC abnormality, or VLDL abnormality.(15) Waist circumference emerged as a significant independent predictor of diabetes among tribal participants, while wealth index, age, and waist circumference were significant predictors of hypertension. The study suggests that the tribal population in remote areas is at a lower risk of developing diabetes compared to non-tribal populations in the same geographic area, although the prevalence of hypertension and dyslipidemia among tribal populations is high and comparable to that of the general population.

## **3. Arunachal Pradesh**

Arunachal Pradesh has reported a notable incidence of hypertension and associated risk factors among its tribal population. Lifestyle changes, dietary habits, and genetic predispositions are key contributors to the high prevalence of these conditions.(16)

## **4. Mizoram**

In Mizoram, the growing challenge of NCDs, particularly hypertension and diabetes, is influenced by dietary habits, socio-economic factors, and limited healthcare access. This underscores the need for comprehensive public health strategies.(17)

## **5. Nagaland**

Nagaland's tribal population exhibits high rates of hypertension and cardiovascular diseases, necessitating targeted health interventions and improved healthcare infrastructure.(18)

## **6. Sikkim**

In Sikkim, diabetes and hypertension are dominant NCDs among tribal populations. Regional studies highlight the pressing health concerns and the need for tailored health policies to address these issues.(17)

## **7. Odisha**

Odisha's tribal populations are burdened with multiple NCDs, including hypertension, diabetes, and dyslipidemia. Socio-economic factors and limited healthcare services significantly influence the prevalence of these diseases.(19)

## **8. Madhya Pradesh /Central India**

The study on hypertension among tribal populations in Madhya Pradesh by Chakma et al reveals a significant prevalence of high blood pressure, affecting approximately 26% of participants, with 9% showing stage-II hypertension (systolic BP  $\geq$  160 mm Hg or diastolic BP  $\geq$  100 mm Hg).(20) Notably, 8% of individuals under 30 years had stage-I or stage-II hypertension. Hypertension prevalence was found to increase markedly with age, rising from 1% in those below 30 to 37.5% in individuals aged 60 or older.(20) Body mass index (BMI) also showed a strong correlation, with 43% of pre-obese and 32% of obese individuals experiencing high blood pressure, compared to 19% of underweight individuals.(20) Salt intake emerged as a critical factor, with nearly all individuals (97%) consuming more than 20 grams per day suffering from high blood pressure, and hypertension rates climbing sharply with increasing salt consumption. Other factors, such as smoking and alcohol consumption, were initially associated with hypertension but became statistically insignificant when adjusted for age, BMI, and total salt consumption. However, smoking and high salt intake remained key contributors. Additionally, high urinary sodium levels were linked to elevated blood pressure, with 71% of individuals with high urinary sodium showing hypertension.(20)

Similarly, the study by Dash S.C. et al. found that hypertension prevalence was significantly higher among urban Oraon tribals (25.6/1000) compared to their rural counterparts (4.6/1000). (21) Higher salt consumption and body weight were linked to increased blood pressure, with hypertensive individuals showing elevated urinary sodium levels, indicating a combination of genetic and environmental factors in hypertension development.(21)

## **Data pertaining to Mortality by NCDs among tribals**

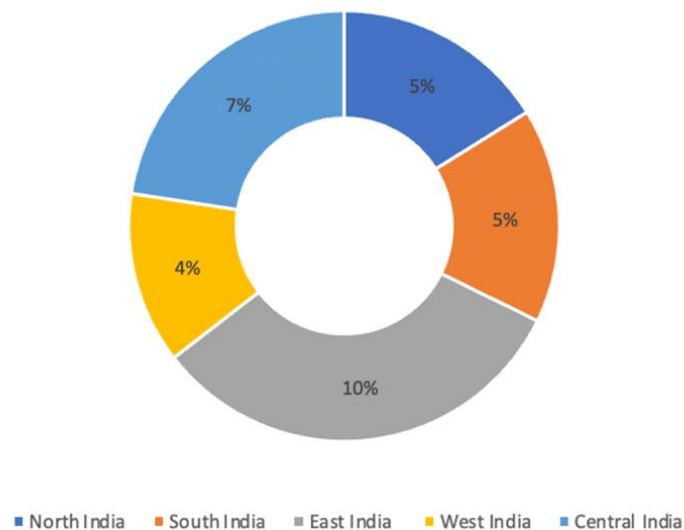
- A survey by the Indian Council of Medical Research (ICMR) in 12 tribal districts revealed that NCDs caused 66% of deaths in these areas.(16)

- Cardiovascular diseases (CVDs) accounted for **45%** of NCD-related deaths among tribals.(16)
- Chronic respiratory diseases contributed **22%**, cancers **12%**, and diabetes **3%**.(22)

## Evidence pertaining to Diabetes and Hypertension among tribals

### 1. Diabetes Mellitus Prevalence Among Indian Tribals:

A systematic review and meta-analysis estimated the prevalence of diabetes mellitus in the Indian tribal community. The pooled prevalence rate across twenty-three studies involving 35,985 participants was approximately 6% (95% CI = 5–7%).(23) The prevalence of diabetes varied across different subgroups within the tribal population (Figure-4).



**Figure-4: Prevalence of diabetes varied across different subgroups within the tribal population**

Another study found that the prevalence of diabetes among tribals was almost similar to that in rural areas. However, the prediabetic status was high, approaching semiurban levels. Specifically, Diabetics: 4.13% among tribal groups and 8.8% among nontribal groups.

### 2. Hypertension Prevalence Among Indian Tribals

Another Systematic Review and Meta-analysis shows the pooled prevalence of hypertension among men, women and combined were 23.66% (95% confidence interval (CI): 23.25 to 24.07%), 23.37% (95% CI: 22.99 to 23.75%) and 16.68% (95% CI: 16.10 to 17.28%) respectively.(24)

### **Rural Urban Comparison of NFHS- 5 (25)**

Although the NFHS-5 doesn't exactly talk about the tribal prevalence of NCDs but it can be interesting to see that the rural prevalence is almost comparable to the urban in case of NCDs and since almost 90% of the tribal population in India is rural,(26) its importance cannot be ignored when it comes to national and state's rural prevalence of NCDs (Table-2).

**Table-2:** National estimates of NCDs among Rural and Urban population

	<b>Rural</b>		<b>Urban</b>	
	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>
<b>Hypertension</b>	15.0%	11.9%	17.1%	13.6%
<b>Diabetes</b>	7.0%	5.9%	7.8%	6.7%
<b>Obesity</b>	19.3%	19.7%	29.8%	33.2%

## **State Scenario**

### **Jharkhand**

In Jharkhand, the burden of NCDs among tribal communities is significant, with high prevalence rates of cardiovascular diseases and diabetes. Studies indicate that socio-economic factors, limited access to healthcare, and lifestyle changes contribute to the increasing rates of these diseases (Table-3).

**Table-3:** State (Jharkhand) estimates of NCDs among Rural and Urban population

	<b>Rural</b>		<b>Urban</b>	
	<b>Male</b>	<b>Female</b>	<b>Male</b>	<b>Female</b>
<b>Hypertension</b>	14.6%	10.5%	16.3%	13%
<b>Diabetes</b>	6.9%	5.2%	6.9%	5.8%
<b>Obesity</b>	12.8%	8.6%	21.7%	21.6%

A study conducted by the Department of Public Health, TATA Steel Foundation in Jamshedpur, Jharkhand, between April 2022 and January 2023, involving a sample size of 4579 individuals aged 30 and above, revealed significant health concerns.(27) The prevalence of diabetes was found to be 16.3%, and hypertension was prevalent in 21.3% of the study population. Notably, 19.7% of females and 24.5% of males were hypertensive, showing a

statistically significant difference. Most hypertensive patients were in the 51-60 age group. Among diabetic patients, 16.37% were females and 16.38% were males, with no statistically significant difference. The highest number of diabetic patients was in the 30-40 age group.(27)

In another study by Lugun J et al., the status of cardiovascular disease (CVD) risk factors among tribal and nontribal populations in Jharkhand was examined.(28) The comparative analysis showed that non-tribals had almost twice the susceptibility to develop hypertension, pre-hypertension, and obesity compared to tribals, with respective rates of 8.0%, 15.6%, and 22.1% in tribals. This trend was even more pronounced in individuals over 40 years old, with non-tribals showing nearly 16-fold and tribals showing 11-fold increases in hypertension risk compared to those under 40. Additionally, 14.8% of tribals were reported to be diabetic, the highest rate recorded in India so far.(28) These findings indicate a significant increase in susceptibility to various CVD risk factors with age, particularly in urban non-tribals compared to rural tribals.

A study by Kumar S. found anaemia in 10.4% of the population and dyspepsia/peptic ulcer syndrome in 17.7% of individuals in a tribal population of Dumka, Jharkhand.(29)

The study "Health Care and Health Among Tribal Women in Jharkhand: A Situational Analysis" provides insights into various health indicators among tribal and non-tribal women in Jharkhand during 1998-99. This includes data on mean height, the percentage with height below 145 cm, mean body mass index (BMI), and the percentage with specified levels of BMI, which are indicators of nutrition and anaemia status.(30)

## **Challenges**

### **Lack of access to healthcare facilities**

Lack of access to healthcare facilities in tribal communities exacerbates the management of non-communicable diseases (NCDs) due to various factors. Recent studies conducted in tribal regions of India have highlighted a significant burden of NCD risk factors, potentially leading to a higher proportion of deaths related to NCDs within these communities.(31) The prevalence of lifestyle diseases among tribal populations in India is on the rise, further complicating the already existing challenges in managing NCDs in these regions.(32) Multi-morbidity, the

presence of two or more chronic conditions, is becoming increasingly common in India, with an estimated prevalence of around 50% among individuals aged 45 years and above.(11) Cardiovascular diseases (CVDs) are particularly prominent among NCDs in India, underscoring the diverse prevalence rates and health disparities within the country.(33) The economic burden associated with out-of-pocket expenditures (OOPE) related to NCD management further adds to the challenges faced by tribal communities in accessing adequate healthcare services for NCDs.(12) Despite NCDs being the leading cause of death in India, the prevalence of these diseases remains high in tribal populations, emphasizing the urgent need for improved healthcare access and management strategies in these underserved communities.(34) Factors such as limited healthcare infrastructure and resources can significantly impact the burden of NCDs among tribal populations, highlighting the critical importance of addressing healthcare disparities to effectively manage NCDs in these marginalized communities.(35)

### **Socio-economic factors**

Non-communicable diseases (NCDs) have become a pressing concern among tribal populations in India, replacing the historical prevalence of infectious diseases like tuberculosis and malaria. Lifestyle diseases are on the rise within these communities, with factors such as increasing consumption patterns being linked to the higher incidence of NCDs among tribal populations.(32,33) The burden of multimorbidity is also escalating, particularly among individuals aged 45 years and older, with a prevalence rate of approximately 50% in India.(11) Cardiovascular diseases (CVDs) stand out as the primary cause of NCDs in the country, underscoring the substantial diversity in disease prevalence across different regions of India.(33) Economic factors play a significant role in exacerbating the burden of NCDs among tribal populations. Household-level analyses have shown a correlation between out-of-pocket expenses and the prevalence of NCDs, shedding light on the economic challenges faced by these communities in accessing healthcare services.(12) Furthermore, major modifiable risk factors for NCDs, such as hypertension, tobacco use, and alcohol consumption, are more prevalent among tribal populations like the Kani tribes in Thiruvananthapuram, highlighting the socio-economic disparities that contribute to the high burden of NCDs in these marginalized communities.(31,34)



## **Gaps/Lacunae**

There are significant gaps in addressing NCDs among tribals, including a lack of culturally sensitive healthcare services, limited data on disease prevalence, and inadequate health education programs. Interventions should focus on creating targeted healthcare initiatives tailored to the specific needs and cultural context of tribal communities. Community-based healthcare programs, capacity building for local healthcare providers, and promoting traditional lifestyle practices that can mitigate the risk of NCDs are essential interventions. It is imperative to prioritize the understanding and management of non-communicable diseases among tribal populations (Rarau et al., 2020).(35-38) This requires a multi-faceted approach that addresses the unique challenges faced by these communities.(36) By recognizing the specific needs and cultural context of tribal populations, implementing targeted healthcare initiatives, and promoting traditional lifestyle practices, we can effectively reduce the burden of NCDs and improve the overall health and well-being of tribal communities. Insights for indigenous populations can be derived from regional and global studies focusing on nonindigenous populations, but generalizing is problematic for indigenous groups where scholarship indicates that impacts, adaptation, and vulnerability are highly place- and culture-specific.(36)

The First tribal health report of 2018 by the National Health Mission in India highlights the specific health challenges faced by tribal populations in the country.(37) According to the report, the burden of non-communicable diseases among tribals is a major concern. The report sheds light on the gaps and lacunae in addressing NCDs among tribal communities, emphasizing the need for culturally sensitive healthcare services, accurate data on disease prevalence, and effective health education programs tailored to the unique cultural context of tribal populations.

Furthermore, the report underscores the significance of interventions such as community-based healthcare programs, capacity building for local healthcare providers, and the promotion of traditional lifestyle practices in reducing the risk of NCDs among tribals. It also emphasizes the importance of recognizing the specific needs and cultural context of tribal populations in order to implement targeted healthcare initiatives effectively.(37)

Research and studies have shown that conditions such as diabetes, hypertension, cardiovascular diseases, cancers, and stroke are increasingly prevalent among tribal communities. (38) This can be attributed to various socio-economic factors, including limited access to healthcare facilities, poverty, and food insecurity. (39) Additionally, traditional lifestyle changes and a lack of awareness about NCD risk factors contribute to the increasing burden of these diseases among tribals. (40) To effectively address the burden of non-communicable diseases among tribal populations in India, targeted interventions are necessary. (36) These interventions should include improving access to healthcare facilities in tribal areas, implementing health education programs that raise awareness about NCD risk factors and healthy lifestyle practices among tribals, and incorporating traditional healing practices into healthcare systems.

Several studies have highlighted the specific challenges faced by tribal populations in India concerning NCDs. For example, a study published in the Indian Journal of Medical Research in 2018 found a high prevalence of hypertension and diabetes among tribal communities in the Nilgiris district of South India. (41) Another study in the Journal of Postgraduate Medicine reported a significant burden of oral cancer among tribes in central India. (37) These studies underscore the urgent need for targeted interventions and healthcare initiatives to address the burden of NCDs in tribal populations. (36) Additionally, it is important to consider the cultural and place-specific factors that influence the impacts, adaptation, and vulnerability of NCDs among indigenous groups in India. Understanding the prevalence of NCDs among tribal

populations is crucial for developing effective public health strategies that cater to their specific needs and challenges.

Research also indicates that the prevalence of NCDs among tribal populations is exacerbated by the lack of culturally sensitive healthcare services and limited data on disease prevalence. In many cases, tribal communities have limited access to basic healthcare facilities, and there is a lack of comprehensive data on the prevalence of NCDs among these populations. This presents a significant challenge in designing and implementing targeted interventions to address the burden of NCDs among tribals.

## Interventions

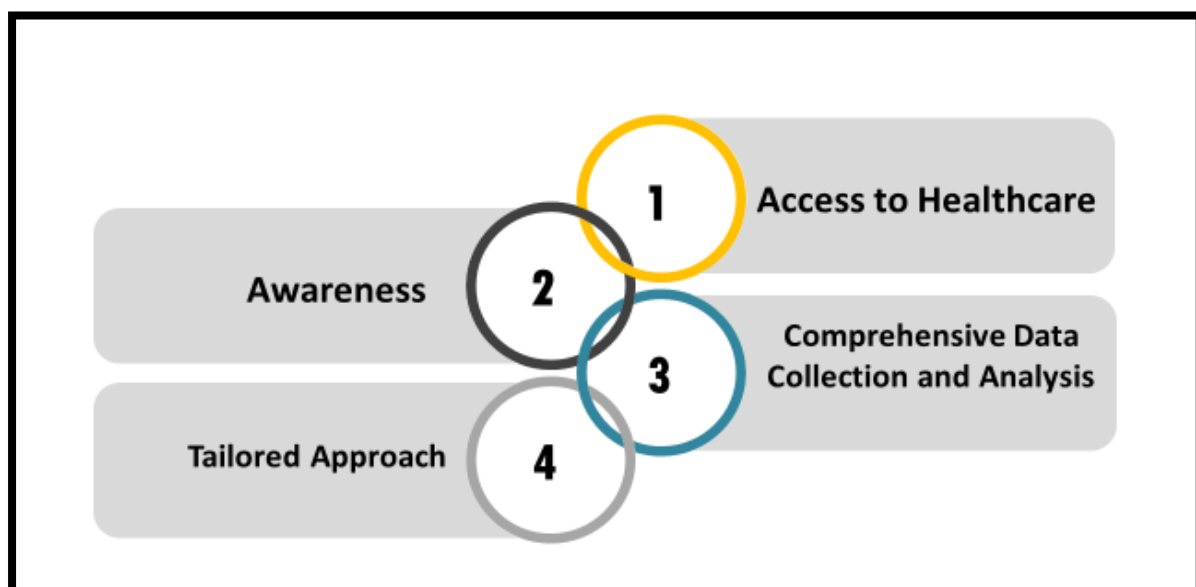


Figure-5: Depicts the four basic approaches required in NCDs.

### Access to healthcare

One of the key aspects of effectively addressing the burden of NCDs among tribal populations is the improvement of access to healthcare facilities in tribal areas. This includes not only enhancing physical access to healthcare centres but also ensuring that these facilities are equipped to provide culturally sensitive and contextually relevant care to tribal communities. Moreover, integrating traditional healing practices into the healthcare systems can play a significant role in improving health outcomes among tribal populations, as these practices are often integral to the cultural identity and well-being of these communities (Figure-5).

### Awareness

Furthermore, implementing health education programs that raise awareness about NCD risk factors and promote healthy lifestyle practices is crucial. These programs should be designed with consideration for the cultural beliefs and practices of tribal populations, ensuring that the information provided is relatable and applicable within their specific cultural context.

### Comprehensive Data Collection and Analysis

In addition, comprehensive data collection and analysis are imperative for understanding the prevalence and impact of NCDs among tribal communities. Without accurate and detailed data,

it is challenging to develop and implement targeted interventions that effectively address the burden of NCDs. Therefore, initiatives to gather and analyse data on disease prevalence and risk factors specific to tribal populations are essential for informing evidence-based interventions.

### **Tailored approach**

It is crucial to address the prevalence of NCDs among tribal populations in India through targeted interventions. Improving access to healthcare facilities in tribal areas, implementing health education programs to raise awareness about NCD risk factors and healthy lifestyle practices, along with incorporating traditional healing practices into healthcare systems, is essential to mitigate the burden of NCDs among tribals.

Interventions aimed at addressing the burden of NCDs among tribal populations should be tailored to the unique cultural context and needs of these communities. Community-based healthcare programs, capacity building for local healthcare providers, and promoting traditional lifestyle practices that can mitigate the risk of NCDs are essential in addressing the prevalent health challenges faced by tribal populations.

Finally, it is important to recognize that the prevalence of NCDs among tribal populations is not solely a healthcare issue but is deeply intertwined with socio-economic and environmental factors. Poverty, food insecurity, and traditional lifestyle changes significantly contribute to the burden of NCDs among tribal communities. Therefore, interventions aimed at addressing NCDs among tribal populations also need to consider broader socio-economic and environmental determinants of health, emphasizing the need for holistic and sustainable solutions.

In conclusion, the burden of non-communicable diseases among tribal populations in India necessitates a comprehensive and nuanced approach that addresses the unique challenges and contextual factors faced by these communities. By improving access to culturally sensitive healthcare, implementing targeted health education programs, gathering comprehensive data, and addressing socio-economic determinants, it is possible to reduce the burden of NCDs and improve the overall health and well-being of tribal populations in India.

## Bottlenecks

The burden of non-communicable diseases (NCDs) extends to tribal populations, but their unique context often remains overlooked. While studies like the one by Ranjit Mohan Anjana and colleagues highlight the severity of metabolic NCDs in India,(42) it's crucial to recognize that tribal communities constitute **8.6%** of India's population. These tribes, residing predominantly in remote forested areas, lack adequate healthcare infrastructure. Notably, a significant proportion of diabetes cases among tribes present as "**lean diabetes**," characterized by low BMI, malnutrition, and insulin-dependent hyperglycaemia.(43) Unfortunately, existing guidelines for diabetes management do not align with the needs of lean diabetes cases.

Access to insulin and sustained treatment poses challenges for impoverished tribal communities due to financial constraints and limited healthcare facilities. As a result, complications associated with diabetes, such as retinopathy, nephropathy, and cardiovascular diseases, disproportionately affect tribal populations. Addressing these issues requires targeted health policies and interventions.(44)

## Way Forward

Moving forward, it is imperative to prioritize the inclusion of tribal health in national and regional health policies. Strengthening primary healthcare infrastructure, conducting regular screenings for NCDs, and integrating traditional healing practices with modern healthcare systems are crucial steps towards addressing the NCD burden among tribal populations. Additionally, raising awareness and promoting lifestyle modifications through community

engagement and education will be vital in reducing the prevalence of NCDs among tribals.

Furthermore, the implementation of these interventions should be coupled with a systematic approach to mobilize resources for research and community-based initiatives. Developing a sustained process to address the indigenous health deficit through a global workplan is essential in effectively addressing the prevalence of NCDs among tribal populations. This approach involves combining research efforts with community-based initiatives to develop comprehensive strategies that account for the cultural diversity and specific challenges faced by tribal communities regarding NCDs.

## **Cancer in Tribal Population**

### **Introduction**

Since India is home to a significant tribal population, with over 104 million individuals belonging to various Scheduled Tribes, according to the 2011 Census of India, these communities are often geographically isolated and socioeconomically disadvantaged, which can impact their health outcomes, including the burden of cancer. This section of the report aims to analyse the burden of cancer among tribal populations in India, highlighting the unique risk factors, challenges in healthcare access, and potential strategies for intervention and research.

Cancer, a significant global health issue, disproportionately affects various populations, including tribal communities in India. These indigenous groups, spread across the nation, face unique challenges in combating cancer. Despite their rich cultural heritage and extensive traditional knowledge, tribal populations often reside in remote areas with limited access to modern healthcare services. This inadequate access, combined with socio-economic challenges, heightens their vulnerability to cancer. Additionally, specific environmental factors, lifestyle practices, and genetic predispositions unique to these communities further complicate cancer prevalence and treatment. Understanding the impact of cancer on India's tribal populations is crucial for developing targeted interventions that address healthcare disparities and ensure equitable treatment and support for these frequently overlooked groups.(45)

In lower middle-income countries like India, cancer has a significant impact due to factors such as low awareness, limited access to affordable healthcare, and poor prognosis. The country's diverse ancestries, socio-economic and cultural characteristics, dietary habits, and lifestyles result in geographical variations in genetic determinants, environmental exposures, and cancer patterns. Therefore, systematic data collection and high-quality reporting of cancer data from both urban and rural areas are crucial to enhance cancer epidemiology in the nation. The National Cancer Registry Programme (NCRP), initiated by the Indian Council of Medical Research (ICMR) in 1981, has established a network of cancer registries to gather and compile reliable cancer data from various regions of India.(46)

## **Burden of Cancer in India**

### **Present Scenario**

According to the ICMR-NCDIR's report released on World Cancer Day, February 4th, 2024, the projected number of new cancer cases in India for 2022 was 1,461,427, with a crude incidence rate of 100.4 per 100,000 individuals. It is anticipated that approximately one in nine people in India will face a cancer diagnosis during their lifetime. Lung cancer was the most prevalent among males, while breast cancer was the most common among females. Among childhood cancers (ages 0-14), lymphoid leukaemia was the leading type, accounting for 29.2% of cases in boys and 24.2% in girls. Looking ahead, a 12.8% increase in cancer incidence is projected by 2025 compared to 2020.(46)

The projected cancer burden in India is anticipated to rise from 26.7 million DALYs (disability-adjusted life years) in 2021 to 29.8 million in 2025, with the northern and north-eastern regions bearing the highest burden. Among non-communicable diseases, cardiovascular disease accounts for the highest death rate at 63.3%, followed by cancer at 18.1%. The increase in DALYs for cancer indicates a reduction in premature mortality. To address this issue, it is crucial to focus on expanding and enhancing non-communicable disease (NCD) screening, education, health promotion, and tobacco control, utilizing digital innovations at the population level.(46)

The rising incidence of cancer in India is driven by various factors, including lifestyle changes, environmental influences, and genetic predispositions. According to the National NCD Monitoring Survey (NNMS) conducted in 2017-2018, the prevalence of tobacco and alcohol use was 32.8%. Furthermore, over one-third (41.3%) of adults were physically inactive, nearly all (98.4%) consumed less than five servings of fruits and vegetables per day, and the average salt intake was 8 grams per day. The increasing cancer burden in India poses a significant public health challenge, requiring comprehensive and sustained intervention efforts.(47)

A study on cancer incidence rates, published in APJCP in 2013, highlighted the situation in India. It is estimated that in 2011, there were nearly 1,193,000 new cancer cases, with a higher incidence among females (603,500) than males (589,800). Projections suggest that by 2026, the number of new cases in males will increase to 934,000, and in females to 935,000.

The three most prevalent cancers: tobacco-related cancers in both sexes and breast and cervical cancers in women, constitute over 50 to 60 percent of all cases. The primary contributors to this increasing cancer burden are population growth, a rising elderly population, urbanization, and globalization. These findings underscore the urgent need to enhance and expand existing diagnostic and treatment facilities, which currently fall short in addressing the current cancer burden.(48)

### **Status of Cancer Amongst the Tribal Population in India**

Cancer has emerged as a significant concern among tribal populations in India, as recent research highlights the prevalence of cancer risk factors and associated health complications. These studies reveal a considerable burden of cancer in tribal areas, resulting in a high mortality rate attributed to lifestyle-related diseases. Additionally, there has been a notable increase in multi-morbidity, where individuals experience multiple chronic conditions concurrently, with an estimated prevalence of around 50% among older tribal members. This rise in cancer prevalence presents a substantial challenge to the healthcare system, as evidenced by research focusing on the economic strain of treatment costs among tribal households. Despite these concerning findings, there remains a lack of comprehensive data on the precise prevalence and impact of cancer within tribal communities, underscoring the urgent need for further research and targeted healthcare interventions to address this escalating health crisis.(49,50)

A study conducted in 2014 indicated that cancer, tuberculosis, and leprosy exhibit higher prevalence rates within tribal communities compared to non-tribal communities in India. However, findings from the NHSRC 2018 report indicate that tribal populations are undergoing an early epidemiologic transition, witnessing a rise in non-communicable diseases such as cancer, diabetes, hypertension, and cardiovascular ailments.(49)

### **Statistical Information on the Burden of Cancer Among Tribals of India**

- 1. Oral Cancer and Pre-cancer Lesions among the Narikurava Population:** A study found a high prevalence of precancerous lesions among the Narikurava tribe in Puducherry state, attributed to tobacco and tobacco-related habits.(50)
- 2. Oral Cancer in Irula Tribes of South India:** A cross-sectional study involving 200 Irula tribe members revealed that 52% of the community exhibited oral mucosal lesions, while



6% had malignant oral tumors. The study also noted that 87% of participants lacked formal education, 38% had never visited a dentist, and 64.5% practiced indigenous brushing.(51)

3. **Prevalence of Tobacco Use and Cancer Among Malayali Tribes:** A study found a high prevalence of tobacco use, limited access to health services, and a lack of awareness about oral health.(52)
4. **Khammam District of Andhra Pradesh:** A study focusing on oral cavity cancer in this tribal area reported an incidence rate of 13.04%, with a male-to-female ratio of 1.03:1. Additionally, the incidence of oral cancer among youths (aged 21 to 30 years) was noted to be 4.85%, higher than observed in previous global studies .(53)
5. **Among Gond Population in Central India :** The study by Kumar S. et al. on tobacco use and cancer among the Gond tribal population in Central India revealed a significant association between tobacco use and the prevalence of oral leukoplakia. Conducted from 2007 to 2009 in the Kundam Block of Jabalpur, Madhya Pradesh, the survey screened 1,552 individuals over 12 years old, finding that 9.3% had leukoplakia. The prevalence was notably higher among tobacco users (11%) compared to non-users (2.5%), with similar rates observed between tobacco smokers and chewers. However, the prevalence was particularly high (21.9%) among individuals who both chewed and smoked tobacco.(54)
6. The findings highlight the heightened risk of leukoplakia among the Gond tribe and underscore the need for targeted screening and intervention programs in this marginalized population.

### **Regional Analysis from Population-Based Cancer Registries (PBCRs)**

1. **Mizoram:** Aizawl district in Mizoram exhibited the highest incidence of cancer in men, with an age-adjusted rate (AAR) of 269.4 per 100,000. The most prevalent cancer sites among men included the stomach (ASIR = 41.4), head and neck, lung, oesophagus, colorectal, liver, urinary, non-Hodgkin's lymphoma, and prostate cancers.(55) The percentage of the tribal population of Mizoram is 94.4%.

2. **Arunachal Pradesh:** Papumpare district of Arunachal Pradesh registered the highest incidence of cancer in women, with an AAR of 219.8. Papumpare also reported the highest incidences of stomach, liver, and cervical cancers among women.(55) The percentage of the tribal population of Arunachal Pradesh is 68.79%.
3. **Meghalaya:** The East Khasi Hills district in Meghalaya had the highest incidence of oesophageal cancer, with an AAR of 75.4 in men and 33.6 in women.(55) The percentage of the tribal population of Meghalaya is 86.15%.

In 2020, the North East Region (NER) recorded an estimated 50,317 new cancer cases, comprising 27,503 males and 22,814 females. Aizawl district in Mizoram had the highest incidence of cancer in men in 2020, with an AAR of 269.4 per 100,000. Papumpare district of Arunachal Pradesh had the highest incidence of cancer in women in 2020, with an AAR of 219.8. The Tripura PBCR reported the highest number of cancer cases in 2021, with 11,473 cases, followed by Kamrup Urban with 11,013 cases. Esophageal cancer was the most prevalent cancer in the NER in 2020, with 5,785 cases. The next most common cancers in the NER in 2020 were breast cancer, with 3,674 cases, and lung cancer, with 3,413 cases. In 2021, tobacco-related cancer sites accounted for 49.3% of cases in males and 22.8% of cases in females. In most registry sites, the age-specific incidence rate was highest in the 70-to-74-year age group for both genders.(55)

## Challenges

The tribal population of India, constituting approximately 8.6% of the total population, predominantly resides in remote and underdeveloped areas. These communities encounter various challenges due to their socio-economic circumstances, exacerbating the prevalence of cancer within their midst. Here are some key factors contributing to the burden of cancer among tribal communities:

1. **Limited Healthcare Access:** Geographical remoteness and inadequate healthcare infrastructure impede timely access to cancer screening, diagnosis, and treatment services.

2. **Lack of Awareness:** There exists a significant gap in knowledge regarding cancer symptoms, preventive measures, and the importance of early detection among tribal populations.(49)
3. **Cultural Beliefs:** Traditional customs and beliefs often deter individuals from seeking modern medical interventions promptly, leading to delayed diagnosis and treatment.
4. **Economic Barriers:** High out-of-pocket expenses associated with cancer treatment pose a significant financial burden for economically disadvantaged tribal populations.(56)

## **Cancer Prevalence and Risk Factors**

### **a. Tobacco Use**

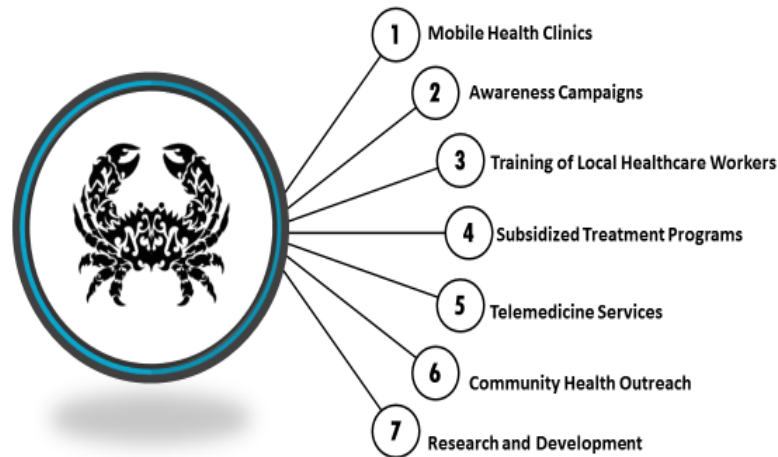
The prevalence of tobacco consumption among tribal communities significantly amplifies cancer risk. In states like Mizoram, the incidence of oral cancers is exceptionally high due to widespread consumption of betel-nut and tobacco. An 18-year study published in *The Lancet Regional Health - Southeast Asia* revealed Mizoram's staggering cancer incidence rates. The Age Standardized Incidence Rate (ASIR) for men was recorded at 197.2 per 100,000 and 164.9 per 100,000 for women. The prevalent cancer sites among women include lung, cervical, breast, stomach, head and neck, colorectal, esophagus, liver, and ovarian. For men, stomach, esophagus, and lung cancers are predominant. Stomach cancer is the leading cause of cancer-related deaths in men, while lung cancer leads among women. Additionally, the Malayali tribes of Yelagiri Hills, Tamil Nadu, exhibit elevated tobacco consumption rates, directly correlating with increased cancer incidence.(54,58)

### **b. Genetic Predisposition**

While environmental factors play a crucial role in most cancer developments, research suggests that genetic predisposition can interact with environmental factors, influencing cancer risk. For instance, genetic polymorphisms may impact cancer risk by altering folate metabolism. Genetic alterations can occur at any stage of life, including prenatal development, due to random DNA mutations or exposure to environmental carcinogens. Although most genetic alterations may not be harmful individually, their accumulation over time can transform healthy cells into cancerous ones. Genetic studies suggest a heightened predisposition to certain cancers among tribal populations, compounded by environmental and lifestyle factors.(57)

## Intervention Strategies

To address these challenges, several intervention strategies can be implemented (Figure-6):



**Figure-6: Implementation of varied strategies to address the challenges**

1. **Mobile Health Clinics:** Deploying mobile health units equipped with primary diagnostic tools and staffed by medical professionals to remote tribal areas improves access to cancer screening and early detection services.(49)
2. **Awareness Campaigns:** Conducting culturally sensitive educational programs to raise awareness about cancer symptoms, prevention, and the importance of early treatment enhances knowledge and encourages timely medical consultations. Leveraging mass media for efficient cancer-related coverage, combined with well-equipped media and professionals, can effectively disseminate information. Innovative mass media messaging, church-based health interventions, and health literacy efforts are essential for managing the burden of cancer, especially in Mizoram, where the majority of the population belongs to tribal communities.(58)
3. **Training of Local Healthcare Workers:** Providing training to local healthcare providers, including traditional healers, in basic cancer detection and referral procedures builds local capacity and facilitates the integration of traditional and modern healthcare practices.(49)
4. **Subsidized Treatment Programs:** Implementing government or NGO-funded programs to subsidize the cost of cancer treatment for tribal populations reduces

financial barriers and increases treatment uptake. Awareness campaigns through mass media and the establishment of AYUSHMAN BHARAT centres and help-desks at government hospitals have facilitated access to improved healthcare facilities for economically disadvantaged and marginalized communities. Programs like the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) aim to integrate cancer care into primary health services in tribal areas.(56)

5. **Telemedicine Services:** Utilizing telemedicine platforms to connect tribal patients with oncologists and specialists in urban centres provides specialist consultations and follow-up care without the need for extensive travel. This initiative has particularly benefited district hospitals in reaching out to tribal populations residing in remote and otherwise inaccessible areas.(49)
6. **Community Health Outreach:** Engaging community health workers to conduct regular health check-ups and follow-ups within the community ensures continuous monitoring and support for cancer patients.(49)
7. **Research and Development:** Investment in cancer research and innovation to develop cost-effective treatments and diagnostics. Encourage partnerships between government, academia, and the private sector.

### **Examples of Innovative Interventions**

1. **Cultural Health Messaging:** In Rajasthan, health messages were disseminated using live performances by drummers, dancers, folk musicians, magicians, and puppeteers to engage tribal populations. Incentives were also linked to the activities of Accredited Social Health Activists (ASHAs) to encourage their participation.
2. **Media Campaigns:** In Tamil Nadu, in addition to traditional methods like posters and hoardings, health messages were broadcasted through radio jingles and video broadcasts featuring popular film stars. This approach effectively reached tribal communities.

3. **Medical Outreach Camps and Mobile Health Clinics:** Initiatives like medical outreach camps and mobile health clinics bring essential health services to remote populations, ensuring access to healthcare for those living in distant areas.
4. **Emergency Transportation and Tribal Health Workers:** Providing emergency transportation for expectant mothers and employing health workers from tribal communities can improve access to healthcare services. Establishing tribal counsellors who visit tribal hamlets regularly to raise awareness about health issues and promote healthy behaviours can also be effective.
5. **Community-Based Healthcare Programs:** Implementing community-based healthcare programs tailored to the cultural context and needs of tribal communities can enhance healthcare access and promote preventive healthcare practices.
6. **Capacity Building and Traditional Practices:** Capacity building for local healthcare providers and promoting traditional lifestyle practices that mitigate cancer risks can contribute to addressing health challenges among tribal populations.

### **Case Studies**

1. **Project ECHO (Extension for Community Healthcare Outcomes):** This telemedicine initiative connects rural healthcare providers with specialists in urban centres to improve the management of complex diseases, including cancer. This project has successfully improved the quality of cancer care in several rural and tribal regions.(49)
2. **Barwani Model in Madhya Pradesh:** This comprehensive cancer control program includes mobile screening units, awareness drives, and subsidized treatment. This project has increased early detection rates and improved treatment outcomes in the tribal areas of Barwani.(49)

### **Gaps and Challenges**

Inadequate health education initiatives, a lack of culturally responsive healthcare services, and scant data on disease prevalence are significant gaps in the treatment of cancer among tribal people. The main goal of interventions should be to develop focused healthcare programs suited to the unique requirements and cultural settings of tribal groups.

Important interventions include supporting traditional lifestyle choices that can lower the risk of cancer, developing the capacity of nearby healthcare practitioners, and implementing community-based healthcare initiatives. Social workers are needed to stop the local practices of possible carcinogenic dried, smoked, fermented, preserved meat, fish, and stinky vegetables. This necessitates a multifaceted strategy that considers the particular difficulties these communities face. Through the implementation of focused healthcare efforts, promotion of traditional lifestyle habits, and recognition of the unique requirements and cultural background of tribal populations, we can effectively lower the incidence of cancer and enhance the general health and well-being of tribal communities.(61,62)

The National Health Mission in India's First Tribal Health Report of 2018 outlines the unique health issues that the nation's tribal inhabitants must deal with. The paper states that one of the main concerns among indigenous people is the prevalence of non-communicable diseases (NCDs). One NCD that is frequently seen in the tribal group is cancer. The report highlights the need for culturally sensitive healthcare services, accurate disease prevalence data, and successful health education programs catered to the particular cultural context of tribal populations. It also highlights the gaps and shortcomings in the current approach to addressing NCDs among tribal communities.

Non-communicable diseases like heart disease, diabetes, cancer, and hypertension are sometimes referred to as lifestyle diseases and are generally associated with urban living. But according to new research on tribal health, non-communicable illnesses like cancer are now a significant source of illness in many tribal societies. These tribes don't have a sufficient infrastructure for healthcare because they live mostly in isolated forests. India, which has 8.6% of its population who are tribal (according to the 2011 census), is having trouble closing the healthcare gap between its tribal and non-tribal populations.

The burden of disease among the tribal people is tripled—actually, quadrupled—by communicable diseases, non-communicable diseases, malnourishment, mental health issues, and addictions exacerbated by inadequate health-seeking behaviour. According to a research study by Kumar et al. (2020), a committee of experts on tribal health has made suggestions in response to growing demands, with the aim of closing the current disparity in the health status of tribal people as soon as possible by 2027.

It has been suggested to create a completely separate health system with governance and financing as its main areas of focus. To provide an overview and report on the current situation regarding the prevalence of disease, the behaviour of people seeking health care, the healthcare delivery system, and a future roadmap emphasizing the role that primary healthcare will play in attaining it. The poor health of the tribal community cannot be solved by the construction of additional healthcare facilities; instead, skilled labour is needed to provide high-quality healthcare. Regarding the enhancement of healthcare facilities, the expert committee's (led by Dr. Abhay Bang) report on "Tribal Health in India" by the Ministry of Health and Family Welfare and the Ministry of Tribal Affairs recommends increasing public expenditure on health to 2.5% of GDP by 2017 and 3% of GDP by 2022 (Kumar et al., 2020; Narain, 2019).(45,61,63)

## **Way Forward**

The report on cancer profile and related health indicators among the tribal population in India provides useful insight into the current cancer scenario and a roadmap to evaluate ongoing measures and plan for newer strategies for cancer control (International Institute for Population Sciences and ICF, 2017). The need of the hour is to strengthen health systems and cancer research in the region.

The following recommendations are categorized as (a) Strengthening of health systems and (b) Measures for cancer prevention and control.

### **(a) Strengthening of Health Systems**

- **Political Will:** Increase public health expenditure and expand the availability of cancer care services and health financing schemes.
- **Capacity Building:** Provide regular training, re-training, and skill enhancement for healthcare providers involved in cancer care.
- **Health Technology:** Adopt and promote the use of digital tools for early detection and telemedicine to improve access to care.

### **(b) Measures for Cancer Prevention and Control**

- **IEC and BCC Activities:** Implement and scale up Information, Education, and Communication (IEC) and Behavioural Change Communication (BCC) activities



focusing on tobacco and alcohol use, unhealthy diets, and physical inactivity. These activities should be culturally specific, using locally acceptable communication channels.

- **Periodic Surveillance:** Conduct regular surveys to measure baseline prevalence and monitor trends in behavioural and metabolic risk factors to track the impact of preventive measures.
- **Tobacco and Alcohol Cessation Services:** Strengthen community-based services for tobacco and alcohol cessation.
- **Primary and Geriatric Care Integration:** Integrate cancer prevention with primary care and geriatric care by providing counselling for a healthy lifestyle.
- **Cancer Screening and Early Detection:** Scale up and enhance the availability and utilization of cancer screening and early detection services in the region.
- **Health Education:** Facilitate early diagnosis through health education on warning signs and symptoms and train healthcare providers to recognize the same.
- **Continuum of Care:** Ensure measures to maintain the continuum of care.
- **Cancer Insurance Programs:** Improve the implementation of regional and state-based cancer insurance programs to enhance accessibility and affordability of cancer care.
- **Accurate Mortality Certification:** Strengthen the medical certification of cause of death to ensure accurate and complete cancer mortality data.
- **Tertiary Cancer Care:** Expand tertiary cancer care services.
- **Follow-Up Care Programs:** Develop follow-up care programs for cancer survivors to improve their quality of life.
- **Community-Based Palliative Care:** Implement and promote community-based palliative care.
- **Prioritized Research Agenda:** Establish a prioritized cancer research agenda to address local and regional needs.

## **Communicable Diseases in Tribals**

### **India and Jharkhand**

Communicable diseases are a significant public health burden among tribal populations in India due to limited access to healthcare, poor sanitation, and lack of vaccination coverage. Tribes, especially those in remote areas, face higher risks of infectious diseases like hepatitis, tuberculosis, malaria, and water-borne illnesses, contributing to elevated morbidity and mortality rates. However, there are very few studies that provide a comprehensive understanding of the prevalence of communicable diseases in India's tribal communities, and many of the existing studies focus primarily on hepatitis B. These studies have revealed alarming findings about the prevalence of hepatitis B, particularly among tribes in the Andaman and Nicobar Islands, highlighting the need for more comprehensive data on other communicable diseases in these populations.

**1. Hepatitis B Virus (HBV):** Hepatitis B is highly endemic among certain tribal populations of India, particularly in the Andaman and Nicobar Islands. Studies indicate that the prevalence of Hepatitis B surface antigen (HBsAg) is extremely high among the indigenous tribes, with rates ranging from 23% to 66% depending on the community. For instance, the Nicobarese tribe shows a prevalence of 23% HBsAg positivity.<sup>(59)</sup> Among pregnant women of these tribes, the prevalence is notably high at 20.5%, indicating significant perinatal transmission. Furthermore, genotype D predominates in most tribes, though genotype C is prevalent among the Jarawas, suggesting possible Southeast Asian influence.<sup>(59)</sup> A mass vaccination program in the Nicobarese community showed promising results, reducing chronic infection rates from 20.7% to 1.86% over three years.<sup>(60)</sup>

**Hepatitis B in other Tribes** In addition to the Nicobarese, other primitive tribes such as the Shompens and Onges also face high infection rates, with seropositivity of 37.8% and 31.0%, respectively.<sup>(61)</sup> The infection appears widespread across all age groups, including children, emphasizing the necessity of vaccination and public health intervention.

**Hepatitis B Genotypes and Origins** Genotyping studies have shown that HBV in these tribes is predominantly of genotype D, with small traces of genotype A found in some samples. These

findings suggest that the virus may have been introduced to these tribes from mainland India, particularly during the British colonial period when these islands became part of a penal settlement.(62)

**Hepatitis Prevalence in Central India** In Madhya Pradesh, another tribal-dense region, hepatitis B and C have an overall prevalence rate of 43% among the "big tribes," highlighting the extensive burden of hepatitis in various parts of the country.(63)

**2. Other Communicable Diseases** In addition to hepatitis, other communicable diseases remain a significant public health concern, particularly in rural and tribal communities. Upper respiratory infections (URIs) are the most common diagnosis, accounting for 18% of cases in a study of 500 patients.(64) Acute gastroenteritis and water-borne diseases follow closely behind, at 15.8%, highlighting the importance of sanitation and clean water access. Anemia, often linked with infectious diseases, was the third most common diagnosis.

### **Implications for Jharkhand**

While specific studies for Jharkhand are not highlighted, the tribal context of the Andaman and Nicobar Islands provides insight into the challenges faced by tribal populations across India, including Jharkhand. Similar to these islands, Jharkhand is home to many tribal communities, where communicable diseases like hepatitis B, gastroenteritis, and respiratory infections likely pose major public health challenges. Public health interventions in these areas should focus on vaccination programs, improved sanitation, and targeted treatment of water-borne and respiratory infections.

### **Challenges**

The primary challenges in addressing communicable diseases among tribal populations include inadequate healthcare infrastructure, particularly in remote regions, limited access to clean water and sanitation, and low vaccination coverage. Cultural barriers, mistrust of healthcare systems, and the nomadic nature of some tribes exacerbate these challenges. Poor awareness about preventive healthcare practices further heightens vulnerability, leading to the persistence of diseases like hepatitis B, tuberculosis, malaria, and water-borne illnesses.

## **Gaps & Lacunae**

Significant gaps exist in the availability of comprehensive epidemiological data on the prevalence of communicable diseases among tribal populations. Most studies focus on specific diseases like hepatitis B, with little attention paid to other critical illnesses such as tuberculosis, malaria, and respiratory infections. Additionally, there is a lack of targeted public health interventions that are culturally sensitive and adapted to the unique needs of tribal communities, resulting in low healthcare uptake and engagement.

## **Way Forward**

A holistic public health approach is essential to address communicable diseases in tribal regions. Strengthening healthcare infrastructure, expanding vaccination programs, improving water and sanitation facilities, and increasing community outreach are vital. Culturally appropriate awareness campaigns, capacity building of local healthcare workers, and regular health monitoring can significantly reduce disease burdens. Tailored interventions for tribal communities in Jharkhand and other tribal-dense states should be prioritized to improve overall health outcomes.

## **Theme-III**

# **Mental Illness and Addiction**



## Introduction

India is home to more than 104 million tribal/indigenous population (Figure-1). They have unique socio-cultural, economic, and health demands, thus placing them in a highly vulnerable position when confronted with the rapid urbanization in today's world (65).

Tribal populations suffer from quadruple burdens of disease, which include communicable and non-communicable diseases, malnutrition, mental illness, and addiction. Evidence suggests that mental health among tribal communities is an important determinant of achieving the 2030 Sustainable Development Goals (SDGs), without which things may be challenging (66).

The National Mental Health Survey 2016 and National Drug Use Survey 2018 did not report the extent of mental health and addiction in tribal populations in their surveys (67). The prevalence, type, and extent of mental health problems among the tribal population in India is largely unknown. A recent systematic review of community-based studies on mental health among the tribal population in India has reported that although there are only eleven community-based studies on this topic, the majority of them are from rural populations. Only a few are from core indigenous groups. The focus of these studies was alcohol, tobacco, anxiety, depression, and suicide (68).

A multitude of factors have made them vulnerable to mental disorders and addictions. These factors have been sparsely addressed till date. People belonging to tribal communities have limited or no access to healthcare facilities, resulting in poor health outcomes in the form of high mortality and morbidity. This has a negative impact on mental health, financial stability, and overall quality of life (69).

The World Health Organization (WHO) defines 'health' as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' It also maintains in its preamble to the constitution that 'The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.' Mental health is an essential component of overall health. There can be no health without mental health (70).

Upholding the mental health of a country's tribal or indigenous communities is one of the basic foundations that stakeholders related to the field can constructively work on. Towards this goal, a basic framework needs to be created, which should commence from understanding the ground realities of mental health and addiction among the tribal population in this subcontinent. The task force members on 'Mental Illness and Addiction among the Tribal Communities in India.' have reviewed the existing research and conducted a couple of stakeholder meetings to prepare the report.

## **Burden**

### ***The burden of mental illness***

The common mental illness (CMI) studied to date in various tribal communities in India are stress-related disorders, depression, anxiety, somatoform disorders, etc. They were mainly studied in the tribes of the North-eastern states of Manipur, Mizoram, Nagaland, Arunachal Pradesh, Central and East Indian states of Jharkhand, Odisha, Chhattisgarh, and those in Southern states of Kerala and Tamil Nadu. Depression (8.3%), stress-related disorders, somatoform & anxiety (6.4%), and alcohol use disorder (36.2%) were found to be quite prevalent in the Idu Mishimi tribes of Arunachal Pradesh. Suicidal attempts (14.22%) were also reported to be high in this community, which is much higher than the national prevalence (12.4%) (71). The same tribal community reported a higher suicide attempt (22.03%) in a study done years later by the same group of researchers, though assessment tools were different. Female gender, aggression, and trait impulsivity were found to be the significant risk factors for the attempts (72). Some research suggests suicide attempts are higher in men compared to women, maybe due to comorbid alcohol use. Most attempts are impulsive through poisoning in the context of interpersonal issues. Aggression and impulsivity cut trans-diagnostically across various CMI and Severe Mental Illnesses (SMI). They are often and commonly manifest in the early neurodevelopmental phase as a part of multiple childhood and adolescent behavioural disorders (conduct disorder, ADHD, Oppositional defiant disorder, etc).

Emotional symptoms (5.12%), conduct problems (9.61%), peer problems (1.41%), and hyperactivity (4.23%) were found to be not uncommon when studied in adolescents in the Munda, Oraon, and Santhal tribes of Jharkhand (73). They are also subjected to violence, as was found in a recent study, wherein tribal adolescent girls in the West Singhbhum district of



Jharkhand were found to have faced emotional (40%), physical (14%), and sexual (0.7%) violence in the past one year. They were also assessed to have depression and anxiety (12%), much higher than the national average. School drop-out was also a common feature found in them (74). These adverse childhood experiences and psychological trauma make them more vulnerable to adult mental health issues and substance use disorders in later adult life.

Findings from a health camp in a tribal village in central India revealed that 67.3% and 24.8% of the camp beneficiaries had CMI and SMI. Comorbid intellectual disability, seizures, and neurodevelopmental disorders were not uncommon. They attribute the symptoms to their life events (33.6%), and although visiting a registered medical practitioner is uncommon, around 82.3% of them never had any treatment. These population groups also reported high nicotine use and dependence (32.7%), more so in males of a higher age group (75).

Depression in late life is also a common finding in tribes of India. Cross-sectional assessment using data from the Longitudinal Ageing Study in India (2016-17) revealed that 4.8% of older tribal adults have depression (though less than non-tribals). This was significantly associated with their unmarried status, dissatisfaction with living arrangements, and those who faced lifetime discrimination (76).

A hospital-based study in central India that caters to the predominantly tribal population (Gonds, Hindi speaking, and Bengali speaking refugees) reported that 14% of their sample had past suicide attempts. Psychiatric issues which were significantly contributing to suicides were, however, different according to their gender. While alcohol use (49%), followed by anxiety and neurotic spectrum disorders (20%), were common in males, depression (20%) topped the list for females (77).

### **Factors associated with Mental Illness**

Multiple factors contribute to mental illness, CMI, SMI, suicide, and SUDs, which were found across data in the last five years and more (68,78). Social factors play an important role in both physical illness and mental health morbidity (79). The disadvantageous socio-economic position of the tribal and indigenous communities in India has made them vulnerable to various forms of mental illness.

- Access to basic livelihood amenities, problems regarding their inclusion in mainstream society, marginalization, and discrimination.
- Poor access to education, school dropouts, child labour, violence at home and workplace, sociocultural discrimination.
- Poor nutrition and physical health (including anaemia).
- The impact of displacement and migration on mental health in the tribals. Tribal people often have to move out to other areas (e.g., big cities) for occupational needs, which may be the reason for mental health issues in them and their families.
- Superstition and reliance on the macro-religious and cultural basis of healing instead of evidence-based healing, etc., and the persistence of views of paranormal/ ghostly influence on the mind are the main reasons for barriers in accessing help.
- Poor mental health is the personal and social stigma attached, more so in the tribal population.
- Poor percolation of public health programs and policies in remote tribal areas, lack of access to quality health care in general and mental health in particular, unawareness of treatment needs, early marriage, and childbearing.
- Poor access to quality mental health services in remote areas and terrain where they commonly live. This has spiralled down to poorer quality of life, predisposition to other non-communicable diseases (NCD), and loss of work and sustainability, thus further leading to poor socio-economic outcomes.

### **The burden of Addiction**

The majority of the publications on tribal mental health included those that involved substance use disorder (SUD)/addiction (80). The literature suggests that substance use among tribal populations is greater than the general population. More than 72% of tribal men in the age group 15–54 years use tobacco, and more than 50% consume alcohol, as against 56% and 30%

of non-tribal men, respectively (81). While 14.6% of Indians have been found nationally to drink alcohol, and 2.1% consume opioids, a systematic review on addictions in the tribal population reported that the pooled prevalence of alcohol use disorder was 40 percent (37-44%); opium use was 7.8% (68). Another study reported an overall SUD prevalence of 67% and that of alcohol up to 49% in the northeast tribal population (82). The substance use prevalence is higher among males compared to females, as seen in the general population. However, the female-to-male alcohol consumption rate was significantly higher in comparison to general population studies, with variability across tribal groups (83).

The prevalence of tobacco use in tribal gypsies in the Thoothukudi district of Tamil Nadu was found to be 64.55% (29.1% were using smoking tobacco, 63.4% were using smokeless tobacco, and 7.5% were using both) as opposed to the national prevalence of 28.6% (GATS-2, 2016-17) (84).

In the tribals of the Wayanad district of Kerala, the self-reported prevalence of alcohol (17.2%), tobacco (18.8%), and betel quid (47.6% were lower (but still higher than the national prevalence). Of note in this study was the higher prevalence of betel quid use by the tribal people (47.6%; males: 53.6%; females: 45.1%), which was higher than the national prevalence for smokeless tobacco (21.4%) (GATS-2, 2016-17) (85). Betel quid is associated with an early age of initiation, which, coupled with low literacy, poor socioeconomic status, and modelling effects from parents at home, leads to poorer health outcomes. It is an independent risk factor for oral cancers and precancerous lesions, which deserves special attention. Their use was also found to be associated with socioeconomic marginalization, domination, and social exploitation.

The picture is not different for other SUDs. Opioids were found to be predominantly used by tribes from the northeast part of the country. A study from Arunachal Pradesh reported a prevalence of opium use of 7.8%, and it was higher in men compared to women (86). Another retrospective analysis of substance users who presented to the emergency of a hospital in Sikkim revealed that 14.8% were opioid users (commonest being dextropropoxyphene and pentazocine). In comparison, 16.66% were injectable drug users (IDU) (87). An increased risk of HIV was observed among IDUs.

### **Factors associated with addiction**

A qualitative study from tribals of Wayanad reported that alcohol consumption, often initiated at a young age, was associated with modelling by observing family members and society, socio-cultural rituals, practices, and exploitation (85). Male gender, increasing age, and no formal education were found to be risk factors for substance use in the tribes of this region. One of the reasons highlighted in the study is the cultural acceptability and unawareness of the harms. Alcohol is part of their rituals and customs life from “birth to death,” births, marriages, festivals, and funerals. Further, alcohol use is also associated with exploitation by landlords. A wider socio-economic marginalization also contributes to alcohol use. Unemployment or seasonal employment is one of the factors.

Because of the availability of indigenously produced alcoholic drinks, they are preferred by some tribal communities. For example, ‘toddy’ (prepared from palm tree) and ‘mahua’ (prepared from mahua flower) are commonly produced and consumed by the tribals of the Eastern part of India, especially the Santhals. Apart from ease of availability, they become alcohol use in festivals, etc., were all emphasized to be contributory factors for early onset alcohol use in tribals. Furthermore, the alcohol content among these locally brewed toddies is unknown and can be spiked for enhanced effects. Many states have a ban on these locally brewed alcohols.

Another study from tribal communities of Tamil Nadu observed that these communities are reported to be semi-vagrant groups facing severe socioeconomic and cultural discrimination, reciprocating into poorer education and poor access to basic amenities and health care (84). Migration of people from other parts of the country and acculturation are important factors responsible for substance use among tribal populations (87).

### **Impact of mental illness and addiction**

Substance use and mental illness have a significant burden on individuals and families, including education, marriage, financial crisis, family stress, disruption of family routine activities, physical abuse, and violence in the family (88). Additionally, there is social isolation, lack of caregiver care and care for other children, and damage to household accessories.

## **Justification**

Addressing the healthcare needs of the tribal communities is important to meet the 2030 Sustainable Development Goals (SDGs). Without prioritizing and focusing on the healthcare needs of the country's indigenous populations, achieving SDGs will be challenging. The report from the expert committee on Tribal Health in India recognizes substance use as a major threat to the tribal populations, adversely affecting health, family dynamics, economy, and law and order. Although mental health problems are steadily increasing, the knowledge about mental illness, accessibility of mental health care services, and help-seeking are minimal. Despite the unavailability of the data, the treatment gap for mental illness appears to be high. Major epidemiological surveys like the National Mental Health Survey 2016, the National Drug Use Survey 2018, and the National Family Household Survey do not report on tribal populations. A recent bibliometric analysis revealed that the research in tribal health has improved from 2000 to 2020, but the focus on mental health is minimal (22). It is also evident from the existing literature that the mental health of the tribal population has been studied very less as an area of interest by academicians and policymakers. Most research on the tribal population is from rural areas and to a lesser extent, on primitive, vulnerable tribal groups. While the prevalence of substance use is high among the tribal populations, the availability of data on patterns of use, dependence, risk factors, clinical correlates, treatment seeking, and healthcare systems for addiction is largely unknown. While the livelihood, art, and culture of the tribals are important determinants of mental health in tribal cultures, many unexplored aspects need research. Understanding tribal populations' mental health morbidities is necessary to address their well-being, develop culturally appropriate interventions, and align healthcare systems accordingly.

## **Challenges**

Faith healers play a significant role in treating mental illnesses.

1. The intricate life patterns, unique language/dialect, culture, tradition, habits, and belief systems of different tribes in different parts of the country (diversity). Furthermore, there is resistance to newer ideas.
2. Difficulty in accessibility, urbanization, acculturation, displacement, dislocation, and migration have caused severe health issues and socioeconomic problems in tribals.

3. The other more significant issues with understanding the psychopathology of common and severe mental problems in these population groups are owing to a lack of culturally sensitive training among mental health professionals and also the language/ dialect spoken by them. For example, a professional outside the culture may consider a thought part of cultural belief a delusional thought, treat it aggressively, and find it unresponsive to any form of treatment. Hence, there is a need to understand the socio-cultural milieu when dealing with patients from tribal groups.

### **Gaps/ lacunae**

1. Insufficient national-level data on mental health morbidity among tribal populations in India.
2. Data on severe mental illness is sparse in the tribal population. Apart from depression, other types of mood disorders are not well studied. Also, there are fewer/ virtually no studies on OCD, maternal mental health, sexual disorders, post-traumatic stress disorders, and other stress-related disorders and dementia.
3. Risk factors for mental health morbidity, both common and unique factors, are unknown.
4. Lack of culturally appropriate tools validated in the local language to assess mental health and illness.

### **Intervention strategies**

1. It is crucial to develop culturally appropriate tools and strategies to estimate the prevalence of mental illnesses in tribal communities and methods to tackle them.
2. Determining the protective and risk factors for mental illness and addiction in tribal communities.
3. Indigenous ethnomedicine knowledge must be combined with modern medicine to improve access and knowledge.
4. While it is crucial to improve the healthcare system, it is equally essential for local tribal healers and young adults to participate. Train local village health-care providers like

Anganwadi staff and ASHA workers in mental health and addiction to bring adequate care to the doorstep of the tribal population.

5. Integration with other health programs like those dealing with maternal and child health, nutrition, etc., as many of these are interrelated.
6. Community-based strategies with a focus on social determinants of health like education, employment, urbanization, and migration.
7. Involvement and empowering the tribal youths and researchers.
8. Understanding the cultural connotations related to addiction in tribal communities and making them aware of the long-term negative impact of addiction on all aspects of health and well-being.
9. Further strengthening of existing addiction treatment avenues in India (eg, Addiction Treatment facility or ATF, Tobacco Cessation Centres or TCC, De-addiction Centres or DAC, etc), by making them more culturally sensitive, and increasing community activities to areas where tribal communities resides.
10. Scaling up and popularizing Tele-MANAS (Tele Mental Health and Networking Across States) in the tribal populations. Healthcare workers from tribal populations should be trained to deliver counseling services.

## **Way forward**

1. Normalizing mental illness (as with any other physical illness, etc.) and promoting positive mental health.
2. Mental health and addiction research among tribal populations in India.
3. Prevention and treatment of substance use.
4. Harm reduction and safer use of substances, as total abstinence may be difficult in some situations.

5. We need to train local brewers about hygienic and scientific ways of brewing, storing, and dispensing country-made local liquor (e.g., it should not be stored in plastic containers, etc.) as one of the harm reduction methods.
6. Empowering the CHOs and ASHAs about mental health issues and addiction, including referral chains.
7. Restrict access to agricultural poisons (pesticides, insecticides, etc.).
8. Available and accessible mental health and addiction treatment services to reduce the treatment gap.
9. Need to scale up existing treatment facilities for mental illness, including SUD. Telepsychiatry (e.g., Tele-MANAS) can play an important role here.
10. Strengthening of excise and tobacco control laws.
11. Information, education, and communication activities for mental health in liaison with physical health.
12. Develop cultural competence to approach and focus on practices, beliefs, and sentiments with respect.
13. Finally, acknowledging and rewarding good practices in social activities and community-based approaches is essential.



# **Theme-IV**

## **Maternal and Child Health**



## Introduction

Tribal and indigenous groups are among the most marginalised groups worldwide. Although they are just 6 percent of total global population but account to 19 percent of extreme poor.(89) In India, the indigenous population have been categorized as Scheduled Tribes (ST) as per constitution of India. Except sex ratio (Sex ratio-ST: 990, Sex ratio - Indian: 933), ST have poor health statistics as compared to rest of the population. Scheduled Tribes have higher infant mortality rates and a lower life expectancy at birth as compared to other less disadvantaged groups in India.(90) Maternal and child health is a critical area of focus in public health because of high rates of maternal and infant mortality. According to UN inter agency estimate, the global mortality ratio has declined from 339 deaths to 223 deaths per 100,000 live births. The Central and Southern Asia are one of the major contributors to global maternal mortality with an MMR of approximately 129. In 2020, India recorded the second-highest number of global maternal deaths, with approximately 24,000 fatalities, ranking just below Nigeria.(91)

Similarly, India also has one of the highest global infant mortality ratios (IMR) among tribals standing at 44.1 deaths per 1000 live births in 2014 which improved to 41.6 in 2019-20.(89,91) Tribal communities in India bear a significant burden, as they account for over 50% of all maternal deaths and IMR in the country.(92) The higher IMR and MMR observed in tribal populations can be attributed to disparities in social determinants of health such as education, adequate and trained healthcare workforce, access to care, and health financing.(93,94) Inadequate healthcare infrastructure, limited access to essential services, malnutrition, and high disease prevalence, hinder overall health and well-being of tribal populations in India.(93)

## Present scenario (4)

The various statistics at National and Tribal level has been depicted in the Table-4 as below:

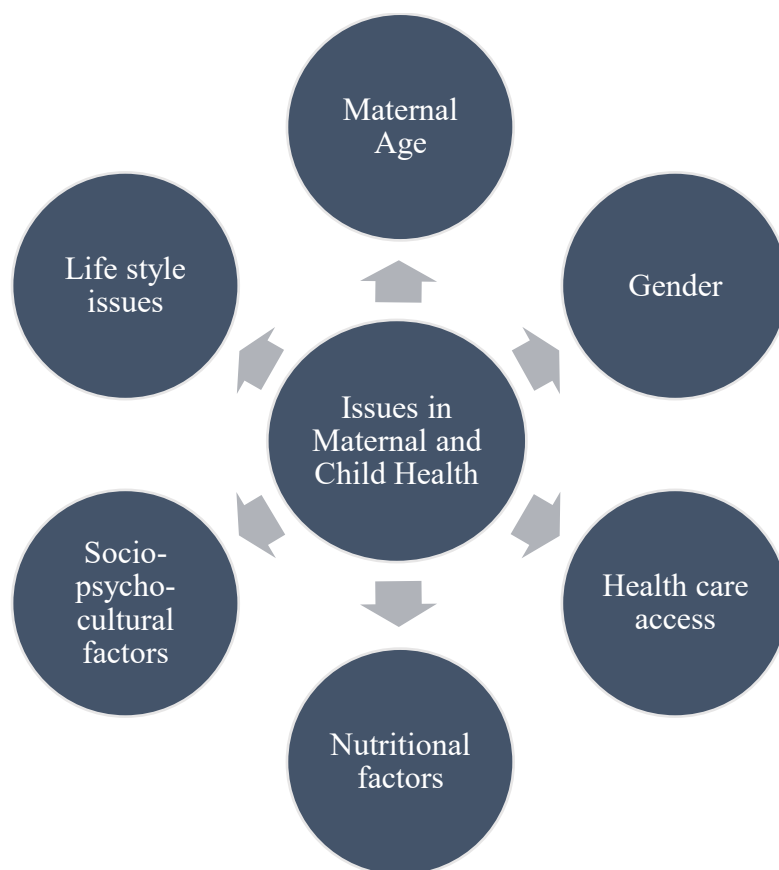
**Table-4:** Statistics as per NFHS-5 at National and Tribal level

	As per NFHS-5	
Statistics	National	Tribal
IMR	35.2	41.6
Under 5 Mortality rate	41.9	50.3

Immunization	76.4	76.8
Minimum 4 antenatal check ups	58.1	54.2
Institutional delivery	88.6	82.3
Current use of contraceptive method	66.7	64
Total fertility rate	1.99	2.08
% age of women aged 15-19 years who had begun child bearing	6.8	8.7

## Justification

The presence of unfavourable social indicators in tribal populations is the result of long-standing discrimination and an infringement of rights of tribal communities. Tribal populations endure the most of systemic and structural marginalization within Indian society due to land disputes, socio-economic disparities, and cultural differences.(94) Social and geographic isolation adversely affects maternal and infant health in tribal communities.(95) Further, almost 90% of tribal people reside in rural areas.(96) Rural areas in India are characterized by numerous healthcare challenges, including limited access to quality healthcare facilities, subpar quality of primary health care, and ineffective training of rural healthcare professionals.(97,98) The intersectionality of belonging to a tribe, with low socioeconomic status, and living in a forest or a remote rural area compounds the disease burden, result in a quadruple challenge for maternal and child health care among tribal populations. There are issues in maternal and child health amongst tribal population depicted in Figure-7 and illustrated categorically further.



**Figure-7: Issues in maternal and child health amongst tribal population**

## **Gaps and Challenges**

### **1. Child health**

Child health is mainly dependent on child care practices and health care services encompassing nutrition related services. The challenges faced in maintaining good child health are traditional child care practices bearing negative impact and issues with nutritional services.

#### **1.1 Traditional child-care practices**

Many of the traditional tribal cultural practices negatively impact the health outcomes of the neonates and infants. As per Priyadarshi et al, tribal women often bathe the new-borns immediately after birth because of the belief that they are covered with harmful dirt and fluids, which increases the chances of infection and hypothermia.(101) The practices during child birth have also important bearing on health, though with the rising rates of institutional

delivery, unhygienic practices of cord clamping and cord care have been checked but still there are negative traditional practices in tribal communities in cases of home deliveries. Cleveland Clinic 2022 report says that tribal women don't feed their new-borns with colostrum; instead they give pre-lacteal feeds in form of honey , sugar water mixed with cow's milk or traditional herbs which hampers the proper growth and development of the child and deprive them from the beneficial effects of colostrum.(103) So, tribal communities have their own perspectives regarding child bearing and caring practices including colostrum, prelacteals and initiation of breast feeding.

### **1.2 Limited access to Nutritional Diet and Health Care services**

The tribal population is one of the most marginalized populations. The limited access to nutritional diet and healthcare services along with poor education especially of the females leads to deterioration of child health. Proper nutrition and early childhood development are critical for a child's well-being.(104) Nutritional programmes have been able to address the issue to some extent but access and acceptance of these government interventions is an area of concern. The nutritious traditional food is lost from the pates of tribes and modern balanced diet is far away from their reach. This may be attributed to poor awareness regarding proper diet for children from complementary feeding to diet for school going children. This has compounded the problem of accessibility, availability and awareness of nutritious diet for children in rural tribal communities. Poor understanding regarding child health and cultural practices in relation to health seeking behaviour has contributed considerably in poor health of tribal children.(105,106) The health system is also unable to address the issue properly and shortfall of specialists at Community health centres and the overburdened Auxiliary Nurse Midwife and ASHAs further adds to the problem.(107)

## **2. Adolescent Health**

Adolescence is a transition period between child and adult age. Its vulnerability is attributed to cultural practices, rapid physiological changes and access to health care services. This is particularly a matter of concern amongst underprivileged sections of the society especially tribes.

### **2.1 Restrictive cultural practices during menstruation**

The menstruation is perceived differently in different cultures. Several studies have reported various types of restrictions and isolation during the menstrual period,. The adolescent girls are not allowed to take bath, cook and enter holy places.(108) In some tribal societies such as Madia Gond tribe, girls and women are isolated in small “Menstrual huts” during menstruation despite severe cramps and fear of snakes. Apart from these, they are restrictions over consumption of some foods such as rice, milk products etc. This gives rise to avoidable anxiety and fear amongst girls and it may also lead to some undesirable practices.(109) Despite many women not liking this, they are compelled to follow such practices. This affects the reproductive health and increase the vulnerability to infections.(105)

### **2.2 Teenage pregnancy and early marriage**

As per NFHS 5, the total fertility rate is 2.5 in tribal population which is higher than scheduled castes (2.3), other backward classes (2.2) and upper castes (1.9).(91) Among ST women, the age of mother at first childbirth is 19.9 years and the percentage of teenage pregnancy being 16% in ST women. There are tribal groups, where premarital relationship is accepted. They have cultural events held 3-4 times a year where adolescent boys and girls dance and propose and also are allowed to spend next few days. So, in these communities, teenage pregnancies are rampant when they have very little knowledge of sexual health. A lack of sexual literacy and maturity often results in adverse health outcomes in adolescent girls.(105) Role of different

groups and acculturation of different cultures have both positive and negative impact on marriages and pregnancies in tribal population.(106)

### **2.3 Barriers related to reproductive and sexual health services and access to care**

Although government has tried to special clinics for adolescents to address their medical needs including reproductive and sexual health, but due to taboo attached to these needs and societal pressure, hesitancy in seeking care is considerable in tribal girls. In Madia Gond community unwed pregnant girls prefer home delivery, the reasons cited being fear of mistreatment at health centre.(105) As per different studies, the tribal population believes that women should not leave the village during pregnancy.(111) This belief impedes women from accessing health services that require some amount of travel and subsequently limits the number of institutional deliveries.

## **3. Adult female health**

Tribal females are the worst sufferers in respect to health, whereas they are the most hardworking and productive but their health is ignored in their reproductive age group. Poverty among the tribes along with other determinants mentioned below is the major challenge in improving maternal health.

### **3.1 Traditional practices on MCH**

The consumption of alcohol and tobacco is deeply ingrained in festive and marriage celebrations of tribal population of India. As per NFHS 5 approximately 25% of women above 15 years have consumed alcohol and tobacco throughout their lifetime.(91) This leads to their children being exposed to the harmful effects of alcohol and tobacco at a very young age. The use of tobacco prenatally, during pregnancy and during post-natal period causes major risks to both mother and baby.(112) Traditional birth practices such as delivery by dais and application



of ash and cow-dung on umbilical cord further hampers the health of mother and baby. Moreover, the mortality and morbidity risks among the tribes were also driven by the challenges and barriers they encountered in accessing healthcare services.

### **3.2 Access to health care facilities and transportation Barriers**

Insufficient economic means, impoverished conditions, transportation barriers and an adherence to traditional healthcare practices created obstacles in obtaining optimum maternal and child healthcare services. Madankar et al stated that in spite of various government schemes such as Janani Suraksha Yojana , the tribal women face challenges accessing entitlements even when choosing institutional deliveries.(105) Financial constraints, cultural barriers and limited awareness about antenatal care along with remoteness of tribal area further hampers access to various available health schemes.(113) Community health workers also face challenge in providing services to tribal population because of language barrier and they being considered outsiders by the tribal population.

### **3.3 Inadequate nutritional support by government schemes**

The nutritional programs run by government have inadequately addressed the nutritional requirement of the underprivileged sections of the society.(113) The reasons are accessibility and acceptability of current nutritional programs for mother and children.(114) As a result, the tribal women and children are malnourished throughout the life cycle, so a more inclusive life cycle approach is needed to resolve the current nutritional problems of the community.

### **3.4 Double burden of Household work and Labour work**

In a study conducted among Gond tribes of Maharashtra it was found that the pregnant women faces a dual burden of household work and labour alongside to financially support her family by working in fields . Such strenuous schedule significantly increases the likelihood of poor

health outcomes.(105) Since most of them work in construction or agriculture on daily wages, they are less likely to visit a health care centre during working hours.

### **3.5 Hereditary diseases**

High vulnerability of tribal communities to hereditary diseases amplifies MCH challenges. Anaemia was already a concern for maternal health but marriages between blood-relatives within tribal communities causes susceptibility to genetic abnormalities such as sickle cell anaemia and thalassemia. These hereditary diseases quadruple tribal women's vulnerability to maternal deaths .(101)

### **3.6 Faith in traditional healers and age old practices**

Age old practices and traditions cannot be undermined and the faith in ethnic medicine since time immemorial in the tribal community has been rooted in their culture.(102) Tribal communities practice Despite the fact that the modern medicine has reached to their doorsteps, their belief and reliability on traditional healers is very strong. This is because they are rendering their services to public in very remote places where the community is in real need of health services.

## **Intervention strategies**

### **A. Understanding the problems from their perspective**

In rural tribal areas, there is a lack of lack of awareness of evidence-based medical care, non-availability of technical personnel, apathy of health care providers, sub-optimal emergency obstetric services and low resource availability which has led to the community to bestow faith in traditional healers. So, involvement of local leaders to understand their problems is important and designing intervention programs with their participation will be more beneficial.(102)

### **B. Improving healthcare infrastructure**

Enhancing access to healthcare facilities in tribal areas can significantly improve mother and child health outcomes.(103) This includes building and upgrading health care centres, ensuring availability of essential medicines and equipment and deploying skilled health care providers. The infrastructure should be improved in consonance with tribal needs and their acceptability.

### **C. Community based health interventions**

Implementing community health worker programs can help bridge the gap between health care facilities and tribal communities. Trained community health workers from the tribal community itself can provide essential maternal and child health services, education and referrals.(118,119) Specific mHealth intervention like mTECHO to improve delivery of proven maternal, neonatal, and child care interventions through community based ASHAs by enhancing their motivation and strengthening their supervision.(104)

### **Open Access**

### **D. Incorporating traditional healers**

Collaborating with traditional healers and integrating traditional medicine practices with modern healthcare can improve healthcare seeking behaviour and promote early detection and treatment of maternal and child health issues.(105)

### **E. Awareness and Education**

Conducting health education campaigns tailored to the cultural context of each tribal communities can raise awareness about maternal and child health issues, importance of prenatal care, immunizations and family planning.(106)

### **Way forward**

- We need to carry out more research studies for more reliable data. On the lines of NFHS, some studies must be planned exclusively for tribals all over country with intersectoral collaboration.
- Multidisciplinary multipronged action is needed to address the maternal and child health issues.
- Participatory approach needs to be adopted to understand the gaps and challenges in delivery of services.
- More focus is needed to find local solutions to local problems.
- Culturally sensitive interventional programs should be designed keeping in mind their traditions and practices.
- Investing in education and other social determinants and addressing certain socio-cultural practices is important to improve maternal health.



# **Theme-V**

## **Oral Health & Hygiene**



## **Introduction**

The communities that are either attached to, or live within a distinct traditional geographical habitat or territories that are ancestral, and who recognize themselves as a part of a culturally distinct group, who have descended from the groups which were present in the area prior to the creation of the modern states are “Indigenous population” as defined by World Health Organization (WHO).(107) There culturally distinct communities and societies are spread in over 90 countries, with an approximate population of 476 million.(108) Over 104 million i.e one-third of the world’s tribal population resides in India.(109) They are stretched across 705 tribes, accounting for 8.6% of our country’s population.(110) They inhabit remote and rural areas primarily, and are amongst the marginalized and most vulnerable section of the society.(111) The prevalence of the chronic diseases like hypertension, diabetes and carcinoma have shown an increasing trend overall, however, a similar acceleration is being confronted by the tribals in India.(111)

Oral health and hygiene are contemplated as the mirror of general health. Diseases of the oral health are either observed as a symptom or as an exacerbation of the general diseases. There are varied dental problems like dental caries/decay, malocclusion, periodontal diseases, edentulous jaws and oral carcinomas. Systematic conditions like pulmonary disease, osteoporosis, kidney disease, atherosclerotic vascular disease, and diabetes have shown an association with periodontal diseases.(112) There is a high burden of oral diseases in the tribal population, however, literature shows scanty reports. It was intriguing to observe that majority of the tribal population sought dental care only when they faced significant problem.(113) Additionally, limited knowledge of the oral health, risk factors, symptoms and its etiology were observed in the tribals. Oral pre-cancerous lesions and oral cancers shows high prevalence in the indigenous population, which can be attributed to tobacco and tobacco-related products.

## **Burden**

A notable strengthening of the facilities in the health care has been seen over the years globally. However, the indigenous population who resides in seclusion, safe-guarding the principles of their ancestors, their practices, myths, and beliefs. Studies in relation to the oral health studies of the tribals have clearly shown dominance of dental caries (untreated), calculus, periodontal diseases, dental fluorosis, tobacco use, and abundant pre-cancerous lesions, thus demanding high treatment needs.(114)

Study by Benjamin et al (113), revealed that 86% of the participants did not seek dental care in a span of one year unless it's a major health issue. In addition, tribals visiting the dentist decreased in the older age, which can be explained by the belief of the people that aging causes dental problems.(115) As far as gender is concerned, there are mixed results, with a few studies considering greater participation by females(113), when compared to males.(116)

There is a limited literature regarding the status of oral health and hygiene in the tribal population. Due to the scarce studies on the tribal population, most comparisons are made with the general population. PubMed database search regarding the studies relevant to oral health and hygiene in the tribal population led to only 20 studies in the last five years (2019 to April 2024), with the maximum studies being published in the year 2021 (depicted in the Pie-chart-1 below).



**Pie-chart 1: Depicting the published literature year-wise in relation to “Oral Health & Hygiene” in Tribal population.**

The details concerning the above mentioned 20 studies have been elaborated in Table-5 as below:



**Table-5:** Depicts the studies in the last five years concerning “Oral Health & Hygiene” in the Tribal population.

S.No .	First Author & Year of Study	Target Population	Type of Study	Aim of Study	Methods used	Results
1.	Meera P R et al, 2024 (117)	Kanikkaran Tribes, Mundandhurai hills in Tamil Nadu, India	Cross-sectional epidemiological study	To assess oral health status	WHO Oral Health assessment form (1997), and its Self-Oral Health Assessment form (2013)	High risk of periodontal disease, pre-malignant lesion and non-carious dental lesions.
2.	Benjamin et al, 2024 (113)	Gond Tribes, Chhattisgarh, India	Cross-sectional study	To evaluate oral healthcare utilization factors	WHO Oral Health assessment form (1997), Oral Health Impact Profile-14 (OHIP-14)	Oral health outcome is significantly associated with occupation, age and positive belief in the dentist, dental caries prevalence and perceived need.
3.	Kumaraguru et al, 2023 (118)	Irulars and Narikuravars Tribes, Tamil Nadu, India	Cross-sectional epidemiological study	To evaluate oral health status and oral health risks	Decayed, Missing, Filled Teeth (DMFT) Index	DMFT score was higher in Irulars. Prevalence of Leukoplakia and tobacco pouch keratosis was 3.3% and

						1.6% in Irulars and Narikuravars respectively.
4.	Gupta B et al, 2023 (119)	Overall Tribal Population, India	Systematic Review & Meta-analysis	To assess the association between tobacco use and oral health outcomes.	Newcastle-Ottawa scale	The findings emphasize the urgency of targeted public health intervention to address tobacco consumption and promote oral health awareness.
5.	Kumari M et al, 2023 (120)	Raisin district Tribes, Madhya Pradesh, India	Prospective study	To address oral health disparities	Focus Group Discussions (FGD), Mobile Technology Networking (MTN), Oral Hygiene Index-Simplified (OHI-S), Gingival Index.	Limited dental care access, inadequate oral hygiene practices, lack of oral health awareness.
6.	Prasad U K et al, 2023 (121)	Manvi and Devadurga Taluks, Raichur district, Karnataka, India	Cross-sectional community-based study	To estimate the prevalence of dental fluorosis in 6 to 12 years of children.	Semi-structured questionnaire	High prevalence of dental fluorosis in 6-12 years old.

7.	Radha et al, 2022 (122)	Tribal migratory shepherds (Gaddi), Northwestern Himalayan region, India	Survey	To document contemporary oral ethnoveterinary knowledge	Direct interviews, questionnaires	Around 181 plant species are being used for ethnoveterinary use.
8.	Khanna et al, 2021 (123)	Rajasthan, India	Prospective study	To assess the impact of oral health training imparted to Anganwadi and Accredited Social Health Activist (ASHA)	DMFT Index, OHI-S Index, OHI-M (modified), Plaque Index, Caries activity (Oratest)	Significant improvement in toothbrushing practices and rinsing
9.	Kumar G et al, 2021(124)	Northern Bhubaneswar , India	Cross-sectional household survey	To evaluate the oral health status and treatment needs	Modified WHO Oral health assessment form (2013), DMFT scores.	High prevalence of dental caries, periodontal disease.
10.	Rajkuwar et al, 2021 (125)	Nicobarese Tribals, Andaman & Nicobar Islands, India	Cross-sectional survey	To determine the	WHO Oral Health assessment form	High prevalence of oral mucosal lesions who consumes tobacco.
11.	Haque H Z et al, 2021 (126)	Santhal tribes, West Bengal, India	Community-bases cross-sectional study	To assess the oral hygiene status and their associated factors.	Pre-designed, pre-tested, structured information sheet	Poor oral hygiene in tribals using smoking tobacco and alcohol.

12.	Chellappa L R et al, 2021 (127)	Tribal Gypsies in Thoothukudi district, Tamil Nadu, India	Cross-sectional study	To determine the prevalence and dependency with tobacco use.	Modified WHO Oral Health assessment form (2013)	Significant association between tobacco use and bleeding gums.
13.	Placek C D et al, 2021 (128)	Karnataka, India	Experimental study	To determine the impact of information about tobacco related health risks.	Power point presentations	Oral health was poor in tribals using tobacco
14.	Kumar G et al, 2021 (129)	Kutia Kandha Tribes, Odisha, India	Cross-sectional study	To assess oral health quality of life and its association with different factors.	Oral Health Impact Profile-14 (OHIP-14), questionnaires	Quality of oral health in tribals is poor and there is prevalence of tobacco.
15.	Aluckal E et al, 2020 (130)	Kuttampuzha Tribes, Kerala, India	Cross-sectional study	To identify tobacco cessation behavior in tobacco users	Tobacco user data and socio-demographic details	Smokers had higher probability predicted of attempting quitting in comparison to smokeless form.
16.	Karuveettil V et al, 2020 (131)	Paniya Tribes (Cheeporam and Madikkunnu), Wayanad, Kerala, India	Qualitative study	To explore the perceptions of smokeless tobacco initiation	Interviews and FGD	Parental influence and peer pressure are key factors for smokeless tobacco initiation.

17.	Gopalankutty N et al, 2020 (132)	Palakkad district, Kerala, India	Population based cross-sectional study	To assess the prevalence of periodontitis and its association with other factors.	WHO Oral Health assessment form, and questionnaires	High prevalence of periodontal disease.
18.	Barman D et al, 2019 (133)	Khurda district, Bhubaneswar	Cross-sectional observational study	To identify barriers to dental services utilization	Questionnaires	Most reported barrier was lack of dental services awareness and knowledge.
19.	Das D et al, 2019 (134)	Juang Tribe, Odisha	Cross-sectional study	To assess oral health status and treatment needs	WHO Oral Health assessment form	Poor periodontal status with loss of gingival attachment and dental caries.
20.	Bose A K et al, 2019 (135)	Tribal residential schools i.e Asharamshala (State not mentioned)	Cross-sectional Interventional study	To evaluate the impact of health education and oral health status	Semi-structured questionnaire, DMFT Index, OHI-S Index	Significant change in oral hygiene was observed as the result of intervention and education.

The state-wise literature of the last five years has been depicted in Table-6. Maximum publications were observed in the state of Tamil Nadu and Kerala, followed by Karnataka, Bhubaneswar and Odisha.

**Table-6:** State-wise tabulation of studies conducted in the tribal population in the past five years concerning “Oral Health & Hygiene”.

S. No.	State (India)	Number of Studies	Year
1.	Tamil Nadu	03	2024 (117) 2023 (118) 2021 (127)
2.	Chhattisgarh	01	2024 (113)
3.	Madhya Pradesh	01	2023 (120)
4.	Karnataka	02	2023 (121) 2021(128)
5.	Northwestern Himalayan region	01	2022 (122)
6.	Rajasthan	01	2021 (123)
7.	Bhubaneshwar	02	2021 (124) 2019 (133)
8.	Andaman & Nicobar Islands	01	2021 (125)
9.	West Bengal	021	2021 (126)
10.	Odisha	02	2021 (129) 2019 (134)
11.	Kerela	03	2020 (130) 2020 (131) 2020 (132)

## Oral Carcinoma

Oral malignancies are known for their high mortality and morbidity, thus impede the patients, relatives and moreover the community as a whole. It is a major health issue, especially in the Indian subcontinent. Presentation of this disease shows a vast range like red, white, ulcerative or proliferative lesions/swellings. Poor knowledge regarding signs/symptoms of oral cancers and incidence of pain at advanced stage only, often delays the detection.

Minimal literature is available as far as prevalence of oral carcinoma is concerned in the tribal population. Only 9 studies could be seen published in the last five years as portrayed in Pie-chart-2.



**Pie-chart 2: Depicting the published literature year-wise in relation to “Oral Carcinoma” in the Tribal population.**

Sub-standard oral health is coupled with various risk factor like betelnut and tobacco consumption, lack of awareness, increased alcohol intake, and limited access to healthcare system. Hence, they contribute as a risk for pre-cancerous lesions and oral cancers. Studies have even demonstrated a positive history of cancer in the first-degree relatives as a risk factor

for Head and Neck squamous cell carcinoma (HNSCC).(136) In India, there are greater than 0.22 million cases and about 0.12 million deaths as per GLOBOCAN, 2020.(137) Table -7 and Table-8 shows the nine studies found in PubMed database related to oral carcinoma in the last five years, along with its state-wise tabulation

**Table-7:** Depicts studies in the last five years concerning “Oral Carcinoma” in the Tribal population.

S.No.	First Author & Year of Study	Target Population	Type of Study	Aim of Study	Methods used	Results
1.	Zami Z et al, 2024 (136)	Mizo Tribals, Mizoram	Retrospective cohort study	To explore the survival outcomes of patients with Head & Neck Squamous Cell Carcinoma (HNSCC)	Medical records	Leucocytosis, neutrophilia, nodal involvement, and cancer sites were associated with poor overall survival.
2.	Ravi K et al, 2023 (138)	Mysuru	Cross-sectional study	To examine whether smokeless tobacco (SLT) is associated with high-risk Human papilloma Virus (HPV).	Questionnaire, Oral sample collected via NIH Human Microbiome Project protocol, and tested using digene Hybrid capture 2 HPV DNA test.	Low prevalence of HPV, however positive case was a chronic SLT use.
3.	Birje S et al, 2022 (139)	Dahanu Taluka, Palghar	Mixed-method study	To identify the enablers and challenges for	FGD, Interviews, and facility surveys.	Tribal women had limited knowledge about common



		district, Maharashtra		screening of common cancers and non- communicable diseases (NCDs) in tribals.		cancers and NCDs.
4.	Muthanandam S et al, 2022 (140)	Narikurava Tribals, Puducherry	Evaluative study	To assess the prevalence of oral cancer and pre- cancerous lesions.	Clinical examination via door-to- door screening	High prevalence of pre-cancerous lesions.
5.	Muthanandam S et al, 2021 (141)	Narikurava Tribals, Puducherry	Survey	To assess knowledge, awareness and attitude towards oral cancer and pre-cancerous lesions.	Questionnaire	Inadequate awareness about oral cancer and pre-cancerous lesions.
6.	Sivanandan N et al, 2021 (142)	Nicobarese Tribals, Andaman & Nicobar Islands	Case report	To report a case of invasive oral squamous cell carcinoma of maxillary alveolus.	As a part of house-to-house community survey, this case was identified.	Emphasizes on clinical presentation on a relatively uncommon site.
7.	Shah A et al, 2020 (143)	Buksa Tribals, Dehradun district, Uttarakhand	Cross- sectional survey	To explore the usefulness of mouth self- examination for finding oral cancer and pre-	Questionnaires, Mouth self- examination	High specificity of Mouth self- examination

				cancerous lesions.		
8.	Khongsti S et al, 2019 (144)	Khasi & Jaintia Tribals, Meghalaya	Epigenomic study	To investigate DNA methylation pattern and expression profiling of the promoter regions of FMS-related tyrosine kinase 3, erythrocyte membrane protein band 4.1-like 3 and stratifin genes in oral cancer	MassArray platform system, relative expression profiling	Hyper- and hypo-methylation of the selected genes plays a potential role in oral carcinogenesis.
9.	Patil A D et al, 2019 (145)	Palghar district	Qualitative study	To assess the training needs and capacity building activity.	Continuous Medical Education (CME) programs, Questionnaires	Healthcare providers were optimistic to implement screening for cancers.

**Table 8:** State-wise tabulation of studies conducted in the tribal population in the past five years concerning “Oral Carcinoma”.

S. No.	State (India)	Number of Studies	Year
1.	Mizoram	01	2024 (136)
2.	Mysuru, Karnataka	01	2023 (138)
3.	Maharashtra	01	2022 (139)

4.	Puducherry	02	2022 (140) 2021 (141)
5.	Andaman & Nicobar Islands	01	2021 (142)
6.	Uttarakhand	01	2020 (143)
7.	Meghalaya	01	2019 (144)
8.	Maharashtra	01	2019 (145)

Majority of the pre-cancerous lesions in the oral cavity are observed in the buccal mucosa, followed by the labial mucosa.(140) As per the guidelines given by National Comprehensive Cancer Network (NCCN), early-stage cancer patients are managed using a single-modality approach with either surgery or radio-therapy.(146) Conversely, patients who are in the advanced stage, it is recommended to have a multi-modality approach which includes chemo-and/or radio-therapy, and surgery.

## Justification

Determining the health care need of the indigenous population using a suitable approach and respecting their culture has become a key challenge. Through various allowances have been offered by the Government, the tribal population do not have an adequate access to dental care.

Studies have highlighted that nearly one-third of the tribals use of inappropriate oral hygiene aids.(147) Periodontal disease prevalence was seen to be high in the females of the age group 30 to 60 years.(131,162,163) Increased consumption of liquid and solid sugars i.e dietary factors, irregular and improper oral hygiene, and unaffordable dental facilities attributes to the high dental caries rate.(117,148) There is a reported use of indigenous/tribal tooth cleaning methods, usually by wooden sticks or charcoal in maximum population, which has led to higher rate of non-carious lesions like abrasions and attritions.(117,149) Dominant pre-malignant

lesions seen are leukoplakia, erythroplakia, tobacco pouch keratosis, and smoker's palate.(117)

It has been observed that about 300 million people use smokeless tobacco (SLT) worldwide, and 80% of these people reside in India and Bangladesh. (150) It is consumed in many forms that can contain unburnt, cured, loose, or finely ground tobacco leaves with tobacco-specific nitrosamines (TSNAs), nicotine alkaloids, toxic metals, and other compounds which are either ingested singly or combined with diverse non-tobacco or flavoring agents. They can be sucked, chewed, inhaled, or gargled.(151) Most popular form of SLT in India is *Betel Quid* which contains areca nut, ground tobacco, catechu and lime rolled in a betel leaf.(151) Many other popular forms are *Khaini* and *Mishri*. Their use is associated with high incidence of esophageal and oral cancers.(151) In addition, women have been seen to be inflicted greater than males with SLT related oral cancers.(152) Survey by Rani M et al revealed that consumption of tobacco is associated remarkably with low education and poverty.(153)

In spite of the known facts, there is restricted evidence on preparation of the health system in the tribal population. Also, there are unmet needs for the screening of oral cancers in the tribal areas. Therefore, priority should be given to the cancer control activities. Early detection of the pre-cancerous lesion, and to constantly monitor the detected cases in the tribals is of utmost importance.

## **Challenges**

There are various reasons of the non-availability of the health care to the majority of the tribal population.(154)

### **1. Inaccessibility to the health facilities**

This challenge is in regards to the service in health and health seeking behavior seems to dominate the tribal population. Access is mainly determined by resource availability, whereas utilization is impacted by both availability and the level of demand. The utilization is also influenced by the person's desire for the health services.

### **2. Lack of Health Staff**

There is inadequacy dentists, dental auxiliaries, and nursing staff to cater to the need of tribal healthcare.

### **3. Un-availability of essential equipment's and drugs**

There are insufficient drugs along with deficient equipment in the centers for tribal health.

### **4. Difficult terrains**

Commonly, they are settled at the outskirts of the districts/city, thus leading to difficult terrains for them to travel to the health care system.

### **5. Time and distance constraints**

Constraints of time and distance lead to difficulty in availing the health facilities.

### **6. Lack of proper transportation**

Extreme exteriors of the civilization lack proper transport services, making it difficult to cater to their health needs.

### **7. Lack of facilities for communication**

Poor socio-economic status, along with geographical isolation makes the communication difficult, hence preventing the tribals from taking advantage of the health services. This leads to dependance on indigenous self-health care.

### **8. Superstitions and traditional practices (local customs and beliefs)**

Underlying cultural beliefs influence oral health and its conditions as they mostly use home-remedies and psycho-somatic therapeutic approaches.(155) This incorporates mysticism, magic, the paranormal, frequently leading to distinct magico-religious rituals. Though one should not disregard these beliefs as just another superstition, but it rather requires meticulous reviewing due to their impact on diseases and management of illnesses.

### **9. Inadequate schooling and education**

Maximum studies have shown that the indigenous population lack formal schooling and are hence less aware of the education importance. This also causes failure of execution of government educational programs in such areas.

## **Gaps/Lacunae**

It has been that there is a gap of 80-20 i.e if the prevalence of oral disease is 80%, then only 20% of the facilities for care are available.(154) Oral health is being low priority when compared to the general health. There is a lack of political as well as professional advocacy for oral health, along with poor living conditions. Furthermore, restorative approach is found to be dominant against tribals. There is lack of preventive knowledge and oral health importance, along with the observed dominance of conservative/restorative approach. Health-seeking behavior is also influenced by financial factors and access.

Widening inequities in the status of the oral health and need for treatment exists among different social groups. Certain ethnic groups stay in isolation, even today, carrying their beliefs and traditional values. Maximum tribals reside in extreme exteriors of the civilization and hence are very difficult to locate.

## **Intervention strategies**

By virtue of the encountered barriers and the oral disease burden among the indigenous/tribal population, promotion of oral health via integrated care at different levels is suggested.

### **1. Community outreach programs**

People of the community can be engaged and a village hospital can be initiated.(156) Interested people can be trained for home-based care, thus expecting a reduction in the oral diseases. They can be educated about tobacco and alcohol control, along with laying the way for ASHA workers.

### **2. School based programs**

Children are most comfortable in the school setting, with teachers as their role models. Additionally, it would be easier to train/educate all the child under one roof. Numerous programs aiming at prevention can be conducted like:

- Oral health screening
- Oral health education
- Tooth brushing technique.
- Pit and fissure programs.

- Prevention of tobacco use
- Tobacco cessation programs

### **3. Training of Allied Health Professionals**

Allied health professionals like Anganwadi workers and ASHA workers can be trained for oral health and hygiene, as they are involved with health services related with evaluation, identification and prevention of diseases. They can be empowered to become guides towards oral hygiene, along with rendering oral health education.(157) Also, these professionals are culturally competent owing to the contextual understanding of the community needs. This can prove to be highly beneficial.

### **4. Mobile dental services**

Portable and mobile dental units are an efficient way to take the services of dentistry to the doorsteps of the indigenous population.(158) These sophisticated services can work with the optimal utilization of dentists and dental auxiliaries.

### **5. Workforce model**

It involves integration of the physicians/nurses who are involved in the screening and management of the patients, with dentists/dental professionals. This model can empower the dentists or the dental auxiliaries to screen for non-dental problems like throat cancer, thus leading to the provision of maximum health care.(159)

### **6. Integrated work model**

There is a need for integration in the network of oral health and systemic health.

**a) Oral examination along with Immunization:** It is possible to carry out oral examination by the allied health professionals, while the oral polio drops are being administered. Once the drops are given, oral cavity can be checked for any obvious abnormality.

**b) Group Toothbrushing and handwashing programs:** This group activity can be implemented in the schools of the rural areas. These will involve a group of children who will be trained to brush their teeth and wash their hands together. In addition to improving their oral health, it will inculcate a good habit among them.

Multiple areas will be seen suffering from shortage of water supply or inadequate infrastructure. Instillation of “Tippy-tap” system can be done in such areas.(160) Testing of this intervention was done at an Anganwadi in India for about two months, and it yielded positive results, with children developing the habit of handwashing before every meal.(160)

## **7. Use of Traditional methods**

Alternative or complementary medicine is referred to as the use of traditional methods like cleaning of the tongue (with the help of steel tongue cleaners, coconut leaf), cleaning of the mouth (neem/miswak, guava, babul, mango), and use of mouth wash (herbal products). They have shown positive results in the oral health by showing reduction in dental decay, malodor, crackling lips, bleeding of the gums, and have shown strengthening of the gums and the teeth.(161)

Programs should be conducted free of cost whenever feasible, thus delivering emergency oral-health and preventive care, thus aiding in connecting tribal and general population, which will help motivate them to pursue dental services. A well-planned program should center on the conversion of deleterious customs into healthy ones.

## **Ways forward**

1. The identified tribal remedies claimed to be used in varied tribal areas should be identified and validated.
2. There is a need to strengthen allopathic medicinal system in tribal areas. This will require the three-tier system of auxiliary nurse mid-wife, village health workers, and primary health centers to be extended to the tribal areas.
3. Traditional medicines should be encouraged, documented and patented.
4. Promotion of medicinal plants cultivation which are maximally used by tribals.



5. Regular conduction of orientation and training programs, so as to help formation of a strong force of Tribal health guides in villages.
6. Need to strengthen the research programs into the diseases affecting the tribal population, and furthermore, initiate required programs.
7. Studies evaluating long-term trends are required to extrapolate the results.



**Theme-VI**

**Haemoglobinopathies and  
Sickle Cell Disease**



## Introduction

Hemoglobinopathies, especially sickle cell anemia (SCA), are important public health problems in India which poses serious impact on the lives of widely distributed heterogenous tribal population of India since its reporting by Lehman & Cutbush in 1952. Hemoglobinopathies are red cell disorders with abnormal hemoglobin. They are responsible for various chronic health issues, such as painful episodes, recurrent infections, organ damage, and other fatal complications of organ damage. The main hemoglobinopathies responsible for these problems in the populations include hemoglobin S (HbS),  $\beta$ -thalassemia and hemoglobin E (HbE). Among these, 70% of all affected worldwide births are due to 'Sickle cell syndromes'. All these hemoglobinopathies segregate at wide variability among various tribal populations, making the management and treatment of these disorders more arduous.(162)

Tribal population groups have higher rates of hemoglobinopathies, which are specifically due to poor healthcare facilities combined with socioeconomic constraints and lack of knowledge. It significantly adds to increased Infant mortality rate of the country and their poor quality of life. Geographical isolation often leads to poor healthcare delivery and the non-availability of medical personnel's that further leads to delays in prevention, diagnosis and treatment.(163)

Another problem related to achieving control of the menace of hemoglobinopathies in India are the marriages among tribal populations, which happen in closed clusters and are purely based on social and cultural considerations, without considering other parameters such as health status. A unique feature of these populations is high rate of consanguinity, which contributes significantly to the high prevalence of hemoglobinopathies. Another reason for the high prevalence of this group of disorders in these communities is due to repeated 'founder effects', of genetic drift. On the other hand, there are culturally entrenched practices that, in turn exaggerate the reproductive losses and overall increase the incidence of genetic disorders.(164) These issues therefore call for a holistic and round developmental approach. Early screening, detection and genetic counselling are steps that could prevent the complications of hemoglobinopathies so that early Intervention could be instituted.

Good quality medical care will benefit the patients having the disease. Availability of apt treatment facilities including provision of drugs, blood transfusion facilities and emergency management of the disease and blood transfusion related complications at nearby home will be of great benefit

considering the remoteness of most of these tribal areas. These can be done by continuously strengthening the healthcare infrastructure, regular training of personnel's and using mobile health units along with cutting edge technology to reach out to the most distant communities.

Awareness needs to be created through educational and sensitization programs that will inform the tribal people about the risks of the disease and importance of management of hemoglobinopathies. The educational programs should be made culturally conducive and deliverable in the local languages. Education will empower the people to seek medical services in time.

Community sensitization and awareness creation programs that involve their leaders and other influential people in the community will help to sensitize the community members about the need for the screening and treatment. Socioeconomic factors that subsequently lead to poor health outcomes have also to be addressed to tackle the health needs of the tribal populations of India. Poverty and low literacy levels keep the people away from health facilities. Socioeconomic development schemes to raise the living standards, level of education, and income among the tribal people will have indirect implications for the improved health outcomes.

Dedicated Central and State Government policies and programs in this respect shall, therefore be directed at tribal health. These shall include resource provisioning regarding health infrastructure, targeted education of health professionals in genetic counselling and management of hemoglobinopathies, ensuring the sustained availability of necessary drugs and treatment facilities at health care levels. The provision of accessible, good quality POC along with equipped laboratories, blood centres and treatment facilities for diagnosed cases by Central and State Government medical colleges in all tribal districts will considerably reduce morbidity and mortality. Establishment of Centre of Excellence and or Centre of Competence in AIIMS like Institute in each State will marshal the strategies of elimination of these diseases.

## **Burden**

Hemoglobinopathies, including sickle cell disease (SCD), place a heavy financial burden and productivity loss of India's tribal populations. Haemoglobinopathies particularly haemoglobin S and E (HbS, HbE) and  $\beta$ -thalassaemia are important health challenges for tribal populations in India. The HbS, HbE and  $\beta$ -thalassaemia genes are variably distributed across various tribal

populations of India.(162) There is no uniform prevalence collective district wise data in most of States including Jharkhand. Mostly they have been from various retrospective and prospective studies (**Table-9&10; Figure-8**).(181-187) Therefore, there is need for larger uniform study to map the disease prevalence in different regions of the country for guidance for health policy makers.

**Table-9:** Burden of Hemoglobinopathies in the State of Jharkhand

<ol style="list-style-type: none"> <li>1. Hemoglobinopathies are different in different regions of Jharkhand &amp; in different tribes.</li> <li>2. Thalassemia &amp; Sickle cell trait frequencies are same (3.6%).</li> <li>3. Beta Thalassemia trait is same throughout the state.</li> <li>4. SCD has uneven distribution, limited to adjoining Chhattisgarh &amp; Odisha. Prevalence was 3% vs 13% in Chhattisgarh.</li> </ol>
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**Source:** National guidelines on management and control of Sickle Cell Disease (165)

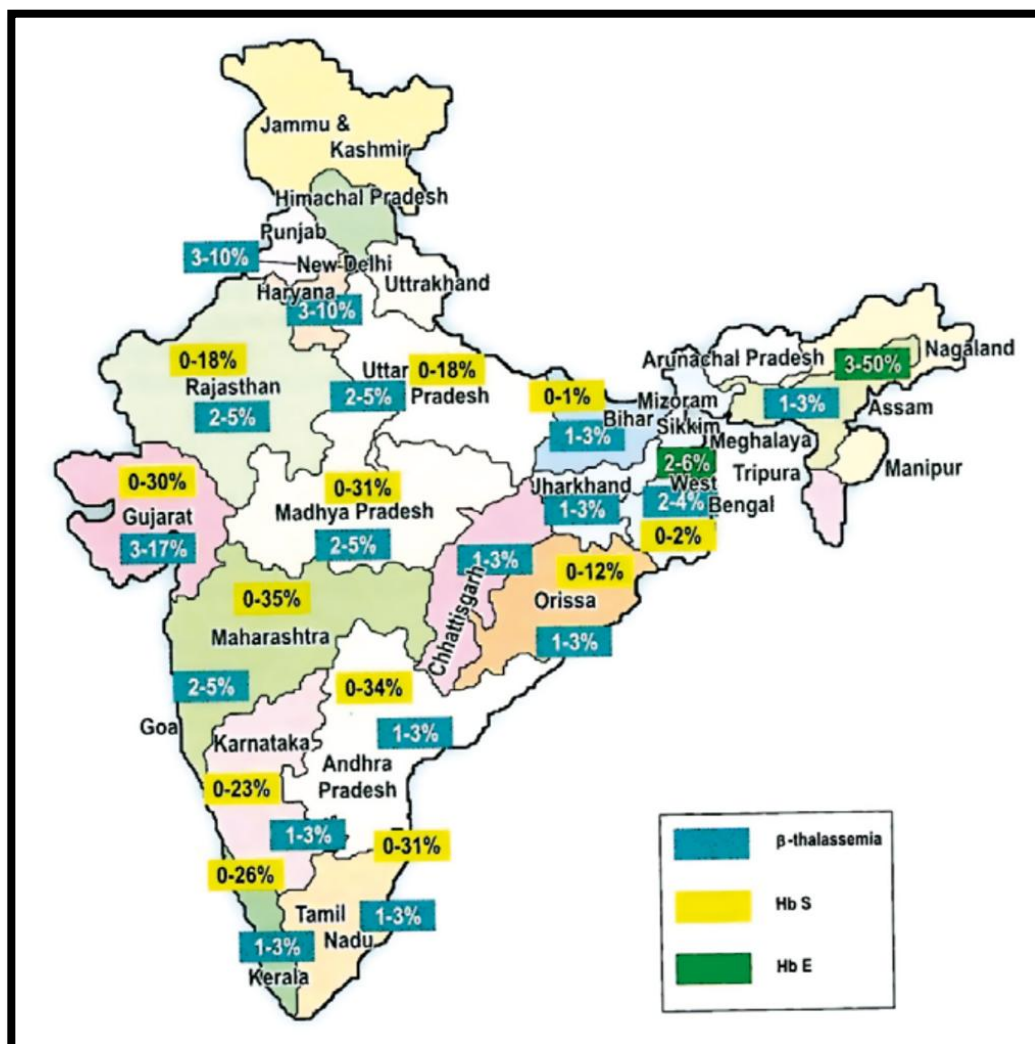
**Table-10:** Prevalence of Hemoglobinopathies amongst Tribal Population

Haemoglobinopathies	Prevalence amongst Tribal Population
HbD	Not been reported on a large scale (162)
HbE	41.1 to 66.7 % (among 6 ethnic groups of Assam) (166)
Sickle Cell	1–40% (167) 1.25 lac SCD, 25 lac carriers Sickle Cell Trait among tribal communities of India varied between 8.5% to 27.7%, whereas the prevalence of Sickle Cell Disease ranged from 0.7% to 5.1%. Sickle cell prevalence in India (Figure-8). (168)(169)(170)(171)(172)
Alpha Thalassemia	Between 11% to 71% (173)
Beta Thalassemia Minor	3.6-3.9 crore carriers of $\beta$ -thalassemia.

	11% (Noted in tribal population of Jharkhand in one of the studies) (174)
Beta Thalassemia Major	0.00-30.50% (Mainly noted in Eastern India) 10000-15000 babies are born each year $\beta$ Thalassemia major in Tribals in Jharkhand was found to be 7% & Sickle $\beta$ Thalassemia in Tribals in Jharkhand was found to be 10% in one of the studies.(190)(175)(176)

Source: ISHBT & ICMR. National guidelines on management and control of Sickle Cell Disease (2021)

<https://www.ishbt.com/ich/assets/pdf/scd-guideline.pdf> (165)



**Figure-8:** Prevention and Control of Hemoglobinopathies in India - Thalassemia, Sickle Cell Disease and Other Variant Haemoglobins (Source : National Health Mission Guidelines on Hemoglobinopathies in India Ministry of Health & Family Welfare Government of India 2016 Blood Cell Blood Cell [Internet]). (177)



**Table-11:** Prevalence of sickle cell trait in various Regions/States

Western India	Gujarat	0.31% - 21.45%
	Maharashtra	04% - 24%
	Rajasthan	5.5% - 31 %
Central India	Madhya Pradesh	10% - 25%
	Chhattisgarh	1.46% - 20.63%
Northern India	Uttarakhand	< 1% along with beta thalassaemia trait
	Uttar Pradesh	< 1% along with beta thalassaemia trait
Eastern India	Odisha	7.4 % - 26.0%
	Jharkhand	3.3% - 10%
	West Bengal	< 1%
Southern India	Tamil Nadu	Up to 28% - 35%
	Kerala	Up to 4.33%
	Andhra Pradesh and Telangana	24.5% Andhra, 30 % in Telangana
Northeast India	Assam	2.4% - 14.2%
	Tripura	Like Assam.

Source: ISHBT & ICMR. National guidelines on management and control of Sickle Cell Disease (2021)

<https://www.ishbt.com/ich/assets/pdf/scd-guideline.pdf> (165)

**ICMR-National Institute of Immunohaematology (ICMR-NIIH)**, Parel, Mumbai was established in the year 1957 with the main aim to carry out multidisciplinary research in relation to Immunohaematology. Furthermore, they aim to offer diagnostic services and training to medical as well as non-medical professionals in the field of Immunology, haematology, genetics, along with conducting awareness programmes on haematological disorder.

Surve et al conducted a descriptive ICMR-multicentric study for screening newborns of SCD in the tribal population at Model Rural Health Research Unit (MRHRU-Dahanu) in Palghar District, Maharashtra. It was observed that after the implementation of certain pragmatic measures like ASHA involvement, virtual platform usage, and flexibility in terms of visit, follow up rate increased 47.5 percent from 26.7 percent post first lockdown in COVID-19 pandemic. Hence, the study emphasized about the importance of building networks, virtual platform use, along with engagement of healthcare workers in tribal settings.(178)

A systematic review and meta-analysis done by Khargekar et al regarding the role of hydroxyurea therapy in the prevention of organ damage in SCD found that dose of hydroxyurea above 20mg/kg/day with a mean rise in HbF by 18.46% post-hydroxyurea therapy had a beneficial role in reducing transcranial doppler velocity, tricuspid regurgitant velocity, albuminuria, and splenic abnormality.(179)

ICMR-National Institute of Research in Tribal Health (ICMR-NIRTH), Jabalpur was established in 1984. It conducts research on the health issues of tribal population such as hemoglobinopathies. Shrivastava et al evaluated Microchip-based Point-of-Care Device “Gazelle” for Diagnosis of SCD in the tribal dominated Indian states of Madhya Pradesh and Chhattisgarh. A total of 1,050 patients were screened by sickle cell solubility, hemoglobin (cellulose acetate) electrophoresis, high-performance liquid chromatography (HPLC) and Gazelle. Gazelle identified all patients with the disease (HbSS and Thalassemia Major) with 100% accuracy, hence proving it as a potential screening tool for the rapid diagnosis in resource limited settings and developing countries with high burden of haemoglobin disorders.(180)

## Justification

The diverse causal issues related to Hemoglobinopathies (Figure-9) are important for development of strategic steps by health policy makers. Following are the important steps for justification for the addressal: (193,194)

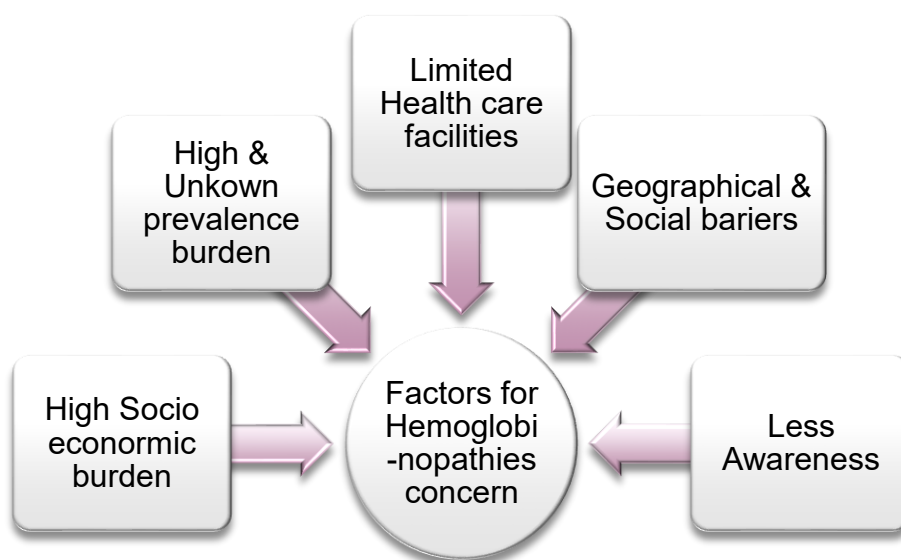


Figure 9: Factors for the need of addressal to eliminate Hemoglobinopathies

### I. High prevalence burden

Hemoglobinopathies are important causes of Infant mortality rate (IMR) with increased mortality and morbidity in last decade. Most of the contributory causes of IMR are on the decline except the hemoglobinopathies and so is the major challenge in coming years.

### II. Socio-economic burden

The two common genetic disorders of SCD and Thalassemia cause great family sufferings and economic hardships to the society and health resources of the country as they require lifelong therapy. There are lot of direct and Indirect factors pertaining to financial implications.

**Direct costs** related to disease:

- Cost of Heath care related to manpower and logistics.
- Diagnosis – Screening, confirmatory, newer POC tests.

- Treatment- Primary care visits, hospitalizations, emergency visits, referrals, availability of newer modalities of treatment that includes Bone marrow transplant, Genetic therapy.
- Blood transfusion
- Drug availability

**Indirect costs** related to disease:

- Productivity loss due to regular absenteeism of family members and future productivity due to childhood illness.
- Financial burden to the family – the cost of treatment, hospitalizations, blood transfusions.

### **III. Geographic and Social Barriers**

Tribal populations often reside in remote, difficult terrains and isolated areas, making access to healthcare challenging. These geographic constraints, combined with social barriers such as language differences and cultural practices, further complicate the availability of medical services.

### **IV. Availability of limited Healthcare Facilities**

There is a pronounced scarcity of primary and specialty care facilities within tribal regions. This lack of infrastructure means that essential health services, including early detection, diagnosis, genetic screening and counseling, blood centers, apt treatment including availability of free medications in nearby health facilities are not readily accessible to these communities. Low awareness of the disease among tribal communities along with regional cultural beliefs.

It is related to many factors particularly:

#### **A. Low literacy rates**

The literacy rate is a crucial measure for the evaluation of the amount of human development achieved within a certain society. The progress and development of a country depend on the quality and attributes of the education offered. The literacy rate among tribes continues to be lower than the national average of 47.1% for all Scheduled Tribes in Jharkhand.

The literacy rate for females belonging to the Scheduled Tribes (STs) was reported as 64.60% based on the data from the 2011 census, however for males it was seen to be 80.90%. According to the statistics, the literacy rate among schedule tribes in Jharkhand is higher than that of schedule castes. The literacy percentage among men in the ST group is 68.25%, whilst the SC category has a literacy rate of 67.01%. The literacy rates of females in both social classes are comparatively lower than those of males.(181)

### **B. High Birth Rate**

The burgeoning birth rate in tribal populations can exacerbate health issues, including the spread of genetic disorders. With more births, the probability of passing on genetic conditions increases, particularly without adequate medical intervention.

### **C. Consanguineous Marriages**

Consanguineous (between closely related individuals) marriages are more prevalent in some tribal communities. Such practices significantly heighten the risk of genetic disorders in offspring due to the increased likelihood of inheriting recessive genetic traits. Parents were consanguineous in 34% of marriages (19.2% mother's brother's daughter (MBD), 13.1% father's sister's daughter (FSD) and 1.7% were double first cross-cousins (DFCC) in one of the studies. In the offspring of consanguineous couples, it was higher (19.7%) than in the offspring of unrelated couples (18.6%) but the difference was not statistically significant. In consanguineous couples the reproductive period was longer than in unrelated couples, probably to allow compensation for increased reproductive losses (infant and childhood deaths).

Raising awareness and educating tribal populations about hemoglobinopathies along with research, can reduce stigma and promote better health practices. It will also enable development of culturally sensitive genetic counselling and education programs.

## **Challenges(193-195)**

**I. Lack of precise prevalence data** of the hemoglobinopathies in tribal populations of the country. The precise burden of the disease is not known leading to improper focussed planning. Proper registry is required for the urgent addressal.

**II. Institutionalization of uniform national policies as well in State with regular monitoring and review from the States.**

**III. Awareness** in tribal communities about the disease and its prevention of the diseases by carrier screening, prevention of consanguineous marriages and genetic counselling is lacking. Moreover, tribals are afraid about the stigma of the disease if diagnosed that will lead to ostracization from family and society.

**IV. Availability of trained staff at all levels of care**

Recruitment and training of adequate manpower preferably from within tribal community for increasing awareness for the need of prevention, screening, detection and treatment of hemoglobinopathies. Apart from it, pathologists and specialized trained doctors' availability in remote areas for diagnosis and management of the diseases and its complications respectfully is also a big challenge.

**V. Optimum appropriate health care services availability at local level**

**For diagnosis:** Equipped laboratory facilities (regular and sustained availability of screening rapid diagnostic kits and confirmatory HPLC machines) with trained staff are required at all levels of care.

**For diagnosed cases:** blood components, medicines and specialized treatment are important. Blood centres with sustained availability of blood components is important specially for  $\beta$  Thalassaemia major (encouraging for blood donation in local community is big challenge). Continuous and sustained availability of medicines like pain killers, hydroxyurea, expensive chelators, penicillin (for prophylaxis) and vaccines (for immunization- pneumococcal) are important challenges in PHCs & CHCs.

**VI. Creation of Center of Excellence (CoE)/ Center of Competence (CoC) of Hemoglobinopathies in a State that will have facilities for:**

- Comprehensive treatment including Allogeneic hematopoietic stem cell transplant (in some cases like  $\beta$  Thalassaemia major as this is the only definitive treatment).

- Prenatal diagnosis if both parents are carriers.
- Supervision awareness programmes in PHCs, CHCs, community level.
- Confirmatory diagnosis in difficult cases.

The health Institute in tribal population is deficient in number by 27 to 40 percent as compared to present norms.

**VII. Translation Research** pertaining to development of newer cheaper point of care diagnostic kits for hemoglobinopathies and newer better definitive treatment modalities using the cutting-edge technologies.

## **Gaps/Lacunae**

The study of the burden of haemoglobinopathies in tribal populations in India has the following gaps which are deterring to the progress. (193,194)

### **1. Advocacy**

There is strong need of uniform policy guidance from Central Government with supervision and frequent reviews for implementation of the program at State level.

### **2. Healthcare Infrastructure Limitations**

- Limitations of accessibility of health care: It should be easily free accessible to all and should be in proximity to ensure the availability of deliverable equipped health services. It should be preferably at walkable distance.
- Inadequate Human resources: Most of the health workers should be from tribal community including ASHA, Anganwadi worker, ANM making it more acceptable as per their cultural beliefs.
- Limitations of Outreach & mobile care services.
- Inaccessible to newer technologies: Use of telemedicine services with the help of Information Technology will augment the health delivery.
- Less number of Health care facilities: Increase in number of equipped health centres from inside the tribal village to tertiary care facilities.

- Inappropriate Rigid model of health care: Flexible, autonomous and dynamic health care provision will be helpful in acceptance and prompt addressal.
- Limited Financial resources – Planned distribution of Central & State funds for health care budget for tribals will help in sustained improvement of health care services.

### **3. Insufficient Awareness and Education**

Low level of literacy in tribal communities is an important factor and needs to be improved. Educational programs about hemoglobinopathies are often not culturally adapted for tribal communities, hindering effective awareness and engagement.

### **4. Cultural and Social Hurdles**

Cultural beliefs and social norms frequently prevent the acceptance of modern medical interventions for hemoglobinopathies in tribal communities- there is a decreased tendency among tribal populations to visit healthcare facilities and hence a subsequent lack of follow-ups is also noted.

### **5. Genetic Counselling Gaps**

The shortage of genetic counselling services tailored to tribal cultural norms limits effective disease understanding and management, particularly in reproductive decision-making.

### **6. Diagnostic limitations**

Sickle cell disease can be screened by rapid test kit but sickle cell trait has limitations. However, there is no validated POC testing for hemoglobinopathies. ICMR has introduced rapid kit tests for diagnosis of Hemoglobinopathies other than SCD but is under validation. Confirmatory test is done by HPLC. There has been introduction of ‘Gazelle’ a microchip based POC device by ICMR with good sensitivity & specificity and the test can be conducted in nearby health centre with skilled trained lab technician under supervision of Pathologist. Such low cost, rapid and portable machines with good diagnostic accuracy is needed for confirmation. So, for diagnosis, continuous conduction of mass screening is needed under National Program.



There is limitation of availability of equipped lab for diagnostic confirmatory test nearby tribal village along with skilled trained lab technician. There is lack of trained health worker for sample collection, lab technicians for diagnosis of anaemia.

### **7. Inadequate screening**

Screening facilities needs to be expedited in tribal districts. School children need to be educated and screened.

### **8. Optimal hierarchical treatment facilities for diagnosed cases**

Blood centre facilities, local availability of treatment facilities. Few dedicated beds to meet the emergencies (tribal village, PHC, CHC, district hospital with good communication with tertiary care centres) and sustained availability of required medicines.

- **Specialized Care Shortage:** There is a notable lack of specialized medical professionals, such as pathologists, physician, haematologists and genetic counsellors in tribal regions, crucial for lab diagnosis of anaemia and personalized disease management. There is also lack of Center of Excellence (CoE) / Center of Competence (CoE) which can be established in AIIMS in each State where newer modalities of treatment, newer lab diagnostic modalities, prenatal diagnosis facilities are available. These facilities can provide supervision and training of health professionals of all health care levels including tertiary care centres, medical colleges and peripheral health centres of the State.
- **Research and Data Deficiencies:** Targeted research and continuous data collection on hemoglobinopathies in tribal populations are lacking (often due to strict geographical locations of tribal populations) essential for developing effective health policies and resource allocation.

## **National Sickle Cell Anaemia Elimination Mission (NSCEM)**

Hon'ble Prime Minister of India launched National Sickle Cell Anaemia Elimination Mission (NSCEM) on 1st July 2023. The overall aim is to enable access to affordable and quality health care to all SCD patients, and to lower the prevalence through awareness, change of practices and screening interventions.(182)

### **Objectives of the Mission**

- Provision of affordable and accessible care to all SCD patients.
- To ensure quality of care for SCD patients.
- To reduce the prevalence of SCD.



These objectives would be attained through strategies spanning awareness generation, strengthening of screening and testing facilities, strengthening of laboratory services for diagnosis, facilitation of management & treatment, establishing linkages across level of care, inter sectoral convergence towards holistic approach and linkages with social security schemes/benefit packages. The strategy emphasizes on three pillars:

### **1. Health promotion**

Awareness generation & pre-marital genetic counselling.

### **2. Prevention**

Universal screening and early detection.

### **3. Holistic Management & continuum of care**

- Management of persons with sickle cell disease at primary, secondary and tertiary health care levels; treatment facilities at tertiary health care facilities
- Patient support system
- Community adoption

The program shall be carried out in a mission mode covering the entire population from zero to 18 years of age and shall incrementally include the entire population up to 40 years as a part of National Health Mission and shall focus on universal population-based screening,

prevention, and management of sickle cell anemia in all tribal and other high prevalent areas States/UTs of India. While in its initial stage, the mission would prioritize its intervention in high prevalence and tribal states/UT, the plan would subsequently expand to include all states/UTs in a phase-wise manner with an incremental approach. The mission aims to cover 7 crore people with screening, counselling for prevention and care for people with SCD in three and half years.

Initially, the focus shall be on 17 states with higher prevalence of SCD viz., Gujarat, Maharashtra, Rajasthan, Madhya Pradesh, Jharkhand, Chhattisgarh, West Bengal, Odisha, Tamil Nadu, Telangana, Andhra Pradesh, Karnataka, Assam, Uttar Pradesh, Kerala, Bihar and Uttarakhand.

The programme would be in integration with existing mechanism and strategies under NHM to ensure utilization of existing resources and also minimizing the duplication of efforts. For example, established platform of RBSK and Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA) would be leveraged to achieve the targets for the Sickle Cell Mission.

### **Modes of Primary Prevention**

- Awareness generation & pre-marital counselling
- **At Individual/Household level:** Individuals with known or detected SCDs would also be encouraged to register on Sickle Cell Disease Support Corner, to bridge the gap between patients and health care services in tribal areas.
- **At Community level:** Platforms such as monthly Village Health Sanitation and Nutrition Committee (VHSNC)/ Mahila Arogya Samiti (MAS) meetings, Village/Urban Health Sanitation and Nutrition Days (V/UHSND) meetings at Anganwadis, Jan Arogya Samitis in AB-HWC, Arogya Sabha, Self-Help Groups (SHG), youth clubs, parent-teachers meetings in schools, etc., shall be leveraged to sensitize people on the importance of sickle cell disease and screening service available at AB-HWCs.

- **Patients Support Groups (PSG)** facilitated by the MPWs/ASHA or other frontline workers to improve treatment compliance and engaging not only those with the disease condition but also family members or care givers.
- Mechanisms to be established at community level for pre-marital and pre-conception screening backed by genetic counselling services. Also, at the level of community, for all individuals detected or known as carrier or patients, extended family screening is to be ensured.
- **At Schools:** In all blocks with sickle cell disease, Community Health Officers (CHO) at Sub Health Centre-Health and Wellness Centre (SHC-HWC) and Medical Officer at Primary Health Centre-Health and Wellness Centre (PHC-HWC) shall conduct talk sessions and counselling at all schools & colleges including tribal residential schools, tribal hostels and Ekalvya Model Residential Schools (EMRS), for early detection of SCD among school going children. AB-Health and Wellness ambassadors would also be trained information in form of interesting activities which would be either classroom based or as an outreach. EMRS, one of the flagship initiatives of GoI, would be utilized as a platform to undertake and ensure all SCD related interventions at this level.
- **At Health Care Facility Level:** Counsellors at the primary health care centres will be primarily responsible for providing counselling services to all individuals diagnosed positive with Sickle cell Anemia.
- **IEC and Mass media:** The Health Promotion strategy recommended by the National Health Policy 2017 emphasizes institutionalizing intersectoral coordination at national and sub-national levels to optimize health outcomes, through constitution of bodies that have representation from relevant non-health ministries. This should be in line with the emergent “**Health in All**” approach as complement to Health for All, and thus making the base for all planned IEC/BCC activities under this programme, Ministry of Tribal Affairs will play the pivotal role in awareness generation. The mentees and mentors of GOAL (Going Online as Leaders) program run by the MOTA with Facebook will be used as ambassadors for generating awareness on health issues including Sickle cell disease.

- Engagement of **CBOs/NGOs**: NGOs working in the area in the sector of health especially tribal health shall also be utilized for the purpose of mobilization, awareness and providing pre-marital and prenatal screening and counselling services. The NGO involvement framework under NHM may also be referred while engaging with an NGO in these areas.

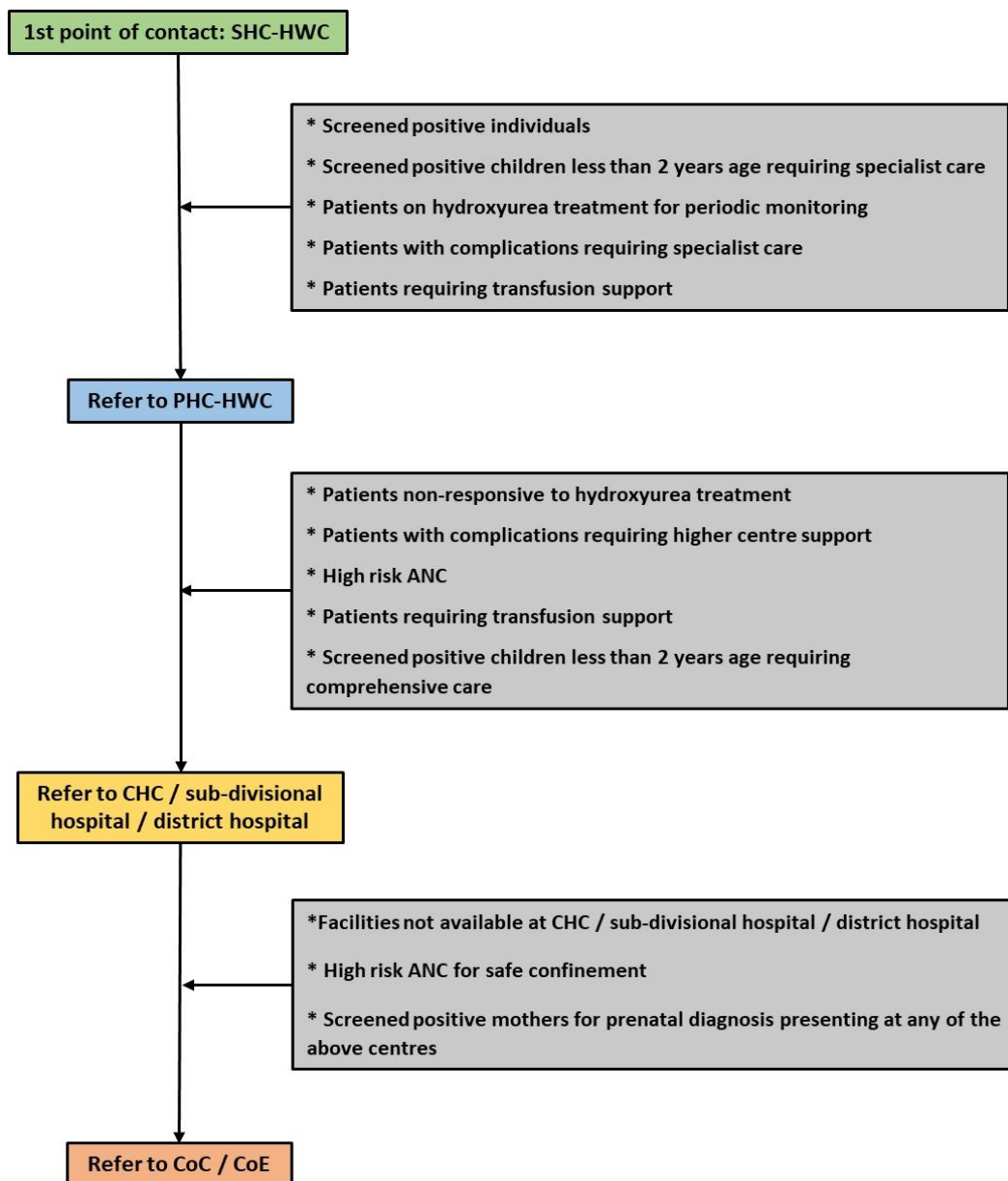
## **Interventions**

The following intervention strategies may be adopted by MoHFW to alleviate the challenges met with in both studying and eradicating the burden of Haemoglobinopathies among tribal populations of India: (193-195)

### **1. Constitution of National & State policy for implementation and monitoring (Under Policy Development and Advocacy function):**

- **Sustained Advocacy** steps for sustained awareness among tribal population of the disease prevalence and the urgent need to curb the disease burden by prevention and comprehensive management.
- **Institution of uniform national policy and monitoring of these policies with frequent reviews by the State.** There is need of coordination among different linked ministries of Family and Health Welfare, Tribal Affairs, Human Resource Development, Social Justice & Empowerment and Women & Child Development for National policy for uniform guidance.
- **Efforts to influence healthcare policies** and improve access to care for individuals with hemoglobinopathies; discussions related to screening, insurance coverage under PM-JAY/ State programmes and other public health initiatives.
- Adoption of tribal villages of the district by AIIMS or Institutions of National Importance (INIs) under Unnat Bharat Abhiyaan programme, and strengthening of community health activities in the district.

- Implementation and improved support to the health care programmes through the community health centres and primary health centres of the region: joint activities with health education, public awareness and community health in a multidisciplinary approach, in collaboration with the state government and district health bodies to strengthen the local government facilities through CoC/CoE.



**Figure 10: Example of continuum of care with chain of referral in collaboration with health care system of the state, with reference to SCD patients. (SHC-HWC: Sub Health Centre-Health and Wellness Centre; PHC-HWC: Primary Health Centre-Health and Wellness Centre; CHC: Community Health Centre; CoC / CoE: Center of Competence / Center of Excellence)**

**2. Enhanced Screening and Counselling** (Under Genetic Counselling and Family Planning function) Outreach camps Screening camps in remote tribal areas can be undertaken regularly by Mobile Medical units or Drone facilities (non-reachable areas).

- Focus on detection of anaemia.
- Carrier screening - screening of school children, college going students, individuals up to at least 40 years of age in phase manner (initially up to 18 years and then Cascade screening i.e screening expansion up to 40 years, pregnant women, newborn, extended family members, screening of husband & wife). These should be undertaken at fixed times may be monthly/weekly with help of SHC-HWC/UHWC, PHC-HWC, UPHC-HWC.
- Premarital genetic counselling- Providing genetic counselling services by trained nurse/counsellor of PHC-HWC/UPHC-HWC to affected families to assess their risk and make informed family planning decisions, assisting individuals and couples in making choices.
- Prenatal diagnosis specially if father & mother are both carriers. They can be referred to Tertiary medical colleges/ CoE/CoC.
- Positive patients should be referred to nearest Primary health facility for further management, diagnostic confirmation, treatment initiation.

**3. Community Engagement.** (Under Patient Education and Support, & Outreach and Public Awareness function):

- Mobilize ASHA workers, Community Health volunteers and local NGOs to increase awareness about the disease through home visits. Detected anaemia should be sent to nearest Health Wellness Centres (HWC) for work up.
- Encourage registration on the 'Sickle Cell Disease Support Corner'.
- Developing strategies for raising public awareness about hemoglobinopathies to reduce stigma and discrimination.

**4. Creative Awareness Initiatives** (Under Patient Education and Support, & Outreach and Public Awareness function):

- Educating patients and their families about the nature of the disease, treatment options, and lifestyle management.

- Utilize street plays, IEC awareness material, folk media, apt media modalities (radio & TV), wall writings, paintings and quizzes.
- School to maximize awareness of the disease by inclusion in the curriculum. GOI flagship initiative: ‘Eklavya Model Residential Schools’ can be utilized to provide all intervention action plans. Frequent parent-student meeting can also be beneficial in awareness spreading.

#### **5. Registry** (under Quality Improvement and Research Translation function)

- Registers should be maintained for diagnosed cases or carriers even at subcentre level under ‘National Hemoglobinopathy Registry’.
- Screening should be done for entire family, relative or whole community if required.
- Implementation of quality improvement programs to enhance patient care and outcomes.

#### **6. Educational Outreach** (under Patient Education and Support, & Outreach and Public Awareness function)

Training of HCW’s to identify and respond to early symptoms of SCD crises in children and use the RKSK platform and its clinics to reach adolescents for screening and counselling.

#### **7. National and Local Campaigns** (Under Outreach and Public Awareness function)

Integrate World Sickle Cell Day into the Annual Health Calendar and conduct monthly outreach screening camps at educational and childcare institutions.

#### **8. Advanced Diagnostic Tools** (Under Diagnosis and Screening function)

- Implement government-approved electrophoresis-based point of care tests for SCD screening and diagnosis at primary health centres, with extended reach through Mobile Medical Units in remote areas.
- Community screening programmes (camps for screening of sickle cell disease and other haemoglobinopathies) with Point-of-care-test HPLC and Biomarkers. Confirmatory lab tests should be available near to home.
- Suspected patients should be referred to CoE/COC, for confirmation of diagnosis in difficult cases.



- Developing state-of-the-art diagnostic services for patients suspected of having haemoglobinopathies. Referral lab at CoE/COC will perform early detection of sickle cell disease and other haemoglobinopathies with HPLC. Molecular lab will perform confirmation of diagnosis of sickle cell disease and other haemoglobinopathies with Sanger Sequencing, which also includes detecting and identifying variants, and carrier detection.

#### **9. Antenatal screening and new-born screening (Under Diagnosis and Screening function)**

- Every woman should be screened before pregnancy.
- Preconception (pre-natal testing) especially in high prevalent areas and considered as high-risk pregnancy, those who have hemoglobinopathies in tertiary care centres. The target population will also include premarital couples.
- New-born screening programs to be conducted to identify affected infants early in life. Also, genetic counselling and carrier screening to be offered for families at risk.
- Furthermore, prevention and treatment of Sickle Cell Disease is guided by the goals, objectives and strategies laid under the National Sickle Cell Anaemia Elimination Mission as stated herewith.

#### **10. Integrated approach of hemoglobinopathies along with Hemophilia like the ‘National Sickle Cell Anaemia Elimination Mission 2023, MoHFW, Government of India (under Multidisciplinary Collaboration function)**

Sickle cell disease has been listed by MoHFW tribal health expert committee as one of the 10 special problems in tribal health affecting the tribal people disproportionately, thus making this an important intervention. For comprehensive prevention, screening and management of Sickle cell in India, National Sickle cell Anaemia Elimination Mission program was launched in 2023.

The Goal should be to eliminate sickle cell disease as a public health problem in India before 2047. The objectives are:

- Provision of affordable, accessible, and quality care to all SCD patients.
- To reduce the prevalence of SCD and sickle cell trait.

The Strategic pillars are as follows:

**Primary prevention strategies:**

- Pre-marital and pre conceptional counselling.
- Genetic counselling and testing interventions in high prevalence districts.
- Widespread community involvement and support.

**Secondary Prevention and Screening:**

- Screening for detection of Sick Cell Trait to reduce the birth of children affected with Sick Cell Disease.
- Screening for early detection of sickle cell disease to achieve a reduction in mortality and morbidity with improvement in quality of life of the affected.
- Integration of the program to eliminate Hemoglobinopathies should be amalgamated with current strategies of National Health Mission (NHM) to warrant optimum judicious use of prevalent resources and curtail effort duplication similar to strategies of mission of Sick cell elimination program which has suggested to utilize the established platforms of Rashtriya Bal Swasthya Karyakram (RBSK), Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA), and Anaemia Mukh Bharat.

**11. Holistic management and continuum of care (under Clinical Care and Management function):**

- Provision of comprehensive accessible care in nearby home for individuals with haemoglobinopathies. Few equipped dedicated beds to be prepared in primary, secondary health centers to deal with emergencies (SCD crisis).
- Developing individualized treatment plans for patients such as:
  - a) Provision of blood transfusions in acute & chronic conditions. Trained health workers & doctors should be available for provision of exchange blood transfusion & treatment of disease along with complications of chronic blood transfusion.
  - b) Sustained provision of specialized costly medicines for treatment of the disease (hydroxyurea, pain killers), prophylaxis (penicillin), treatment of complications of blood transfusion (like iron chelation therapy). Availability of Vaccines specially Influenza & Pneumococcal will be beneficial.

- Managing complications and comorbidities associated with these disorders, such as infections, pain crises, and organ damage; with availability of emergency medical treatment, and facilities of intensive care units / high dependency units.
- Advanced diagnostic and treatment facilities at CoE/CoC like expertise of hematopoietic stem cell transplants, prenatal diagnosis, Patient support system. Financial support can be linked to MoTA, NHM.
- Community adoption & rehabilitation. It will contribute to holistic care.
- Establishment of Hemoglobinopathy patients Support System. List of patients should be maintained by Community Volunteer/ASHA/ANM/MPW for treatment monitoring and adherence. Jan Arogya Samitis (JSA) of SHC/PHC/UPHC shall facilitate awareness, prevention & treatment. They should also have skill development programs and Community adoption. VHSNC (Village Health, Sanitation, and Nutrition Committees), VHSND Village Health, Sanitation, and Nutrition Day to support for providing nutrition to the patients.
- Encouraging Adoption of Community by voluntary organizations to facilitate better treatment services, additional family support, improve nutrition facilities.

## **12. Capacity Building**

Module development for Comprehensive Hemoglobinopathies management – Prevention, screening and holistic treatment for medical officers posted in PHC/CHC, Community health officers at SHC, Staff nurses, ASHA/ANM/MPW should be developed by MoHFW and supervised by CoE/CoC.

Newer training modalities like ‘ECHO model’ would be very helpful.

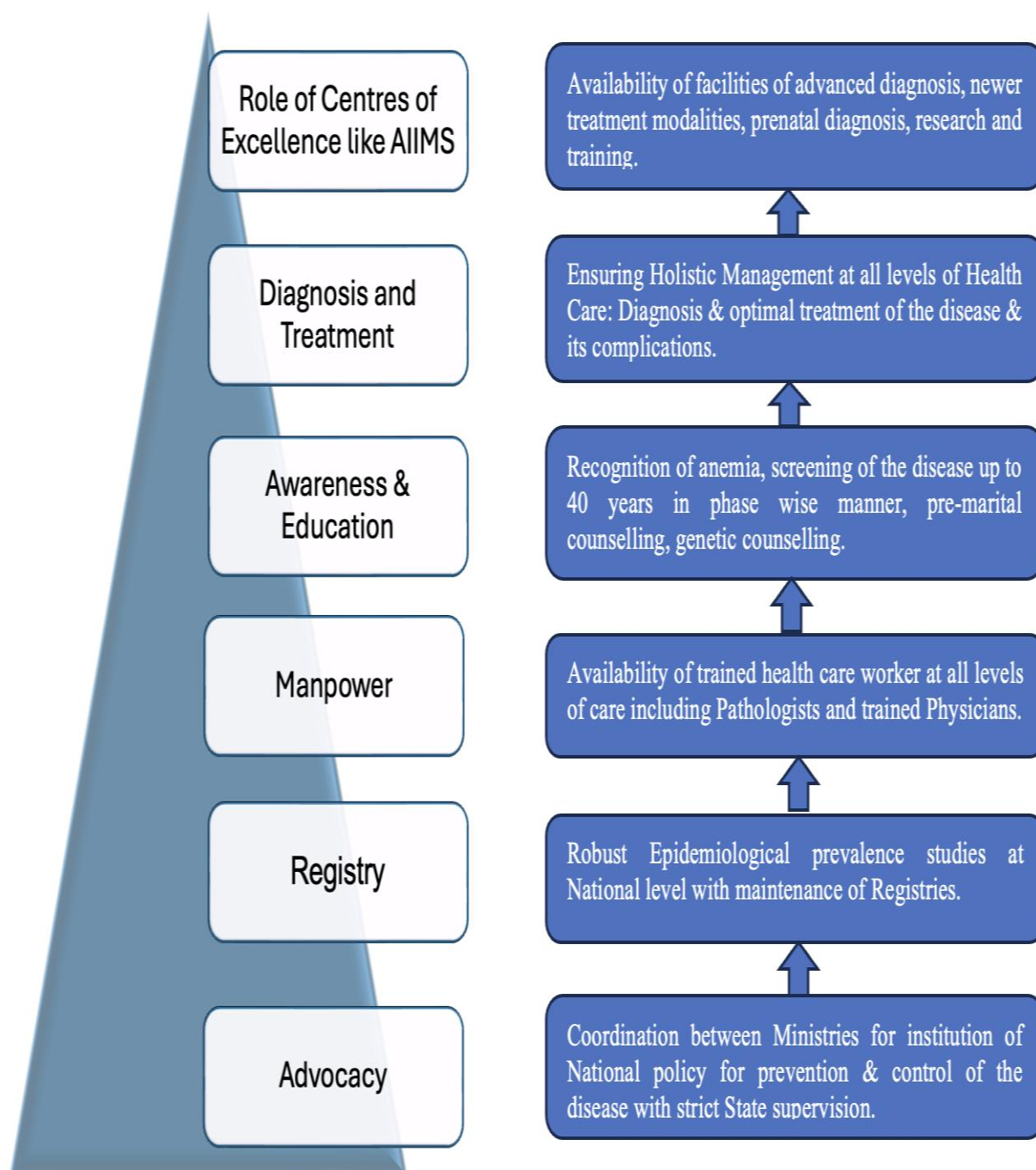
## **13. Collaborative research & Regional training center (Under Research and Clinical Trials, & Healthcare Professional Training functions)**

Research is required for:

- Precise prevalence phase wise data collection of districts wise of the country.
- Newer and cheaper robust methods of diagnosis.
- Newer modalities of molecular treatment.

- A regional training centre at CoE/CoC in State like All India Institute of Medical Sciences (AIIMS) that will conduct training of relevant stakeholders in prevention, identification & counselling. It will also play important role in provision of newer modalities of definitive treatment and diagnosis.
- Regular training of all levels of health care providers supervised by medical colleges/COE by newer cost-effective innovative methods like telemedicine services, ECHO model boon.
- Mutual International collaborative research can be undertaken e.g. TIF expertise (Thalassemia International Federation) for improving the scenario.

The above actions should be stepwise undertaken as in Figure-10.



**Figure-11: Intervention Steps in prevention & control of Hemoglobinopathies: Pyramidal approach**

Summary of the roles at various levels of health care are given in **Table 12(a) & 12(b)**.

**Table-12(a):** Summary of role of various levels of Health-Care (Part-1)(193-195)

**Community level**

*Role of ASHA/ANM/MPW:*

- Awareness through various IEC & multimodal medias by involving local tribal heads/health healers.
- Premarital & marital counselling - Use of color-coded cards is an innovative method for prevention of transmission of the diseases.
- Conduct screening camps from time to time. Positive cases to be transferred to nearest SHC-HWC/PHC-HCW for diagnostic confirmation & treatment.
- Ensure good follow up for patients for treatment adherence and encourage community adoption.

**Primary care level**

- ABHA registration of all patients for better follow up.
- Regular Screening of patients – from outpatients, fixed screening camps.
- Confirmation of diagnosis of positive patients referred from community level.
- Initiation of treatment of confirmed cases with proper follow up.
- Blood transfusion facilities and emergency treatment facilities to be provided.
- Teleconsultation services: if required, consultation can be provided from higher referral centers.
- Encourage community adoption.

**Secondary Health care level**

- Screening of patients
- Diagnostic confirmation of the disease
- Initiation of holistic treatment – provision of medicines (hydroxyurea, penicillin prophylaxis, chelators), blood transfusion as when required, Vaccines.
- Provision of beds for management of complications of the disease.
- Telemedicine services with tertiary centers, medical colleges, CoE/CoC.

**Table-12(b):** Summary of role of various levels of Health-Care (Part-2) (193-195)

### **Tertiary health care/CoE/CoC**

#### **1. Treatment:**

- Provision of definitive treatment like BMT, HSCT.
- Gene therapy.
- Transfusion services as when required.

#### **2. Diagnosis**

- Prenatal screening – provision of CVS (Chronic Villous Sampling).
- Confirmation of Diagnosis in case of difficult scenarios referred by SHC/PHC/UPHC.

#### **3.Training & Supervision:**

- **Teleconsultation services:** Provision of support to primary & secondary health care facilities through Telemedicine / e-Sanjeevani.
- **Supervision: Capacity building**-regular training of medical officers & health care workers regarding awareness, screening & treatment.

#### **4. Research**

- Undertaking of studies for Hemoglobinopathy prevalence studies, newer diagnostic & treatment modalities.

### **Role of Ministry**

- Coordination among different Ministries like MoHFW, MOTA, Ministry of Education, Ministry of Child and Women Development, Ministry of Human Resource Development for drafting of uniform policy regarding prevention, screening & treatment.
- Ensure adequate timeline development with adequate funding.
- Supporting of starting of CoE/CoC in each AIIMS of the State.
- State Ministry should ensure regular monitoring of National Program & adequate time allocation of resources from NHM/MOTA grants.

## **Way Forward**

As we move forward, it becomes increasingly evident from this discussion that inclusion of Tribal Health in national and state level regional policies is of paramount importance. Integrating this into national health programmes require tremendous efforts at all levels of healthcare and will only be possible with proper intersectoral coordination and proper delineation of focussed goals and objectives.

There are three focussed areas: prevention, diagnosis and management of cases with appropriate follow-up care. For prevention, new National Health Policy and Universal Health coverage as recommended by HLEG should be adopted. Addressing the burden of hemoglobinopathies and sickle cell anaemia among India's tribal populations requires a multifaceted approach.

First, widespread implementation of screening programs is essential for early detection of carriers and affected individuals. These programs should be accompanied by robust genetic counselling to help families understand and manage the risks. Improving healthcare infrastructure in remote tribal areas is crucial to provide timely and adequate treatment. This includes recruitment of adequate human resources maximally from tribal community: Arogya Mitras, ASHA, ANM with support from Gram Sabha. Additionally, public health campaigns must focus on raising awareness about these conditions, reducing stigma, and promoting preventive health practices. Collaborations between government agencies, non-profits, and community leaders can enhance the reach and effectiveness of these initiatives. Colour coded cards to be provided to carriers and diseased so that it would be helpful during marriage counselling. Screening of married couples and prenatal diagnosis of the disease would be helpful in prevention.

Diagnosis of hemoglobinopathies is another area of development and research. Newer cost-effective portable machines need to be developed that has almost matchable sensitive and specificity for confirmatory diagnosis. Such machines need to be installed in PHCs proximity to tribal village.

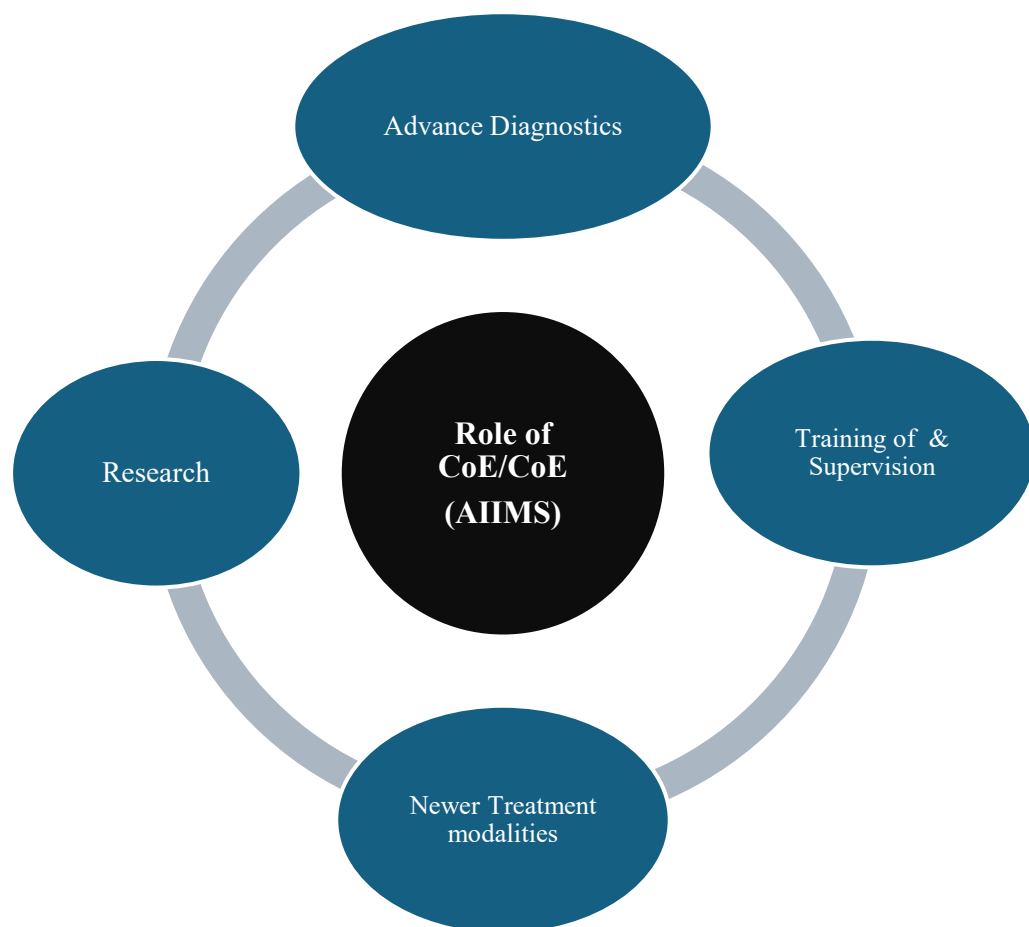
Rapid kit tests/POC for diagnosis of Hemoglobinopathies needs to be developed for early detection like SCD. Application of Artificial Intelligence in future would be helpful in confirmatory diagnosis of various hemoglobinopathies without the need of presence of pathologist in all cases. Drone facilities initiation will be of great help in inaccessible areas for transport of blood samples for diagnosis and medicines.

Early detection of patients with Haemoglobinopathies, managing them to give Day Care facilities, while having a multi-specialty approach and a patient-friendly environment will result in more effective management of the disease and early detection of chronic



complications. These can reduce the rate of disease progression and improve the quality of life. Helping patients with people suffering from sickle cell disease and other haemoglobinopathies, with much-needed emotional and educational support to their family members, will contribute to the longevity of the patients' lives.

Establishment of CoE/CoC in AIIMS in each state with multimodal role as illustrated in **Figure-11** that will help in capacity building of all districts of the country including Jharkhand to effectively deal with Hemoglobinopathies.



**Figure-11: Role of CoE/CoC to be established in AIIMS in each State**



# **Theme-VII**

## **Access to Healthcare**



## Introduction

All people, everywhere, have the right to achieve the highest attainable level of health.(183) However, indigenous peoples' life expectancy is up to 20 years lower than the life expectancy of non-indigenous peoples worldwide.(184) The life expectancy at birth for tribal (Schedule Tribe: ST) population in India is 63.9 years, as against 67 years for general population.(185) (186) The uneven access to health services drives life expectancy gaps.(187) A strong primary healthcare (PHC) system is paramount to optimising population health, yet PHC services are not always readily accessible.(188) From a human rights perspective, access to healthcare should be within reach of all, regardless of race, gender, culture, religion, political belief or socioeconomic condition.(189) Improving access to primary healthcare (PHC) for vulnerable populations is important for achieving health equity, yet this remains challenging. Evidence of effective interventions is rather limited and fragmented. We need to identify innovative ways to improve access to primary care for vulnerable populations, and to clarify which elements of health systems, organisations or services (supply-side dimensions of access) and abilities of patients or populations (demand-side dimensions of access) need to be strengthened to achieve transformative change.(190)

The 705 tribal communities of India mostly inhabit rural and inaccessible forested areas that are dispersed all over the country, and are devoid of the privilege of public health-care facilities that people living in urban areas of India have access to.(111) This disparity between tribal and non-tribal areas of India results in poor health outcomes for tribes, with increased local burden of communicable diseases in particular. Furthermore, sociocultural practices that involve high consumption of alcohol and tobacco and substance misuse, and poor awareness about public health system add to the suffering. The principal aim of tribes in India is to earn a satisfying meal a day that makes them feel content; local traditional tribal healers are relied upon when tribe members fall sick.(191)

Another important aspect is that near complete absence of participation of people from the tribal communities or their representatives in shaping policies, making plans, or implementing services in the health sector.(192)

Also, tribal communities' socio-behavioural practices prevent them from seeking public healthcare facilities, which are otherwise far from their homes. Unless equitable healthcare access is prioritised in all areas of society, a country such as India cannot be self-reliant. Therefore, empowering the tribal population can be a step towards mitigating the health issues in underprivileged communities (Figure-12).(193)

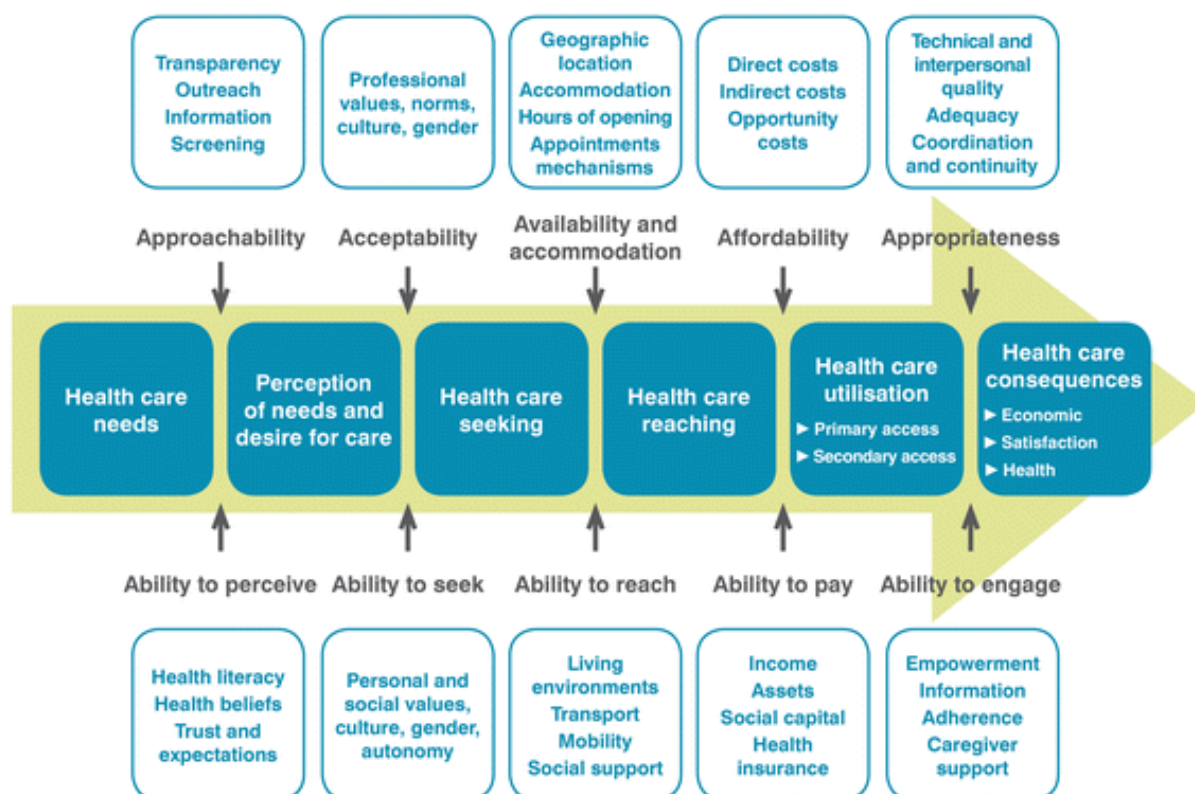


Figure-13: Conceptualisation of access adapted from Levesque et al.(194)

## Present scenario/Burden

“Public Health and Hospital” is a state subject, the primary responsibility of ensuring availability of healthcare facilities including access to healthcare facilities in tribal dominated areas lies with the respective State Governments.(195) The healthcare infrastructure and the number of specialists posted in tribal areas is worse than scarcity. The shortfall of healthcare infrastructure across 18 states and 3 Union Territories is found to be 27% Health Sub-Centres (HSCs), 40% Primary Health Centres (PHCs), and 31% Community Health Centres (CHCs), lacking penetration of primary healthcare services. In India, across 10 states with sizable tribal population, the percentage surplus/deficit of healthcare providers in tribal areas is found to be +64% ANMs at HSCs and PHC, -33% Allopathic doctors at PHC, and -84% specialists at CHC which depict the huge deficiency of specialist doctors and thus quality healthcare, lacking

Human Resources for Health (HRH) in the existing primary healthcare system. This is the state of healthcare delivery system in tribal areas despite having more than 50% and 66% of tribal population being dependent on public health system.(196)

### **Health-seeking behaviour**

Only availability of healthcare facility does not indicate a good health of the people of that particular area, if the people do not utilize this facility. Many studies have found that utilization of modern healthcare facilities is very poor among tribal population. A study conducted on tribal women at Odisha, India by Mahapatra M, et al (197) in 2000 have reported only 6% of participants exclusively use the allopathic type of treatment and 49% of them use traditional measure of treatment mainly provided by local quacks. It was also reported that 21.2% of women considered their illness not so serious and can be cured by home remedy or by traditional therapy. Also 11% of them have a belief that illness is God's wish and nobody can do anything about it. Other studies also came up with the similar findings that a disease is always caused by hostile spirits, ghosts, breach of some taboos, and curse of Gods.(211,212) Therefore, they seek remedies through religious and magical practices to propitiate the supernatural powers. They do not come to avail modern system of medicines and on the other hand, herbal medicine or indigenous medicines are their next preference of treatment which is obtained through local people. So, the gap is not only to the availability of modern and quality healthcare but also to develop behaviour change model to motivate them to use both quality Indian system of medicine with allopathic treatment.(196)

### **Justification**

Access to healthcare for tribal communities in India is a critical thematic area for several reasons:

- **Health Disparities:** Tribal communities in India face significant health disparities compared to the general population. They have higher rates of mortality, malnutrition, and disease prevalence. Improving access to healthcare is a crucial step in addressing these disparities. In 2021, for most of the indicators (**81 out of 129**), the non-tribal population were better off than the tribal populations.(191)

- **Socioeconomic Factors:** Tribal communities often live in remote, rural areas with limited access to healthcare facilities. (213,214) They also tend to have lower socioeconomic status, which can further limit their access to healthcare.(68,215) Focusing on this area can help address these socioeconomic barriers to health.
- **Cultural Sensitivity:** Tribal communities have unique cultural practices and beliefs that can impact their health behaviours and interactions with the healthcare system. A focus on culturally sensitive care can improve healthcare access and outcomes for these communities. (216-218)
- **Government Commitment:** The Indian government has made commitments to improve the health and wellbeing of tribal communities. This includes the National Tribal Policy and various schemes under the Tribal Sub Plan. Prioritizing healthcare access can help fulfil these commitments.(198)
- **Human Rights:** Access to healthcare is a fundamental human right. Ensuring that tribal communities in India have access to quality healthcare is an important part of upholding this right.
- **Public Health Impact:** Improving access to healthcare for tribal communities can have a significant impact on public health. It can lead to better disease control and prevention, improved health outcomes, and a healthier population.

Focusing on improving access to healthcare for tribal communities in India is justified due to the significant health disparities they face, the impact of socioeconomic and cultural factors on their health, the government's commitments to improving their health, the importance of upholding human rights, and the potential for significant public health impact. It's a critical area that requires attention, resources, and targeted interventions.



## Challenges

The major challenges to access to healthcare : (196,199)

- **Geographical Barriers:** Many people live in remote or rural areas where healthcare facilities are not easily accessible. This is particularly true for tribal and marginalized communities.
- **Lack of Awareness:** Many people are not aware of the importance of preventive healthcare and regular check-ups. This can lead to delayed diagnosis and treatment of diseases.
- **Cultural and Language Barriers:** Differences in language and cultural beliefs can hinder access to healthcare. Patients may not seek care if they feel that providers do not understand their culture or language.
- **Shortage of Healthcare Providers:** There is a global shortage of healthcare providers, particularly in rural and underserved areas. This can result in long wait times and reduced quality of care.
- **Health System Challenges:** This includes factors like inadequate infrastructure, lack of essential medicines, and poor quality of care.
- **Social Determinants:** Factors such as education, employment, income, and social status can impact a person's ability to access healthcare.
- **Financial Constraints:** Healthcare can be expensive and not everyone can afford the cost of treatment, medicines, or hospital stays. Inadequate health insurance coverage can also be a significant barrier.
- **Policy and Regulatory Barriers:** These can include restrictive laws and regulations, lack of health policy, or ineffective implementation of health policies.

Addressing these challenges requires concerted efforts from all stakeholders, including

government, healthcare providers, and communities. It's important to develop strategies that are context-specific and take into account the unique needs and circumstances of different populations.

## **Gaps/Lacunae**

Access to healthcare for tribal populations in India faces several gaps and lacunae, leading to disparities in health outcomes and services. Some key issues include:

- **Lack of Infrastructure:** Although the government has provided for the establishment of Primary Health Centres (PHCs) in tribal areas for every 20,000 population and sub-centres for every 3,000 population, quality healthcare is not available to the majority of tribals. Posts of doctors and paramedical are often vacant.(200)
- **Social Stigma:** The social stigma attached to tribals/adivasis often result in medical services never reaching their communities. This stigma, combined with tribal/adivasi traditions and culture, can lead many to seek spiritual healing rather than medical assistance. Addressing these social determinants of health is crucial for improving healthcare access.(201)
- **Reliance on Traditional Healing Practices:** Most Indian tribes have limited access to healthcare facilities and rely heavily on traditional healing practices. This can lead to a gap in the implementation of healthcare services and in accessing and availing these services by the indigenous population in India.(202)
- **Health Workforce Shortage:** There is a shortage of healthcare professionals willing to work in tribal regions, leading to understaffed healthcare facilities.

## **Intervention strategies**

There are several strategies for improving healthcare access among tribal populations:

- **IMPACT Model:** The IMPACT (Innovative Models Promoting Access-to-Care Transformation) model aims to identify, implement, and trial best practice interventions to improve access to primary healthcare for vulnerable populations. It uses an

environmental scan to identify a wide range of innovations improving access to primary healthcare.(190) It aims to transform PHC organizational structures, develop partnerships, identify effective interventions, and evaluate the scalability of these innovations. It focuses on co-creating care models that reduce unmet needs, avoidable emergency department visits, and hospitalizations.(203)

- **Hub-and-Spoke Design:** This model has been identified as successful for delivering healthcare services in rural and remote areas of the world. It strengthens partnerships resulting from careful implementation, which can improve the odds of a rural hospital's survival and success.(204) This model can be effectively used in tribal communities. It establishes an education centre within an existing community facility, such as an orphanage or hospital, to serve as the hub. This system allows for inter-hamlet information sharing, such as education, health care, nutrition, and agriculture. It also enables multiple interconnected services to the entire community.(205)
- **Strengthening Primary Healthcare:** Primary Health Centres (PHCs) are often the first point of contact for tribal communities. Strengthening these centres, ensuring they are adequately staffed, and providing them with necessary resources can improve access to healthcare.(206) Strengthening primary healthcare involves making services available closer to communities, reducing costs, and providing more trained health workers.(207) Strong primary healthcare can improve health outcomes, lower mortality, and result in significant cost savings.(208)
- **Mobile Health Units:** Mobile Health Units (MHUs) are customized vehicles that travel to communities to provide healthcare. They serve an important role in healthcare, ensuring access to care for millions and advancing health equity. MHUs can improve access by serving as a vital link between the community and clinical facilities.(209) Given the remote locations of many tribal communities, mobile health units can be an effective way to deliver healthcare services. These units can provide regular check-ups, vaccinations, and basic healthcare services.(210)
- **Culturally Sensitive Care:** Culturally Sensitive Care is an approach to healthcare that respects and recognizes the unique cultural background of each patient. Culturally

sensitive care is vital **to** providing holistic, effective treatment for physical and mental health issues.(211) Healthcare providers should be trained to provide culturally sensitive care. This includes understanding tribal customs and beliefs, and incorporating them into healthcare delivery.(212)

- **Community Health Workers:** Community Health Workers (CHWs) are frontline public health workers who live in or are trusted by the community. They promote wellness by helping people adopt healthy behaviours and advocate for people who may have limited access to health resources and social services.(213) Training members of the tribal community as health workers can be an effective way to bridge the gap between the healthcare system and the community. These workers can provide basic healthcare services, and can also act as a link between the community and the healthcare system.(214)
- **Health Education:** Health Education to tribal communities involves providing basic health information and promoting healthy behaviours. Health education increases awareness of local environmental conditions, potential exposures, and the impacts of exposures on individual and public health.(215) Providing health education to tribal communities can help them understand the importance of preventive healthcare, and can also help them navigate the healthcare system.(216)
- **Public-Private Partnerships:** Public-Private Partnerships (PPPs) have been effective in delivering healthcare services to tribal communities. When these partnerships are implemented effectively, they empower Tribes to take the lead and utilize their knowledge for the collective betterment of their communities.(217) Partnerships between the government and private entities can help in delivering healthcare services to tribal communities. This can include partnerships with NGOs, private hospitals, and other healthcare providers.(218)
- **Telemedicine:** Telemedicine in tribal communities is a powerful tool for overcoming barriers such as geographic isolation and limited resources.(219) Telehealth can help reduce socioeconomic burdens and health disparities by providing a more convenient, lower-cost model of care.(220) This can include consultations with specialists, follow-up care, and monitoring of chronic conditions.(221)

- **Government Policies:** The government should formulate and implement policies aimed at improving healthcare access for tribal communities. This can include policies related to healthcare infrastructure, healthcare financing, and healthcare personnel.(222) Addressing key determinants such as lack of knowledge, traditional healing practices, and poor utilization of healthcare services is crucial.(223)

## **Role of Faith healers**

Faith healers or tribal healers or traditional healers play a significant role in health interventions, particularly in sub-Saharan Africa, where they are often integrated into the health systems due to their influence and accessibility within communities.(224)

**First Point of Contact:** Faith healers often serve as the initial point of contact for individuals seeking cure and prevention of diseases. In urban Ghana, for instance, faith healing practices are a primary choice for many, and users generally perceive their health status to be good due to the effectiveness they attribute to faith healing.(244,245)

**Influence on Health Behaviour:** Faith leaders can influence health behaviour not only on an individual level but also on a socio-cultural and environmental level. They exert influence through scriptural teachings, social influence, and by serving as role models, which can significantly impact health practices and decisions.(225)

Faith-inspired healthcare providers are involved in public-private partnerships, playing a crucial role in the health service delivery system. They account for a significant share of health facilities in some countries, ranging from long-standing missionary establishments to newer services set up by faith communities.(226)

## **Drone Delivery of healthcare**

Many countries in the world are using drone delivery of healthcare to deliver blood products to remote health facilities for its use in maternal care for obstetric haemorrhages, and in surgical procedures. They found drone delivery led to shorter delivery times and less blood component wastage in health facilities. However, its cost-effectiveness, and whether drone delivery might be effective for other pharmaceutical and health supplies was not explored.(227) Also, to

improve bystander defibrillation for out-of-hospital cardiac arrests is to dispatch and deliver an automated external defibrillator (AED) directly to the suspected cardiac arrest location by drone. This intervention potentially decrease time to attachment of an AED, before the arrival of ambulance.(228)

There might be multiple reasons for these use-cases. Commercially available rotor-wing drones have a maximum range of ~50-60 km, requiring battery replacement at relay points. Also, in urban areas, the comparison of delivery times must consider the traffic situation, and the time savings from drones could be greater in cities with more congested traffic.(229) However, a significant deficiency was found in the number of reported studies analysing mode of medical products transportation and adaptation of drones in maternal healthcare.(230)

In Scotland, air mobility company Skyports transport medical supplies including COVID-19 test samples and personal protective equipment between remote health facilities. CAELUS project aims to develop a network of drones to deliver a range of medical products including medicines and transplant organs. In Uganda, Johnson and Johnson is supporting a project that uses drones to transport antiretroviral therapies.(231)

"The Medicine from the Sky initiative has demonstrated how the country can successfully make use of cutting-edge drone technology to ensure no one is left behind, in terms of access to primary healthcare. We are hopeful that subsequent phases of this initiative will mainstream drones in healthcare."— Jyotiraditya Scindia, Minister for Civil Aviation and Steel, India.(232) In hard-to-reach areas, saving minutes can save lives during health emergencies. On-demand drone delivery can cut delivery times to under an hour, a stark improvement over traditional ground transportation method. The pursuit of these solutions is not merely a technical endeavour but also an ethical imperative and a guide toward a future where essential services are accessible to all, irrespective of geography or socioeconomic conditions.(233)

Optimisation of supply chains, pandemic response, search and rescue, defibrillator deployment, engineering and design considerations, cost-effectiveness, blood and organ transport, ethical and social considerations, overcoming remoteness, emergency response, disaster relief are some of the areas where drone have been experimented and found to have a future.(234) Half

of the world's population have limited access to healthcare and help may be on the way in the form of medical delivery drones.(235)

## **Artificial Intelligence (AI) in Healthcare**

It's a powerful area of computer science, with a great potential to transform the practice of medicine along with healthcare delivery. Healthcare around the world is facing significant challenges in achieving the 'quadruple aim' i.e improving health of population, improving the experience of patients towards care, enhancing the caregiver experience, and reducing the rising care cost.

The application of AI in healthcare can address some of these supply-and-demand challenges. The increased availability of multimodal data (genomics, demographic, phenotypic and clinical) coupled with innovations in technology like mobile, internet of things (IoT), computing power and data security is leading towards a convergence between healthcare and technology to fundamentally transform healthcare delivery models through AI-augmented systems.

AI is not one ubiquitous, universal technology, rather, it represents several subfields like machine learning and deep learning, that either individually or in combinations adds intelligence to applications.

**Machine Learning (ML)** itself can be classified as 'supervise', 'unsupervised' and 'reinforcement learning (RL)'. **Deep Learning (DL)** is a class of algorithms that learns by using a large, multiple-layered collection of connected processes, and then exposing these processors to a large set of examples. The first stage is to design and develop AI solutions for the right problems using a human-centred AI and experimentation approach and engaging appropriate stakeholders, especially the healthcare users themselves. This requires building a multidisciplinary team.

Research in the application of AI healthcare continues to accelerate rapidly, with potential use cases being demonstrated across the healthcare sector (both physical and mental health) including drug discovery, virtual clinical consultation, disease diagnosis, prognosis, medication management and health monitoring.

In the long term, we expect that healthcare clinics, hospitals, social care services, patients and caregivers to be all connected to a single, interoperable digital infrastructure using passive sensors in combination with ambient intelligence.(236)

## **Health Referral**

World Health Organization (WHO) defines, “Referral is a process in which a health worker at one level of the health system, having insufficient resources (drugs, equipment, skills) to manage a clinical condition, seeks the help of a better or differently resourced facility at the same or higher level to assist in.” To fulfil the existing gaps in Health Infrastructure a sound referral is needed, as there are only less than 20% of Sub-Centers, Primary Health Centers & Community Health Centers that meet Indian Public Health Standards; 80% of them fall short of Gynaecologists, Paediatricians and Physicians.(237)

In India, the real challenge is, anyone can go to any level of health care system without any referral. This poses a burden on the secondary and tertiary level hospitals or health settings where a large number of patients with minor ailments throng the out-patient departments (OPD) and increases the bulk of patients who can be easily tackled at the lower level health care settings.

The problems in implementing a successful referral system in India are : (1) non availability of adequate trained manpower, infrastructure (laboratory facilities, drug supplies, equipment's, furniture etc.) in the primary health care settings, (2) lack of strict regulation on the referral system, (3) lack of strict regulation in avoiding minor cases coming directly to secondary or tertiary care hospitals, (4) non-availability of universal health-card indicating the health facility for initial screening. This problem can be solved by demarcating the areas for health facility for each citizen using either the Aadhar card (digitized identity card) or universal health-card and making a strict regulation that only those seen in the designated health centres would be considered for health services once referred. This will lessen the burden in the tertiary health facilities and the health care providers can dedicate their time and energy in taking care of those referred with quality service provision.(238)

AIIMS in collaboration with Delhi Govt to establish referral system for system for emergency patients. This referral system would be a forward and backward referral system which means



patients requiring tertiary level of care can be referred to AIIMS from other hospitals and patients who do not require immediate care would be referred to secondary level care hospitals across Delhi.(238)

Online referral management system (ORMS) will not only save the initial golden hour but will also lead to decline in mortality. The ORMS will save unnecessary paper work in the hospitals. There will be real-time monitoring of the data entered by health workers on mobile phones and easy integration of data with the existing systems, e.g. HMIS along with cloud storage of patient records will also provide a dashboard window for State/Hospital/Department Health Activity statistics  $24 \times 7$ . The test reports can be exchanged online, that will bring ease in prior appointments and online prescriptions. Overall, there will be a seamless integration with Public/Private Sector as patients reports/treatment from Private Sector will also be made shareable with Govt. Hospitals.

e-Referrals can reduce 'DISTANCE' between Periphery & the Tertiary Centers. Further, this will aid health workers for timely management of cases. Most importantly, it will streamline the existing unorganized referral process. Thus, for effective e-Referral System, there should be a collaborative platform where easy search and discover for health care providers is possible and help in decision making. Lastly, it should be universally accessible. e-Referral should be incorporated in our health system to strengthen it by bridging the access gap through Public Private Partnership model.(237)

## **Recommendations**

### **Policy**

- A National Plan of Action for the Health of tribal people is required to engage and support full, effective and equal participation of tribals, through their own representative institutions, in the development, as well as monitoring and evaluation of the implementation, of the relevant health plans, strategies or other measures for tribals, including those related to public health emergencies.
- It is essential to develop knowledge about the health situation of tribals through ethical data collection with the purpose to identify specific needs and gaps in access to and

coverage by current physical and mental health services and obstacles in their use, identification of reasons for these gaps and solutions on how to address them.

- It is imperative to encourage the attraction, training, recruitment and retention of tribals as health workers, as well as training and capacity-building of human resources to care for tribals with an intercultural approach, including in the context of public health emergencies.

### **Services and training**

- Cultural sensitization and education of primary health care providers about common ailments of tribals and their treatment. Screening, intervention and referral to treatment can be more frequently used in primary care, by providing access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative, rehabilitative and palliative essential health services and strengthening access to immunization in tribal areas and for tribals irrespective of where they live.
- Tele-education & tele-mentoring of frontline healthcare workers and medical professionals about issues affecting tribals most such as sickle cell disease etc. As a long-term goal, there is a need to sensitize undergraduates by incorporating tribal centric modules in the curriculum at the MBBS level.
- Expanding the healthcare services available and making a basket of services available to cater to different needs of the population using telemedicine, drone delivery of healthcare and strong referral system.

### **Education and awareness**

- Health literacy is to be improved in a systematic manner especially through younger population in educational institutions for tribals such as Eklavya Model Residential Schools (EMRS), ashram schools & residential & non-residential tribal schools/hostels.
- Health promotion measures to enhance awareness about healthy lifestyle and reduce substance use among the tribal population, with full consideration to their social, cultural and geographic realities.

## **Way forward**

Improvements in the information landscape for India's Scheduled Tribes is a significant step towards the development of an efficient knowledge management repository to promote the well-being of all marginalized sections in India. Now it is an opportune moment to expand the data landscape assessing the health status of tribal population v/s the non-tribal population, as well as the progress that Scheduled Tribes are making as a group. Engagement with sub national data for monitoring tribal health can support policymaking and program implementation. Data analysis of the progress of these tribal populations also has vital implications for equitably aligning resources with community needs.

## **DECLARATION OF CONFLICT OF INTEREST**

There is no conflict of interest to declare by any of the contributors/authors. All the authors have equally contributed to the conceptualization, data curation, formal analysis, methodology, drafting, reviewing and editing of this report. All the authors have read and approved the enclosed report. There is no financial support or grants in any form to declare.

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%20would%20be,Delhi%2C%E2%80%9D%20the%20letter%20stated

## **ANNEXURES**

**Annexure-I:** Local & Forest vegetables, along with their nutritional value.

<b>S. No.</b>	<b>Name of vegetables</b>	<b>Iron mg/100 g</b>	<b>Protein (%)</b>	<b>Vitamin C mg/100 g</b>
1.	Lal Math (Red Amaranth)	106	12.04%	16
2.	Latari Bhaji	85	29.7%	17
3.	Chawali Bhaji (Green Amaranth)	90	19.50%	5
4.	Kuda Flower (Holarrhena antidysenterica)	34	12.78%	27
5.	Mahua Flower (Madhuca longifolia)	22.42	3.76%	15.73
6.	Moringa leaves	29	18.14%	19
7.	Cassia fistula Flower	31	11.30%	3796
8.	Cauliflower	16	15.53%	37
9.	Halim / Chansur	19	21.70%	-
10.	Sesbania grandiflora	10	40.55%	-
11.	Aamala	3	1.87%	1224
12.	Bathua Bhaji	27	24.38%	-
13.	Hibiscus cannabinus Leaves	47.40	22.90%	13.80
14.	Aratfari	26.29	27.69%	6.77
15.	Lal Bhaji	56.57	25.10%	-
16.	Cassia tora	44.66	27.17%	4.01
17.	Lengada Bhaji	54.08	21.67%	8.82
18.	Kanda Bhaji	23.14	19.79%	30.14`
19.	Sherdire Vegetables	23.28	18.54%	1.40
20.	Kheda Bhaji	23.14	19.79%	30.14

**Annexure-II:** Nutritive value of Rice, Finger Millet, Kodo Millet and Kutaki Millet

<b>Particular</b>	<b>Protein (g)</b>	<b>Fiber (g)</b>	<b>Salt (g)</b>	<b>Iron (g)</b>	<b>Calcium (g)</b>	<b>Carbohydrates (mg)</b>	<b>Vitamin B1 (mg)</b>	<b>Vitamin B2 (mg)</b>	<b>Niacin (mg)</b>	<b>Vitamin A</b>
Rice	6.8	0.2	0.6	0.7	20	76	0.41	0.04	4.3	0.00
Finger Millet	7.3	3.6	2.7	3.9	344	72.6	0.42	0.19	1.1	42
Kodo Millet	8.3	9	2.6	0.5	27	66.6	0.15	0.15	2	4
Kutaki Millet	7.7	7.6	1.5	9.3	17	60.9	0.3	0.09	3.2	5



**Annexure-III:** Nutritive value of Vitamins & Minerals in Polished Rice and Hand Pound Rice.

S. No.	Vitamins & Minerals	Polished Rice	Hand Pound Rice	Difference
1.	Vitamin B1	0.03 mg/per 100 g	0.10 mg/per 100 g	3 Times
2.	Vitamin B2	0.04 mg/per 100 g	0.09 mg/per 100 g	2 Times
3.	Iron	0.64 mg/per 100 g	2.20 mg/per 100 g	3 Times
4.	Fiber	0.90 mg/per 100 g	1.80 mg/per 100 g	2 Times
5.	Zinc	0.37 mg/per 100 g	0.63 mg/per 100 g	2 Times
6.	Folic Acid	2 mg/per 100 g	4 mg/per 100 g	2 Times
7.	Phosphorus	55 mg/per 100 g	83 mg/per 100 g	2 Times

**Annexure-IV:** Comparison chart of Nutrients in Mahua flower and Milk

<b>S.No.</b>	<b>Particular</b>	<b>Mahua Flower(100gms)</b>	<b>Milk (100gms)</b>
1.	Edible portion	89	-
2.	Moisture Content	18.6	7.5
3.	Proteins	4.4g	3.2
4.	Fat	0.6g	0.8
5.	Minerals	2.7g	-
6.	Fiber	1.7g	-
7.	Carbohydrates	72g	4.4
8.	Energy	311 Kcal	67
9	Calcium	140 mg	120
10.	Phosphorus	140 mg	90
11.	Iron	15 mg	0.2
12.	Carotene	23 ug	174
13.	Thiamine	0.03 mg	0.5
14.	Riboflavin	0.88 mg	0.10
15.	Niacin	5.2 mg	0.1
16.	Vitamin C	7 mg	2.0

**Annexure-V:** Comparison chart of Nutrients in Jaggery and Sugar

<b>S.N.</b>	<b>Particular</b>	<b>Jaggery (100 g)</b>	<b>Sugar (100 g)</b>
1.	Proteins	0.4 g	-
2.	Minerals	0.6 g	-
3.	Carbohydrates	95 g	99 g
4.	Calcium	80 mg	-
5.	Phosphorus	40 mg	-
6.	Iron	11.4 mg	-
7.	Carotene	168 g	-
8.	Thiamine	0.02 mg	-
9.	Riboflavin	0.04 mg	-
10.	Niacin	0.05 mg	-

**Annexure-VI:** Details of the Expert Members of the National Task Force

<b>S.No.</b>	<b>Task Force Member</b>	<b>Email</b>	<b>Contact number</b>
1.	<b>Prof. (Dr.) Saurabh Varshney</b> Chairman of Task Force Executive Director & CEO All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drsaurabh68@gmail.com	+91-8475000273
2.	<b>Dr. Aparup Das</b> ICMR, New Delhi	das.aparup@icmr.gov.in	+91-9968074889
3.	<b>Dr. (Mrs.) Sanghamitra Pati</b> Director & Scientist G ICMR-RMRC (Regional Medical Research Centre) Chandrashekharapur, Bhubaneswar, Orissa	sanghamitra.pati@icmr.gov.in	+91-9437093306
4.	<b>Dr. K. Rekha Devi</b> Scientist-F ICMR-RMCR (Regional Medical Research Centre) Dibrugarh, Assam	krdevi.rmrcne@gov.in  krekha75@yahoo.co.in	+91-7838218708
5.	<b>Dr. Pradeep Dwivedi</b> Additional Professor Department of Pharmacology All India Institute of Medical Sciences (AIIMS) Jodhpur, Rajasthan	dwivedi@aiimsjodhpur.edu.in  dr.prad99@gmail.com	+91-8003996952  +91-9024902940
6.	<b>Prof. (Dr.) G. Jahnavi</b> Professor & Head Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	gjahnavi108@gmail.com	+91-7063956228
7.	<b>Dr. N. Arlappa</b> Scientist-G ICMR-National Institute of Nutrition Hyderabad	arlappan@yahoo.com	+91-9849543946

8.	<b>Dr. Tapas Chakma</b> Scientist-G ICMR-NIRTH (National Institute of Research in Tribal Health) NIRTH Complex, Nagpur Road P.O.Garha, Jabalpur (MP)	chakmat@gmail.com	+91-9425386345
9.	<b>Dr. Dheeraj Kattula</b> Associate Professor Department of Psychiatry CMC, Vellore	askdheeraj@gmail.com	+91-8220498458
10.	<b>Prof. (Dr.) Rajkumar Lenin Singh</b> Professor Department of Psychiatry RIMS Imphal, Manipur	leninrk@yahoo.com	+91-9862088736
11.	<b>Dr. Satish Gogulwar</b> Convenor and Founder Trustee Amhi Amchya Arogyasathi Gadchirolli, Maharashtra	satish.arogyasathi@gmail.com	+91-9422123016
12.	<b>Dr. GVL Narasimha</b> Assistant Professor Centre for Addiction Medicine Department of Psychiatry NIMHANS, Bengaluru	narasimha.gvl.mbbs@gmail.com	+91-9742857330
13.	<b>Dr. Dewesh Kumar</b> Associate Professor Department of Community & Family Medicine RIMS, Ranchi	dr.dewesh@gmail.com	+91-7728960405
14.	<b>Dr. Subarna Roy</b> Director National Institute of Traditional Medicine	roys@icmr.gov.in	+91-9449033133

<b><u>Co-opted Members</u></b>			
15.	<b>Dr. Rajesh Kumar</b> Associate Professor Department of General Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drrajeshdr@yahoo.co.in	+91-8809663800
16.	<b>Dr. Santanu Nath</b> Associate Professor Department of Psychiatry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	santanu.psychiatry@aiimsdeoghar.edu.in	+91-9337434349
17.	<b>Dr. Richa</b> Associate Professor Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	dr-richapsm@gmail.com	+91-9631519173
18.	<b>Dr. Arshad Ayub</b> Assistant Professor Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drarshadayubcommed@gmail.com	+91-7077786137
19.	<b>Dr. Adity Bansal</b> Assistant Professor Department of Dentistry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	aditybansal@rediffmail.com	+91-9876611900
20.	<b>Dr. Indranil Das</b> Assistant Professor Department of Transfusion Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	indranil.bloodbank@aiimsdeoghar.edu.in	+91-7598072067

Secretariat			
1.	<b>Dr. Richa</b> Associate Professor Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drrichapsm@gmail.com	+91-9631519173
2.	<b>Dr. Adity Bansal</b> Assistant Professor Department of Dentistry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	aditybansal@rediffmail.com	+91-9876611900

**Annexure-VII:** List of the Members of the Drafting Committee/Internal Committee Members

1.	<b>Prof. (Dr.) Saurabh Varshney</b> <b>Chairman of Task Force</b> Executive Director & CEO All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drsaurabh68@gmail.com	+91-8475000273
2.	<b>Prof. (Dr.) G. Jahnavi</b> Professor & Head Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	gjahnavi108@gmail.com	+91-7063956228
3.	<b>Dr. Rajesh Kumar</b> Associate Professor Department of General Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drrajeshdr@yahoo.co.in	+91-8809663800
4.	<b>Dr. Santanu Nath</b> Associate Professor Department of Psychiatry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	santanu.psychiatry@aiims deoghar.edu.in	+91-9337434349
5.	<b>Dr. Richa</b> Associate Professor Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	dr-richapsm@gmail.com	+91-9631519173
6.	<b>Dr. Arshad Ayub</b> Assistant Professor Department of Community & Family Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	drarshadayubcommed@gmail.com	+91-7077786137



7.	<b>Dr. Adity Bansal</b> Assistant Professor Department of Dentistry All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	aditybansal@rediffmail.com	+91-9876611900
8.	<b>Dr. Indranil Das</b> Assistant Professor Department of Transfusion Medicine All India Institute of Medical Sciences (AIIMS) Deoghar, Jharkhand, India	indranil.bloodbank@aiimsdeoghar.edu.in	+91-7598072067

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