# From the Margins to the Centre

## A study on the health inequities among the tribal communities in selected districts of Chhattisgarh, Jharkhand and Odisha

Research by

Sama – Resource Group for Women and Health

Supported by National Human Rights Commission

This research was conducted between 2017 and 2018

by

**Sama – Resource Group for Women and Health**

B-45, 2nd Floor, Shivalik Main Road,

Malviya Nagar,

New Delhi 110017

Email: sama.womenshealth@gmail.com

Website: http://www.samawomenshealth.in

Sama, a Delhi-based resource group for women and health, was initiated in 1998 by a group of feminist activists from the autonomous women's movement. Sama advances an understanding of health from a gender, caste, class and rights perspective, and seeks to locate the concerns of women's health in the context of socio-historical, economic and political realities.

Sama believes that equality and empowerment, can be ensured only when poverty, curtailment of capabilities, lack of livelihood rights, lack of health services and access to health care, illiteracy and multiple forms of discrimination based on caste, class, gender religion, ethnicity, sexuality, disability and many other rubrics are structurally challenged. Sama is committed to integrate gender, caste, class and rights analysis within the wider context of other social relations in order to emphasize the complexity of existing power relations that work towards exclusion and marginalization. Through its work, Sama seeks to bridge the gap between community voices and policy outcomes as well as facilitate understanding and action on health through inter-sectoral and inter-movement linkages.

The research has been supported by

**National Human Rights Commission**

# Contents

# Acknowledgements


### *The Research Team*

Overall coordination of the Research: Sarojini N, Deepa V and Rizu

**State level field work:** Rizu, Adsa Fatima, Sarojini N, Ruchi Bhargava, Susheela Singh with Kalyani Badola, Geetika Vashist (both were formerly with Sama during the field work) and Mr. Gouranga Mohapatra (Jan Swasthya Abhiyan, Odisha)

**Analysis and writing:** Sarojini N, Deepa V, Rizu, Adsa Fatima, Ojaswini Bakshi, Ruchi Bhargava, Oshin Siao Bhatt, Prathibha Sivasubramaniam with Ranjan De.

**Local Investigators:** Mr. Pranaya Kumar Panda, Nuapada; Ms. Kusum Rajwadi, Koriya; Mr. Md. Arif Ansari, Gumla; Mr. Prasan Tirkey, Latehar.

**Other research support:** Megha Kain

### *Acknowledgments*

We would like to thank, first of all, the women, men and children and their families who participated in the research and generously shared their experiences regarding their health problems. This report is dedicated to them. Our sincere thanks to the participants from the focus group discussions in the villages. We hope that their voices and concerns, reflected here, will inspire introspection and action towards the fulfilment of the rights of tribal communities. We hope that the recommendations will be considered by the Centre and State governments towards achieving right to health of tribal communities in the country.

We extend our sincere thanks to the National Human Rights Commission (NHRC) for their unstinting support that has not only made this research possible, but also strengthened Sama's overall engagement with the issue. Special thanks to the Chairperson, Hon'ble Justice H. L. Dattu, Mr. Ambuj Sharma (Secretary General, Chief Executive Officer of the Commission), Dr. M. D. S. Tyagi Jt. Director (Research), Dr. Ranjit Singh (Joint Secretary for P and A), Mr. Nishchith and Ms. Priyanka from NHRC. We also thank NHRC's technical and administrative staff for their cooperation. We are grateful to Mr. J. S. Kochher (former Jt. Director, Research, NHRC) for his support and also for contacting district officials to make arrangements for our stay in places where it was not available. Thanks to Dr. Savita Bhakhry (formerly with NHRC) for encouraging Sama to take up this important Study.

We are extremely grateful to our advisor – Dr. Yogesh Jain, Jan Swasthya Sahyog (JSS) for his support throughout the study, and for his guidance, inputs to the various sections of the report, suggestions to the recommendations that have shaped this research and analysis.

Our special thanks to Dr. Indranil Mukhopadhyay (JSA, Jindal Global University) for contributing to the chapter on Health Systems. We are extremely grateful to Mr. Samir Garg, State Health Resource Centre (SHRC), Chhattisgarh for his suggestions, inputs to the recommendations and also introducing us to the Mitanins. We sincerely acknowledge Ms. Sulakshana Nandi and Ms. Deepika Joshi of Public Health Resource Network (PHRN) and Chaupal, for sharing their experiences of working with tribal communities, relevant documents and their inputs. We thank Dr. Prabir Chatterjee, SHRC for his prompt suggestions on specific technical parts.

Special thanks to Ranjan De for his meticulous review of the drafts, editing and for the layout of the report. Without his support the report would not have been completed in such a short period.

We would like to thank Dr. Mamta Bhushan Singh, Professor, Neurology, All India Institute of Medical Sciences (AIIMS), Ms. Malini Ghose, Adv. Veena Johari and Mr. Vivek Divan for their comments and inputs on specific sections of the report. Thanks to Ms. Meena Seshu, Ms. Aarti Pai and Dr. B. Subhasri for providing valuable inputs on certain recommendations.

We also thank Ms. Malini Sood and Ms. Oshin Siao Bhatt for editing a few sections of the report within a tight schedule.

We are grateful to Ms. Jashodhara Dasgupta, Dr. Rakhal Gaitonde for sharing the reports, studies on maternal health among tribal women; conflict and health. We acknowledge the contribution of Prof. Padmini Swaminathan, Ms. Philomena Vincent, Prof. Rama Baru, Dr. B. Subhasri, Ms. Prabha Nagaraja and Ms. Vrinda Marwah (all Sama Board members) for their initial observations and inputs.

We acknowledge Ms. Noyana Khatoniar (Sama) for helping with the data compilation for the profile section and Ms. Pallavi Gahlaut (Sama) for her support. Thanks to Mr. Ashok Yadav, Mr. Chandan Prashad and Mr. Antony Kurien for their support with finances and administration. We would like to thank Mr. Kishor Goswami for the initial layout.

### *Special thanks statewise*

#### In Odisha

We are grateful to Mr. Gouranga Mohapatra, JSA for his contribution, contacts and support for conducting the research in Nuapada and Rayagada in Odisha. Thanks to Mr. Abani Panigrahi from Lokdrushti for his inputs on issues particularly on migration and also providing local investigators for the research. We would like to thank the team at Chale Chalo for sharing their work. Thanks to Haridas from Youth for Action and Research, Maagriha and Mr. Kuturam Sunani for providing us support and helping with contacts.

A special thank you to Dr. John Cherian Oommen and his team at Christian Hospital, Bissam Cuttack, Rayagada for their inputs and suggestions.

We are extremely grateful to Nuapada District Collector and District Magistrate Dr. Poma Tudu, and Additional District Magistrate (ADM) and Mr. Trilochan Minz providing us all the support during the visit, and also for introducing the research team to the CDMO. A big thank you to Dr. Jagdish Mahanand, CDMO and other doctors from the District Hospital, staff nurses, para medical staff who remained available to us during the entire duration; for their cooperation and for providing all the necessary data without any hassle. Special thanks Mr. Prashant Kumar Baral, Deputy Manager, RCH for providing all the data, information and accompanying us to the field along with other members of NHM team. Special thanks to Mr. Biswa Kumar Behera, DPM (NHM) for sharing the data and information. The staff at Komna and Khariar CHCs, PHCs, SCs, the ASHAs, ANMs, AWWs, DAMAN teams in the area deserve a big thank you. Without their support, the fieldwork would have been incomplete. Thanks to Dr. Dibakar Ojha, in charge-CBDA, Nuapada for sharing the information on CBDA.

Thanks to Ms. Vidyawati and Mr. Basudev Panda in Rayagada who helped the team in translation from Kui and Odiya language during the interview and discussions on field. Thanks also to Mr. Bhubaneshwar Raut, Mr. Sadhuram Podh, Mr. Prakash Kumar Bandichhor, and Mr. Himanshu Panda for their help during field work; and to the Panchayat Pradhans in the villages that the team visited.

### Chhattisgarh

Thanks to the staff of Jan Swasthya Sahyog, Bilaspur for sharing their reports and other relevant documents. Thanks to Sister Elizabeth Nalloor, RAHA, Jashpur; Ms. Rekha Shivhare, Phulwari Coordinator, Koriya; Thanks to Ms. Roshini, Mitanin District Coordinator, Mitanin Programme, and Sukhmani, Block Coordinator, Mitanin Programme and the other Mitanins for their cooperation and support during the visits to Koriya and Jashpur. Thanks to the staff at the SCs, PHCs and CHCs visited and also the DH officials. Thanks to all the AWWs, ANMs.

### Jharkhand

Thanks to the Ekjut team members in Gumla and Latehar, who provided us inputs about the areas; Sister Anjana and Sister Sujata from Nazareth Health Center, Mahuadanr, Latehar; Dr. Vasavi Kiro, Torang Trust; NAWO; Mr. Balram, Right to Food Campaign and Mr. Haldar Mahto, member, Jharkhand State Food Commission. Thanks to all the Medical Officers and the other staff at PHC sand CHCs, Sahiyas, ANMs, AWWs for sharing their experiences.

Errors and omissions, if and when they occur, are all ours.

# Abbreviations

| | |
|---|---|
| ACF | Active Case Finding |
| ACT | Artemisinin-based Combination Therapy |
| AEDs | Antiepileptic drugs |
| AHS | Annual Health Survey |
| AIDS | Acquired Immune Deficiency Syndrome |
| ANC | Ante-Natal Care |
| ANM | Auxiliary Nurse Midwifery |
| APH | Ante Partum Hemorrhage |
| API | Annual Parasite Incidence |
| ARI | Acute Respiratory Infection |
| ASHA | Accredited Social Health Activist |
| ASV | Anti-Snake Venom |
| AWC | Anganwadi Centre |
| AWW | Anganwadi Worker |
| AYUSH | Ayurveda, Yoga and Naturopathy, Unani, Siddha and Homoeopathy |
| BMI | Body Mass Index |
| BPL | Below Poverty Line |
| BMO | Block Medical Officer |
| C-Section | Caesarean Section deliveries |
| CBNAAT | Cartridge Based Nucleic Acid Amplification Test |
| CEDAW | Convention on the Elimination of all forms of Discrimination Against Women |
| CHC | Community Health Centre |
| CMO | Chief Medical Officer |
| CPR | Contraceptive Prevalence Rate |
| CVD | Cardio Vascular Diseases |
| DAMaN | Durgama Anchalare Malaria Nirakaran |
| DBT | Direct Benefit Transfer |
| DGHS | Directorate General of Health Services |
| DH | District Hospital |
| DHO | District Health Officer |
| DLHS | District Level Household and facility Survey |
| DMHP | District Mental Health Programme |
| DOTS | Directly Observed Treatment, Short Course |
| DR-TB | Drug Resistant Tuberculosis |
| EAG | Empowered Action Group |
| EDL | Essential Drug List |
| EmOC | Emergency Obstetric Care |
| FIR | First Information Report |
| FRU | First Referral Unit |
| GBV | Gender Based Violence |
| GDP | Gross Domestic Product |
| GoI | Government of India |
| Hb | Haemoglobin |

| | |
|---|---|
| HBNCC | Home Based New-born and Child Care |
| HbS | Sickle Haemoglobin |
| HIV | Human Immunodeficiency Virus |
| HMIS | Health Management Information Systems |
| HR | Human Resource |
| ICDS | Integrated Child Development Services |
| ICESCR | International Covenant on Economic, Social and Cultural Rights |
| ICMR | Indian Council of Medical Research |
| IEC | Information Education and Communication |
| IIPS | International Institute for Population Sciences |
| IMR | Infant Mortality Rate |
| IPD | In-Patient Department |
| IPHS | Indian Public Health Standards |
| IRS | Indoor Residual Spray |
| ITDA | Integrated Tribal Development Agency |
| ITDP | Integrated Tribal Development Projects |
| ITNs | Insecticide Treated Bednets |
| IUCD/IUD | Intrauterine Contraceptive Device/ Intrauterine Device |
| IVM | Integrated Vector Management |
| JSS | Jan Swasthya Sahyog |
| JSSK | Janani Shishu Suraksha Karyakram |
| JSY | Janani Suraksha Yojana |
| LAP | Leprosy Affected Persons |
| LCDC | Leprosy Case Detection Campaign |
| LHV | Lady Health Visitor |
| LLINs | Long Lasting Insecticide Treated Nets |
| MADA | Modified Area Development Approach |
| MAPEDIR | Maternal and Perinatal Death Inquiry and Response |
| MCR | Micro Cellular Rubber |
| MCTS | Mother and Child Tracking System |
| MDR | Maternal Death Review |
| MDT | Multi Drug Therapy |
| MIS | Management Information System |
| MLC | Medico-Legal Case |
| MMR | Maternal Mortality Ratio |
| MMU | Mobile Medical Unit |
| MNREGA | Mahatma Gandhi National Rural Employment Guarantee Act |
| MO | Medical Officer |
| MoHFW | Ministry of Health and Family Welfare |
| MoTA | Ministry of Tribal Affairs |
| MPW | Multipurpose Workers |
| MTP | Medical Termination of Pregnancy |
| MTPA | Medical Termination of Pregnancy Act 1971 |
| MUAC | Mid Upper Arm Circumference |
| MWCD | Ministry of Women and Child Development |

| | |
|---|---|
| NABARD | National Bank of Agriculture Rural Development |
| NACO | National AIDS Control Organization |
| NCD | Non-Communicable Diseases |
| NFHS | National Family Health Survey |
| NFSA | National Food Security Act |
| NGO | Non-Governmental Organisation |
| NHM | National Health Mission |
| NHP | National Health Policy |
| NHRC | National Human Rights Commission |
| NHSRC | National Health Systems Resource Centre |
| NIMR | National Institute of Malaria Research |
| NIRTH | National Institute for Research in Tribal Health |
| NLEP | National Leprosy Eradication Programme |
| NMA | Non- Medical Assistant |
| NMR | Neonatal Mortality Rate |
| NNMB | National Nutrition Monitoring Bureau |
| NPDCS | National Programme for Prevention and Control of Diabetes, Cardiovascular Diseases and Stroke |
| NRC | Nutritional Rehabilitation Centre |
| NREGA | National Rural Employment Guarantee Act |
| NSSO | National Sample Survey Office |
| NVBDCP | National Vector Borne Disease Control Programme |
| OBC | Other Backward Class |
| OOPE | Out-of-Pocket Expenditure |
| OPD | Out-Patient Department |
| ORS | Oral Dehydration Salts |
| OT | Operation Theatre |
| PCPNDT | Pre-Conception and Pre-Natal Diagnostic Techniques (Prohibition of Sex Selection) Act |
| PDS | Public Distribution System |
| PESA | Panchayat (Extension to Scheduled Areas) |
| PHC | Primary Health Centre |
| PIL | Public Interest Litigation |
| PMMVY | Pradhan Mantri Matritva Vandana Yojana |
| PMSMA | Pradhan Mantri Surakshit Matritva Abhiyan |
| PNC | Post-Natal Care |
| PPH | Postpartum Haemorrhage |
| PPIUCD | Postpartum Intrauterine Contraceptive Device |
| PPP | Public-Private Partnership |
| PRI | Panchayati Raj Institutions |
| PVTGs | Particularly Vulnerable Tribal Groups |
| PWE | Persons With Epilepsy |
| RBSK | Rashtriya Bal Swasthya Karyakram |
| RCH | Reproductive and Child Health |
| RCS | Reconstructive Surgery |
| RDT | Rapid Diagnostic Test |
| RHS | Rural Health Statistics |

| | |
|---|---|
| RMNCH+A | Reproductive, Maternal, New-born, Child and Adolescent Health |
| RNTCP | Revised National Tuberculosis Control Program |
| RSBY | Rashtriya Swasthya Bima Yojana |
| RTI | Reproductive Tract Infections |
| SAM | Severe Acute Malnutrition |
| SBA | Skilled Birth Attendant |
| SC | Sub-centre |
| SC | Scheduled Caste |
| SCA | Special Central Assistance |
| SCA | Sickle Cell Anaemia |
| SCC | Short Course Chemotherapy |
| SCD | Sickle Cell Disease |
| SCM | Surveillance and Case Management |
| SCP | Special Component Plan |
| SCSP | Scheduled Caste Sub Plan |
| SDG | Sustainable Development Goals |
| SEARCH | Society for Education, Action and Research in Community Health |
| SHGs | Self-Help Groups |
| SNCU | Sick Newborn Care Unit |
| SRS | Sample Registration System |
| ST | Scheduled Tribe |
| STI | Sexually Transmitted Infection |
| TB | Tuberculosis |
| TBA | Traditional Birth Attendants |
| TFR | Total Fertility Rate |
| THR | Take Home Ration |
| TMAP | Tribal Malaria Action Plan |
| TSP | Tribal Sub-Plan |
| TT | Tetanus Toxoid |
| U5MR | Under-five Mortality Rate |
| UDHR | Universal Declaration of Human Rights |
| UNDRIP | United Nations Declaration on the Rights of Indigenous Peoples |
| UNICEF | United Nations Children's Fund |
| UT | Union Territory |
| VHND | Village Health Nutrition Day |
| VHSNCs | Village Health, Sanitation and Nutrition Committee |
| VHW | Village-level Health Worker |
| WASH | Water, Sanitation and Hygiene |
| WHO | World Health Organisation |
| WWE | Women With Epilepsy |

Chapter I

# Introduction

According to the 2011 census, 8.6 per cent of India's total population is that of tribal people, amounting to almost 104 million people.[1] There are intense debates regarding the definition of the term 'tribe' itself; not only is it a colonial construct, but it carries with it a host of stereotypes that outsiders had towards the communities that they did not fully understand – from romantic and mystical to backward, uncivilised or even criminal – or even felt hostile towards. Many tribal communities hence prefer to call themselves 'Adivasi', which literally means 'original inhabitant';[2] and the terms 'tribal' or 'Adivasi' broadly connote a community or a cluster of communities that share a common territory, language and cultural heritage. The Constitution of India does not use this term. It instead uses 'Scheduled Tribes' (STs) or 'Anusuchit Jana Jati' to refer to tribal communities.[3]

Tribal communities have traditionally lived in or near forests, and depended crucially on forest resources for their food, shelter, fuel and medicines. For centuries, their needs could be comfortably met as they had unrestricted access to the forests, even though there have been conflicts when outsiders have encroached on tribal lands or forests. However, their equation with the forests went through a sea change with the coming of the British. The British saw the forests as a colossal reserve of raw materials and revenue waiting to be exploited, and they certainly did not want anybody in their way. They went about the process systematically. In

1864, the British government established the Imperial Forest Department and passed the Indian Forests Act in 1865, taking its first step towards establishing its control over forest resources in India.[4] The subsequent imposition of restrictions on the forest dwelling communities in accessing and using forest resources, the establishment of local mechanisms to actualise this control, and the enactment of laws such as the Land Acquisition Act of 1894, ultimately resulted in large scale alienation, eviction and pauperisation of tribal communities. Even though there were significant tribal revolts against the British – some of whose demands were actually met by the colonial government – the process of alienation continued unabated as the resistance was sporadic and localised.

In the years following independence, several legislations were put in place by the Indian State in an attempt to rectify these afflictions. Post-1950, when the Constitution was adopted, the communities that the British had classified as tribes, were reclassified as Scheduled Tribes (ST) and certain administrative and political concessions were extended to them. The Indian Constitution, however, did not have any specific criteria for the recognition of STs.[5] An Advisory Committee on the Revision of the Lists of Scheduled Castes (SC) and STs, called the Lokur Committee, was created in 1965 to look into this issue. Unfortunately, the criteria put forth by this committee – primitive traits, distinct culture, geographical isolation, shyness of contact with the community at large and backwardness – was problematic as they exhibited the same biases, prejudices and ignorance that existed about tribes in general. Not only did the Lokur Committee continue to perceive tribes through the colonial lens, viewing them as backward, uncivilised and primitive, it was also guilty of homogenising the realities of different tribes.[6] Tribal communities are often perceived as being homogeneous, because their social and political marginalisation across regions seems to indicate similarities. In reality, however, these communities vary greatly in terms of language, livelihood, ecological setting, population, development, and social stratification.[7] Owing to this misconception, with the reorganisation of state boundaries in Independent India, many tribal communities found themselves listed as ST in some states, but not in the other – often neighbouring – states where they also belonged. For example, Pahariya tribes were listed as ST in Chhattisgarh, but classified under the Other Backward Classes (OBC) administrative category in Odisha.[8] This categorically excluded them from claiming any benefits from the various government policies and programmes meant for the development of STs, as well as from their own tribal identity.

While different tribes have distinct cultures and histories, together they constitute the most marginalised sections in the country. The main reasons for this marginalisation include land alienation and indebtedness, loss of access and control over forests, enforced displacement due to development projects and lack of proper rehabilitation.[9] Tribal areas in most parts of India are rich in mineral, forest and water resources. Over time, their habitat has been declared as Reserved Forest or Protected Forest, National Park or Sanctuary, in the name of forest conservation, leaving them vulnerable to further displacements. Large-scale industrial projects, extraction of mineral resources, and the construction of dams and power projects in tribal areas have relentlessly displaced tribal people from their lands, forests and habitation.[10] Around 245 Baiga families in Chhattisgarh were evicted from the Achanakmar Tiger Reserve in 2009. The families were moved to an area where their traditional livelihood of collecting Sal leaves, Tendu and Bamboo was no longer viable. The poorly built houses for their rehabilitation became dilapidated soon after. Further, the families did not receive pattas for farming and neither did they receive the full compensation owed to them under the Project Tiger Relocation Scheme.[11] In the Niyamgiri Hills of Odisha, the Dongriya Kondhs, unanimously voted against a Bauxite mining project, headed by the Odisha Mining Corporation Limited (OMC) and Vedanta Limited, a British Multinational Corporation, for the latter's aluminium refinery in the neighbouring area.[12] The people's decade long agitation and their decision to vote against the mining bodies was further upheld by the Supreme Court in 2013, stating that the mining could only go forward with consent from the Gram Sabhas. The OMC, once again however, filed a petition challenging the 2013 resolutions of the Gram Sabhas. The Supreme Court scrapped the petition on May 6, 2016.[13]

Since 1996, certain tribal communities have also been recognised as Particularly Vulnerable Tribal Groups (PVTGs) on the basis of their greater 'vulnerability' even among the other tribal groups. PVTGs who were earlier known as Primitive Tribal Groups (PTGs), have been identified as such "on the basis of the following criteria: 1) forest-dependent livelihoods, 2) pre-agricultural level of existence, 3) stagnant or declining population, 4) low literacy rates and 5) a subsistence-based economy".[14] Currently there are 75 PVTGs across 18 states and UTs.[15]

Both displacement and denial of access to forests have impacted tribal lives, particularly the PVTGs in a significant way. PVTGs are primarily forest dwellers and have traditionally

depended heavily on forest resources for their subsistence. Following displacement, communities have been relocated to unfamiliar and hostile environments, away from their traditional habitats causing substantial psychological trauma. The loss of their land, resources and displacement have pushed them into poverty, unemployment, exploitation, chronic malnourishment, starvation and general ill health. Basic education services, as well as opportunities for decent jobs and livelihoods continue to elude them.

Apart from the above issues, some pockets of the tribal areas are also affected by the on-going conflict between the Maoists and the security forces deployed by the State to counter the insurgency. There is a perception that the SCs and the STs inhabiting these areas are easily drawn to the Maoist movement as the State is either non-responsive to the needs of these marginalised communities or is complicit with the forces that are responsible for their merciless exploitation and disempowerment. While insurgents and security forces battle it out against each other, a double-edged sword hangs over the tribal people who are perceived as collaborators by either party.

Working together, all these issues inadvertently cause severe harm to most of the tribal population. Hence, despite various constitutional measures for their protection and development, or programmes run by the concerned ministries, the general condition of the tribal population, far from being ameliorated in the last seventy years, has progressively become worse.

## Scheduled Areas and the Fifth Schedule

To promote the interest of the tribal people, the Indian Constitution grants certain provisions that enable tribal communities to govern themselves. Through provisions in the 5th or 6th schedule [Articles 244 and 244(a)], the Constitution empowers states to declare areas inhabited by tribes as 'Scheduled Areas' and provide special privileges for their administration.[16] The criteria for declaring an area a Scheduled Area are laid down by the Report of the Scheduled Areas and Scheduled Tribes Commission, 1960–61 and are as follows:[17]

- preponderance of tribal population,
- compactness and reasonable size of the area,
- underdeveloped nature of the area,
- marked disparity in the economic standard of the tribal population compared to the general population.

Currently, ten states, namely Chhattisgarh, Odisha, Jharkhand, Rajasthan, Himachal Pradesh, Madhya Pradesh, Maharashtra, Gujarat, Andhra Pradesh and Telangana, comprise areas that are under the jurisdiction of the Fifth Schedule. It is important to note that there are many areas with significant population of tribal communities, but these are not among the Scheduled Areas and hence, are not covered by the provisions of the Fifth Schedule. These include tribals living outside the Scheduled Areas within the nine states, as well as tribal communities living in West Bengal, Bihar, Uttar Pradesh, Uttarakhand, Goa, Tamil Nadu, Kerala, Karnataka and the Union Territories of Daman and Diu, Dadra and Nagar Haveli, Lakshadweep, and the Andaman and Nicobar Islands.[18]

The Scheduled Areas and Scheduled Tribes Commission, also known as The Bhuria Commission (2002-04), focused on a wide range of issues from the Fifth Schedule to tribal land and forests, health and education, the working of Panchayats and the status of tribal women. The Commission requested states with large tribal populations to reassess the validity of some of the Fifth Schedule criteria in modern-day contexts, such as the in-migration or influx of non-tribals in tribal areas. The commission recommended that the criteria should be made more specific, because terms like 'preponderance' remain open to interpretation and introduce ambiguity in discussions regarding the administrative unit—such as district, block or village—on the basis of which the size of the population is calculated.[19] The Bhuria Committee's recommendations led to the enactment of the Provisions of the Panchayats (Extension to Scheduled Areas) Act, 1996 – PESA Act in short. PESA Act was formulated to ensure that tribal communities living in the Scheduled Areas could practice self-governance through their traditional Gram Sabhas. Further, the Act also stated, "Panchayats shall be in consonance with the customary law, social and religious practices and traditional management practices of community resources."[20]

However, because of multiple problems – legal, political, as well as in understanding of tribal practices and culture, the lack of political will and utter disregard to consider tribal people as equal citizens as well as the refusal of local authorities to give up control and allow Gram Sabhas to function independently – a powerful and enabling legislation like the PESA Act failed to bring about any change in the plight of the tribal communities. In fact, several Gram Panchayats have been reportedly reclassified as Nagar Panchayats, in order to circumvent the provisions made for tribals in Scheduled Areas under the PESA Act.[21]

## Tribal Governance

While reclassifying communities that the British had identified as tribes into Scheduled Tribes, Article 342 of the Indian Constitution created the ground for such communities to be listed in the Schedule so that the State could extend certain administrative and political concessions to them. It thus drew a distinction between 'tribe' as a socio-cultural entity and a politico-administrative category.[22] However, until the late 1990s, tribal affairs did not have an exclusive Ministry. Although tribal development was one of the five prongs of Nehru's Panchsheel,[23] tribal governance was the responsibility of the Tribal Division of the Ministry of Home Affairs until 1985, the Ministry of Welfare until 1998, and the Ministry of Social Justice and Empowerment until 1999. In 1999, the Government of India (GoI) established the Ministry of Tribal Affairs (MoTA) with the objective of pursuing a more focused approach on the integrated socio-economic development of the STs.[24] Seeking to fill critical gaps in institutions and programmes concerning tribal communities, the programmes and schemes of the Ministry were designed to support and provide financial assistance to the efforts of other Central Ministries, State Governments and voluntary organisations, through specially tailored economic, educational and social development interventions.[25] In 2006, the MoTA drafted the National Tribal Policy, which recognised that "a majority of Scheduled Tribes continue to live below the poverty line, have poor literacy rates, suffer from malnutrition and disease and are vulnerable to displacement."

While the Ministry has stated the need to prepare a "new, comprehensive, concise and focused National Tribal Policy"[26] in the future, no timeline has been stipulated for its formulation.

## Tribal Sub Plans (TSP)

Other initiatives under the MoTA include grants, as Special Central Assistance (SCA), to states for developing Tribal Sub Plans (TSP), put in place during the Fifth Five Year Plan; to ensure the socio-economic development of tribal populations. All the 23 states that have notified STs are eligible to receive grants under this programme.[27] By streamlining the flow of funds from the different Ministries, the TSP seeks to include the ST communities in the larger scheme

of amelioration. However, this financial support is supposed to be complementary to the pre-existing funds allocated to the STs. Despite this, however, these funds rarely materialise into 'well-monitored' and 'well-planned' programmes and states seldom put in additional support over and above the regular obligations, as mandated under the TSP. The primary reasons for the failure of the TSP to improve the conditions of the tribal populations, as defined by the Report of the Expert Committee on Tribal Health (unpublished), range from a "lack of unified planning, implementation and monitoring mechanism" to "the ritualistic utilisation of TSP funds, rather than an outcome based effort."[28]

Additionally, the MoTA also runs a scheme that provides grants to voluntary organisations or non government organisations (NGOs), which work in tribal areas for their welfare and development, called the Scheme of Grant in Aid to voluntary organisations working for welfare of STs, with effect from 1st April, 2008.[29] As measures to promote development among the PVTGs, the MoTA has begun implementing schemes to facilitate socio-economic development in a holistic manner by adopting a habitat development approach and intervening in every sphere of the population's social and economic life.[30]

## Health and human rights of tribal communities

Human rights principles seek equality and access to health care for all, including for tribal communities. While the Constitution of India, does not make an express mention of health as a fundamental right, however the Courts have interpreted the right to health as a part of right to life under Article 21 through judicial pronouncement. While interpreting

and expanding Article 21, the Supreme Court emphasised that right to life goes beyond protecting limb or faculty and includes the 'right to live with human dignity and all that goes along with it, such as adequate nutrition, clothing and shelter and facilities for reading, writing and expressing oneself in diverse forms, freely moving about and mixing and co-mingling with fellow human beings.[31] Recognising that preservation of human life is paramount, the Court held that the Article 21 of the Constitution casts the obligation on the State to preserve life.[32] When approached by an injured person aggrieved by the denial of treatment in Government hospital due unavailability of beds, the Supreme Court held that providing adequate medical facilities is an essential part of the obligation undertaken by a welfare state. The Government should discharge this obligation by running hospitals and health centers. It observed that the failure to provide medical treatment would result in the violation of right to life. The lack of financial resources cannot ignore the Constitutional obligation of the State to provide adequate medical services to the people. The Court has also held that the State renders this obligation by opening Government hospitals and health centers, but in order to make it meaningful, it has to be within the reach of its people and provide all the facilities which are provided for in other hospitals.[33]

The international legal framework regarding indigenous peoples and the right to health is mentioned in the Universal Declaration of Human Rights (UDHR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), and the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW).[34]

Article 25 of the UDHR emphasises the recognition of the right of all persons to an adequate standard of living, including guarantees for health and well-being. It acknowledges the relationship between health and well-being and its link with other rights, such as the right to food and the right to housing, as well as medical and social services. It adopts a broad view of the right to health as a human right, even though health is but one component of an adequate standard of living. Article 24 of the UNDRIP specifically talks about the rights of indigenous people to health; right to access health care and social services without discrimination, and the right to use traditional medicines and health practices that they find suitable. It is therefore the duty and responsibility of the government to deliver this right to the indigenous peoples.

Article 12 of the CEDAW talks about the responsibility and the accountability of States Parties towards the elimination of discrimination against women (which applies to tribal women too) in the field of health care in order to ensure, on the basis of equality of men and women, access to health care services including those related to "family planning, pregnancy, confinement and the post-natal period, as well as adequate nutrition during pregnancy and lactation". The Declaration of Alma Ata, adopted at the International Conference on Primary

Health Care in 1978, also affirms "the crucial role of primary health care, which addresses the main health problems in the community, providing promotive, preventive, curative and rehabilitative services accordingly" (Article VII). It stresses that access to primary health care is the key to attaining a level of health that will permit all individuals to lead a socially and economically productive life and contribute to the realisation of the highest attainable standard of health.

The Sustainable Development Goals (SDGs), specifically Goal 3, reiterates the need for countries to "ensure healthy lives and promote well-being for all, at all ages". According to the Office of the United Nations High Commissioner for Human Rights (commonly known as the Office of the High Commissioner for Human Rights [OHCHR]), access to medicines is intrinsically linked with the principles of equality and non-discrimination, transparency, participation, and accountability. It reiterates that states are obliged to develop national health legislation and policies, and strengthen their national health systems. Further, it states, "access to medicines must be taken into account such as: sustainable financing, availability and affordability of essential medicines; price and quality control; dosage and efficacy of medicines; procurement practices and procedures, supply chains, etc." However, despite the States Parties' obligations to uphold the rights of the people—in this instance, their right to health, including health care —the health indicators reflect their non-fulfilment.

## Current status of tribal health

The tribal community lags behind the national average on several vital public health indicators, with women and children being the most vulnerable. Several studies have pointed to the high prevalence of malaria and tuberculosis (TB) among tribal communities; a substantial part of the tribal areas are also considered to be malaria-endemic. Although it is generally believed that tribal populations seldom suffer from diseases like cancer, diabetes, and hypertension, there is increasing evidence of the incidence of such non-communicable diseases (NCDs) among them. Sickle cell disease (SCD) is also prevalent in tribal communities and acknowledged as a significant public health issue. Several studies on maternal health show chronic malnutrition, higher levels of morbidity and mortality, and lower provision of antenatal and postnatal services among tribals, particularly among the PVTGs. Under-five mortality rates among rural tribal children remain startlingly high.

Although abortion and contraception do not conform to the category of 'illnesses', they are important in the context of sexual and reproductive health of women in tribal communities, but do not receive much attention. Similarly, tribal communities experience distress, severe anxiety and other mental health issues due to displacement, the onslaught of market economy, conflict, discrimination, exploitation, and unemployment. They are highly

vulnerable to mental health problems, but are challenged by the lack of remedy due the unavailability of requisite health care.

This dismal health conditions of tribal communities are the result of poverty induced by large-scale displacement, increased migration, and frequent conflict, coupled with food insecurity, poor access to potable water and lack of sanitation, poor living conditions, and most importantly the lack of access to health services.

In terms of the public health infrastructure, the pattern for tribal areas is similar to that for rural areas, only differing in terms of population ratio. However, as the tribal population falls in the underserved category, human resources and infrastructure data indicates the gaps in tribal areas. The Rural Health Statistics (RHS) data, has consistently reported shortfalls in the recent past in terms of specialists at community health centers (CHCs), doctors at primary health centers (PHCs) and paramedical staff across all levels of facilities in tribal areas.[35,36]

The significant deficits in skilled human resources coupled with the non-availability of drugs and diagnostics, has led to high out of pocket expenditure (OOPE) on health care and vicious cycles of indebtedness, poverty and ill health. This, along with the lack of motorable roads and inadequate transportation in several tribal areas, severely curtails access of the tribal communities to health care.

Further, tribal communities often experience discriminatory and unfriendly behaviour by the health personnel, which stems from deep-rooted biases held against the tribal population, and language barriers, leading to low utilisation of the existing health care institutions in Scheduled Areas.[37]

(Refer Chapter 5 for more information on health)

## Policies and programmes on tribal health

The Twelfth Five Year Plan (2012-17) had certain provisions with regard to Tribal Health. It recognised the need for evolving a new strategy that combines indigenous tribal medicine with other medical systems. It called for a systematic effort to document the traditional tribal knowledge of medicinal/herbal plants, standardise the information, and recognise it as an independent system of medicine. The plan even suggested involving traditional healers in providing health care by training them and entrusting them with the responsibility of treating people for remuneration. The plan acknowledged the problem of malnutrition in tribal areas and called for a modification in the system of public distribution by involving local tribals, and providing local foods. The need for providing safe drinking water supply sources and sanitation facilities in tribal areas, upscaling the frequent immunisation campaign, and

holding regular IEC programmes on health related behaviour, also find mention in the plan document.

The High Level Expert Group (HLEG) Report on Universal Health Coverage (UHC) for India (HLEG Report) instituted by the Planning Commission of India in 2011 is yet another policy framework to look into while discussing tribal health issues. It emphasises that the tribal areas remain mostly underserved when it comes to human resources, making the people in those areas extremely vulnerable. The necessity of well-functioning primary health care teams, which could potentially work towards the promotion of health equity, and the value of empowering communities to participate in their own health and well-being is also argued for by the report. The report also draws attention to the need for higher financial allocations to states that have districts with significantly high tribal populations to meet the need for special dispensations of health infrastructure and human resources.

The National Health Policy (NHP) was endorsed by the Parliament of India in 2017. The policy recognises the inequities in health indicators, such as IMR and MMR, between states, especially in remote and tribal areas. It acknowledges that even in states where overall health indicators are improving marginalised communities like the tribal communities continue to fare poorly. It suggests that geographical and infrastructural challenges of the tribal areas should be recognised and special efforts should be made to provide improved health services in these areas. For this, the policy advocates enhanced outreach of public health care through Mobile Medical Units (MMUs), etc. The policy also upholds the need for research and validation of tribal medicine in the public health sector. While the NHP upholds the state's

role in providing health services, it also underlines the need to engage the private sector, through adoption of tribal or backward areas, in raising health care awareness and providing services as part of their corporate social responsibility. These pubic–private partnerships (PPPs) that are being promoted are a part of the abdication of the State's responsibility towards market forces and alliances, without any plan for the overall reorganisation of the health system, any regulation of the private sector, any system to rationalise practices or costs and any mechanisms to enforce accountability or patients' rights.

The National Advisory Council (NAC), set up in 2004 by the first United Progressive Alliance (UPA) government, in its recommendations to the GoI called for an approach towards the development of PVTGs, focused around assessing the vulnerabilities of these communities across different states, the recognition of their rights and entitlements, their livelihood and development, along with strengthening their governance institutions and improving the levels of nutrition, health and education amongst the communities.[38] There are certain state-led initiatives towards development of STs and PVTGs in particular. As the NAC seeks to address the issues of PVTGs, such as promoting the preservation of their distinctive culture, the promotion of education and livelihood, ensuring their 'right to land', ensuring steady functioning of the public distribution system (PDS) and others, states such as Odisha are implementing it through state level bodies such as Odisha PVTG Empowerment & Livelihoods Improvement Programme (OPELIP) and more region specific bodies like the Chaukhutia Bhunjia Development Agency (CBDA).

While National Health Mission (NHM) initiatives on the communitisation of health care provide opportunities for the strengthening of community involvement in health programmes, through the Community health worker programme (ASHA programme), the Village Health Sanitation and Nutrition Committees (VHSNC), and the Community Based Monitoring (CBM); experience has shown that even in these initiatives, PVTGs often remain excluded.[39] One such state policy has been that of disallowing PVTGs to access sterilisation services offered through government programmes (this policy still remains active in Chhattisgarh for the Baigas and other PVTGs in the state). Such policies further marginalise the community by discriminating against them and limiting their access to health care services. The policy in question denies PVTG community members the right to make free and informed reproductive choices, along with denying bodily autonomy and rights to women of these communities, who have to bear the burden of these fallacies within government policies. Issues of non-provision of health services, along with the denial of their right to food security, are all sidelined. (For more on this, ref chapter 4)

Their overall political marginalisation necessitates the need for specific plans, within larger or community level initiatives, which address the needs of tribal population and specifically the PVTGs.[40] Moreover, aspects such as their 'conservation' and 'the protection of their

declining population', within government policies, are deeply problematic and should instead be replaced with a recognition of their rights, entitlements and autonomy, as guaranteed under constitutional provisions and other health and human rights instruments.

## Local Health systems

Tribal communities have been using traditional folk medicine to take care of their health since time immemorial. However, today these practices face a challenge with increasing displacement, deforestation and urbanisation as well as the hegemony of other knowledge systems. Many studies have shown that the traditional health care systems continue to find acceptance within tribal communities. Even today, many families visit local healers or use their own folk wisdom and traditional knowledge to treat certain illnesses; they also seek the service of the traditional birth attendents (TBAs) for child birth.

Considering the socio-cultural, economic and geographic locations of the tribal groups, their health care needs, attitudes towards treatment, and health care-seeking behaviours may differ. This may challenge the present service-delivery system towards providing meaningful and strengthened health care to tribal communities and may require a careful review of the prevalent system so that it takes into account the health needs beyond health care, as well as the indigenous knowledge and skills of the diverse tribal communities.

Traditional healers are known by different names in the tribal areas—gunia, pujari and ojha etc. These healers are often the first point of treatment. Traditional healers also allow for delays in the payment and in terms of treatment is available at all times to the tribal communities. Therefore, people mostly prefer to go for the gunia for treatment first, rather than to a health centre or doctor. Similarly, the TBAs are important resources of information, experience and skills to treat maternal health issues, especially for all pregnancy-related and matters related to birthing.

Although other AYUSH (Ayurveda, Yoga and Naturopathy, Unani, Siddha, and Homoeopathy) systems are a part of the health system to an extent, the tribal knowledge and healing practices, which are extremely diverse, remain largely unacknowledged and marginalised. The pluralism of health and medicine, evident in the everyday lives of tribal communities, need to be critically understood and built upon, while discouraging patent regimes that seek to appropriate their traditional knowledge.

## Reports of High Level Committees

A High Level Committee of seven members was set up in 2013, in order to develop a position paper on,"the current socio-economic, health and educational status of the tribal communities across the country, and formulate policy initiatives and outcome-oriented

measures to promote public service delivery to the Scheduled Tribes".[41] Professor Virginius Xaxa, an eminent sociologist from the Indian Institute of Technology (IIT) Kanpur, who has written extensively on tribal communities in the country, was the Chairman of the Committee and along with other experts drafted the report that looked into a wide range of issues. The Xaxa report included the administrative framework, employment status, education, health, land alienation, displacement, enforced migration, and legal and constitutional issues. The report tracked the historical developmental trajectory of all these issues from the pre-independence era to present-day India and delineated highly nuanced recommendations to address them in a holistic and sustainable manner. The Ministry of Tribal Affairs (MoTA), GoI, published the Xaxa report in May, 2014. Despite the recommendations in the report by the Committee, little has changed in terms of the reality of the tribal communities.

In 2013, an expert committee of 12 members was set up by the MoTA and the MoHFW to assess the health status of the tribal community and suggest measures for its improvement. Under the chairmanship of Dr. Abhay Bang, a prominent physician, social activist working in the field of community health, the committee attempted to draw upon the current status of health and health care in tribal areas and devised a roadmap to address the existing gaps. This report, however, is yet to be published.

## Conclusion

Health is a fundamental requirement for enjoying other human rights such as dignity, non-discrimination and participation in social, political and economic life. For the already marginalised, vulnerable and the impoverished populations, inequality, social exclusion and the lack of respect for human rights can actually impact their health. Most significantly, the values enshrined in human rights focus on people as right holders than as patients. Hence, the right to health is a fundamental right of every human being and it implies the enjoyment of the highest attainable standard of health without distinction of race, religion, political belief or social condition. The international human rights standards have created a framework to hold governments accountable towards upholding and fulfilling the right to health and health care, along with other civil political and socio-economic and cultural rights of their people.

Even after 70 years of Independence, however, tribal populations have been deprived of development of all public services including road connectivity, availability of public transport, potable water, education, livelihoods, alternative employment, nutrition and quality health services. The Xaxa report has extensively documented the impact of migration, displacement and conflict particularly on the health of women and children.The dismal state of the health of tribal communities, and the health inequalities between tribal and non-tribal populations, reflect a fundamental failure to ensure the freedom of tribal peoples

to fully realise their human, social, economic, and political capabilities. It is important to understand the reasons for poor health among tribal populations in order to develop and implement evidence-based and context-specific interventions that address the health inequalities of tribal populations. In other words, we need to ask, understand and identify the reasons for health care services not reaching the 'doorstep' of tribal communities, along with the reasons for tribals not utilising the health care services in their areas.

Therefore, restructuring and strengthening of the public health care system, in accordance with the needs of the tribal communities, and with their full participation, should be the highest priority for both the Centre and the State Governments.

## Endnotes


1. Census of India 2011.Office of the Registrar General & Census Commissioner, Ministry of Home Affairs, Government of India.
2. People's Union for Civil Liberties (PUCL). (n.d.). *The Adivasis of India - A History of Discrimination, Conflict, and Resistance.* Retrieved from http://www.pucl.org/Topics/Dalit-tribal/2003/adivasi.htm
3. Roy Burman, J. J. (2009). Adivasi: A Contentious Term to denote Tribes as Indigenous Peoples of India. *Mainstream Weekly,* XLVII(32). Retrieved June 25, 2018, from https://www.mainstreamweekly.net/article1537.html
4. Ribbentrop, B., & Rawat, A. S. (1989). Forestry in British India. New Delhi: Indus Publishing Company. doi:http://krishikosh.egranth.ac.in/bitstream/1/2027691/1/355589.pdf
5. *Scheduled Tribe Status: The Need for Clarification* (Pub.). (2017, March 13). Retrieved June 25, 2018, from Center for Advanced Study of India. University of Pennsylvania website: https://casi.sas.upenn.edu/iit/cristinaioanadragomir
6. Ambagudia, J. (2011). Scheduled Tribes and the Politics of Inclusion in India. *Asian Social Work and Policy Review,* 5(1), 33-43. doi:10.1111/j.1753-1411.2010.00047.x
7. *Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India.* Ministry of Tribal Affairs, Government of India, May 2014.
8. Paharias - The Struggle of a Tribe for Recognition. UNDP Report. (August, 2008). Available online at- http://www.in.undp.org/content/dam/india/docs/paharias.pdf
9. Saxena, N. C. (n.d.).Hunger, Under-Nutrition and Food Security in India. Chronic Poverty Research Centre - *Indian Institute of Public Administration*.Working Paper 44. Retrieved May 3, 2018, from https://assets.publishing.service.gov.uk/media/57a08ac540f0b652dd0008cc/CPRC-IIPA44.pdf.
10. *Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India.* (May 2014) Ministry of Tribal Affairs. Government of India.
11. Ibid.
12. Vedanta Limited is a British multinational metals and mining company, with its headquarters located in London.
13. Dash, J. (May 6, 2016). Supreme Court quashes Odisha's plea on Niyamgiri. *Business Standard.* Retrieved June 2, 2018, from https://www.business-standard.com/article/current-affairs/supreme-court-quashes-odisha-splea-on-niyamgiri-116050601256_1.html
14. Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India (Rep.). (2014). Ministry of Tribal Affairs. Government of India.
15. Particularly Vulnerable Tribal Groups (PVTGs).Ministry of Tribal Affairs. (n.d.). Retrieved May 19, 2018, from https://tribal.nic.in/pvtg.aspx
16. *Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India.* (May 2014) Ministry of Tribal Affairs. Government of India.

17. Ibid.
18. Ibid.
19. Report of The Scheduled Areas and Scheduled Tribes commission. Volume- I. (2004). Government of India.
20. The Provisions of The Panchayats (Extension to the Scheduled Areas) Act, 1996.No.40 Of 1996. Available at https://tribal.nic.in/actRules/PESA.pdf. Accessed on 2nd June 2018.
21. An Anti-Forest Policy: Rhetoric or Sleight of Hand? (2018, April 23). *The Wire.* Retrieved June 2, 2018, from https://thewire.in/environment/an-anti-forest-policy-rhetoric-or-sleight-of-hand
22. Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India. (May 2014) Ministry of Tribal Affairs. Government of India.
23. Nehruvian Panchsheel: (1) Tribals should be allowed to develop according to their own genius, (2) Tribals' rights in land and forest should be respected, (3) Tribal teams should be trained to undertake administration and development without too many outsiders being inducted, (4) Tribal development should be undertaken without disturbing tribal social and cultural institutions, (5) The index of tribal development should be the quality of their life and not the money spent.
24. Annual Report (Rep.). (2016-17). Ministry of Tribal Affairs Government of India. Retrieved on 5 May, 2018, from https://tribal.nic.in/writereaddata/AnnualReport/AnnualReport2016-17.pdf
25. Ibid
26. Press Information Bureau, Government of India, Ministry of Tribal Affairs. Formulation of Tribal Policy.03-August-2016 15:00 IST. Retrieved on 5 May, 2018, fromhttp://pib.nic.in/newsite/PrintRelease.aspx?relid=148227
27. Tribal majority states are excluded. Eligible states are-Andhra Pradesh, Assam, Bihar, Chhattisgarh, Goa, Gujarat, Himachal Pradesh, Jammu & Kashmir, Jharkhand, Karnataka, Kerala, Madhya Pradesh, Maharashtra, Manipur, Odisha, Rajasthan, Sikkim, Tamil Nadu, Telangana, Tripura, Uttar Pradesh, Uttarakhand, and West Bengal.
28. *Draft report of the Expert Committee on Tribal Health - 'Tribal Health in India: Bridging the Gap and a Roadmap for the Future'.* (2014) (unpublished)
29. Scheme of Grant-In-Aid to Voluntary Organisations Working for the Welfare of Scheduled Tribes. (2008). Ministry of Tribal Affairs, Government of India. Retrieved on May 3, 2018 from https://tribal.nic.in/writereaddata/Schemes/NGO-GIAtoVOsGuidelines.pdf
30. Press Information Bureau, Government of India, Ministry of Tribal Affairs. Primitive Tribal Groups. 16- March-2015 14:59 IST. Retrieved on 5 May, 2018, from http://pib.nic.in/newsite/PrintRelease.aspx?relid=117104
31. Francis Coralie Mullin vs The Administrator Union Territory of Delhi, 1981 CriLJ 306
32. Pt. Paramanand Katara vs. Union of India & Ors, 1989 (4) SCC 286
33. State of Punjab vs. Ram Lubhaya Bagga, 1998 (4) SCC 11734.
34. The Universal Declaration of Human Rights, 1948 also mentions health as part of the right to an adequate standard of living (Article 25). The right to health is again recognized as a human right in the International Covenant on Economic, Social and Cultural Rights, 1966.
35. Rural Health Statistics. Report. Statistics Division. Ministry of Health and Family Welfare, Government of India. 2015-16.
36. Rural Health Statistics. Report. Statistics Division. Ministry of Health and Family Welfare, Government of India. 2016-17.
37. *Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India.* (May 2014) Ministry of Tribal Affairs. Government of India.
38. *'Development Challenges Specific to Particularly Vulnerable Tribal Groups (PVTGs)'* - Recommendations of the National Advisory Council. Available online at Ministry of Tribal Affairs, Government of India website https://tribal.nic.in/writereaddata/AnnualReport/NACRecommendationsforPVTGs.pdf
39. *Tribal Health;* JRHMS. (n.d.). Retrieved June 5, 2018, from http://jrhms.jharkhand.gov.in/Tribal_Health.aspx
40. Sundaraman, T., Vandana Prasad, and Sulakshana Nandi, et al. eds. *Tribal Health [Module No. 15].*Public Health Resource Network, 2010.
41. *Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India.* Ministry of Tribal Affairs, Government of India, May 2014.

Chapter 2

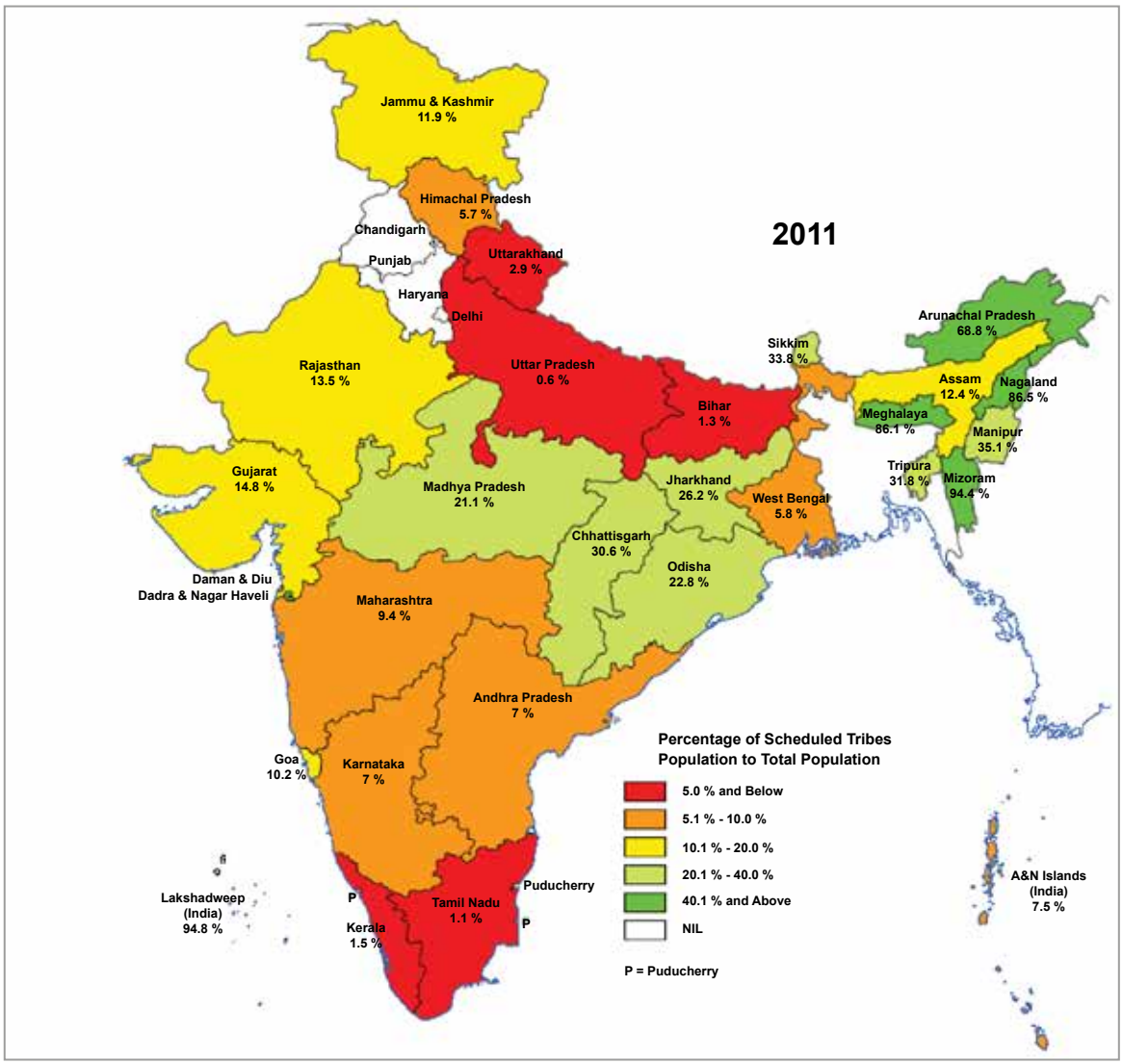
# Methodology

The National Human Rights Commission (NHRC) assigned Sama Resource Group for Women and Health[1] to undertake a study on the health situation of tribal communities. The research aimed to understand the status of public health services in the study areas, their availability and utilisation by the tribal population, and the factors that impact their access to health care. The research therefore studied the available health care facilities to understand existing gaps, particularly in the context of tribal communities based on their experiences with health issues and their interface with the health system. The study was initiated in April 2017 and completed in June 2018.

## 2.1. Rationale for the selection of the States and districts

The Scheduled Tribes (STs) currently comprise about 8.6 per cent (10.45 crore) of the population of India, as enumerated by the Census of 2011. The Census records 705 groups as scheduled tribes (STs); a majority of this population resides in nine states – Odisha, Jharkhand, Chhattisgarh, Rajasthan, Gujarat, Andhra Pradesh, Madhya Pradesh, Maharashtra, and West Bengal. About 12 per cent of the ST population resides in the north-eastern states of India, five per cent in the southern states, and three per cent in the northern states.[2]

**Figure 2.1 Percentage of ST Population to Total Population**




*Source: Census 2011*

The research was conducted in three states – Chhattisgarh, Jharkhand, and Odisha. These states and the districts were selected for:

a) the significant proportion of tribal communities, including the Particularly Vulnerable Tribal Groups (PVTGs), who are particularly socio-economically marginalised.

b) the poor socio-economic and health indicators in the states, especially amongst tribal communities, as well as their health status and a weak public health care system.

## 2.1.1. Percentage of ST population including PVTGs

The states – Jharkhand, Chhattisgarh and Odisha – have been selected given the substantial proportion of tribal population, especially in the rural areas, as can be seen in Table 2.1.

| Table 2.1: Percentage of ST population | | |
|---|---|---|
| State | % of tribal population to total population of the state | % of ST population in the state to India's total ST population |
| Jharkhand | 26.2 | 8.3 |
| Chhattisgarh | 30.6 | 7.5 |
| Odisha | 22.8 | 9.2 |
| All India | 8.6 | 11.3 |

*Source: Census 2011*[3]

Of the 27 districts In Chhattisgarh, seven districts have over 50 per cent ST population and six districts have ST population between 25 and 50 per cent. Jharkhand currently has five out of 24 districts with more than 50 per cent ST population, and eight districts with ST population between 25 and 50 per cent. Odisha also depicts a similar pattern, with eight districts out of the 30 having ST population of more than 50 per cent and six districts with ST population between 25 and 50 per cent (Table 2.2).

Two districts were selected in each of these states for the study where the percentage of the tribal population is above 30 per cent.


**Figure 2.2 Chhattisgarh**

**Figure 2.3 Odisha**

**Figure 2.4 Jharkhand**


**Figure 2.5 Latehar, Jharkahand**


**Figure 2.6 Gumla, Jharkhand**


**Figure 2.7 Koriya, Chhattisgarh**


**Figure 2.8 Jashpur, Chhattisgarh**


**Figure 2.9 Nuapada, Odisha**


**Figure 2.10 Rayagada, Odisha**

| Table 2.2: District wise ST population | | |
|---|---|---|
| **State** | **District** | **Percentage of tribal population in district** |
| Chhattisgarh | Koriya | 46.2 |
| | Jashpur | 62.3 |
| Jharkhand | Gumla | 68.9 |
| | Latehar | 45.5 |
| Odisha | Nuapada | 33.8 |
| | Rayagada | 55.9 |

*Source: Census District Handbook 2011*

In each of the six districts, administrative blocks were selected on the basis of factors like accessibility and concentration of tribal groups, including PVTGs (Table 2.3).

| Table 2.3: Selection of Blocks | | |
|---|---|---|
| **State** | **District** | **Administrative Block(s)** |
| Jharkhand | Gumla | Chainpur |
| | Latehar | Mahuadanr |
| Chhattisgarh | Jashpur | Pathalgaon and Bageecha |
| | Koriya | Sonhat and Bharatpur |
| Odisha | Nuapada | Komna and Khariar |
| | Rayagada | Kalyansinghpur and Bissam Cuttack |

### *Presence of PVTGs*

A number of the PVTGs also live in these states with poor socio-economic and health indicators. For example, in Odisha, there are 13 PVTGs, the largest number amongst all the states in the country (Table 2.4).[4]

| Table: 2.4 PVTGs in the States | | |
|---|---|---|
| **Jharkhand** | **Chhattisgarh** | **Odisha** |
| Asurs | Abujh Maria | Birhore |
| Birhor | Baiga | Bondo |
| Birjia | Bharia | Didayi |
| Hill Kharia | Hill Korba | Dongaria-Khond |
| Korwa | Kamar | Juang |
| Mal Paharia | Sahariya | Kharia |
| Parhaiyas | Birhor | Kutia Kondha |
| Sauria Paharia | | Lanjia Saura |
| Savara | | Lodha |
| | | Mankirdia |
| | | Paudi Bhuiyas |
| | | Saura |
| | | Chaukhutia Bhunjia |

*Source: Ministry of Tribal Affairs*

## 2.1.2. Poor socio-economic indicators

The selected states and districts[5] have poor socio-economic indicators, with comparatively low household incomes, low literacy levels and loss of traditional livelihoods. A majority of the tribal communities live in rural areas, and invariably in remote areas with difficult terrains, etc. These areas continue to experience poor accessibility, connectivity and infrastructure that adversely affect the health of the tribal population.[6] Although all the three states are rich in mineral reserves and forests; unfortunately, much of the forest land has been diverted for mining purposes resulting in extensive environmental degradation, loss of livelihood, land acquisition, and displacement of tribal groups. All these factors have adversely affected the health of the tribal population in the three states.[7]

### *Poverty*

The percentage of persons living below the poverty line is significantly higher among STs than the national average. Out of the 33.8 per cent of the population that live below the poverty line in rural areas, 47.4 per cent are from ST communities. In urban areas, 30.4 per cent of STs live below the poverty line as against 20.9 per cent overall. The same pattern exists across the three study states of Chhattisgarh, Jharkhand and Odisha, as demonstrated in Table 2.5 below.

**Table 2.5: State-wise percentage of persons below poverty line for ALL and STs, 2009-10**

| States | Rural | | Urban | |
|---|---|---|---|---|
| | All | ST | All | ST |
| Chhattisgarh | 56.1 | 66.8 | 23.8 | 28.6 |
| Jharkhand | 41.6 | 51.5 | 31.1 | 49.5 |
| Odisha | 39.2 | 66 | 25.9 | 34.1 |
| All India | 33.8 | 47.4 | 20.9 | 30.4 |

*Source: Ministry of Tribal Affairs*[8]

### *Literacy*

In terms of literacy rates, there exists a clear distinction between tribal and non-tribal communities at national as well state levels. The selected states have lower levels of literacy amongst tribal communities compared to the national average of 59 per cent. The literacy rate for STs at the state level is much lower as compared to the state average. For example, in the three states, the literacy rates for STs was less than 35 per cent as compared to the overall state average of 65 per cent (Table 2.6).

| Table 2.6: State and district level literacy rates | | | | | |
|---|---|---|---|---|---|
| State | Total literacy rate (%) | Total literacy rate for ST (%) | District | Total literacy rate (%) | Total literacy rate for ST (%) |
| Chhattisgarh | 70.2 | 30.6 | Koriya | 70.6 | 46.1 |
| | | | Jashpur | 67.9 | 62.2 |
| Jharkhand | 66.4 | 26.2 | Gumla | 65.7 | 68.9 |
| | | | Latehar | 59.5 | 45.5 |
| Odisha | 72.8 | 22.8 | Nuapada | 57.3 | 33.8 |
| | | | Rayagada | 49.7 | 55.9 |

*Source: District census handbook, Census of India 2011*

The disparity in literacy rates between women and men is also very significant in these states, with the literacy level being greater than 60 per cent for men, while it continues to remain below 50 per cent for women.[9] Within these districts also, there is a significant disparity between literacy rates of men and women.

| Table 2.7: District level literacy rates for Men and Women | | | | | | | |
|---|---|---|---|---|---|---|---|
| State | Districts | Literacy rate (%) | Literacy rate (%) for ST Total | Literacy rate (%) Male | Literacy rate (%) Female | Literacy rate (%) for ST Male | Literacy rate (%) for ST Female |
| Chhattisgarh | Koriya | 70.6 | 46.1 | 80.4 | 60.6 | 45.6 | 46.7 |
| | Jashpur | 67.9 | 62.2 | 77.3 | 58.6 | 62.8 | 62.6 |
| Jharkhand | Gumla | 65.7 | 68.9 | 75.5 | 55.9 | 68.5 | 69.3 |
| | Latehar | 59.5 | 45.5 | 70.0 | 48.7 | 45.0 | 46.0 |
| Odisha | Nuapada | 57.3 | 33.8 | 70.2 | 44.7 | 33.2 | 34.3 |
| | Rayagada | 49.7 | 55.9 | 61 | 39.1 | 54.8 | 57 |

*Source: District Census Handbook for Koriya, Jashpur, Gumla, Latehar, Nuapada and Rayagada districts in Chhattisgarh, Jharkhand and Odisha, Census of India 2011*[10,11,12,13,14,15]

The literacy rate amongst certain tribal communities in these states is even below 30 per cent, indicating extremely deficit infrastructure, shortage of teachers, poor access to schools, lack of opportunity to pursue education, gender discrimination and financial constraints.[16]

### *Basic amenities*

With regard to water and sanitation, access to 'improved source of drinking water' for ST communities in Chhattisgarh is lower (84.1 per cent) when comparted to the national average (85.3 per cent). It is marginally lesser (72.4 per cent) in Jharkhand, while it is the same (83.3 per cent) as 'others' in Odisha. However, use of 'improved sanitation facility' is abysmally low in the three states; 10.5 per cent (48.1 per cent for 'others'), 5.2 per cent (37.4 per cent for 'others') and 4.1 per cent (30 per cent for 'others') in Chhattisgarh, Jharkhand and Odisha respectively.

### *Occupation and work*

With regard to occupation in the states, tribal communities are primarily involved in agriculture through self employment as well as farm labour. Over 50 per cent of the workers in Jharkhand (53 per cent), Odisha (51.13 per cent) and 39.73 per cent in Chhattisgarh are marginal workers, i.e. they work less than six months in a given reference period. This situation highlights the limited work available and its implications on affordability and access to health care.

Thus, some of these indicators reiterate the poor socio-economic status of tribal communities in the study states that increases the vulnerability of the people to health problems and affects their access to health care.

## 2.1.3. Key health indicators in the study areas

The other criteria for the selection of these states and districts were the poor health indicators, including infant and maternal mortality and morbidity, malnutrition, prevalence of anaemia, etc.

### *IMR and MMR*

Infant mortality rate (IMR) and maternal mortality ratio (MMR) are important indicators used to assess the health status of a state or community. Chhattisgarh and Jharkhand depict higher IMR (54 and 44 respectively) than the national average of 41. The IMR of Odisha is just a point lower (40) than the national average (Table 2.8).[17,18]

**Table 2.8: IMR, MMR of Chhattisgarh, Jharkhand, Odisha and overall India**

| Indicators | Chhattisgarh | Jharkhand | Odisha | India |
|---|---|---|---|---|
| Infant Mortality Rate (per 1000 live births) (NFHS 4) | 54 | 44 | 40 | 41 |
| Maternal Mortality Ratio (per 100000 live births) (SRS:2012-13)[19] | 221* | 208** | 222 | 167 |

** MMR has been calculated for Madhya Pradesh and Chhattisgarh together*
*** MMR has been calculated for Jharkhand and Bihar together*

All three states and the selected districts show a significantly higher MMR than the national average of 167. Similarly, the under-five mortality, neonatal and infant mortality rates are also significant in these districts. The under-five mortality rates are higher in tribal communities compared to non-tribal population in each of the three states (Table 2.9).

This points to substantial gaps in the health care system as well as paucity in access to information, nutrition and other socio-economic determinants of maternal health. The

MMR raises questions regarding availability, accessibility, acceptability and quality of the maternal health services in these states. Jharkhand has the lowest percentage of women having received full antenatal care in comparison to Chhattisgarh and Odisha with a difference of almost 11 and 15 points respectively.

**Table 2.9: IMR, Neonatal and Under-five mortality rates of the selected districts**

| State | District | Infant Mortality Rate (per 1000 live births) | Neonatal Mortality Rate (per 1000 live births) | Under 5 Mortality Rate (per 1000 live births) |
|---|---|---|---|---|
| Chhattisgarh | | 46 | 32 | 60 |
| | Koriya | 52 | 36 | 67 |
| | Jashpur | 56 | 36 | 84 |
| Jharkhand | | 36 | 23 | 51 |
| | Gumla | 45 | 34 | 70 |
| | Latehar*[20] | NA | NA | NA |
| Odisha | | 56 | 37 | 75 |
| | Nuapada | 60 | 36 | 80 |
| | Rayagada | 58 | 28 | 98 |

*Data source: Annual Health Survey 2012-2013* [21,22,23]

### *Anaemia and malnutrition*

According to NFHS-4, the health indicators specific to STs in each of the states indicate that more than 50 per cent of the tribal women are anaemic; 55.9 per cent of the tribal women from Chhattisgarh, 75 per cent from Jharkhand and and 63.3 per cent of those from Odisha respectively are anaemic.[24,25,26] More than 30 per cent of the women in all the three states have BMI less than 18.5 kg/m$^2$. More than 20 per cent of the men in the three study states have BMI less than 18.5 kg/m$^2$. This reflects a serious health concern that needs to be addressed by the health system.

The nutritional status of children from tribal communities in all the three states is extremely poor; the percentage of stunted children in each of the states is above the national average as is the percentage of "severely stunted" except in Chhattisgarh where it is marginally lower than the national average. Both, Jharkhand and Odisha reflect very poor indicators with regard to the nutritional status of children from tribal communities, with Chhattisgarh only marginally better. More than 40 percent of ST children aged between six and 59 months have some degree of anaemia (haemoglobin levels below 11.0 g/dl), which in the case of Jharkhand is as high as 78 per cent.

The socio-economic and health indicators discussed above form the basis for the selection of the states and districts.

## 2.2. Research Process

The research began in April 2017 and was completed in May 2018. The main objective of the study was to understand the nature and extent of the burden of illnesses borne by tribal communities, and the barriers faced by them in accessing the public health care facilities.

Other key obectives include:

1. Assess the utilisation of the public health care system by the tribal communities, especially the PVTGs, and the barriers they experienced in access to health care;
2. Understand the current status of the public health care delivery system in the selected study areas, which are predominantly tribal;
3. Offer recommendations for bridging the gaps in the making of policies and programmes, as well as in their implementation.

### 2.2.1. Research questions

To understand the nature and extent of the burden of illnesses borne by tribal communities, and the barriers faced by them in accessing the public healthcare facilities, the following research questions were formulated:

1. What are the most common illnesses found among the tribal population in these study areas?
2. What factors influence and determine the tribal population's access to health care?
3. What is the status of health infrastructure, drugs, diagnostic services, and health personnel in the public health care system? To what extent are these facilities available and accessible for the tribal population?

### 2.2.2. Study design

The study was designed as a multi-sited qualitative study. The study attempted to assess the health situation on the ground in these tribal areas and to draw conclusions and recommendations based on a qualitative analysis.

The research employed qualitative methods and involved data collation from various primary and secondary sources. Focus group discussions (FGDs), in-depth interviews, and participant-observation techniques were used for comparing, triangulating, and filling of information gaps.

In addition, a review of relevant demographic and health data, other research reports, government review reports, journal articles, and newspaper reports was undertaken to gain

a comprehensive understanding of the issues and of the nature and dimension of the health situation in these areas.

Meetings were held with experts who had many years of experience of working with tribal communities; in conducting research on tribal health issues and the health system. Meetings were held to discuss the research methodology, design, tools, etc., in conceptualising the research study, before undertaking the fieldwork. These meetings, in the later stages of the study were used to update on the progress of the study, and to seek feedback on the framework adopted for review and analysis.

### 2.2.3. Data collection

A checklist for in-depth interviews and guidelines for FGDs were developed for data collection. These were reviewed by an external expert with experience of working with tribal communities and public health.

Separate interview guides were prepared for key informants, including healthcare providers in each district at various levels: for frontline workers (Auxiliary Nurse Midwives (ANMs), Accredited Social Health Activists (ASHAs) or Mitanins, and Anganwadi Workers (AWWs) or Sahiyas); for other health care providers (medical officers, nurses, etc.).

The Indian Public Health Standards (IPHS) were referred to for developing the tools for the assessment of the health system in the study areas. Interview guides with open-ended questions were developed in English and translated into Hindi and Oriya for the purpose of data collection.

An informed consent form was developed for respondents containing information about the purpose of the study and laying out the ethical principles of anonymity, confidentiality, etc. The form was translated into the local languages. A copy of the form was given to each respondent and was also explained in detail in the local dialect by the local investigators.

### 2.2.4. Research team

The team comprised of researchers from Sama as well as local investigators in each of the study districts in the three states. The local investigators were selected based on their knowledge of the local contexts, and previous experience of working on health research or projects, especially with regard to tribal communities. The local investigators were also familiar with the local dialects, which facilitated communication with some of the tribal communities.

The research team from Sama and the local investigators were oriented about the research objectives, methodology, research tools and ethical processes before the start of the primary research; regular inputs and feedback were also provided throughout the research process.

The objectives and the overall purpose of the study were initially discussed with local organisations and networks working in the areas. Discussions were also held with local administrators, government medical officers and frontline workers regarding the study locations, respondents, transportation and security issues.

### 2.2.5. Study respondents

Study respondents included men, women, and children who were experiencing ailments during the year preceding the study, or suffering from an acute or chronic illness at the time of the field visits. Interviews were also conducted with pregnant women as well as with women who had given birth around the time of the study, to assess the status of maternal and child health in the study areas. Responses were sought from the caregivers of the respondents in the case of children and persons who were experiencing serious health issues. Efforts were

made to include respondents from different gender and age groups. A committed effort was made to reach out to respondents belonging to the PVTGs.

In all, 173 in-depth interviews were carried out with respondents in the community; the district wise break up is provided in Table 2.10. A few of the in-depth interviews were also conducted at the public health facilities,where the respondents had come to seek treatment.

**Table 2.10: In-depth interviews with respondents**

| Name of State | Name of District | Number of IDIs |
|---|---|---|
| Jharkhand | Gumla | 26 |
| | Latehar | 34 |
| Chhattisgarh | Jashpur | 30 |
| | Koriya | 34 |
| Odisha | Nuapada | 29 |
| | Rayagada | 20 |
| | Total | 173 |

### *Health care providers and other officials*

The research team also carried out an assessment of the public health facilities – District Hospitals (DH), Community Health Centres (CHCs) and Primary Health Centres (PHCs), using a guide based on the Indian Public Health Standards (IPHS). The research team visited a total of 18 public health facilities (5 PHCs, 8 CHCs and 5 DH) in the selected districts.

Interviews and discussions were conducted with a total of 78 health care providers across all levels [Chief Medical Officers (CMOs), Chief District Medical Officers (CDMOs), Medical Officers (MOs), NHM consultants and community/ frontline workers]. Initially, obtaining permission from public health officials to interview providers was quite a challenge. The research team had to submit written applications in some places, deal with bureaucratic delay, absentee officials, etc., before the actual interviews could take place. However, a letter from the NHRC facilitated the interviews with the bureaucrats and health personnel and also helped gain access to data in certain states and districts.

Wherever possible, the research team also held discussions with the District Magistrate (DM)/ District Collector (DC), Sub-Divisional Magistrate (SDM), and other administrative officials, including those who were managing tribal welfare development programmes; for example, the Director of the Chaukhutiya Bhunjia Development Agency (CBDA) in

Nuapada (Odisha). Discussions were also held with the representatives of NGOs, health networks, in the respective states that were working on tribal health and development issues and also with the local journalists, who cover health issues in the selected areas.

### *Focus Group Discussions (FGDs)*

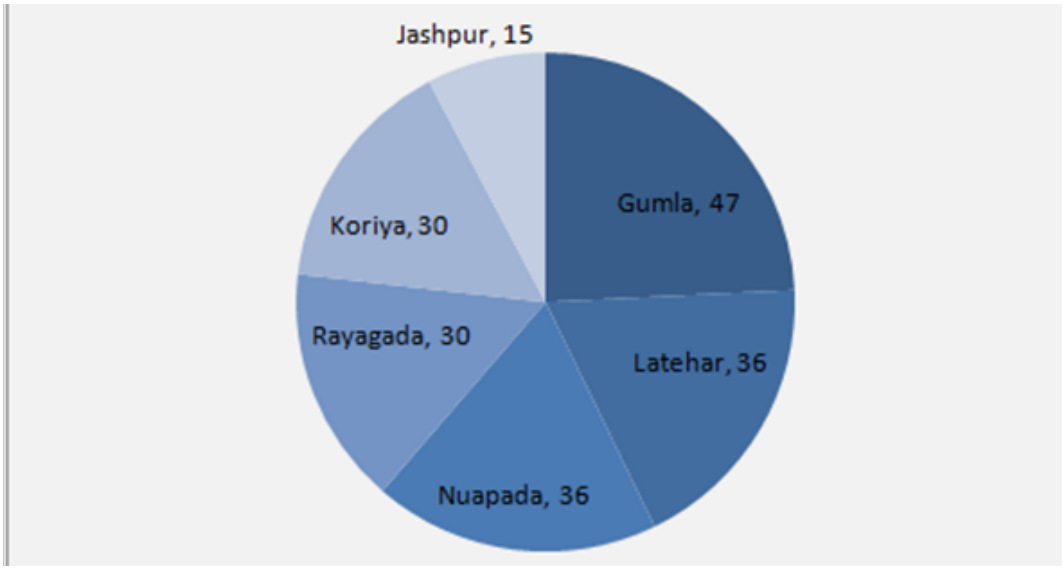
The FGDs sought to discuss the larger socio-economic and health care access issues, health seeking behaviours, treatment pathways, and the quality of care that was available to the tribal communities.

**Table 2.11: Number of Focus Group Discussions Conducted**

| Name of State | Name of District | Number of FGDs |
|---|---|---|
| Jharkhand | Gumla | 7 |
| | Latehar | 4 |
| Chhattisgarh | Jashpur | 3 |
| | Koriya | 6 |
| Odisha | Nuapada | 5 |
| | Rayagada | 4 |
| | Total | 29 |

Each FGD included a mapping exercise to understand the locations, distance of the health facilities from the habitations, the terrain and modes of transport that the community generally used to access health care at these facilities, as well as the health services that were available. The FGDs were held in easily accessible locations that were chosen by the respondents themselves. These included school buildings, respondents' houses and tribal cultural centres. Along with women and men from tribal communities, community leaders, representatives of organisations working in the area and frontline workers took part in the 29 FGDs that were conducted in the study areas. The number of respondents from tribal communities, interactions with whom took place during FGDs is provided in Figure 2.11.

**Figure 2.11 FGD Respondents**



### 2.2.6. Observations at the health facilities

The research team visited the public health facilities in the study areas and observed the interactions between patients and service providers to understand the factors influencing the provider–patient relationship in a facility setting. The records at the facility were checked. The pharmacy, maternity ward, Nutrition Rehabilitation Centre (NRC), and Sick Newborn Care Unit (SNCU) in the DHs of some of the districts were also visited. The observations helped the research team to gain a clear picture of the availability and the conditions in the health facilities, cleanliness, methods of waste disposal, etc. A field diary was maintained for recording the dates of the visits and interviews with all respondents.

### 2.2.7. Review of secondary data

A review of secondary data and literature was undertaken to obtain an overall understanding of the socio-economic and political contexts relevant to tribal communities, including in the study areas. The secondary data was also reviewed to understand the status of health and access to health care for tribal communities, particularly in the study areas. The review provided information on health and other socio-economic data regarding health policy and programmes, especially in the context of tribal health, and existing infrastructure standards for the public health facilities. A comparative assessment of the secondary information with the evidence from the primary data provided a comprehensive view of the gaps and inconsistencies.

Secondary data collection was primarily done through electronic searches of government websites, online databases, research reports and academic journals using the Internet search engine Google and Google Scholar. Relevant health and demographic data, guidelines, national and state health programmes and schemes, research reports on tribal health, etc. were also referred to. Some of the data was also collected from the health facilities visited during the study. The main sources of secondary data were:

- Census, National Family Health Survey (NFHS-4), District Level Health Survey (DLHS), Annual Health Survey (AHS)
- Health Management Information System (HMIS), Common Review Mission Reports
- National Sample Survey Organisation (NSSO) reports
- State Programme Implementation Plans (PIP)
- Rural Health Statistics reports (RHS)
- State Department for Tribal Welfare reports
- Health facility records from the district hospitals of all three states
- Articles, studies, media reports, NGO reports
- Reports from the Ministry of Health and Family Welfare (MoHFW)

### 2.2.8. Ethical considerations

Ethical considerations were central to the research process, while approaching and conducting interviews with the research respondents and in the course of interactions with other key informants. The study objectives as well as the use of data collected from them were explained in detail to the respondents. Consent was sought from the respondents before the interviews. The researchers also sought prior consent for audio documentation of interviews. All the names of the respondents have been anonymised; pseudonyms have been used wherever appropriate. A formal letter stating the research objectives was given to the health providers. These were sent to the state and district officials prior to the interviews.

### 2.2.9. Analysis and data management

At the field level, individual interviews and FGDs were conducted in the local language. These interviews were documented in detail through note-taking and audio-recordings. The interviews were translated as closely and accurately as possible, into English, although certain phrases and words did not have an appropriate equivalent in English. The field notes were then compared with the recordings to identify gaps and errors. They were also matched with other sources, such as data from the facility and patient prescriptions, records, and observation notes, to triangulate the information.

Once fully documented, the research team went through every interview in detail. These observations were used to fill in missing information, as well as to substantiate information that needed further elaboration. Feedback was incorporated from the field notes, tapes, transcripts, etc. In some cases, the researchers made subsequent visits to the field to conduct follow-up interviews and to obtain the required information.

For the purpose of analysis, the complete interviews were then categorised in different chapters. All the chapters were peer reviewed by experts involved with public health issues, specific health problems, or expert committees that have conducted studies on tribal health. Their inputs were then incorporated in the report. Regular meetings were held to map the progress of the chapters, and discuss the conclusions and questions that emerged.

### 2.2.10. Challenges in the process of data collection

#### *Generalisability*

Given that the study has been conducted in the select states and districts on the basis of certain socio-economic and health indicators, no definite generalisation can be made from the research results. While qualified inferences can be drawn from the primary data, it must be borne in mind that the sample size, which was purposively selected rather than chosen at random, can be a limiting factor.

Further, tribal communities are not homogeneous – they differ from each other in various aspects, including the language they speak, cultural practices and socio-economic backgrounds.

Within the vast domain of health problems, the study covered and analysed only those that emerged from the respondents' narratives and group discussions. Many other health problems that were not visible, or those that were not expressly identified as problems by the respondents were not addressed in the study – such as occupational health and substance abuse. Hence, this study can be considered as an attempt to bring together a range of issues, each of which requires further inquiry.

### *Limited access to disaggregated data and information*

The study team found that the available data on tribal health in existing national surveys was extremely limited. Moreover, disaggregated data by social groups, especially PVTGs, was also lacking. Therefore the analysis was informed by the limited data that was available.

### *Interior location of villages, difficult terrain and poor transport*

It was difficult to conduct certain interviews because of logistical problems. Most of the tribal villages are located at a considerable distance from the block headquarters and gaining access to them often requires travelling in difficult terrain. It is particularly difficult to travel in these areas during the monsoon season (when most of the field visits were undertaken). Some of the areas in the field were completely inaccessible due to rains, thereby hindering the team's access to some communities, especially the PVTGs.

Some areas in the study districts, such as Nuapada, Rayagada (Odisha), Latehar and Gumla (Jharkhand), were affected by insurgency and counter-insurgency activities. For security reasons, the local authorities discouraged the research team from visiting these villages beyond 4 PM. On the other hand, during the day, most of the people were occupied with agricultural and other forest based work. Hence, the team had to take multiple visits to meet with an adequate number of people who could participate in the study.

Most of the villages and hamlets visited during the study had poor or unreliable connectivity. With no mobile networks, it was often impossible for the research team to inform anyone in the villages (like the ASHA/Mitanin) prior to the visit. Hence, the team was able to coordinate and identify respondents for the study, whether interviews or FGDs, only after reaching the villages. Moreover, the houses in the villages being widely scattered, this process was time consuming. Thus, only a very few villages or hamlets could be covered in a day.

### *Language barrier*

In some areas, language was a barrier for the research team. In spite of having local investigators, given the heterogeneity of tribal communities and languages or dialects that they used, phrases, expressions or terms used by the tribal communities were sometimes challenging even for the local investigator to translate unless they were from the same tribal group.

The research team attempted to manage these challenges despite the limited human resources, limited finances, and more importantly, the short duration of the study.

## Endnotes

1. Sama is a Delhi based resource group that works at the intersection of public health, gender, marginalisation and rights. Sama considers health a fundamental human right and believes that the curtailment of capabilities and multiple forms of discrimination based on caste, class, gender, religion, sexual orientation and other rubrics must be structurally challenged. Through its work, Sama seeks to bridge the gap between community voices and policy outcomes
2. *Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India.* Report. (May 2014). Ministry of Tribal Affairs, Government of India.
3. Census. (2011). Scheduled Tribe (ST) Statistical Profile - at a glance. Retrieved October 12, 2017, from https://tribal.nic.in/ST/Statistics8518.pdf
4. Ministry of Tribal Affairs. (n.d.). State wise List of Particularly Vulnerable Tribal Groups. Retrieved February 10, 2017, from https://tribal.nic.in/ST/StatewisePvTGsList.pdf
5. These states are also part of the Empowered Action Group (EAG states), which was constituted under the Ministry of Health and Family Welfare, to focus special attention on these states because they had high fertility rates and weak socio-demographic indicators. However, the EAG's main focus was especially to ensure population stabilization and inter-sectoral convergence, and not to address health-related issues.
6. *Draft report of the Expert Committee on Tribal Health -Tribal Health in India - Bridging the Gap and a Roadmap for the Future.* (2014) (unpublished)
7. Ibid

8. Tribal Profile at a Glance (Rep.). (2014, May). Retrieved May 26, 2018, from Ministry of Tribal Affairs. Govt. of India. https://tribal.nic.in/ST/Tribal Profile.pdf
9. Ibid.
10. Census (2011), *District Census Handbook- Koriya* (Part XII- A). Chhattisgarh: Directorate of Census Operations.
11. Census (2011), *District Census Handbook- Jashpur* (Part XII- A). Chhattisgarh: Directorate of Census Operations.
12. Census (2011), *District Census Handbook- Gumla* (Part XII- A). Jharkhand: Directorate of Census Operations.
13. Census (2011), *District Census Handbook- Latehar* (Part XII- A). Jharkhand: Directorate of Census Operations.
14. Census (2011), *District Census Handbook- Nuapada* (Part XII- A). Orissa: Directorate of Census Operations.
15. Census (2011), *District Census Handbook- Rayagada* (Part XII- A). Orissa: Directorate of Census Operations.
16. *State wise and District wise information on very low ST literacy rate (where Female LR below 35 %).* (n.d.). Retrieved from https://tribal.nic.in/ST/Statement-State-DistrictwiseSTLiteracyRate-edited.pdf
17. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16:* Mumbai: IIPS.
18. Census (2011) Sample Registration System. Maternal Mortality Ratio Bulletin 2011-13. Office of the Registrar General & Census Commissioner, India. Retrieved April 3, 2018, from http://www.censusindia.gov.in/vital_statistics/mmr_bulletin_2011-13.pdf
19. Maternal Mortality Ratio (MMR) (per 100000 live births) Retrieved from http://niti.gov.in/content/maternal-mortality-ratio-mmr-100000-live-births
20. Data not available for Latehar district in Annual Health Survey 2011-12.
21. *Annual Health Survey 2011-12 Fact Sheet. Chhattisgarh* (Publication). (2011-12). Vital Statistics Division. Office of the Registrar General and Census Commissioner, India.
22. *Annual Health Survey 2011-12 Fact Sheet. Jharkhand* (Publication). (2011-12). Vital Statistics Division. Office of the Registrar General and Census Commissioner, India.
23. *Annual Health Survey 2011-12 Fact Sheet. Odisha* (Publication). (2011-12). Vital Statistics Division. Office of the Registrar General and Census Commissioner, India.
24. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16:* Chhattisgarh. Mumbai: IIPS.
25. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16:* Jharkhand. Mumbai: IIPS.
26. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16:* Odisha. Mumbai: IIPS.

Chapter 3

# Profile

This chapter presents the profile of the respondents, including the health care providers who were interviewed for the study.

## 3.1. Respondents' profile

During the course of the study, in-depth interviews were held with a total of 173 respondents from tribal communities, including 53 persons from particularly vulnerable tribal groups (PVTG) across six districts, in the three states. Out of the total number of 173 respondents, 78 (45 per cent) were male respondents and 95 (55 per cent) were female respondents. Of the male respondents, 70 per cent were from non-PVTG ST communities and 30 per cent from PVTGs. Of the total female respondents, about 68 per cent were from non-PVTG ST communities and nearly 32 per cent were from PVTGs.

| Table 3.1: Number of Male and Female Respondents (tribal (ST), including PVTG) | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | Non PVTG ST | | | PVTG | | | |
| States | Districts | Male | Female | Total | Male | Female | Total | Total ST incl PVTG |
| Chhattisgarh | Jashpur | 10 | 10 | 20 | 4 | 6 | 10 | 30 |
| | Koriya | 11 | 19 | 30 | 2 | 2 | 4 | 34 |
| Jharkhand | Gumla | 7 | 9 | 16 | 6 | 4 | 10 | 26 |
| | Latehar | 15 | 9 | 24 | 4 | 6 | 10 | 34 |
| Odisha | Nuapada | 9 | 16 | 25 | 2 | 2 | 4 | 29 |
| | Rayagada | 3 | 2 | 5 | 5 | 10 | 15 | 20 |
| Total | | 55 | 65 | 120 | 23 | 30 | 53 | 173 |

The total number of children below the age group of 18 years is included in the 173 respondents; 12 children were from PVTGs, and 16 were from non-PVTG ST communities.

### 3.1.1. Tribal groups

The study respondents belonged to a total of 25 tribal groups; while the number of groups varied across the districts, they were representative of the tribal communities in the respective research sites (Table 3.2).

| Table 3.2: Tribal groups to which the study respondents belong | | | |
|---|---|---|---|
| State | District | Tribal Groups | PVTG |
| Chhattisgarh | Jashpur | Oraon (12), Kawar (1), Paekra (1), Gond (4), Nagasiya (2) | Pahari Korwa (10) |
| | Koriya | Gond (8), Chirwa (2), Pando (11), Manjhi (1), Kherwar (6), Agaria (2) | Baiga (4) |
| Jharkhand | Gumla | Lohara (1), Oraon (15) | Asur (10) |
| | Latehar | Munda (4), Oraon (14), Nagasia (4), Lohara (2) | Korwa (5) Birjia (5) |
| Odisha | Nuapada | Gond (15), Khadia (1), Dal (4), Sabar (2), Bariah (2), Bhoi (1) | Chaukhutia Bhunjia (4) |
| | Rayagada | Kondh (5) | Dongria Kondh (15) |

*Note: The number of groups in the table is 31; the 25 groups mentioned above do not include multiple enumeration of the same tribal group across districts.*

The study included interviews and discussions with 53 respondents from seven PVTGs across the selected districts. Thirty per cent of the respondents across the six districts – 14 out of 64 in Chhattisgarh, 20 out of 60 in Jharkhand and 19 out of 49 in Odisha – were from PVTGs. All the three states in the present study were selected for their substantial proportion of PVTGs. Compared to the other tribal groups, these communities experience greater socio-economic and political marginalisation. The blocks and villages with PVTG habitations were particularly focused on to ensure that their health issues including access to health care are adequately heard and documented as part of the study.

### 3.1.2. Age of Participants

The age of the respondents (those whose health issues were covered by the study; not necessarily those with whom intervie were conducted) ranged from one month to eighty years. The highest numbers of study respondents (41) were in the age group of 55 years and above, followed by 34 respondents in the age group of 19-25 years; 26 respondents between 36-45 years and 20 respondents in the 46-54 years age group.

**Table 3.3: Age of respondents**

| Age group | Male | Female | Age group | Male | Female |
|---|---|---|---|---|---|
| 0-9 months | 3 | 2 | 19-25 years | 9 | 25 |
| 1-2 years | 5 | 3 | 26-35 years | 10 | 14 |
| 3-6 years | 1 | 1 | 36-45 years | 14 | 12 |
| 9-13 years | 3 | 2 | 46-55 years | 10 | 10 |
| 14-18 years | 3 | 5 | Above 55 years | 20 | 21 |

About 54.9 per cent of the total respondents were women and children, of which a maximum number of women were in the age group of 19-25 years; 21 women respondents were above 55 years of age and 36 were between 26 and 55 years. The study sought to include a substantial number of women respondents across age groups to ensure that the gendered experiences of health and access to health care amongst tribal communities find focus in the study.

### 3.1.3. Education

Nearly a half of the respondents, i.e. 81 persons (46.8 per cent) from non-PVTG ST communities and 53 persons (67.9 per cent) from PVTGs said they had never received any formal education. Only 59 (34.10 per cent) of the respondents from non-PVTG ST communities and merely 12 respondents (22.64 per cent) from the PVTGs had completed their primary education. Twenty four respondents from non-PVTG ST communities had finished high school (12th class),while only two male respondents from PVTGs had completed high school. While two persons from Gumla (both men) from non-PVTG ST communities had completed their graduation and post graduation respectively, none of the respondents from the PVTGs had done so.

The educational backgrounds indicate very low literacy levels amongst the study respondents with a substantial proportion not having had any formal education. The literacy levels among PVTG respondents were much lower, with women respondents across all the tribal communities having the lowest levels of education.

The low levels of education among the respondents have serious implications for their health status, including access to health care. Education is intrinsically correlated to poverty and health; low levels of education pose barriers to access to livelihoods, to social, economic and

political entitlements and participation in development processes. Similarly, in the context of health, access to health information regarding causes, prevention and care for health problems, about health programmes, schemes, etc., is limited due to low literacy levels. Education level is an important indicator for the socio-economic, including health status in tribal communities.

### 3.1.4. Income

The average monthly incomes of the majority of the respondents and their families ranged between Rs.1,001–Rs. 2,000. Forty seven per cent of non-PVTG ST families in the study stated that their average family monthly income was Rs. 2,000 or less, while 18 families earned only upto Rs.1,000. Merely four respondents had family incomes above Rs.10,000 – three of whom, had government jobs and one was self employed. A family in Koriya, Chhattisgarh had the highest income; both the husband and wife were in government jobs and their joint earnings were Rs. 35,000 per month. The three highest incomes following this were in the range of Rs. 10,000-Rs. 15,000.

Among the respondents from PVTGs, twelve had household incomes of less that Rs. 1,000 per month, while sixteen had incomes between Rs. 1,000 and Rs. 2,000. Of the remaining respondents from PVTGs, 11 of them earned between Rs. 2,000 and Rs. 4,000 on an average in a month, with only four respondents earning above Rs 4000. Four earned about Rs. 500 per month. Information about respondents' incomes was important to contextualise the poor health status, the assess the affordability of health care for tribal communities, the out of pocket expenditures (OOPE) on health care and their possible impact on the health status of the respondents and their families.

### 3.1.5. Work and occupation

The respondents and their families were engaged in a range of work, often in multiple income earning activities. A majority of the respondents (67 per cent) were involved in agricultural work and for almost 50 per cent of the non-PVTG ST respondents, it was their only source of livelihood. Agricultural work involved cultivation on their land as well as working as farm labour for remuneration. Amongst the respondents from the PVTGs, 39 persons and their families were engaged in agricultural work, of which for 26 families agriculture was their sole occupation.

Thirteen PVTG respondents were involved in daily wage work along with agriculture work. Twenty four non-PVTG ST respondents said that they and their families were entirely dependent on daily wage work in the informal sector, especially construction work and brick making, for which they migrated often to other districts within the state as well as to other states. Six of the PVTG respondents and their families were engaged only in daily

wage labour. Very few of the non-PVTG ST respondents were engaged in government jobs or were self-employed, while none of the PVTG respondents nor their family members had government employment.

This information about respondents' work and occupation is necessary to gain a deeper understanding of the sources of income of the respondents, the implications of absence from work temporarily or permanently during episodes of ill health and the consequent loss of wages. It also enables a strengthened understanding about the nature of work, e.g., migration, marginal work, etc. that may determine health status and access to health care.

### 3.1.5. Land holding

About 56 (32 per cent) of the respondents, thirty one from non-PVTG ST communities and 25 PVTG respondents stated that they did not own any land. Fifty three (30 per cent) of the respondents, including 15 PVTG respondents and their families and 38 respondents from non-PVTG ST owned up to two acres of land or less. Of the 89 respondents and their families from non-PVTG ST communities that owned land, only 59 families had *patta*[1] for their lands. This information, however, was not available for five of the respondents. Amongst the PVTG respondents, less than half of the families had patta for their land, while the information was not available for two respondents. Tribal communities, particularly PVTGs, are dependent on land for livelihood and subsistence and the meagre land ownership presents the extent of marginalisation.

## 3.2. Health care providers at the community and facility levels

In-depth interviews were conducted with health system officials, such as the district and block medical officers, district programme managers, hospital managers, and other consultants under the National Health Mission (NHM). Fourteen medical officers (including Chief

Medical Officers, Block Medical Officers) and 15 other officers including NHM consultants for specific programmes such as sickle cell disease, reproductive and child health (RCH) programme, malaria, TB, etc. were interviewed as part of the study.

Interviews and discussions were carried out with 49 frontline workers including 31 ASHAs/ Mitanins/Sahiyas and 18 Auxilliary Nurse and Midwives (ANM), Anganwadi Workers (AWW), Lady Health Visitors (LHVs) and Multi Purpose Workers (MPWs). The interviews and discussions tried to assess the status of public health infrastructure, facilities and services available, and the challenges in the implementation of the health programmes.

Interviews were also conducted with the teachers of the *Ashram Pathshala* (residential schools) in one district to understand the health issues as well as government schemes for nutrition and health care meant for adolescent girls residing there.

### 3.2.1. Interviews with the representatives of NGOs

Discussions were also held with the representatives of NGOs [Lokdrushti, Chale Chalo] and missionary hospitals [Christian Hospital in Bissam Cuttack] (Odisha); Chaupal, Jan Swasthya Sahyog (Chhattisgarh); Right to Food Campaign, Ekjut, Torang Trust (Jharkhand)], networks such as Jan Swasthya Abhiyan (JSA Odisha, Jharkhand and Chhattisgarh) and National Alliance of Women (NAOW-Jharkhand) who were mainly working on health, education, livelihoods and issues related to migration. Discussions were also held with the representatives of the State Health Resource Centre (SHRC) in Chhattisgarh to understand the socio-economic contexts of tribal communities in the state as well as get an overview about the health system infrastructure and health programmes being implemented.

## Conclusion

The profiles provide insights into the socio-economic contexts of the tribal communities that determine their health status, including their access to health care. The socio-economic variables discussed here, for example, education, income, work and occupation, reiterate the extent of marginalisation of the respondents and the tribal communities that they belong to, which are critical to contextualise the findings of this study.

## Endnotes

1. Patta is a land deed issued by an appropriate authority that establishes the ownership of a person over a particular piece of land.

**Chapter 4**

# Social determinants and health

The health of any section of the population is tied to several factors and cannot be seen in isolation. The health and wellbeing of communities are dependent on a number of larger determinants. With regard to the tribal communities in India, their health indicators reflect glaring inequities when compared with the health indicators of the general population. The differential socio-economic status between tribal and non-tribal communities accounts for much of these inequities.

Poverty, 'forced' migration, displacement, conflict, environmental factors, limited sources of livelihood, lack of education, lack of connectivity and remoteness, etc., play a crucial role in determining the overall conditions of health in tribal areas. During the course of research, these issues emerged from interviews, FGDs and interactions with health officials and civil society representatives, as having a significant impact on the social fabric of tribal societies.

In this chapter we have attempted to briefly address some of these determinants in order to present the situation in the areas drawing largely from the narratives of the respondents. Even though this may be a limited exploration, it underscores the need for further research and understanding of these determinants that have an impact on health and the human rights of tribal communities.

## 4.1. Migration and impact on health

Out-migration by the tribal communities living in areas that are in the present-day Jharkhand, Odisha, and Chhattisgarh has been taking place for more than 300 years in search of employment.[1] During the last three decades, seasonal migration has been undertaken to bigger cities like Delhi, Kolkata, and Mumbai, and also to different parts of the states of Andhra Pradesh, Telangana, Gujarat, Uttar Pradesh, etc.

Tribal migration has increased in independent India due to various factors. These include fragmentation of land, loss of land due to its acquisition by non-tribals, displacement due to the establishment of industries or the implementation of infrastructural projects, conflict between insurgents and security forces of the State, drought, deforestation, and decreasing access to forests.[2] In the absence of adequate avenues of employment to sustain them in their native lands or villages throughout the year, tribal people are forced to undertake poverty-induced/ distress migration. As the Xaxa report (2014) concludes, "given the compulsion to migrate in search of work, it would be more accurate to describe such migration as 'forced migration'"[3] Forced migration has led to an increasing number of people from tribal communities working as contract labourers in the construction industry, in brick factories

and as domestic workers in cities. According to a health official in Nuapada, Odisha, "The villagers in this area do not get any work in the village other than agricultural work. But that is also limited because the villagers have small landholdings." Most of the time they are dependent on wage labour but when schemes like MNREGA do not prove sufficient, it forces them to migrate in search of work.

Most of the respondents' households in the study areas were landless. The few, who had land, had very small landholdings; cultivating the land can barely sustain the household for two or three months in a year. The residents of Jampani village, in Nuapada district in Odisha, corroborated the harsh reality that migration is the only alternative for earning a livelihood for households like theirs. "We at least get food to eat for those six months when we work outside, plus some money in advance. If we are lucky, we may even [manage to] save a little at the end of it."

Migrants from tribal communities primarily work in factories, agro-processing plants, brick kilns, and diamond factories.[4] They also do other daily wage work including working as porters, domestic servants, rickshaw pullers, street hawkers, petty traders, construction workers, etc. Migrants are often willing to take on jobs that others cannot or do not want to do; work that is often low-paid and insecure, but is nevertheless attractive to the tribal migrants who are in distress. The living conditions at construction sites or other work sites of the migrants are also appalling. The labour contractors provide only the most basic shelter. Many of the migrants have to live in cramped spaces situated in the midst of unhealthy environments or make do in inadequate, temporary shelters in the workplace itself.

In the course of the study, it was apparent that Odisha and Jharkhand have become 'labour pools from which cheap labour can be drawn seasonally'.[5] Every year, thousands of people from Odisha leave their native villages in search of work outside. Andhra Pradesh and Telangana are the most attractive destinations for migrants because of the large number of brick factories located in these states, which require a steady supply of cheap labour. In order to fulfill the demand, labour contractors known as *mukadams*, and their middlemen visit villages in Odisha to identify suitable persons and motivate them to go to Andhra Pradesh and Telangana by giving them advance loans. Since they usually go back to the same factories every year, the people from the communities are acquainted with the work and familiar with the living conditions. Hence, they are generally agreeable to migrating to the places in Andhra Pradesh and Telangana. Some migrants from Odisha also work in the diamond industry of Surat, Gujarat. Brick kilns offer seasonal employment, whereas the diamond industry requires labour for longer durations.[6]

Out migration from Jharkhand also indicates that it takes place in the form of 'a close kin network of families'. The process of migration is a collective activity wherein households in distress migrate together, stay together, etc. Evidence from Jharkhand indicates that seasonal migration is enforced due to shortage of food as well as failure of agriculture and is more a means of survival rather than 'capital formation'. Nearly a quarter of the migrants migrate to nearby cities and towns for daily wage work as porters, rickshaw pullers, etc., while others migrate to Punjab and Western Uttar Pradesh. for agricultural labour, yet other families are known to have migrated to Assam to work in tea gardens for an entire year.[7]

A new trend of tribal migration can be seen in recent years from these states, which is the large-scale migration of women to cities. This is a dramatic shift from the times when only men would migrate to urban centres. Tribal families driven by poverty are finding it more lucrative to send unmarried daughters to the cities because of the high demand for domestic labour, as well as higher wages.[8]

Monthly incomes of the tribal migrant women in the three cities of Delhi, Kolkata and Mumbai ranges from Rs. 1,000 to Rs. 5,000, with a quarter of the women reporting a monthly salary of Rs. 2,001 to Rs. 2,500 and Rs. 3,501 to Rs. 4,000. About one fifth reported salary of less than Rs. 2,000 with few tribal migrants in Kolkata and Mumbai earning above Rs. 5,000 per month. However, their situation is often vulnerable in alien and hostile environments that they migrate to; they are often defenseless against any exploitation – economic, physical or sexual – not only by their employers but also by agents, landlords, and others. They work under highly exploitative and dismal conditions, and are treated inhumanly at the workplace. Moreover, it is common for those who migrate for work to get embroiled in situations of trafficking and face dire consequences, henceforth.

The health status of the migrant population is generally poor due to their low economic condition. In addition, their health status is adversely affected by the alien environment at the migration site, different and unfamiliar conditions of food, water, and sanitation, as well as a demanding workload. These factors together have a serious impact on their security, safety, and their mental and physical health. Their inability to afford nutritious food and medicines hampers early recovery. In addition, the fear of being reprimanded by the employer and loss of wages pushes them to resume working before fully recovering from an illness, because they are compelled to meet set targets. After several recurrences of this cycle, they become chronic patients by the time they return to their native village. "We work very hard, often for 12 to 13 hours every day. Even if we are sick, we can't stop. They won't let us rest. That leads to further ill health. We try and suppress any sign of illness for as long as possible, otherwise we may lose the job," said Mamata of Jampani village.

Migration also affects people under treatment for tuberculosis and sickle cell disease (SCD). With the constant movement of people in and out of the state, it becomes difficult to maintain the continuity of treatment for both diseases. In the absence of robust DOTS treatment or regular blood transfusions, patients of TB and SCD suffer extreme ill-health.

Migration is particularly difficult for pregnant women. Hard physical labour in an overall situation of undernutrition and low BMI leads to increased incidences of maternal mortality, stillbirths, and low-birth-weight children. Pregnant women also do not have access to regular antenatal care (ANC) services such as immunisation, iron tablets, and maternity care at the workplace. Anita from Gumla, Jharkhand stated, "Even after returning to the

(native) village, the women feel fatigued and suffer from various illnesses. They are unable to do any work for almost two-three months."

Gross violations of child rights are also evident, whether in education, health and nutrition, or in working conditions. Deprived of their childhood and denied education, the children of migrant parents have no choice but to follow the same path as their parents. According to Lok Drushti, an NGO,[9] which works on migration, "Nuapada block has the highest percentage of migrants among the Scheduled Tribes from Khariar and Boden blocks who migrate as entire families. This form of family migration is called the *pathuria* system, which is a work unit comprising of a man, a woman, and one or two children in the age group of 6–14 years. Advance cash is paid to them on this basis, which means that children form an important component of distress migration in Nuapada district. At the brick kiln, children are assigned specific tasks like arranging and flipping raw and semidried bricks and making balls of wet mud. They are preferred for such work because of their small size and low weight. Children remain away from their village and school for more than six months, from October or November to early June."

At the work site, children, both boys and girls, are made to work the same number of hours as their parents; they are also subjected to verbal and physical abuse similar to that of their parents. No allowances are made for sick or injured children; they are expected to work even during illnesses. Children suffer from respiratory, stomach, eye, and skin problems as well as water-borne diseases. Malnutrition also affects limbs of many children causing them to become knock-kneed. Burns and injuries resulting from accidents are very common, which cause disability and even death, but are completely ignored by the employers. Girls and women often face sexual abuse.[10]

With specific reference to migrant tribal populations, the Constitution of India guarantees freedom of movement and freedom to settle within the territory of India.[11] However, in the absence of suitable policies and measures, migrant tribal populations have no residential security. They are compelled to live in crowded spaces, in unhygienic conditions without adequate civic amenities. They are also denied access to basic health services. Additionally, in the absence of documents like the ration card and other domiciliary records, migrant tribal populations are often unable to access the special schemes and programmes for STs that they are entitled to. Even PDS entitlements are not transferable from their native village

to the site of migration, and hence they are compelled to buy provisions from the open market. Their children's access to facilities like the Integrated Child Development Services (ICDS) programme and schools is also disrupted.[12]

The Constitution of India also contains basic provisions relating to non-discrimination,[13] equal pay for equal work,[14] health and strength of workers,[15] to ensure that citizens are not forced to take up any employment unsuited to their age or strength due to economic necessity.[16] There are also provisions for protection against the abuse and exploitation of workers,[17] right to work,[18] humane conditions of work,[19] living wage, conditions of work, and decent standard of life,[20] participation of workers in management, etc.[21] These principles are laid down in the Directive Principles of State Policy, which are the guiding principles for governance, and the state is obliged to apply these principles while making laws. In addition to the above-mentioned laws, the Parliament passed the Inter-State Migrant Workmen (Regulation of Employment and Conditions of Service) Act in 1979, specifically to deal with malpractices in the recruitment and employment of workers, who migrate across state boundaries. This Act provides for the registration of only those establishments that engage inter-state migrant workers.[22] The Act entitles the migrant worker to equal or higher wages than what a local worker is paid for the same work, along with allowances for displacement, home journey, suitable accommodation, and to register complaints about accidents.

However, the Act has several limitations. It applies only to migrants who are recruited through contractors or middlemen and only to those establishments that employ five or more such workers on any given day. The Act does not effectively monitor unregistered contractors. It is also silent on the provision of crèches, educational centres for children, or mobile medical units for labourers, especially for workers at brick kilns and construction sites. More importantly, it does not provide for any inter-state cooperation, in terms of letting these workers gain access to the PDS or to other such entitlements. Provisions such as those pertaining to minimum wage, displacement allowance, medical facilities, and protective clothing (in Delhi and in other cities in northern India) are not ensured under the Act either.[23] It also fails to address issues of social protection of migrants and the specific vulnerabilities of children and women migrants.

## 4.2. Forest reserves, wildlife sanctuaries and mining

A large proportion of the forests in the states with high concentration of tribal population, have been declared either as Reserved Forests, Protected Forests, Wildlife Sanctuaries or National Parks for the purposes of forest conservation and wildlife protection. A majority of the mineral reserves are found underground in the same regions where more than a quarter of the country's tribal population lives. The three states of Chhattisgarh, Jharkhand and Odisha account for 70 per cent of India's coal reserves, 80 per cent of its high-grade iron ore, 60 per cent of its bauxite and almost 100 per cent of its chromite reserves.[24] Over the years, a steadily increasing demand for minerals and land for industries or 'development' projects has made this dichotomy rather complicated.

According to a 2011 study conducted by Nalin Negi and Sujata Ganguly for the University of Bielefeld, Germany, around 50 million people have been displaced in India due to 'development' projects in over 50 years. Of these, dams, mines, industrial development and others account for over 21 million 'development'-induced Internally Displaced Persons [IDP]. Tribal communities are the worst affected when it comes to displacement due to 'development' projects representing almost 34 per cent of the affected population.[25] According to the Ministry of Tribal Affairs, nearly 85 lakh persons from tribal communities were displaced until 1990 on account of mega 'developmental' projects like dams, mining,

industries and conservation of forests, etc.[26] Thereafter, in the nineties, large numbers of tribal communities have been displaced; the discourse around tribal displacement is incomplete without taking into account the role of liberalisation policies in the country. What Neelmani Jaysawal (2014) calls the 'Liberalisation, Privatisation and Globalisation' (LPG) model of development has had a significant impact on the lives of tribal communities. While the New Economic Policy introduced in 1991 was meant to usher in an era of equity, it has merely marginalised the poor and vulnerable sections of the society further.[27] Prakash Loius, in his paper 'Liberalisation, Privatisation and Globalisation and the Scheduled Tribes' (2006) has argued that ST communities, who were already on the margins of society, ended up paying for these processes of economic change. Not only have mega-development projects and the growing industry led to large-scale displacement of tribal communities from their original habitations, they have also "forced (them) into the ever-expanding, low paid, insecure, transient and destitute labour market", to make ends meet in a market dominated society.[28] The neoliberal society is antithetical to the community based way of life of the tribal communities, and their indigenous knowledge is rarely documented and fostered. In the absence of natural resources and traditional systems of subsistence, tribal communities end up facing the brunt of the growing global markets, forcing them out of their homes to look for other means of sustenance (Jaysawal, 2014).[29]

In Raigarh, Chhattisgarh, almost 400 Kawar Adivasi families in the village of Lat were forced out of their ancestral lands because of blasts and water contamination caused by the Chhal coal mine of the South Eastern Coalfields Limited, India's largest coal producer.[30] Raigarh and its surrounding districts have extremely dense forest cover. Unfortunately, much of this forest land has been diverted for mining purposes, resulting in irreversible environmental degradation, loss of livelihoods and displacement of tribal communities. Similar situations were reported from Odisha as well.

On the one hand, the concern to save forests and wildlife drives the government to restrict more and more forest areas from human intervention, while on the other, massive areas of forest lands are being diverted every year to mining, dams, industries, roads or other such 'developmental activities'. In these actions initiated by the State, tribal communities are treated as encroachers and hence are the first ones to be targeted for complete eviction. However, they are often not compensated, nor rehabilitated. This leads to the loss of homes, cultures and livelihoods, and pushes the communities further into situations of poverty and poor health.

In Sunabeda in the Nuapada district of Odisha, the villagers expressed their concerns about the proposed tiger reserve as part of the Sunabeda Wildlife Sanctuary. The sanctuary area harbours a great diversity of wildlife habitats, with a vast plateau, canyons and many

waterfalls. There are about 64 villages, with a human population of 20,000 in the area and a majority of the population is ST, comprising of Gond and Bhunjia tribes and also the Paharia community. The villagers depend crucially on forest produce as their land holdings have poor yield. The major source of livelihood of the village is collection and selling of Non-Timber Forest Products (NTFPs) such as Mahua, Char, Amla, Harida, Kendu leaf, etc. Collection and sale of NTFP provides the tribal communities sustenance for 5 to 6 months in a year.[31] Based on the recommendations of the steering committee on the upgradation of Sunabeda wildlife sanctuary into a tiger reserve, the wildlife wing of the Forest Department has decided not to evict hamlets from the core area of the proposed Sunabeda Tiger Reserve. The department has instead decided to cordon off the hamlets from the core area, without evicting them.[32]

According to a newspaper report, the National Commission for Scheduled Tribes (NCST) has temporarily banned displacement of tribals from forest areas and critical tiger reserves, and has asked the environment ministry to revisit the rehabilitation policy to ensure that tiger conservation does not infringe on tribal rights. The move follows a circular issued by the National Tiger Conservation Authority in March 2017. The committee will study the issue of transfer or settlement of forest rights and the modalities of compensation to be given to Scheduled Tribes during voluntary relocation from tiger reserves.

*Source: The Economic Times, No tribal to be evicted from tiger reserves, 22 Feb 2018*

However, the villagers said that before the Sanctuary Authorities imposed restrictions, they had access to an abundance of forest produce in the area. The restriction on the collection of NTFP has led to a lot of hardship for the inhabitants of the Sunabeda sanctuary, as they have to grapple with the scarce livelihood resources and the constant anxiety of conflicts with forest officials. The latter are seen to be hand in glove with the timber traders, to whom they sell much of the forest timber, only to cast aspersions against tribal communities for theft. This has adversely affected their livelihoods. They were unanimous about their dependence and respect for the forest and categorically rejected the allegations that tribals were responsible for the destruction of the forests.

In the absence of adequate access to the forests, tribal communities are not only deprived of their livelihoods and the source for various forest produce, they experience impoverishment, which ultimately leads to poor health in these communities. With the public health infrastructure in these areas being virtually non-existent, or grossly inadequate and inaccessible, it is extremely challenging for tribal communities to address their health needs. With no medical care and an isolated existence, the impact of extraction and other industries affecting the environment, as well as the shifts in traditional dietary practices, further exacerbates the poor health conditions.[33]

## 4.3. Health care in 'conflict' areas

'Development'-induced displacement of human settlement has been an important issue engendering Maoist conflict in many States of India. Most of the large-scale 'development' projects are constructed in and around hilly and forest areas making the people belonging to the tribal belt vulnerable to displacement. "The Maoist affected districts in Odisha, Jharkhand and Chhattisgarh are more underdeveloped and poorer in comparison to other districts."[34] In the study States, which comprise mineral-rich forest areas, tribal communities have been affected by the on-going conflict between the Maoists and the State. Nearly non-functional educational and health systems, the breakdown of governance, and the consequent lack of well-being have led to further instability in these areas, fuelling the ongoing conflict.

In the absence of adequate response by the State to address the needs and challenges faced by tribal communities in these areas, the deep-seated grievances as well as the repression of struggles against exploitation and oppression, remain. In a sustained process of

strategic exclusion and isolation, the tribal communities living in these areas are ignored. Consequently, many of the areas here have been proclaimed as 'dangerous' and abandoned by the local authorities for being under 'Maoist occupation'. This, coupled with the already remote locations of the tribal communities, in isolated and arduous geographical settings, results in a complete lack of services, including health care. Increasingly, however, this is also emerging as part of a conscious strategy of the State and allied non-State actors, to ease commercial access to the forest tracts, for extraction in the future.

Alienation from their lands and forests, which are some of the key reasons for the conflict situation in these tribal areas, along with a host of other factors have led to chronic poverty and deprivation. These persisting factors are historically constructed – a trajectory that has led to the alienation of tribal communities from self-determination and from the natural resources with which they are deeply connected; this has taken place through a 'license raj' perpetuated by the unholy nexus of the government and forest officials, the local rich and the contractors. This has facilitated the manipulation and violation of the rights and interests of the tribal communities and the other rural poor in these areas. An immense number of people from tribal communities have also been displaced as a consequence.[35]

During the study, in some of the tribal dominated districts in Chhattisgarh, Jharkhand, and Odisha, the deep sense of fear was palpable. Most of the people avoided talking about the conflict. Some of those who did, did so on condition of anonymity. During discussions in the course of the study, some of those who responded to the issue of conflict opined, "while both Maoists as well as the government security forces claim to be protecting tribal communities, they are actually engaged in a battle for their own benefit. The government never really cares about the tribals or the other poor communities who live in these areas. They care only about what lies beneath the soil – the minerals. That is why the government and companies have started to make rounds in this area, because they can't tolerate the Maoists. But when questions are raised about tribal rights, it infuriates them."

There is not much research focused on the health inequities in conflict affected regions. Conflict contributes to the emergence of poverty amongst tribals, on account of restricted or complete lack of access to resources. The ongoing conflict in these regions has caused significant distress for the tribal populations, who are stuck between the two factions, and has limited their access to even the most basic health care. The resulting tension and constant fear, has a significant impact on the mental and physical health of a large section of the tribal population in these regions.

There is a complete lack of counseling or grievance redressal mechanisms for those who face the trauma of living in these volatile conditions on a daily basis. Evidence of sexual assault and violence against women of tribal communities, by the state armed forces as well as the

Maoists, is not uncommon. Even in the face of these atrocities, there are no provisions to deal with the victims of these crimes. Moreover, non-combat related ailments, like malaria, malnutrition and common childhood diseases are also high in these regions, given the lack of resources and health care, as well as the breakdown of supply chains and increasing population displacements caused by the conflict. Treatments such as DOTS for TB are irregular and unmonitored in situations where the state of public health care is abysmal and devoid of trained health care personnel. It is not surprising, therefore, that the need for requisite health care mechanisms to deal with both physical and psychological trauma is considerably high in these areas of conflict. These areas, unfortunately, present a rather dismal picture, with the overall 'development' indicators, including health care, being in shambles.

In the course of field work, the research team was advised against visiting the area around the Sunabeda plateau and also informed that it has been declared as a conflict zone and thus is unsafe for outsiders. The District Medical Officer (DMO) and the CDMO expressed their concerns when the research team went along with the DAMAN team that was engaged in its routine malaria screening. We were also told by local health officials that the conflict has caused a disruption in the health care services and while there are three CRPF camps based in the region, there is little communication or transportation available to the large number of PVTG communities who reside there. This complete absence of health care facilities for the people living in the interiors of a conflict zone led us to explore the situation further, in order to understand their experiences of accessing health care. The people of Sunabeda plateau described the challenges they face due to the conditions of isolation and conflict they reside in. They complained that the Primary Health Centre (PHC) building in Sunabeda Village has been abandoned and no Medical Officer (MO) has even visited the centre for a few years. According to the District Administration, the PHC staff is unwilling to work due to the fear of Maoists. Several interactions with administrative officials in Nuapada also indicated that Sunabeda is considered to be a 'dangerous' or an 'unsafe' area to visit. It is, therefore, only the ASHAs and the ANMs who are qualified to provide health care in these areas. At the same time, however, even they have little support and often run out of medicines, leaving the community no resort other than to visit the local healers.

The only Community Health Centre (CHC) with the availability of doctors and other facilities is in Komna Village, 42 km from Nuapada District and 54 km from Sunabeda, with no form of communication or transportation to get there. When emergency care is required, therefore, the villagers prefer to go to the District Hospital at Nuapada. Even though the villages in the Sunabeda area are very far from the Nuapada District Headquarter, they either walk down the hill to the road where they might get some public transport, or hire private transport, which is very expensive. According to the residents of Sunabeda, the ambulance service was withdrawn, fearing that the Maoists would seize it and this made it all the more difficult to travel the long distances, especially in the case of emergencies. According to an online media platform[36] that covers many social issues, a resident of Junapani Village, "Netri, was unable to have an institutional delivery because she could not pay for the transport to visit the CHC at Komna. Junapani is one of several remote villages located in the Sunabeda Plateau of Nuapada District." An ambulance was supposed to be stationed at the Komna CHC, but when Netri's husband, Hareram, contacted the driver of the ambulance, he was informed that the ambulance needed repair. After waiting for a day, in the hope that the ambulance would arrive after repair, he got the same answer and eventually, seeing the deteriorating condition of his wife, requested the ASHA workers to assist with the delivery. With no other alternative, the ASHA workers, who are not equipped to conduct such deliveries, took on the responsibility. Fortunately, the child was born safe, without complications.

The ASHA of Junapani village has conducted five deliveries in the last three months at Sanbaheli and Junapani villages, despite not being trained in it."[37] The lack of emergency health care, particularly for pregnancies, along with the absence of proper ANC services in the region, however, can also result in maternal and neonatal deaths.

The delivery of health care services in conflict zones with tribal populations is a matter of grave concern. As Leaning and Guha-Sapir (2013) have argued, ensuring proper health care in conflict zones involves adequate disease control, reproductive health care, maternal care, psychosocial support, emergency medical/surgical interventions, as well as sanitation and nutrition services.[38] Further, it is also difficult to motivate health functionaries to work in such areas as they don't have adequate incentives, and feel a sense of insecurity. In Chhattisgarh many of these conflict-affected areas are underserved, doctors are not available to work and there is a lack of adequacy in other staff also. There is also a lack of local providers who can provide health care in these areas. Keeping this in mind, the state and district authorities need to develop a specific health plan for conflict affected areas, to ensure that health infrastructure and services are available, and access to health facilities in terms of diagnostics, treatments, medicines, referral and transport services, etc. are facilitated by the state.

## Conclusion

The Constitution of India posits that unless social, economic, and political justice is secured for all citizens, it would be difficult to achieve a life with dignity. The government has a positive obligation under Article 21 to take the necessary steps to enable an individual to live with human dignity.[39] Currently, however, tribal populations face many atrocities due to the contexts they reside in. Many live in conflict zones, faced with the constant fear of violence and loss of life. This conflict, coupled with the various 'development' projects in the regions, the loss of livelihoods due to the lack of access to forest produce and the absence of services such as health care, education, etc., leads them to migrate to bigger cities, in search of daily wage labour and odd jobs. These jobs, however, provide little security leading to deterioration in their health and well-being. The life with dignity as promised by the Constitution, therefore, is highly compromised for the tribal communities in the areas where the study was conducted.

## Endnotes


1. *Migration of Tribal Women: Its Socioeconomic Effects - An in-depth Study of Chhatisgarh, Jharkhand, M.P and Orissa* (Rep.). (2010). New Delhi: Society for Regional Research and Analysis & Planning Commission, Government of India. Retrieved from http://planningcommission.nic.in/reports/sereport/ser/ser_mig.pdf
2. Xaxa, V. et al. (2014).Report Of the High Level Committee On Socioeconomic, Health and Educational Status of Tribal Communities of India.Ministry of Tribal Affairs.Retrieved June 23, 2017, from http://www.indiaenvironmentportal.org.in/files/file/Tribal%20Committee%20Report,%20May-June%202014.pdf
3. Xaxa, V. et al. (2014).Report Of the High Level Committee On Socioeconomic, Health and Educational Status of Tribal Communities of India.Ministry of Tribal Affairs.Retrieved June 23, 2017, from http://www.indiaenvironmentportal.org.in/files/file/Tribal%20Committee%20Report,%20May-June%202014.pdf
4. Smita. (2008). *Distress Seasonal Migration and its Impact on Children's Education. Create Pathways to Access.* Research Monograph No. 28. National University of Educational Planning and Administration.
5. *Impact of increasing migration on women in Orissa: Study in the Districts of Bolangir and Nuapada.* (2006-07). New Delhi: Jasmine Giri, Sansristi & National Commission for Women.
6. Gudavarthy, V. & Sengupta, T. (2015). A Survey of Migration from Western Odisha to Brick Kilns in Telangana.
7. Xaxa, V. et al. (2014). Report of the High Level Committee on Socioeconomic, Health and Educational Status of Tribal Communities of India. Ministry of Tribal Affairs.Retrieved June 23, 2017, from http://www.indiaenvironmentportal.org.in/files/file/Tribal%20Committee%20Report,%20May-June%202014.pdf
8. Deogharia, P. C. (2012). Seasonal Migration From Rural Areas Of Jharkhand: A Study Of Remote Tribal Villages Of South Chotanagpur Region. *Journal of Economic and Social Development,* 3(1). Retrieved from http://www.iesd.org.in/jesd/Journal pdf/2012-VIII-1 Prakash Chandra Deogharia.pdf
9. Lokadrusti experience with Children of the Migrant Parents. (2012, July 31). Retrieved April 9, 2018, from http://www.lokadrusti.org/?p=274

.10. Personal communications with Dr. Abani Panigrahi.

11. Constitution of India, Part IIII, Article 19(1) (d).
12. *Status Report on School Participation and Availing of Health & Nutrition Services for Children of Migrant labourers* (Rep.). (2015). National Commission for Protection of Child Rights (NCPCR). Government of India. Retrieved from http://ncpcr.gov.in/showfile.php?lang=1&level=2&&sublinkid=576&lid=998

13. Constitution of India, Part III, Article 23(2).
14 Constitution of India, Part IV, Article 39(d).
15 Constitution of India, Part IV, Article 39(e).
16. Ibid.
17. Constitution of India, Part IV, Article 39(f).
18. Constitution of India, Part IV, Article 41.
19 Constitution of India, Part IV, Article 42.
20 Constitution of India, Part IV, Article 43.
21 Constitution of India, Part IV, Article 43-A.
22. Press Information Bureau, Ministry of Labour & Employment. Government of India. (2015, December 21). *Migrant Workers* [Press release]. Retrieved April 9, 2018, from http://pib.nic.in/newsite/mbErel.aspx?relid=133690
23. Xaxa, V. et al. (2014).Report Of the High Level Committee On Socioeconomic, Health and Educational Status of Tribal Communities of India. Ministry of Tribal Affairs. Retrieved June 23, 2017, from http://www.indiaenvironmentportal.org.in/files/file/Tribal%20Committee%20Report,%20May-June%202014.pdf
24 Ibid
25. Salve, P. (2014, June 17). Tribals Account For A Third Of Communities Displaced By Large Projects. India Spend. Retrieved April 21, 2018, from http://www.indiaspend.com/cover-story/tribals-account-for-a-third-of-communities-displaced-by-large-projects-11821
26. Tribal Displacement in the Name of Development [Web log post]. (2012, September 7). Retrieved March 27, 2018, from https://socialissuesindia.wordpress.com/2012/09/07/tribal-displacement-in-the-name-of-development/
27. Jaysawal, N. and Saha S. (2014). Marginalisation of Tribal Communities due to Globalization. *Indian Journal of Dalit and Tribal Studies.* 2(2). pg 37-54.
28. Louis, P (2004). Liberalisation, Privatisation and Globalisation and the Scheduled Tribes.
29. Jaysawal, N. and Saha S. (2014). Marginalisation of Tribal Communities due to Globalization. *Indian Journal of Dalit and Tribal Studies.* 2(2). pg 37-54.
30. Puranam, E. (2016, July 7). The mine that displaced India's indigenous people [Web log post]. Retrieved March 27, 2018, from https://www.aljazeera.com/blogs/asia/2016/07/displaced-india-indigenous-people-160707062855721.html
31. *Impact Of Conservation Policies (Specific Focus on NTFP Ban Order by Supreme Court) On Lives and Livelihood of Local People Living in and Around the Protected Areas* (Publication). (n.d.). Retrieved March 2, 2018, Vasundhara. https://www.vasundharaodisha.org/Research Reports/Impact of NTFP ban on the lives and livelihood of the local people in and around PAs.pdf
32. Ramanath, R. V. (2016, August 11). Sunabeda sanctuary redraws core area, rules out eviction. *The Times of India.* Retrieved March 27, 2018, from https://timesofindia.indiatimes.com/city/bhubaneswar/Sunabeda-sanctuary-redraws-core-area-rules-out-eviction/articleshow/53644921.cms
33. Mishra, A. (2017). Shift in Tribal Food Habits: From Sustainable to Non Sustainable. Pradan. Retrieved from http://www.pradan.net/wp-content/uploads/2017/02/Shift-in-Tribal-Food-Habits.pdf
34. Behera, A. (2016). Maoist Conflict in Odisha (B10-2016, Rep.). Bengaluru, Karnatak: National Institute of Advanced Studies. Retrieved June 15, 2017, from http://eprints.nias.res.in/1024/1/B10-2016-Anshuman-Behera.pdf
35. Ibid
36. Odisha Villagers Denied Access to Basic Health Facilities. (2015). People's Voice.
37. Ibid
38. Leaning, Jennifer & Guha-Sapir, Debarati. (2014). Natural Disasters, Armed Conflict, and Public Health. *The New England Journal of Medicine.* 370. 783-4. 10.1056/NEJMc1315507
39. Nandini Sundar & Ors vs State of Chhattisgarh. (2011). Retrieved June 15, 2017, from https://indiankanoon.org/doc/920448/

**Chapter 5**

# Specific Health Problems and illnesses

Though tribal communities experience the burden of severe health problems, in this chapter we focus on the following illnesses, experienced by the respondents at the time of study. Although abortion and contraception do not conform to the category of 'illnesses', they are important in the context of sexual and reproductive health of women in tribal communities. Similarly, there were many instances of snakebites, dog bites and animal attacks, which are also addressed in this chapter as these are significant public health issues.

5.1. Communicable diseases – malaria, tuberculosis, leprosy.

5.2. Non-communicable diseases

5.3. Mental health and well being

5.4 Women's health related issues

- 5.4.1. Maternal health
- 5.4.2. Uterine Prolapse
- 5.4.3. Abortion
- 5.4.4. Contraception

5.5 Undernutrition

5.6 Acute respiratory infections

5.6. Haemoglobinopathies

5.7. Epilepsy

5.8. Snakebites, dog bites and other animal attacks

Each section is built on the narratives of the respondents along with the availability of services and the analysis of the programmes/schemes addressing the health problem.

# 5.1.1 Malaria


Rasika Huika is a 30-year-old woman from the Dongria Kondh, which is a PVTG in Odisha. She lives with her mother-in-law, husband, and their one-year-old daughter in Bissam Cuttack block, Rayagada. The family owns  less than an acre of land. Their only source of livelihood is *podu*, a form of shifting cultivation. They manage to earn between Rs. 10,000 and Rs. 15,000 in a year by selling some of the surplus produce from their land. Rasika's older daughter, Rani, died of malaria in October 2017, when she was four years old. Rasika recalls:

> *"Rani suddenly felt drowsy and fainted one day. Her fists were clenched and she had chills. We called the ANM immediately, who then called an ambulance. The terrain around our village is hilly, so the ambulance can only travel to a certain point. We had to walk, carrying Rani to the main road, where the ambulance was waiting. It took us one hour by a kutcha road to reach the CHC, which is in Kalyansinghpur, about eight km from here. On reaching the CHC at around 10.00 AM, Rani was given an injection along with saline*

*solution. A blood test confirmed that she had malaria. After being admitted in the CHC, Rani's condition gradually deteriorated. In the evening, she had convulsions once again. At around 11.00 PM, Rani died due to (complications from) malaria. After her death, the ambulance dropped us back to our village. The staff at the CHC was helpful and the facilities were fine, but somehow my daughter still died."*

Rani's death exposes the harsh realities that people confront every day, and the unchecked spread of malaria, which claims thousands of lives in tribal areas. Malaria has become a harbinger of grief for families like Rani's, despite being a preventable and curable disease. The narrative raises issues regarding the need for an early diagnosis of malaria, accessible and timely health care at the community level that may be able to address a large majority of 'uncomplicated' cases of malaria. While the narrative suggests that immediate health care was facilitated by the ANM through referral and also by the CHC where Rani was admitted, it can only be surmised (in the absence of other details) that her condition was already very poor at the time of admission at the CHC.

The narrative of Dhananjay Majhi a 16-year-old boy who belongs to the Gond tribal community, Odisha, also raises critical issues in terms of accessibility and affordability of health care for malaria. Dhananjay Majhi is from Lakhana village, in Nuapada district, Odisha. A family member recounted Dhananjay's experience with malaria:

*"There are seven members in our family and we have about two acres of land. Dhananjay's grandmother's old age pension is our only source of regular income. Dhananjay has completed his tenth class at an ashramshala (residential school), which is around 20 km from this village. While he was at school, he felt feverish and nauseous and informed his teacher about it. The teacher gave him some medicines to prevent the nausea; he was not taken to the PHC nor did they consult the ANM or ASHA at the time. But when Dhananjay's fever did not recede, the school informed us and we brought him home. First, we consulted a local unlicensed practitioner (jholachaap) in the village, who gave Dhananjay an injection and some medicines. He had the medicines for two days but the fever persisted. We then decided that Dhananjay should be taken to the District Hospital, which is about 15 km from our village. On 23rd July (2017), we called the 108 ambulance but were informed that the ambulance was not available. So, we hired a private vehicle to reach the hospital, which cost Rs. 600. After Dhananjay was admitted, blood tests were conducted and he was diagnosed with malaria. We were also told that his Hb count was very low (6 g/dL according to his medical reports); the staff advised us that he should get a blood transfusion at the hospital. The blood transfusion took place through the Odisha Red Cross blood bank service at the hospital, for which we paid Rs. 350. He was also given saline and injections along with the medicines. After the treatment at the hospital, he felt better and his fever subsided. On the first day of his hospitalisation, we spent around Rs.1,600, which included the travel, medicines from a private medical store (Rs. 220), food for those of us who accompanied him (around Rs. 500) and charges for the blood*

*units (Rs. 350). We have a RSBY card, which will be used for some hospital charges. Otherwise, all these expenditures were out of our own pockets."*

Due to the illness, Dhananjay also had to miss his school and his family members experienced loss of wages for the duration of his hospitalisation. Dhananjay Majhi's narrative points to the high OOPE in accessing health care for malaria. It also raises the issue of anaemia and malaria that necessitates more specialised treatment, including blood transfusion. Given the prevalence of anaemia and malaria, it is a major public health issue especially in tribal communities.

Evidence on the prevalence of malaria in the country, estimates 10.9 lakh cases of malaria in India, as per the National Vector Borne Disease Control Programme (NVBDCP).[1] An analysis of the NVBDCP data from the year 2008 to 2012 that was carried out as part of a study in 2015 reveals that ten States and Union Territories with 30 per cent or more of tribal population, experienced 14 per cent of the total malaria in the country.[2]

As per the NVBDCP, the present study states account for 68 per cent of all the malaria cases reported in the country.[3]

**Table 5.1.1.1: Malaria cases in Chhattisgarh, Jharkhand, and Odisha (2016)**

| S. No. | State | Malaria cases | Pf cases | Percentage of Pf Malaria | Deaths |
|---|---|---|---|---|---|
| | India | 10,90,724 | 7,16,213 | 66 | 331 |
| 1 | Chhattisgarh | 1,48,220 | 1,21,503 | 82 | 61 |
| 2 | Jharkhand | 1,41,414 | 83,232 | 59 | 15 |
| 3 | Odisha | 4,49,697 | 3,89,332 | 87 | 77 |
| | | 7,39,331 | 5,94,067 | 80 | 153 |

*Source: National Vector Borne Disease Control Programme (2016)*

Further, as per the NVBDCP data for 2016 (Table 5.1.1.1), Chhattisgarh, Jharkhand and Odisha, accounted for 80 per cent of the cases of P. Falciparum (Pf) malaria in the country. The states also recorded 46 per cent of all deaths in the country due to malaria for 2016.[4] Of the two most common species of malarial parasites (Pv and Pf) in India, Pf is known to be more dangerous and contributes significantly to deaths caused by all malaria in the country. This is also the type of malaria that is seen to be most common in the three states as stated above.

Given the socio-economic and ecological characteristics of tribal areas, multiple factors determine the prevalence of malaria. These include dense forest cover and the proximity of tribal settlements to forests, the substantial presence of water bodies and streams, which provide a breeding ground for mosquitoes all through the year. Further, the nature of work of a majority of tribal communities including agricultural work in the fields, collection of firewood or other non-timber produce from the forests, etc. heightens the exposure of people

to mosquitoes and increases the risk of vector–human contact.[5] Moreover, drastic changes in the ecology of tribal areas, due to damming, mining, deforestation, etc. are also said to increase the risk of malaria in these areas. The prevalence of poverty and food insecurity induced malnutrition in tribal communities further make them vulnerable to malaria and other infections.[6,7]

Skilled health care at the community level towards early diagnosis and treatment can significantly manage malarial infections. Unfortunately, the provision of health services in hilly and forested areas,which are also malaria-endemic zones, is particularly limited. Further, the lack of access to free medicines and diagnostics makes the treatment of complicated cases of malaria cost-intensive, which can pose barriers to health care, particularly for impoverished tribal communities. Therefore, robust public health infrastructure and services are required in these states to address the significant burden of malaria. In the absence of which, tribal communities, as is evident from the narratives and data, experience extremely adverse consequences.

## Community-level health care for malaria


Kamal Pando, a 17-year-old boy from the Pando Adivasi community in Sonhat block in Koriya district, left school in 2017 after passing the eighth standard, and was helping his family with agricultural work. His village was located near the forest, a little away from the main village. According to Kamal,

> *"On 25 August (2017), I experienced severe chills, felt feverish, and had a terrible headache. My family approached the Mitanin of the village for medicines. The Mitanin tested my blood (using a rapid diagnostic kit). The test took around 15 minutes to confirm that I had malaria. The Mitanin gave me some medicines for three days and explained the proper method of taking them. I completed the dose as per the Mitanin's instructions. After taking the medicines for the three days, my fever came down. I did not feel the need to go to any hospital or seek any further medical advice."*

Kamal's experience highlights the crucial role of community level early diagnosis and treatment of malaria. Mitanins/ASHAs and ANMs are often the first point of contact and should, therefore, be equipped with the necessary resources like slides, rapid diagnostic kits (RD kits), and essential drugs to diagnose and manage malaria at the village level. They

can provide the necessary treatment for P. vivax or Pf malaria with Chloroquine, Primaquine and Artemisinin-based combination therapies (ACT). However, they also need adequate training, support, and supplies of diagnostic aids and drug kits. In order to provide timely diagnosis and treatment for malaria, the skills to prepare the slides and use the RD kits to diagnose malaria need to be improved.

In the course of the study, discussions in a village in the Mahuadanr block in Latehar District, for example, indicated that RD kits, slides and anti-malarials like chloroquine and ACT, which are supposed to be part of the ASHA drug kit, were not available. As a result, when persons approached the ASHA with fever or symptoms of malaria, they were referred to the CHC at Mahuadanr, about 35 km away. The irregular supply of RD kits, anti-malarials and other essential drugs interfere with the ASHAs' efforts to diagnose and provide treatment for malaria. It is important to strengthen community level health care for malaria, as a majority of malaria can be treated at community level with adequate skills, diagnostic equipment and medicines provided to skilled community based health workers. This would address a large proportion of the malaria burden, which is "uncomplicated" malaria without any severe symptoms.

## Malaria treatment at secondary and tertiary levels of care

Anand Majhi is a 25-year-old from to the Gond tribal community of Godpula village, Nuapada district. There are five members in his family. They have about two acres of land. Agriculture is their primary source of income. During the lean agricultural season, the family migrates to Uttar Pradesh,Telangana and Andhra Pradesh to work in brick kilns for almost six months.

In July 2017, Anand Manjhi had returned to his village after working in Uttar Pradesh for eight months:

> *"I had fever, headache, nausea, and experienced the loss of appetite. After two days of fever, I went to the jholachaap (an unqualified local medical practitioner) in the village. He gave me an injection and some medicines and charged Rs. 300 for them. I went to the jholachaap because he is in the village and is always available. Despite the treatment provided by the jholachaap, I did not get any relief. When the fever continued for about*

*five days, my family took me to the DH in Nuapada. They borrowed a motorcycle from a neighbour to take me to the hospital; the fuel had to be paid for by us. I was admitted in the hospital, where a blood test was done. The first night in the hospital, I was administered two bottles of saline solution. I was also prescribed some medicines. We had to buy these medicines from a medical store and spent about Rs. 250 on them. In addition, we were asked by the staff at the district hospital to get another blood test and a urine test in a private lab, but we could not get these done. In less than two days at the hospital, we had already spent around Rs. 500 on medicines and food. This sudden illness cost my family almost a week's worth of wages.*

*"Any illness means heavy expenses for the family; it can mean the loss of a month's wages sometimes. I frequently experience this because my wife has sickle cell anaemia and requires regular blood transfusions. When she was admitted to this hospital a month earlier, our family members had given three units of blood, and the total cost incurred on her treatment was almost Rs. 9,000. Our family has a RSBY card in my father's name. It was made in 2013, but has not been renewed since then. I didn't know how we could use the card and ended up spending a large amount on the treatment anyway."*

Anand Majhi's narrative highlights how a common ailment like malaria can become a major financial burden for a family because of a poorly functioning and inadequate public health system. Further, in Anand Majhi's case, the family had to borrow a neighbour's motorcycle to reach the hospital even though his village is only three km away from the district hospital. In most cases where transport or ambulance services are not available especially in tribal areas, the patients bear these costs out of their own pockets. In such circumstances, accessing health care is perceived as a burden and often delayed, leading to deleterious consequences for persons with malaria, in this context. Furthermore, the general orientation of the health system that prevents comprehensive information about the patient's health condition, treatment, etc. from being communicated to them, is reiterated through this narrative. This can have poor implications for future prevention and health seeking behaviour.

## Malaria during pregnancy

Sona Jani, a 29-year-old woman from the Dal tribal community in Nuapada district was expecting her third child. Sona and her husband depend on agricultural work and the sale of some surplus agricultural produce, from which they earn about Rs. 2,000 a month.

*"In the ninth month of my pregnancy, I went to the village immunisation day camp for a check-up because I had been experiencing severe nausea and weakness. The ANM in-charge suggested that I should visit the CHC in Komna, about 6 km from the village. My family hired a private vehicle for Rs.400 to take me to the CHC. Following a blood and urine examination at the CHC, I was diagnosed with malaria. In addition, I was told that I was anaemic. While the tests and some of the medicines were provided free of cost*

*by the CHC, most of the prescribed medicines were not available there. We spent almost Rs. 500 buying these from a private medical store. I got better, but my family had to spend Rs. 2,000 on this emergency. This unforeseen expense exhausted my family's savings. I was not able to work given the delivery in the same month; it was a huge financial burden on my family."*

In tribal areas, the prevalence of malaria among pregnant women is considerably high. In the case of Sona Jani, her reports mentioned that her haemoglobin level was 8.8 gm/dL, well below the normal range particularly for a woman during pregnancy.

A study undertaken by Sama Resource Group for Women and Health in 2005 in Jharkhand revealed the double burden imposed by malaria on women, as compared to the men This study observed that even in comparable economic situations (poor households) men were better positioned as compared to women in terms of vulnerability to and impact of malaria because they got more rest and care.[8] The study also highlights the harassment faced by women especially in the age group of 35-40 years, from their husbands and in-laws for the expenses incurred due to the women's illness (malaria) as well as their inability to work as a consequence.[9] In this situation, daughters are often forced to become the main caregivers. Further, prior health conditions, the lack of decision-making power within households and the work burden both inside and outside their homes, increase their vulnerability to frequent episodes of malaria.

According to the epidemiological report of Nuapada district[10] (2016), of the 6,080 malaria cases in the district, 3,005 were diagnosed in women, 147 of whom were pregnant at the time of diagnosis. This is a matter of concern because malaria during pregnancy can pose several risks such as maternal anaemia, intrauterine growth restriction, intra-uterine death, stillbirth, premature delivery, low birth weight and neonatal death.[11,12] A study by Médecins Sans Frontières (MSF)[13] on the prevalence of malaria among pregnant women in the forested tribal areas of Andhra Pradesh, Telangana, and Chhattisgarh observed that the prevalence of malaria was 29.3 per cent, with 64 per cent of cases caused by Pf alone. Around 20.8 per cent of the women were found to have asymptomatic malaria. The study also underlined the association of malaria with severe anaemia.[14] This has serious public health consequences because a large number of tribal women are already anaemic during pregnancy. The NFHS-4 reported that women from the ST community had a greater prevalence of mild, moderate, and severe anaemia compared to their non-tribal counterparts.[15] Treatment often requires specialised care from secondary and tertiary level facilities, such as intensive care, blood transfusion and respiratory support.

Prevalence of malnutrition and anaemia in the tribal community, coupled with malaria, poses a great threat to women in these areas, including in terms of maternal health outcomes. Severe anaemia and malaria can be life threatening and result in maternal deaths. To address

these complications, access to functioning secondary-level services is crucial. Availability of safe blood, required for the treatment of severe malaria is also of utmost importance. In the study areas, all five district-level facilities visited by the research team reported having blood transfusion facilities. However, blood transfusion facilities were not available at the eight block-level CHCs visited during the study.

This is a major concern because the district hospitals are often located far from the block-level facilities, and even further from the habitations of patients. These distances and the geographical locations often make it challenging for patients to reach these facilities in case of medical emergencies, which can be imminent for cases of severe malaria, especially among pregnant women.

Thus, despite the national programmes to address malaria and promote maternal health, several women like Sona continue to experience poor health and pregnancy outcomes such as low birth weight, pre-term birth, stillbirth and spontaneous abortion etc. due to inadequate health care. Greater intersections between initiatives for the diagnosis and treatment of malaria and maternal health programmes, especially for girls and women from tribal communities and malaria-endemic tribal areas are needed.

## Availability of data on malaria

Data available on malaria has several gaps as even the country level data collated from the NVBDCP falls short in representing the true extent of the burden of malaria on people living in tribal areas.[16] The official records are drawn largely from laboratory reports of health facilities. However, people often go to the health facilities only in cases of severe symptoms and many do not access the health facilities at all. Over the years, especially in Malaria endemic regions, asymptomatic malaria has also emerged as a major issue, causing delays in diagnosis and subsequent treatment. Moreover, since most of the deaths take place at homes, very few actually get recorded as having been caused by malaria.

For instance, with data from health facilities, the NVBDCP reported an all-India figure of 10,90,724 confirmed cases of malaria in 2016, while the number of deaths due to Malaria

was 331. However, in the country profile for malaria for the same year, the World Health Organisation (WHO)[17] estimated almost 13 million cases of malaria in the country and an estimated 23,990 deaths. As per these estimates, India barely reported eight per cent of the actual malaria cases in 2016.[18]

Similarly, the 'Chronicles from Central India: An Atlas of Rural Health', a report[19] by Jan Swasthya Sahyog (JSS) mentions an epidemic that broke out in Chhattisgarh between October and December 2010. The State Government reported 32 deaths in the state. However, in Bilaspur district alone, where the JSS is based, there were nine deaths, seven of which were reported from the JSS hospital in Ganiyari. Moreover, through verbal autopsies done by its community health workers, there were estimates of almost 250 deaths, 200 of which were confirmed to be caused by malaria.[20] A report prepared by the State Health Resource Centre (SHRC) that documented deaths through community level monitoring of the Village Health Sanitation and Nutrition Committees (VHSNCs) in the year 2016, reported 3,531 deaths due to fever or suspected malaria.[21] In the same year, the NVBDCP reported only 61 deaths due to malaria in the state.[22] Both these reports highlight a serious, larger concern regarding the under-reporting of malaria morbidity and mortality, with serious implications especially for health care in the malaria endemic tribal areas.

In the absence of accurate data on malaria, given the inaccurate representation of its spread and severity, the strategies and resources employed for its control are severely compromised. Improved methods of reporting on malaria incidence, prevalence and deaths is critical.

## Programmes and policies for malaria prevention and control

The key strategies under the NVBDCP for the prevention and control of malaria in India are Surveillance and Case Management (SCM), Integrated Vector Management (IVM), Early Detection and Containment of Malaria Outbreak and other supportive interventions.

The Indian Public Health Standards (IPHS) for public facilities such as Sub-Centres (SC), PHCs, and CHCs also highlight the integration of the NVBDCP in the services available in the facilities, which are essential in malaria-endemic areas.[23,24,25] The diagnosis, treatment, and examination are performed at both the PHC and the CHC levels. In addition, CHCs

are also the designated first referral units (FRUs) for treatment of severe and complicated malaria cases. Services here include diagnosis of malaria cases, microscopic confirmation, and treatment. As cases of complicated malaria need to be managed by secondary and tertiary-level health care facilities, it is essential to address the fundamental challenge of poor public health care infrastructure, functioning and quality of services, which are hugely deficit when compared with the IPHS.[26] Additionally, the difficulty in accessing these facilities and services, due to their distance from the tribal habitations impose high costs on the patients. As a result, cases of severe and complicated malaria are not dealt with adequately and the morbidity associated with malaria continues to take a heavy toll on these communities.

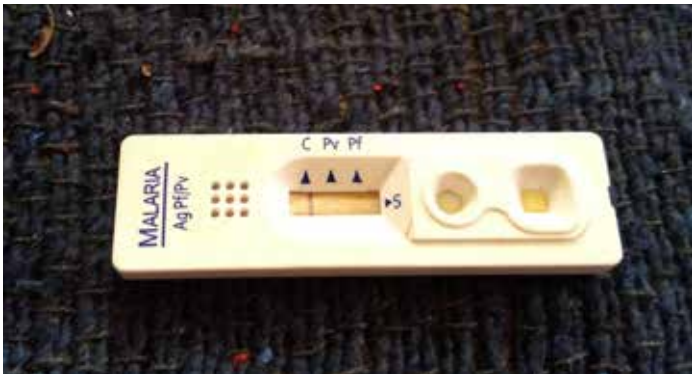
Other strategies for the prevention of malaria, recommended by the "Operational Manual for Malaria Elimination in India (2016)"[27] focus on the reduction of the adult mosquito population using indoor residual spraying, the adoption of personal protection measures like the use of long-lasting insecticide nets (LLIN), insecticide-treated bed nets (ITNs), and implementation of larvae-control and source-reduction measures. These measures are recommended for sub centres based on the Annual Parasite Incidence (API) of the said area. These strategies need to be integrated with the health care system's response to providing the required equipment as well as promoting the use of the equipment through community participation.[28]

As per the data for Nuapada district that was provided by the health officials with the research team, two rounds of Integrated Vector Management (IVM) in 2016 covered almost 2.8 lakh people and 78 per cent of the total target population. Distribution of LLINs was also underway, although the previous rounds of distribution were in 2009–10 and 2011–12, when 14.9 per cent and 28.09 per cent of the population were covered respectively. At the time of reporting, the district had received only 15 per cent of the allotted number of LLINs. Distribution of LLINs or mosquito nets is again in the domain of the health system, but this is frequently hampered by supply-related issues. In Latehar district, Jharkhand, the staff from Mahuadanr block flagged concerns about the inadequate supply of LLINs or mosquito nets from the district.

Gaps in supply of equipment for the prevention of malaria, diagnostic kits as well as medicines continue to remain key barriers to addressing malaria. There is a need to explore

possible local solutions for malaria control by involving communities and ensuring regular, adequate, free availability of treatment, that is proximal to the people.

Rapid Diagnostic Tests (RDTs) allow for the monitoring and testing of malaria and reduce the dependence on traditional microscopy. RDTs are commonly used for screening cases of fever for malaria by ASHAs, ANMs and MPWs in endemic areas. RDTs provide accessibility to malaria screening at the community level itself, which means that the appropriate treatment (based on the diagnosis of P. Vivax or Pf can be started on time. In the three states, which are major contributors to the malaria burden in India, ASHAs, ANMs and MPWs use RDTs as a standard practice for testing cases of fever. While microscopy is the gold standard for malaria diagnosis, the distance to health facilities and the lack of availability of health personnel and equipment make RDTs a viable option in resource starved settings, like tribal areas.




In this context, the availability of RDTs with health workers becomes crucial, in the absence of which they have to turn away people who approach them or refer them to health facilities. This further delays the process of timely diagnosis and treatment for malaria. During interactions with ASHAs, those who had a regular supply of RDTs were observed to be more proactive in using them and screening fever patients. In the two districts of Koriya and Jashpur, FGDs with Mitanins revealed that a regular supply of RDTs, and regular training on their use with anti-malarials, made it customary for them to screen fever patients. In contrast to this, Sahiyas in Jharkhand, both from Gumla and Latehar districts, reported during FGDs that the irregular supply of the RDTs prevented them from screening cases of fever for Malaria, and deterred them from starting the first line of treatment at the community level. Regular availability of RDTs was found to be key to the motivation of frontline workers in terms of the timely diagnosis and treatment of malaria.

Screening 'at the doorstep' is an important measure towards early detection. The Odisha State, for example, has launched a comprehensive case management programme, Durgamma Anchalare Malaria Nirakaran (DAMaN) in 22 districts. The programme aims at vector control as well as the early detection and containment of malaria (in a mission mode). This is a joint initiative by the Indian Council of Medical Research (ICMR) and the National Institute of Malaria Research (NIMR), and works in collaboration with NVBDCP. The initiative was being carried out in both the study districts – Nuapada and Rayagada – in the State. In Nuapada district, 100 inaccessible and difficult to reach villages have been identified for the programme.

| Table 5.1.1.2: Report of 1st round of DAMaN - 2017, Nuapada | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| S. No. | Name of the block | No. of camps to be conducted as per guideline | First week | Second week | Number of Fever cases screened | Number of Pf cases screened | Number of Pv cases detected | Total positive case detected |
| 1 | Khariar Road | 45 | 10 | 12 | 3,395 | 41 | 27 | 68 |
| 2 | Komna | 54 | 14 | 13 | 3,292 | 73 | 13 | 86 |
| 3 | Khariar | 14 | 3 | 2 | 1,373 | 29 | 9 | 38 |
| 4 | Boden | 33 | 8 | 1 | 2,267 | 43 | 15 | 58 |
| 5 | Sinapali | 27 | 11 | 16 | 2,925 | 44 | 11 | 55 |
| | Total | 173 | 46 | 54 | 13,252 | 230 | 75 | 305 |

*Source: Internal report from District Hospital on DAMaN programme, Nuapada*

Such a programme, however, will have to be operationalised along with other initiatives to strengthen malaria control measures to reduce human–vector contact as well as to strengthen the screening, diagnosis, treatment for malaria at various levels of the health care system. Services to address other complications, arising from existent co-infections, morbidities and conditions such as pregnancy along with malaria, necessitate improved convergence of programmes.

The recent National Framework for Malaria Elimination in India (2016–2030)[29] has proposed several measures for the elimination of the disease. It also takes cognisance of tribal areas as exclusive areas of concern and recognises the need for a more intensive and integrated approach to address malaria in these areas. The approach involves the adoption of the Tribal Malaria Action Plan (TMAP), which is to be implemented in 96 tribal districts. The main objective of the TMAP is to reduce the annual parasite incidence (API) to less than one for a population of 1,000 in tribal districts.[30] Though the National Framework for Malaria Elimination does include some promising measures, like a greater emphasis on community participation in managing malaria and inviting non-profits to monitor the malaria programme, it's implementation remains to be assessed as the plan was introduced only in 2016.[31]

Further, to control the unrestrained spread of malaria, it is important for programmes to adopt interventions that are specific to tribal areas and are tailored to the social and cultural realities of the community like their lifestyle, their livelihoods and their cultural practices. A study by SEARCH, an NGO based in Gadchiroli, a malaria endemic area in Maharashtra, which tried to understand the barriers to malaria control among marginalised tribal communities, also suggests that geographic, cultural, and social factors are the greatest barriers to malaria control among tribal communities in India. It recommends that malaria interventions need to be aimed at improving community-level knowledge about malaria using

culturally-appropriate health education materials and making traditional healers partners in malaria control. Further, it also suggests the promotion of rapid diagnosis and treatment within the village, and increasing the distribution and use of ITN in these communities to decrease infection.[32] Another initiative undertaken by Dr. John Cherian Oomen of Christian Hospital, Bissam Cuttack, found a co-relation between malaria and malnutrition among Adivasi children, who presented as severely underweight. He launched a programme called 'Mal-Mal' wherein, following a diagnosis of Malaria induced Malnutrition by the doctors at Christian Hospital, these children were treated with chloroquine prophylaxis. As a result, their nutritional status and growth patterns improved significantly. The integration of malaria control and prevention measures should also include the extension of services to *ashramshaalas* (residential schools). The availability of prevention and control measures, and the timely treatment of malaria to the children living in these schools is important because their health needs are often neglected since that they stay away from their families.

## Conclusion

Management of malaria related morbidity and mortality critically depends upon a system of early diagnosis and prompt rational treatment, which was absent in most of the study areas. Despite programmes for the prevention and control of malaria being implemented since 1953, albeit under different names – from a 'Control' programme to an 'Eradication' programme, an 'Anti-Malaria' programme and now an 'Elimination' programme for vector-borne diseases – malaria remains a major public health issue, particularly for tribal communities. All these programmes, however, have been characterised by a limited bio-medical-technological understanding and approach to malaria,[33] which has largely overlooked the socio-economic, geographical and cultural determinants of the infection. Without these structural issues being addressed, the elimination and control strategies for malaria have a long way to go.

## Endnotes


1. *Malaria Situation (2013-2017 [upto December])*. National Vector Borne Disease Control Programme. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India.
2. Sharma, R. K., Thakor, H. G., Saha, K. B., Sonal, G. S., Dhariwal, A. C., & Singh, N. (2015). Malaria situation in India with special reference to tribal areas. *The Indian Journal of Medical Research,* 141(5), 537–545. http://doi.org/10.4103/0971-5916.159510
3. *Malaria Situation (2013-2017 [upto December])*. National Vector Borne Disease Control Programme. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India.
4. Ibid.
5. Sundaraman, T., Prasad V, and Nandi S, et al. eds. (2010) *Tribal Health [Module No. 15]*. Public Health Resource Network.

6. *Malaria and Poverty.* (2007) European Alliance Against Malaria. Retrieved April 28, 2018, from https://www.malariaconsortium.org/userfiles/file/Past events/factsheet2 - malaria and poverty.pdf
7. Shankar, A. H. (2000). Nutritional Modulation of Malaria Morbidity and Mortality. *The Journal of Infectious Diseases,* 182(1), S37-S53. doi:https://doi.org/10.1086/315906
8. Sama Resource Group for Women and Health. (2005). *The Interrelationship Between Gender and Malaria Among the Rural Poor in Jharkhand.* Achutha Menon Centre for Health Science Studies.
9. Ibid.
10. *Epidemiology Report of District Nuapada.* Odisha (2016). Accessed from the District hospital, Nuapada during the visit in the year 2017.
11. Ugwu, E. & Dim, C. & Uzochukwu, B. & Iloghalu, E. & Ugwu, A. O. (2014). Malaria and anaemia in pregnancy: A cross-sectional study of pregnant women in rural communities of Southeastern Nigeria. *International health.* 6. doi: 10.1093/inthealth/ihu009.
12. Schantz-Dunn, J., &Nour, N. M. (2009). Malaria and Pregnancy: A Global Health Perspective. *Reviews in Obstetrics and Gynecology,* 2(3), 186–192. Retrieved April 25, 2018, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2760896/
13. Corrêa, G., Das, M., Kovelamudi, R., Jaladi, N., Pignon, C., Vysyaraju, K., . . . Isaakidis, P. (2017). High burden of malaria and anemia among tribal pregnant women in a chronic conflict corridor in India. *Conflict and Health,*11(1). doi:10.1186/s13031-017-0113-1
14. Ibid
15. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4)*, 2015-16: India. Mumbai: IIPS.
16. *Operational Manual for Malaria Elimination in India* (2016). National Vector Borne Disease Control Programme. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India. P 14. Retrieved May 13, 2018, from https://www.punjabnvbdcp.in/Download/Operational-Manual-Malaria-2016-Version-1.pdf
17. *Malaria: Country Profiles – India* (Publication). (2017). Retrieved April 27, 2018, from WHO website: http://www.who.int/malaria/publications/country-profiles/profile_ind_en.pdf?ua=1
18. Ghosh, A. (2017, November 30). 'India's malaria surveillance mechanism detects only 8% cases, finds new report.' *The Indian Express.* Retrieved April 27, 2018, from https://indianexpress.com/article/india/world-malaria-report-surveillance-india-cases-deaths-4959610/
19. *Chronicles from Central India: An Atlas of Rural Health.* (2016). Jan Swasthya Sahyog.
20. Ibid.
21. *Analysis of Community Reported Deaths in Chhattisgarh* (Draft Report). (2016). Retrieved April 27, 2018, from State Health Resource Centre, Chhattisgarh website: http://www.shsrc.org/webupload/PUBLICATION/STUDIES/VHSNC_CBM_AND_SPY_STUDIES/ANALYSIS_OF_COMMUNITY_REPORTED_DEATHS_IN_RURAL_CHHATTISGARH_2016.pdf
22. *Malaria Situation (2013-2017 [upto December])*. National Vector Borne Disease Control Programme. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India.
23. *Indian Public Health Standards (IPHS)*, Guidelines Sub-Centres (Revised 2012), Directorate General of Health Services, Ministry of Health & Family Welfare. Retrieved - May 23, 2018, from http://www.nhm.gov.in/images/pdf/guidelines/iphs/iphs-revised-guidlines-2012/sub-centers.pdf
24. *Indian Public Health Standards (IPHS)*, Guidelines for Primary Health Centres (Revised 2012), Directorate General of Health Services, Ministry of Health & Family Welfare, Retrieved April 27, 2018, from http://www.nhm.gov.in/images/pdf/guidelines/iphs/iphs-revised-guidlines-2012/primay-health-centres.pdf
25. *Indian Public Health Standards (IPHS),* Guidelines for Community Health Centres (Revised 2012), Directorate General of Health Services, Ministry of Health & Family Welfare. Retrieved April 27, 2018, from http://www.nhm.gov.in/images/pdf/guidelines/iphs/iphs-revised-guidlines-2012/community-health-centres.pdf
26. *Operational Manual for Malaria Elimination in India.* 2016. National Vector Borne Disease Control Programme. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India. P 14. Retrieved May 13, 2018, from https://www.punjabnvbdcp.in/Download/Operational-Manual-Malaria-2016-Version-1.pdf
27. Ibid

28. Bharti, P. K., Silawat, N., Singh, P. P., Singh, M. P., Shukla, M., Chand, G., … Singh, N. (2008). The usefulness of a new rapid diagnostic test, the First Response® Malaria Combo (pLDH/HRP2) card test, for malaria diagnosis in the forested belt of central India. *Malaria Journal,* 7, 126. http://doi.org/10.1186/1475-2875-7-126

29. *National Framework for Malaria Elimination in India (2016–2030)*. National Vector Borne Disease Control Programme (NVBDCP), Directorate General of Health Services (DGHS), Ministry Of Health & Family Welfare. Retrieved April 21, 2017, from http://nvbdcp.gov.in/Doc/National-framework-for-malaria-elimination-in-India-2016%E2%80%932030.pdf.

30. Ibid

31. Nemana, V., & Rao, A. (2016, February 6). "On malaria, the government's rhetoric must meet reality." *The Hindu*. Retrieved April 27, 2018, from http://www.thehindu.com/opinion/op-ed/on-malaria-the-governments-rhetoric-must-meet-reality/article8203628.ece

32. Sundararajan, R., Kalkonde, Y., Gokhale, C., Greenough, P. G., & Bang, A. (2013). Barriers to Malaria Control among Marginalized Tribal Communities: A Qualitative Study. *PLoS ONE,* 8(12), e81966. http://doi.org/10.1371/journal.pone.0081966

33. *Health System in India: Crisis & Alternatives.* Towards the National Health Assembly II. Booklet 2. (2006). National Coordination Committee, Jan Swasthya Abhiyan.

# 5.1.2 Tuberculosis

India has the largest burden of Tuberculosis (TB) in the world, with the incidence of about 27.9 lakh cases in the year 2016.[1] The mortality due to TB in the same year was about 4.5 lakh, even though it is curable.[2] A study conducted in 2015 reported that a pooled pulmonary prevalence of TB was an estimated 703 per 1,00,000 for the tribal population,[3] which is significantly higher than that for the country (256 per 1,00,000).[4] Another study by an NGO, Jan Swasthya Sahyog (JSS) in 2015 found that "tribals had [a] significantly higher proportion of all tuberculosis, sputum positive tuberculosis more than non tribals."[5]

According to NFHS-4 (2015-16), the number of persons per 1,00,000 usual household residents suffering from any tuberculosis, including medically treated tuberculosis, (suffering from tuberculosis and received medical treatment) is much higher in Odisha and Jharkhand compared to Chhattisgarh. The prevalence of TB in Odisha and Jharkhand is higher than the national average of 316 cases per 1,00,000 people (Table 5.1.2.1).[6]

| Table 5.1.2.1: Prevalence of Tuberculosis | | |
|---|---|---|
| State/Country | Number of persons per 1,00,000 | |
| | TB (includes medically treated TB) | Medically treated TB |
| Chhattisgarh | 167 | 157 |
| Jharkhand | 328 | 312 |
| Odisha | 338 | 322 |
| India | 316 | 305 |

*Source: NFHS-4*

However, disaggregated data regarding TB in the tribal population was neither available from NFHS nor from the HMIS data, an indication of the need for epidemiological studies on TB in the tribal areas, as well as the availability of disagregated data.

During the study, a parent from the Oraon tribe from Chiknipani village in Jashpur district, narrated his daughter's experience with TB.

> *"Since her early childhood, Nisha, my twelve-year-old daughter, would keep falling ill regularly. She had pneumonia and for the last two years, she had lost weight and suffered from frequent cough. She had lost her appetite and looked very weak. We took her to a local practitioner in the nearby village. He gave her some medicines, but that did not help much. The Mitanin, who lives close to our house, insisted that we take Nisha to the CHC in Pathalgaon.*
>
> *The doctor at the CHC prescribed a few tests that we had to get done from a private laboratory. After these tests, we were asked to get an X-ray done. We had to pay Rs. 10 for the out patient department [OPD] slip and Rs. 150 for the X-ray in the CHC.*
>
> *Anisha's X-ray showed that she had TB. Medicines were prescribed for a month. We purchased them from the medical shop opposite the hospital. We must have spent almost Rs. 3,000 on the medicines for one month. The doctor told us to continue these medicines for three months. We have visited the CHC in Pathalgaon three times now. Most of the expenses were on the medicines and transport. We must have spent around Rs. 12,000-15,000 to buy the medicines from the private chemist."*

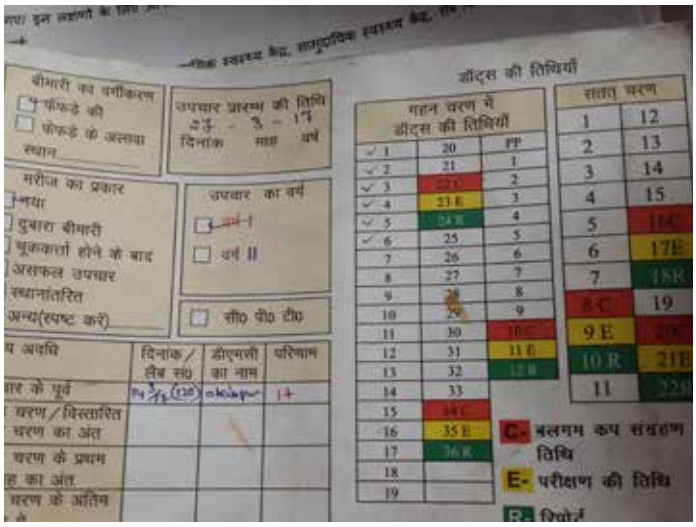
Nisha's narrative highlights the factors responsible for her condition and in a way, represent those of many people with TB. These factors include poverty, lack of nutrition as well as lack of timely and affordable treatment. In addition, the high OOPE on investigations, medicines, and transportation to health facilities. Access to affordable health care, including for TB, is one of the biggest issues facing the tribal population in all the three states. However, the programmes to address TB are often unable to reach those residing in remote locations, which is a grave issue for those living in the tribal areas. Further, tribal communities, particularly the PVTGs, who live in distant habitations are often unable to access the health facilities due to the terrain and the distance.

## Treatment interruptions and MDR TB

Hardik Ram Sidar, a 50-year-old man from the Gond tribal community, from Balajhar village, Jashpur district, has had TB for five years with intermittent treatment.

> *"I began the treatment in July 2012. When I felt better after the initial months, I discontinued the treatment. I restarted the treatment again in 2013 because I had severe cough and pain in the chest. However, I again stopped the treatment after six months as I felt better. In 2017, when I visited the PHC in Tampta, the Medical Officer referred me to the CHC in Pathalgaon. There I underwent tests and the doctor told me that because of repeated discontinuation of the treatment for TB, I have now become resistant to the TB drugs."*

When patients begin to feel better, many of them discontinue the regimen without completing the course of treatment; this may be for various reasons such as the lack of money to buy medicines, the lack of access to health services, or the lack of awareness. Some patients may also discontinue the treatment due to seasonal migration, that maybe a further deterrent to health care.




Ramlal Wadka, who belongs to the Dongria Kondh (PVTG) community from the village Khambesi, Rayagada district, recalled,

> *"I had chest pain and a severe cough in 2015. I visited the local healer and took charmuri (a local traditional medicine) for a month. However, I decided to go to the CHC in Bissam Cuttack as the charmuri did not help in reducing the cough and the chest pain. At the CHC, a [sputum] test was done free of cost and I was asked to go to the Muniguda CHC to collect the reports. Since the post of the laboratory technician at the CHC in Bissam Cuttack was vacant, all the samples [sputum smears] were being sent to the Muniguda CHC for analysis. The test results showed that I had TB. I was treated under DOTS and continued the medicines for six months. The doctor at the CHC in Bissam Cuttack had asked me to visit the hospital after six months. I started feeling better, and hence did not visit the CHC for a check-up. But a few months later, I started experiencing chest pain and weakness. I have yet to visit the facility".*

These narratives clearly show that the reason for the discontinuation of treatment is the perception of being cured before the completion of the full course of treatment. Persons

with TB are usually prescribed medicines for a duration of six months. In the absence of information and counselling, they often discontinue the medicines after a few weeks under the mistaken impression that they have been cured. Others may not continue due to the side effects of the medication or because they cannot afford the medicines and diagnostics, due to the unavailability of public health care facilities. This is a critical concern because discontinuation of the treatment leads to an increased resistance to the drug.

During the study, it emerged clearly that most patients were not counselled prior to starting the TB treatment and were not explained the need to continue the treatment without any interruption and regular follow up. Persons with TB were also not informed about the possible side effects of the drugs. However, merely informing patients to have the medicine and then to return to the health facility once the medicines are finished, implies incomplete information and is inadequate to ensure that the patients follow up and adhere to treatment.

During group discussions in Nuapada district, some of the respondents explained that when a person with TB migrates for work, the treatment is invariably discontinued. Being migrants, they are not provided medicines by the health care facilities as they are outside the jurisdiction of their home states. Some may not be aware about the health facilities in an unfamiliar location. Several of the respondents shared that with Aadhaar (a unique identity number issued by the government) becoming mandatory for accessing TB medicines, patients without Aadhaar are left with little option but to access treatment from the private sector at high costs. Out-migration also affects children with TB as they often accompany their parents. This pushes patients to stop treatment or to approach the private sector.

Parents of Harish Suar, a 10-year-old boy from Chaukhutia Bhunjia PVTG tribe of Junapani village, Nuapada district, narrated their experience:

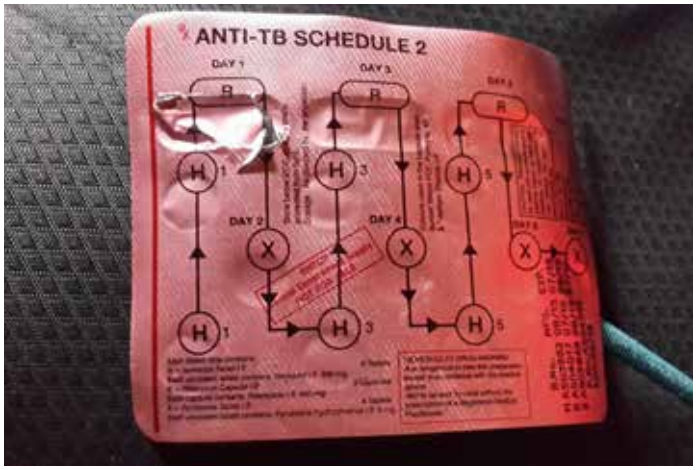
> *"We are wage labourers and our entire family migrates to Andhra Pradesh in search of seasonal employment. Our son Harish had a cough along with chest pain and weakness. Harish's tests were conducted at the Komna CHC and TB was confirmed. He was started on DOTS treatment and was given the medicines at the CHC. However, Harish had to discontinue the treatment because he left with us to work at a brick kiln in Andhra Pradesh. There was no health facility available in the area to which we had migrated."*

A similar experience was shared by Vijay Birijiya, a 32-year-old man from the Birijiya PVTG of Nawatoli village in Latehar:

> *"We migrated to Varanasi to work at a brick factory for a few months during the lean agricultural season. Both my wife and I worked for many hours without even a day's leave. We must have earned almost Rs. 40,000 in six months. But my health gradually deteriorated and I was unable to work for long hours at the kiln. My wife and I consulted a private doctor in Varanasi who gave me some medicines. I must have spent around Rs. 10,000 on the medicines. When we returned home, we consulted the Sahiya, who took*

*me to the CHC at Mahuadanr. A sputum test confirmed that I had TB. My treatment was started and I was given medicines for a month. After that, I started feeling better and discontinued the medicines. I had to go to Varanasi again to work in the brick factory because my family did not have any other source of income. Soon, my health started deteriorating again, and I could no longer work at the kiln. I returned home. But this time I was in a worse condition with a severe cough and blood in my sputum. My father took me to the TB sanatorium in Itki (near Ranchi) where I was admitted for five days.*

*After that I went back to the CHC Mahuadanr. They did another sputum test which again confirmed TB. I was informed that I would be on DOTS and that the Sahiya will provide the medicines. The doctors at the Mahuadanr CHC told me to get my family members tested as well, but that has not been done yet. Currently, I am taking medicines after a gap of nearly one year. I am still suffering from chest pain, cough, severe weight loss, and loss of appetite."*




While the migration was inevitable for the families from these states, their narratives highlighted the serious consequences for their health due to the lack of health facilities, access to counselling, medicines and the lack of information available to people with TB on the importance of continuation of treatment. A study conducted among 204 TB patients in India found that they often drop out even though medicines are provided free of cost, due to low socio-economic status, family liabilities and burden of losing income from work.[7]

This frequently leads to adverse consequences such as relapse of TB, prolonged illness or even DR-TB. DR-TB often develops due to the mismanagement of treatment, misuse of anti-TB drugs, use of poor quality medicine, or when a patient does not complete the TB regimen.[8] This is particularly significant given the large number of families from Odisha and Jharkhand who migrate in search for work, raising concerns particularly about the resulting Drug Resistant TB (DR-TB).

The Annual Health Survey (AHS) shows that the percentage of cases of DR-TB lost to follow-up is over 15 per cent in all the three study areas. The consequences of losing such a significant fraction of DR-TB cases to follow-up can lead to development of multiple or extreme form of drug resistance in TB. Further, in the absence of treatment, a more severe form of DR-TB may develop that can potentially cause infection to others.

India has the highest TB burden globally and has over 1,00,000 cases of DR-TB. Yet the health system pays little attention to DR-TB, a type of TB that is unresponsive or resistant to at least two of the first line of TB drugs. According to the 2018 Revised National Tuberculosis Control Programme (RNTCP) report, 7,34,247 of presumptive DR-TB patients were subjected to Drug Resistance and Drug Susceptibility Tests (DRT/DST), while 38,605 persons of Multi-Drug Resistant and Rifampicin Resistant TB (MDR/RRTB) patients were notified in 2017.[9]

## Discrimination and abandonment faced by patients

Stigma and discrimination due to TB was an issue raised by respondents in the study. During the FGDs, several respondents in Odisha and Jharkhand shared:

> *"Women face stigma, discrimination, delayed access to health care services, delayed treatment and worst of all, abandonment by their families. The stigma against young girls with TB is particularly severe. The unmarried girls and women prefer the diagnosis of TB to be kept confidential to avoid being labelled as 'TB patients'. Having TB can affect marriage prospects or break engagements, or even marriages."*

Stigma and discrimination often translates to women being ostracised by their families and communities as well.[10] During an FGD in Odisha, a participant expressed that women with TB are the worst sufferers, especially during seasonal migration. One of the respondents, who also migrates out to work in a brick kiln shared, "Men can take out time and visit the local hospital but we hardly get to visit a hospital and may not get permission from the bhatti managers either."

A senior medical officer at the CHC in Komna said, "Even in a tribal community, a woman with TB is often isolated and discriminated by her family and relatives. She is forced to eat and sleep separately". The discussions also indicate that there is usually someone to take care of the men when they fall ill, and ensure that they are on the path to recovery, while women are left to look after themselves without the necessary care. The gender and financial barriers can act as major obstacles for women accessing treatment, with higher chances of DR-TB and other co-morbidities.

## Aadhaar and TB treatment

The Union Health Ministry has made Aadhaar a compulsory document for TB patients availing treatment under the RNTCP.[12] According to a gazette notification dated 16 June 2017, "…an individual eligible to receive the benefit under the Scheme is, hereby, required to furnish proof of possession of Aadhaar number or undergo Aadhaar authentication."[13] TB patients, hospitals and health care workers availing cash assistance from the government were also required to enrol with Aadhaar by 31 August 2017.

## The Gazette of India. (2017, June 19)

**Ministry of Health and Family Welfare on Revised National Tuberculosis Control Programme (RNTCP) for availing treatment under Nikshay (web based solution for monitoring of TB patients under the RNTCP)**

(1) An individual eligible to receive the benefit under the Scheme is, hereby, required to furnish proof of possession of Aadhaar number or undergo Aadhaar authentication.

(2) Any individual desirous of availing the benefit under the Scheme, who does not possess Aadhaar number or has not yet enrolled for Aadhaar, shall have to apply for Aadhaar enrolment by 31/08/2017, provided he or she is entitled to obtain Aadhaar as per the provisions of section 3 of the said Act and such person may visit any Aadhaar enrolment centre (list available at Unique Identification Authority of India (UIDAI) website www.uidai.gov.in) for Aadhaar enrolment.

(3) As per regulation 12 of the Aadhaar (Enrolment and Update) Regulations, 2016, the Department of Health and Family Welfare, which is responsible for implementation of the Scheme in the State Government or Union territory Administration is required to offer Aadhaar enrolment facilities for the beneficiaries who are not yet enrolled for Aadhaar and in case, there is no Aadhaar enrolment centre located in the respective Block or Taluka or Tehsil, the Department responsible for implementation of the Scheme in the State Government or Union Territory Administration shall provide Aadhaar enrolment facilities at convenient locations in coordination with the existing Registrars of UIDAI or by becoming UIDAI Registrar.

*Source: (Excerpts from) http://egazette.nic.in/WriteReadData/2017/176763.pdf*

The major problem with linking of Aadhaar with TB treatment is that it fails to recognise that fundamental rights such as the right to health including treatment cannot be made conditional. These rights are inalienable and inherent and the State has a non-derogable duty to provide the same. The State cannot deny treatment for not having an Aadhaar or any other identity card and is bound to provide it regardless.

Making Aadhaar mandatory for TB treatment would lead to denial of treatment and exclusion especially of the poor, marginalised communities such as tribal and Dalit communities, migrant workers, rickshaw pullers, domestic workers, the homeless and those working in the large informal sector. It would in effect deny the benefits to the people who are most vulnerable and in turn violate their rights to life as enshrined in the Article 21 of the Constitution of India. This is also likely to increase the already prevalent inequity in health care among patients who are invariably the most vulnerable.

The argument put forth by the government is that Aadhaar would ease the cash transfer, a scheme that incentivises doctors and pharmacists for notifying TB and providing medication. In practice, however, this implies that the access to TB medication and its provision, also necessitates access to the TB patients' Aadhaar details by the providers, which violates

their privacy and confidentiality. Other arguments include the reducing of corruption and enhancing transparency; however, managing issues of corruption and pilferage, which is largely an administrative oversight, at the cost of fairness and justice by jeopardising the patients' rights to treatment is extremely violative.

Although the State under Article 21 read with Article 47, has a primary duty to secure the health of the people living in India, this conditionality requiring the mandatory disclosure of status and identity of a person is demeaning and contrary to the affirmative duties of the State.

## Access to medicines and diagnostics

The shortcomings of India's Tuberculosis Control Programme are further compounded by a lack of infrastructure to efficiently diagnose the drug-resistant strains and the limited access to the necessary drugs even after a diagnosis.[14] The narratives in this section have clearly indicated the urgent need for free, quality treatment as many persons with TB are forced to access care in the private sector.

Moreover, access to diagnostics and treatment of Multiple Drug Resistant TB (MDR-TB) is a critical issue, which needs to be addressed urgently. Currently, in India, an estimated 1,30,000 of MDR-TB patients emerge annually (Central TB Division, Annual Status Report, 2017).[15] Bedaquiline and delamanid are two new drugs that are used in the treatment of MDR-TB. India currently offers bedaquiline only as part of the second line treatment for patients with MDR-TB at pilot sites under a conditional access programme (CAP), while delamanid is yet to be rolled out. Scaling up of treatment for patients with MDR-TB is necessary for significant reduction in new infection and deaths. However, once this CAP concludes, the price for a six-month course of bedaquiline in India per patient will be USD 900 and delamanid USD 700. One of the reasons for the high cost of these TB drugs is the intellectual property regime, in this case, patents which disallow the entry of low-cost generic substitutes into the market. Thus, although bedaquiline and delamanid can help patients suffering from MDR-TB, their inclusion in the national programme for TB control is determined by the huge cost implications. To include these drugs in the TB programme, the price of the drugs have to be brought down substantially. This is possible by the government issuing a compulsory license, allowing domestic production. Generic production of these life saving drugs can reduce their prices by up to 95 per cent; "the target generic price for a six-month course of bedaquiline and delamanid is between USD 48 to 102 and USD 36 to 96, respectively, according to a study published in the Journal of Antimicrobial Chemotherapy."[16]

The diagnosis of TB in India is largely reliant on the use of sputum microscopy, which remains a major challenge. Evidence suggests that the use of sputum microscopy fails to

identify a substantial number of the TB cases due to its low sensitivity.[17] To address this concern, the Government of India, began scaling up the availability of the Cartridge Based Nucleic Acid Amplification Test (CB-NAAT) since 2013, which can detect TB bacteria in small samples as well as smaller amounts of bacteria in samples as in the case of children. In India, CB-NAAT is under-used due to a huge shortfall, with merely 628 CB-NAAT machines located in major cities across the country. Other infrastructural challenges also exist for CB-NAAT such as availability of electricity or skilled human resources, which remain challenges in tribal areas. However, CB-NAAT also has its limitation as it only tests for rifampicin resistance, which is inadequate for diagnosis of other drug resistance in TB patients. According to the report of the 'First National Anti-Tuberculosis Drug Resistance Survey (2014-16)', published by the MoHFW, while resistance to rifampicin stands at an approximate of 2.86 per cent among new patients, resistance to isoniazid is considerably higher, at approximately 11 per cent among new patients. A similar pattern is seen among patients with resistance against rifampicin who were previously treated; resistance was at 11.67 per cent to rifampicin, and 25.09 per cent to isoniazid.[18] While CB-NAAT testing is rapid and efficacious, it is also expensive and inaccessible. Government action to enable transfer of technology so that the requisite machines can be manufactured at cheaper rates in the country towards wider use is important. Most crucially, the government must secure the health system with the full range of diagnostic facilities for TB, including culture tests to accurately determine drug resistance.

## Nutrition and TB

While medicines are important for TB treatment, the effective control of the disease depends on a range of public health measures, including addressing poverty and systemic inequality that lead to undernourishment.

*Food Basket for TB patients at Pathalgaon CHC, Jashpur, Chhattisgarh*

Most of the persons with TB in the study were also undernourished, which reinforces the strong relationship between malnutrition and tuberculosis. Evidence is increasingly showing that treatment outcomes for TB patients are greatly impacted by improved nutrition among them. Since, TB patients require nutritional support in the long term, food assurance should not be limited to providing nutrition to people when they have TB, but throughout their lifetimes. This is to ensure that the

marginalised, particularly the tribal communities who experience food insecurity, are not trapped in a cycle of undernutrition and TB even after they have recovered. In terms of the law, the Food Security Act has to be implemented more effectively. It may also require to be amended in relation to TB to increase the diversity of food, not restricted to food grains and cereals, but to also include proteins. The PDS also needs to be linked to TB nutritional support so that food assurance, as discussed above, is beyond the TB period. Therefore, adequate budgets are necessary to provide support to families affected by TB in the long term.[19]

### Case study of the Chhattisgarh TB nutrition programme

The link between malnutrition and infections has been well documented and there also exists a strong relationship between under-nutrition and TB. To address this, the Chhattisgarh government initiated a nutrition programme for people undergoing treatment for TB.

In 2016, the State Government of Chhattisgarh approved a budget for a pilot in the state to test the efficacy of a nutrition programme linked with TB treatment in two districts in Chhattisgarh. Around 290 persons with TB were enrolled in Rajnandgaon (with support from SHRC, Chhattisgarh) and 108 cases were enrolled at the Jan Swasthya Sahyog (JSS) Hospital in Ganiyari, Bilaspur for the pilot. The programme offered an additional 800 calorie supplementary nutrition in the form of groundnuts, milk powder and groundnut oil or eggs to the patients over the course of 4 months between February 2016 to May 2016. For this, the Health Department allocated Rs 600 per person per month. After the initial two months, it was seen that more than 70 per cent of the enrolled patients came regularly to the health facilities to collect their monthly food baskets. Findings from the pilot also suggested a mean weight gain of about 1.63 kg across 225 people who were undergoing treatment for TB from public facilities in Rajnandgaon district and the JSS hospital and regularly consumed the food basket provided to them. The positive findings from the pilot study and the advocacy by the JSS and also SHRC prompted the State Government to scale up the TB nutrition programme across the state in November 2017.

A study (2013) by JSS, Chhattisgarh, found that under-nutrition was the most prevalent condition present in more than 85 per cent of rural men and women with pulmonary TB at diagnosis. The study recommended nutritional support for severely underweight patients with pulmonary TB to decrease their risk of mortality.[20]

At present, Chhattisgarh and Kerala are extending supplementary nutritional support in kind instead of cash. During a visit to the CHC in Pathalgaon, Jashpur, it was observed that TB patients were given supplementary nutritional support in kind. This is a significant initiative by the Chhattisgarh government, as per which, a food basket is provided to all patients diagnosed with TB. The basket includes one kg each of milk powder and edible oil, and one and half kg of groundnut per month per patient.[21]

In April 2018, the Government of India (GOI) announced the Direct Benefit Transfer (DBT) of Rs. 500 per month to ensure that TB patients are able to meet their nutritional needs during

treatment.[22] The strategy expects to identify unreported cases and to partly supplement the income of a family in which the earning member of the family is suffering from TB.[23] However, the major concern with the DBT for TB is the mandatory link with Aadhaar to avail benefits under the scheme,[24] which has been discussed in detail earlier. Some of the respondents, who were unable to secure Aadhaar due to lack of proof of residence could not access the benefits under the DBT scheme.[25] The impact of the scheme with regard to women's access to treatment will have to be assessed, given the gendered experience of TB, the inequity in access to health care, the systemic oppression that exists within the family structure, coupled with the stigma faced by women suffering from TB.[26]

## The role of the private sector in TB prevention and treatment

The narratives and the FGDs from the study also indicate that many patients approach the private sector, which is quite diverse; the private sector ranges from unlicensed practitioners, local healers, licensed physicians, and to many others who provide treatment for TB. In some districts, the medical officers from the government facilities also run private practice. The lack of standardisation of treatment regimen for TB in the private sector is a major concern as it leads to significant OOPE.

In 2012, the Government of India made the notification of TB mandatory for both the public and private health sectors.[27] The notifications from the private health sector remain suboptimal – of the 40 per cent of the TB cases being treated by the private sector, nearly half of them are missed by the notification system, which is a big lacuna.[28] The lack of accurate numbers on TB detection, treatment, and cure rates in the private sector in the RNTCP also pose challenges to the government's efforts to prevent and treat the disease.

One of the primary purposes of the recent National Strategic Plan (NSP)[29] 2017-2025 is to address TB patients in the private sector. To achieve this goal, the strategy offers incentives to doctors in the private sector to ensure regular reporting; a scheme to provide TB medicines free of cost to patients in the private sector is also being envisaged. Through its multipronged approach, the NSP also aims to establish a robust management information system (MIS) to monitor all cases, to ensure proper delivery of drugs, and to ensure treatment adherence. To further support treatment adherence among patients, the MoHFW plans to introduce customised short messaging services (SMS) services for patients that will act as reminders to consume their drugs. In terms of diagnostic facilities, the NSP intends to make rapid molecular tests like Mantoux available for patients, who have been referred by any private doctor or facility. In 2018, a MoHFW notification announced that medical practitioners and pharmacists could face a jail term in case of failure to notify the government about TB patients. Doctors, laboratory technicians, and chemists, including those in the public sector, could face a jail term of between six months and two years under Section 269 (negligent

act likely to spread infection of disease, dangerous to life) and Section 270 of the Indian Penal Code (malignant act likely to spread infection of disease dangerous to life). However, this move was strongly opposed given its potential to violate the principle of doctor-patient confidentiality, especially given the deep-seated stigma associated with TB. Criminalising doctors and other health care providers may also inhibit provision of care to persons with TB and is likely to create barriers to treatment for persons with TB.

Any programme on TB should instead, provide comprehensive information, spread awareness in areas of high prevalence or vulnerability to the infection, foster efforts to reduce stigma and create enabling conditions for voluntary testing. Active Case Finding (ACF) in the manner that it is currently envisaged, would be a violation of the human rights to privacy, confidentiality and a life with dignity. Private health care providers, however, need to provide information, spread awareness on prevention and to motivate voluntary testing in areas especially where the prevalence is high.

## Policies, programmes and strategies to address TB

The National Tuberculosis Programme (NTP) was launched in the year 1962 and was preceded by at least five decades of efforts to understand and control the TB situation in the country. The NTP was responsible for the development of a self-administered TB treatment and drug regime, over a 12–18 month duration. In addition, the NTP was also responsible for the development of an extensive network of infrastructure for TB control, which comprised of district TB centres and TB clinics. Although the programme was responsible for the growing awareness about TB and its treatment facilities, which was largely responsible for placing around 1.3 million patients on TB treatment annually, it did little to address the epidemiological situation of TB in India.[30] Despite the introduction of the short-course chemotherapy (SCC) regimen (1983-86), comprising rifampicin and pyrazinamide, which reduced the length of the treatment from twelve to six months, it did not improve compliance to the treatment.[31]

In 1992, almost 40 years after the launch of the National Programme, a review was undertaken by the GoI, and the international agencies – the Swedish International Development Agency (SIDA) and the World Health Organisation (WHO).[32] The review pointed to the major shortfalls of the programme that included the use only of X-rays in diagnostics, interruptions in the availability of drugs and poor compliance with the treatment regime. The review thus highlighted the pitiable condition of the programme in which only about 30 per cent of the TB cases were being diagnosed, with merely 30 per cent of them completing the treatment.[33]

To address these shortfalls, in 1997, the RNTCP was launched as a national programme to be rolled out in phases and had several salient features. The programme was based on

the recommended direct observation of treatment (DOTS) that provides medicines to the patients directly on alternate days, promotes diagnosis by sputum smear microscopy, follows standardised regimens, recording and reporting of notified cases and treatment outcomes.[34] The RNTCP used national procurement, supply, and distribution of quality-assured anti-TB drugs, allocated drugs for the entire course of treatment in individual patient-wise boxes and further decentralised diagnostic and treatment services.[35] However, since 2001, several new challenges emerged in the context of TB; one major issue was HIV and the other was drug resistant TB (DR TB).[36] The National AIDS Control Programme (NACP) and RNTCP developed the "National framework of Joint TB/HIV Collaborative activities" in 2007 and revised it in 2015. The framework articulated the policy of TB and HIV collaborative activities in India.[37]

Further, to improve access by tribal and other marginalised groups, the RNTCP also developed a Tribal Action Plan in 2005. The programme called for relaxation of norms in setting up designated Microscopy centres and TB units and coordination with the Integrated Tribal Development Agency (ITDA) to encourage persons with TB from the tribal communities to report early for diagnosis, and to promote closer supervision in tribal areas by RNTCP staff for enhanced treatment outcomes.[38] The programme recommended additional TB units and District Microscopy centres in tribal and difficult areas, additional staff and compensation for transportation to the patient and attendant, as well as higher salaries for contractual programme staff.


However, a study carried out by the Indian Council of Medical Research (ICMR) on the performance of the RNTCP in tribal districts in India observed the programme's poor performance in terms of case detection rate (CDR) in tribal and backward districts as compared with other districts in India. It observed that in 2012, 26 per cent of the tribal dominated districts had CDR of less than 51 per cent. More than 50 per cent of the tribal districts were not able to achieve cure rates of more than 85 per cent. These findings suggested that the overall RNTCP performance in tribal areas was not optimal.[39] Another study by Ramachandran *et al.* showed that even after a decade of RNTCP implementation, the lack

of awareness among patients about the availability of local, free diagnostic and treatment facilities under RNTCP. The patients use facilities in hospitals, medical colleges or private practitioners. Considering the incidence of TB, more than half of the total TB patients bypassed RNTCP services and were either undergoing treatment in the private sector or were untreated. According to the study, one of the key reasons behind the poor outcomes in the poorer and backward districts was the low agricultural productivity, unemployment, and critical gaps in physical and social infrastructure.[40]

The National Strategic Plan (NSP) for Tuberculosis Elimination (2017-2025) was launched by the MoHFW and acknowledges the vulnerability of the tribal community to TB due to their adverse social and economic conditions and the issues of accessibility and availability to health services.[41] The strategic plan also recognises the urgent need for comprehensive support to address TB in tribal communities. It includes the mainstreaming of TB into other key Ministries, including Finance, Mines, Food and Civil Supplies, Social Justice and Empowerment, Tribal Welfare, Rural and Urban Development, Women and Child Development, and Environment and Forest.[42] However, the NSP has been initiated only a year ago and its implementation is yet to be reviewed.

Recently, the GoI in collaboration with Stop TB partnership and WHO organised the Delhi End-TB Summit in March 2018, during which the Tuberculosis Free India Campaign was launched. The campaign seeks to ensure that every TB patient has access to quality diagnosis, treatment, and support over the next couple of years;[43] its outcome will be known gradually as it is implemented.

## Conclusion

The experience of the TB programmes discussed previously points to their inadequacy in achieving their goals; this has largely been the result of a weak and systematically neglected public health system, despite multi-sectoral inputs being available in the NTP's development and its integration within the health system. Thus, the impact of any programme, including the RNTCP, is determined by a well-functioning, affordable, accessible and sensitive public health system with a wide outreach.

Moreover, the increasing proportion of microbial strains showing resistance to single and multiple drugs does not portend well for the overall situation in India; it implies that there will be an ever-increasing number of patients in need of care. TB is also a social concern, given the deep stigma associated with it; stigma is also a key barrier in the successful implementation of the RNTCP. Stigma necessitates a robust response by the RNTCP; it is also particularly critical to address the gendered nature of stigma so that TB programmes are equally accessible to women. Access to information, counselling, diagnostics towards

early identification and sustained and quality care and treatment for TB are the basis for any programme to be effective. The non-availability of free diagnostics and drugs in the government facilities and the consequent high OOPE for patients is a major barrier particularly for persons with TB from tribal communities. Patients spend a lot of money in travelling to health care facilities for screening and treatment. For daily wage earners, who are suffering from TB or those whose family members are suffering from TB, it could mean loss of livelihoods and subsequent wages, causing their income and levels of subsistence to reduce dramatically. The OOPE on health care is known to create vicious cycles of ill-health and poverty. The non-availability of free services in tribal areas, push patients to take medicines and advice from unqualified medical practitioners that could lead to wrong diagnosis and treatment, causing tremendous harm and delays in the diagnosis and treatment of TB. Due to the ancillary costs of travel, diagnostics and treatment, patients are unable to complete their treatment course and experience relapse frequently.

The poor living, housing and environmental conditions, migration, poor access to quality health care are all determining factors of TB, and combine to put the tribal communities at greater risk. Addressing these determinants and enabling accessibility to health care in the remote habitations and tribal areas ought to be a priority of the government; as also the promotion of the right to health in the context of TB for tribal communities that are amongst the most neglected in the country. The government should ensure access to free diagnosis, medicines and nutritional support for those affected by TB without any conditionality.

## Endnotes


1. *India TB Report 2018. Revised National TB Control Programme. Annual Status Report.* (2018, March). Retrieved June 18, 2018, from Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare, Govt. of India website.
2. Ibid.
3. Thomas, B. E., Adinarayanan, S., Manogaran, C., &Swaminathan, S. (2015). Pulmonary tuberculosis among tribals in India: A systematic review & meta-analysis. *The Indian Journal of Medical Research,* 141(5), 614–623. http://doi.org/10.4103/0971-5916.159545
4. Annual Status Report. New Delhi: RNTCP; 2013. Revised National Tuberculosis Control Programme (RNTCP). Zero TB deaths, Stop TB: In my lifetime: TB India 2013; p. 225. Cited inThomas, B. E., Adinarayanan, S., Manogaran, C., & Swaminathan, S. (2015). Pulmonary tuberculosis among tribals in India: A systematic review & meta-analysis. *The Indian Journal of Medical Research,* 141(5), 614–623. http://doi.org/10.4103/0971-5916.159545
5. Jain, Y., Kataria, R., Patil, S., Kadam, S., Kataria, A., Jain, R., Shinde, S. (2015). Burden & pattern of illnesses among the tribal communities in central India : a report from a community health programme. *The Indian Journal of Medical Research,* 141(5), 663–672. http://doi.org/10.4103/0971-5916.159582

6. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16. Mumbai: IIPS.
7. Aurora, H., & Kapoor, S. (2016). Determinants of lost to follow up during treatment among tuberculosis patients in delhi. International Journal of Medical Research & Health Sciences,5(1), 145-152. Retrieved from http://www.ijmrhs.com/medical-research/determinants-of-lost-to-follow-up-during-treatment-among-tuberculosis-patients-in-delhi.pdf
8. Mehra, C. (2016, August 17). Living with drug-resistant tuberculosis in India [Web log post]. Retrieved June 15, 2017, from http://www.bbc.com/news/world-asia-india-36950201
9. *India TB Report. Annual Status Report.* (2018, March). Retrieved February 27, 2018. RNTCP. Central TB Division. Directorate General of Health Services. Ministry of Health and Family Welfare. Govt. of India. website: https://tbcindia.gov.in/showfile.php?lid=3314
10. Courtwright, A., Turner, A. N. (2010). Tuberculosis and Stigmatization: Pathways and Interventions. *Public Health Reports,* 125(Suppl 4), 34–42.
11. Rao, M. (2017, June 21). Aadhaar made mandatory for TB patients seeking cash assistance from the government. *Scroll.in.* Retrieved April 27, 2018, from https://scroll.in/pulse/841250/aadhaar-made-mandatory-for-tb-patients-seeking-treatment
12. *Revised National Tuberculosis Control Programme (RNTCP) using a web based application called Nikshay* (1721). *The Gazette of India.* (2017, June 19). Retrieved April 15, 2018, from Ministry of Health and Family Welfare website: http://egazette.nic.in/WriteReadData/2017/176763.pdf
13. Hamid, Z., & Koshy, J. (2017, June 21). TB patients will need Aadhaar for cash benefits. *The Hindu.* Retrieved April 27, 2018, from http://www.thehindu.com/sci-tech/health/tb-patients-will-need-aadhar-for-cash-benefits/article19120123.ece
14. Rao, M. (2018, May 17). Beyond The Numbers: India's First Anti-TB Drug Resistance Survey Reveals The Shortcomings Of The Tuberculosis-Control Programme. *The Caravan.* Retrieved March 27, 2018, from http://www.caravanmagazine.in/vantage/anti-tb-drug-resistance-survey-reveals-shortcomings-control-programme
15. Indian civil society pushes for 'Government Use' compulsory license on MDR-TB Drugs, Ankita Ramgopal, 12 March 2018, Available at: <http://www.lawyerscollective.org/news/indian-civil-society-pushes-government-use-compulsory-license-mdr-tb-drugs>. Lawyers Collective.
16. Ibid.
17. Horne, D. J., Royce, S. E., Gooze, L., Narita, M., Hopewell, P. C., Nahid, P., & Steingart, K. R. (2010). Sputum Monitoring during Tuberculosis Treatment for Predicting Outcome: A Systematic Review and Meta-analysis. The Lancet Infectious Diseases, 10(6), 387–394. http://doi.org/10.1016/S1473-3099(10)70071-2
18. Report of the First National Anti-Tuberculosis Drug Resistance Survey. (2014-16). India: World Health Organization, USAID & Ministry of Health and Family Welfare, Government of India. Retrieved April 8, 2018, from https://tbcindia.gov.in/showfile.php?lid=3315.
19. Personal Communications with Vivek Divan (lawyer and researcher) over email
20. Bhargava, A., Chatterjee, M., Jain, Y., Chatterjee, B., Kataria, A., Bhargava, M., Menzies, D. (2013).Nutritional Status of Adult Patients with Pulmonary Tuberculosis in Rural Central India and Its Association with Mortality. *PLoS ONE,* 8(10), e77979. http://doi.org/10.1371/journal.pone.0077979
21. State Health Resource Centre, Chhattisgarh. (2015, October 12). Retrieved from http://www.shsrc.org/webupload/PUBLICATION/PUBLIC_HEALTH_PROGRAMME/TB_Patients_Food_preferences_survey_Report.pdf
22. Ghosh, A. (2017, December 27). TB patients to get Rs 500 per month during treatment. *The Indian Express.* Retrieved January 12, 2018, from http://indianexpress.com/article/lifestyle/health/tb-patients-to-get-rs-500-per-month-during-treatment-5000321/
23. Ibid
24. *Nutritional Support to TB patients (Nikshay PoshanYojana).* (2018). Retrieved April 12, 2018, from Government of India Ministry of Health & Family Welfare (Central TB Division) website: https://tbcindia.gov.in/showfile.php?lid=3318
25. Rao, M. (2017, December 15). TB patients asked to submit Aadhaar for a compensation scheme that is yet to be finalised. *The Scroll.* Retrieved April 12, 2018, from https://scroll.in/pulse/861574/tb-patients-are-being-asked-to-submit-aadhaar-for-a-compensation-scheme-that-has-not-been-finalised

26. Padmapriyadarsini, C., Shobana, M., Lakshmi, M., Beena, T., & Swaminathan, S. (2016). Undernutrition & tuberculosis in India: Situation analysis & the way forward. The Indian Journal of Medical Research, 144(1), 11–20. http://doi.org/10.4103/0971-5916.193278
27. Central Tuberculosis Division, TB Notification Order No.Z-28015/2/2012-TB, 3 C.F.R. (2012).Ministry of Health and Family Welfare. Retrieved January 12, 2018 from https://tbcindia.gov.in/showfile.php?lid=3136
28. Satyanarayana, S., Nair, S. A., Chadha, S. S., Shivashankar, R., Sharma, G., Yadav, S., … Dewan, P. K. (2011). From Where Are Tuberculosis Patients Accessing Treatment in India? Results from a Cross-Sectional Community Based Survey of 30 Districts. *PLoS ONE,* 6(9), e24160. http://doi.org/10.1371/journal.pone.0024160. Retrieved January 12, 2018, from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3166304/
29. Revised National Tuberculosis Control Programme. National Strategic Plan For Tuberculosis Elimination 2017–2025. Central TB Division, Directorate General of Health Services, Ministry of Health with Family Welfare
30. *A brief history of tuberculosis control in India* (Rep.). (2010). Geneva: WHO.
31. Ibid
32. Verma, R., Khanna, P., & Mehta, B. (2013). Revised National Tuberculosis Control Program in India: The Need to Strengthen. *International Journal of Preventive Medicine,* 4(1), 1–5.
33. Training Module for Medical Officers and Health Staff on National Health Programme. (n.d.). Directorate of ayush chhattisgarh & State Health Resource Centre, Chhattisgarh. Retrieved from http://www.shsrc.org/webupload/TRAINING/TRAINING_MODULE_FOR_MEDICAL_OFFICERS_AND_HEALTH_STAFF_ON_NATIONAL_HEALTH_PROGRAMME_JANUARY_2015.pdf
34. TB Treatment in India. (n.d.). Retrieved April 8, 2018, from https://www.tbfacts.org/tb-treatment-in-india/
35. DOTS-Plus Guidelines. (2010). New Delhi: Revised National Tuberculosis Control Programme. Ministry of Health and Family Welfare. Government of India. Retrieved from http://health.bih.nic.in/Docs/Guidelines/Guidelines-DOTS-Plus.pdf
36. *A brief history of tuberculosis control in India* (Rep.). (2010). Geneva: WHO.website: http://apps.who.int/iris/bitstream/handle/10665/44408/9789241500159_eng.pdf?sequence=1
37. Ibid
38. India, RNTCP, Central TB Division, DGHS. (2005). *Tribal Action Plan (Proposed for the World Bank assisted RNTCP II Project)*.
39. Muniyandi, M., Rao, V. G., Bhat, J., &Yadav, R. (2015).Performance of Revised National Tuberculosis Control Programme (RNTCP) in tribal areas in India. *The Indian Journal of Medical Research,* 141(5), 624–629. http://doi.org/10.4103/0971-5916.159553
40. Verma, R., Khanna, P., & Mehta, B. (2013). Revised National Tuberculosis Control Program in India: The Need to Strengthen. *International Journal of Preventive Medicine,* 4(1), 1–5.
41. Revised National Tuberculosis Control Programme. National Strategic Plan for Tuberculosis Elimination 2017–2025. P-25, 77.Central TB Division, Directorate General of Health Services, Ministry of Health with Family Welfare.
42. Ibid
43. Ghosh, Abantika. "TB Patients to Get Rs 500 per Month during Treatment." *Indian Express,* December 27, 2017. Accessed April 2, 2018. http://indianexpress.com/article/lifestyle/health/tb-patients-to-get-rs-500-per-month-during-treatment-5000321/.

# 5.1.3 Leprosy


Prashant Bhagat, 64 years of age was diagnosed with leprosy in 2016. He belongs to the Oraon tribal community and is a resident of Sukhrapra village, Pathalgaon in Jashpur district. Prashant noticed a large patch on his leg at the end of 2016 and immediately consulted the Non-Medical Assistant (NMA) from the leprosy department. The NMA told him he had leprosy and asked him to get in touch with the Mitanin of the village. After the evaluation, he took the treatment from the Mitanin for one year. It was not clear how a Mitanin got the multi drug therapy (MDT)[1] for leprosy without an evaluation. However, he did not receive any further information on the side effects of his leprosy medicines nor was he told about self-care techniques.

Soon after he started taking the medicines, Prashant noticed a swelling in his leg. To treat this, he went to the CHC in Pathalgaon, which is 13 km from the village. The doctors at the facility examined him, prescribed medicines and asked him to take them for some time. Prashant did not see much improvement and visited the CHC again. He was referred to the District Hospital (DH) at Ambikapur where he consulted a doctor who asked him to visit him at his private clinic. The doctor then asked him to get a blood test done and later prescribed medicines, which he was taking, at the time of the interview.

As revealed by Prashant Bhagat's narrative, medicines and diagnostics for leprosy, which should have been provided free of cost, were not. Further, the referral by the government doctor to his private clinic is an extremely serious issue that should be looked into. The lack of counselling about side effects and self-care measures also significantly affects a patient's health seeking, and in turn, the recovery from leprosy.

Leprosy affects the skin, the nerves, the respiratory tract and the eyes[2]; this often results in sensory and muscular weakness, leading to physical disability and deformity, due to the impact on the nerves. Dry, hardened skin, blisters and ulcers are a common consequence of the sensory impairment. Neglecting the ulcers can worsen the condition of the patient and muscular paralysis may lead to deformity. Leprosy Affected Persons (LAP), despite being cured, may require Reconstructive Surgery (RCS) for the correction of their existing deformities of the hand, foot or eye. Pre and post-operative physiotherapy is integral to RCS for successful outcomes of the surgery.[3]

Discussions with the communities pointed to the common perception that people affected by leprosy blame the disease on the their 'sins'. In an FGD in Rayagada district, a respondent said that his relative developed white patches on the cheek, elbow and legs and later it was confirmed as leprosy. "My relative went through so much trauma and low self esteem. He tried to keep himself away from others," he said. Another respondent explained that there is stigma associated with leprosy, making it difficult for families to accept leprosy patients who often move to 'leprosy colonies' in other places. Leprosy patients hesitate to speak about the patches on their skin fearing discrimination not just from others but even from their own families.

During the interviews, a health worker from Nuapada said, "Leprosy is associated with stigma and quite often they face discrimination. Many patients often do not receive any support or care." The stigma and discrimination is so deep seated that even health workers sometimes discriminate against leprosy patients. A key barrier to identification and treatment of leprosy is the prevalent stigma, discrimination and ostracism that is commonly experienced by persons with leprosy. This was reiterated by health officials in the three study states.

## The situation in the study states

The study states of Chhattisgarh, Jharkhand and Odisha report a relatively high prevalence rate of leprosy, as compared to other states as well as to the national average of 0.66 (Table 5.1.3.1).[4] These states also contribute significantly to the country's case load for leprosy.

**Table 5.1.3.1: State Level Data from the National Leprosy Eradication Programme (2016-17)**

| Indicator | Chhattisgarh | Jharkhand | Odisha | India |
|---|---|---|---|---|
| No. of new cases | 12,609 | 6,253 | 10,045 | 1,35,485 |
| Prevalence Rate per 10,000 population | 2.52 | 0.92 | 1.19 | 0.66 |
| Annual Case Detection Rate per 1,00,000 population | 43.69 | 16.8 | 22.13 | 10.17 |
| % of country's case load | 8.24 | 3.87 | 6.11 | NA |

*Source: Annual Report 2016-17 (NLEP)*

With regard to multi-drug therapy (MDT), the PHC in Kathgodi village, Sonhat block, Koriya district, refers persons with leprosy to the DH in Baikunthpur, located about 18 km away. While the Kathgodi PHC, does carry out the necessary follow-up, the non-availability of health care at the primary health care level often forces patients to spend out of pocket, which increases their financial burden and nullifies the purpose of a national programme aimed at providing free of cost treatment to persons with leprosy. However, in Nuapada, the programme seemed to be implemented more effectively.

## Programmes

Programmes to control leprosy have been part of the public health system of India for a long time, beginning with the National Leprosy Control Programme (NLCP) launched in 1955. Later the National Leprosy Eradication Programme (NLEP), launched in 1983, aimed to "arrest the disease among all known cases through multidrug therapy (MDT), early case detection, health education and rehabilitation". In 2001, the NLEP began working towards the goal of elimination of leprosy. In 2005 lleprosy was declared eliminated as a public health problem in India, as it was supposed to have reached a prevalence of less than one per

According to a NLEP official in Nuapada, in 2016, a new initiative – Leprosy Case Detection Campaign (LCDC) – was started in the district. According to the list at the time, 141 new cases were identified. The goal of the programme is eradication of leprosy – to reduce it from the current prevalence rate of two per cent to one per cent per 1000 population. In Nuapada district, 63 new cases of leprosy were identified at the district hospital during the April-June 2017 quarter. The multidrug therapy regimen varies from case to case and may be required for a duration of six months to 12 months.

At the Nuapada district level, the Disability Prevention and Medical Rehabilitation (DPMR) Clinics are being implemented in five blocks. As part of this initiative, persons with leprosy are provided ulcer kits, and micro cellular rubber (MCR) footwear.[5] However, MCR footwear is not easily available and hence the programme is trying to procure customised footwear free of cost from Sonepur district in Odisha.[6]

This initiative has received recognition and has been awarded by the Governor.

10,000 populations, through the use of a faulty epidemiological measure, the altering of the definition of a case, and by the simple act of decreasing the intensity of case detection.[7]

This experience of 'eliminating' leprosy might embolden the government to eliminate virtually any kind of disease, however this statistical and programmatic chicanery had grave implications for the lakhs of patients with leprosy who were suffering the consequences with continued pain, stigmatisation and disabilities. The NLEP wound up after the statistical and programmatic chicanery in 2005, and thereafter restarted in 2012 due to the large number of cases being reported.[8]

In 2016, NLEP came up with the guidelines stating the importance of promoting early case detection, through active case-finding in the endemic areas, for the management of leprosy. Introduction of such initiatives, along with the existing NLEP treatment methods, have successfully reduced the prevalence of leprosy from 24/10,000 population in 1992[9] to 0.66/10,000 in 2016.[10] Despite these claims, significant gaps continued to exist in terms of implementation, particularly in tribal areas where accessibility to functional health facilities and the availability of human resources are a major problem.

The Sparsh Leprosy Awareness Campaign (SLAC) was initiated in 2016 to raise awareness about leprosy and reduce the stigma and discrimination against persons affected with Leprosy, through information education and communication (IEC) initiatives regarding the importance of early detection and treatment. At the district level, reconstructive surgeries are also being done for persons affected by leprosy.

Sahiyas and the health staff at the CHCs in Koriya, Chhattisgarh, Mahuadanr, Jharkhand, Nuapada and Rayagada in Odisha stated that outreach programmes were being conducted to detect cases, especially in tribal areas. Awareness about prevention, early symptoms and treatment of leprosy at the community level is necessary to help reduce the stigma and misinformation that exists about leprosy. Deep-rooted stigma as well as discrimination is

associated with leprosy, affecting persons with leprosy in multiple ways; this creates barriers to seeking health care and to recovery, and can potentially lead to disability and deformity.

To ensure patient-centred care, all diagnostics and MDT must be provided free of cost for persons with leprosy. Following early detection, prompt initiation of treatment as well as adherence and follow up support from the health system to address adverse effects, deformities or disabilities is critical. Long term follow up and support may also be necessary, in terms of protective eye gear (sunglasses), micro cellular rubber (MCR) footwear as well as self-care techniques, for the prevention of disability.[11] In the absence of access to comprehensive health care, as is evident from the narrative of Prashant Bhagat, it is extremely difficult, as well as unaffordable, for a majority of persons with leprosy in tribal communities to access treatment and care.[12]

## Endnotes

1. WHO has supplied MDT free of cost to leprosy patients in all endemic countries, since 2005. The drugs used in WHO-MDT are a combination of rifampicin, clofazimine and dapsone for multibacillary (MB) leprosy patients and rifampicin and dapsone for paucibacillary (PB) leprosy patients.
2. Leprosy: The disease. (n.d.). Retrieved April 8, 2018, from http://www.who.int/lep/leprosy/en/
3. Bhatt, N. R., Kakked, G. A., Vyas, K., & Merchant, R. (2016). Reconstructive Surgery Camp for Leprosy Deformities in a Tertiary Hospital: An Example of Service Delivery at Low Costs. *Journal of Clinical and Diagnostic Research* : JCDR, 10(7), LC01–LC04. http://doi.org/10.7860/JCDR/2016/15082.8158
4. *NLEP Annual Report*. (2016-2017). New Delhi: National Leprosy Eradication Programme. Central Leprosy Division. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India. Retrieved from http://www.nlep.nic.in/pdf/Annual report_ 2016-17.pdf
5. *Annual Report.* (2012-13). Odisha: National Rural Health Mission. Health and Family Welfare Department. Government of Odisha. Retrieved from http://www.nrhmorissa.gov.in/writereaddata/Upload/Documents/NRHM Annual Report2012-13.pdf
6. Personal communication with NLEP official in Nuapada, 2017
7. *Health System in India: Crisis & Alternatives* (First ed.). (2006). Delhi: National Coordination Committee, Jan Swasthya Abhiyan. Retrieved from http://www.mumbaidp24seven.in/reference/JSA_Health_system_in_India.pdf
8. *Health System in India: Crisis & Alternatives* (First ed.). (2006). Delhi: National Coordination Committee, Jan Swasthya Abhiyan. Retrieved from http://www.mumbaidp24seven.in/reference/JSA_Health_system_in_India.pdf
9. *Operational Guidelines For Leprosy Case Detection Campaign*. (2016). National Leprosy Eradication Programme. Central Leprosy Division. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India. Retrieved from http://nlep.nic.in/pdf/Final_OG_LCDC (1).pdf
10. *NLEP Annual Report.* (2016-2017). New Delhi: National Leprosy Eradication Programme. Central Leprosy Division. Directorate General of Health Services. Ministry of Health and Family Welfare. Government of India. Retrieved from http://www.nlep.nic.in/pdf/Annual report_ 2016-17.pdf
11. *Workshop for Health Service Managers in charge of Leprosy Control Programmes; From Global Strategy to National Action; Participant Guide* (Publication). (2008). World health Organization. Retrieved from http://apps.searo.who.int/PDS_DOCS/B2396.pdf
12. Maske, A. P., Sawant, P. A., Joseph, S., Mahajan, U. S., & Kudale, A. M. (2015). Socio-cultural features and help-seeking preferences for leprosy and turberculosis: a cultural epidemiological study in a tribal district of Maharashtra, India. Infectious Diseases of Poverty, 4, 33. http://doi.org/10.1186/s40249-015-0064-y

# 5.2 Non-communicable diseases

The term non-communicable diseases (NCDs) is commonly used to refer to illnesses that are not transmitted from one person to another. NCDs are characterised by their development over long periods of time, sometimes extending over years. Persons affected by NCDs may not exhibit any symptoms, which makes it challenging for early diagnosis and treatment. Moreover, given their largely chronic nature, NCDs may require regular monitoring and treatment for several years, if not life-long. However, the discourse on NCDs also warns against water-tight compartmentalisation of these various categories of communicable, or non-communicable, acute, chronic, etc., as overlaps are inevitable.

India is believed to be undergoing an epidemiological transition, with shifts in disease pattern across the country over the past few years. Cancer, Diabetes, Cardio Vascular Diseases (CVDs) and Stroke are considered the NCDs that contribute substantially to morbidity and mortality in India.[1,2] In addition to this, chronic respiratory diseases (chronic obstructive pulmonary disorders and asthma) and mental health problems are also classified as NCDs.[3]

The understanding of the etiology of NCDs, however, has been largely in the frame of "lifestyle diseases", i.e. they are diseases caused due to high consumption and sedentary lifestyles or limited physical activity. This understanding, however, overlooks other evidence that increasingly points to the socio-economic factors such as poverty, undernutrition, etc., as relevant determinants of NCDs, especially in the context of tribal communities.

NCDs contributed to 37.9 per cent of the total deaths in India in 1990, while in 2016, it was a total of 61.8 per cent deaths.[4] They contributed to 55.1 per cent of all deaths in the Empowered Action Group (EAG) states alone in 2016, which include the states of Chhattisgarh, Jharkhand and Odisha, where the study was conducted. Data on NCDs in these states (Table 5.2.2.1) indicates their significant proportion of the disease burden, and necessitates an integrated public health response.[5]

**Table 5.2.2.1: Proportion of disease burden due to NCDs in Chhattisgarh, Jharkhand and Odisha**

| States/Country | Proportion of disease burden due to NCDs |
|---|---|
| Chhattisgarh | 50.4 % |
| Jharkhand | 48.3% |
| Odisha | 52.1% |
| India | 55.4 % |

*Source: Health of the Nation's States, 2017*

The prevalence of some of the NCDs, such as hypertension and diabetes is found to be substantial among tribal communities, according to the NFHS-4, the National Nutrition Monitoring Bureau (NNMB) survey,[6] and other studies with tribal communities, which are discussed later in this chapter.[7,8] However, ascertaining the accuracy of data on NCDs, is challenging at the national as well as at the state levels. Since many of the NCDs have a significant number of people, who are asymptomatic, an accurate estimate of the burden is possible only if robust screening methods as well as a functional and effective health system is accessible to the people.

Moreover, public health systems in general are challenged by the management of NCDs; provision of long term care and treatment, especially in the difficult, remote and resource poor settings. Comprehensive programmes that can provide regular screening for early diagnosis, proximally accessible monitoring and treatment over several years, access to counseling and health information towards adherence to treatment in the long term are some of the imperatives of care for NCDs; this is particularly challenging in the context of tribal communities, given the relatively deficit status of the health infrastructure and services presently in many of the rural and remote tribal areas.

The following sections discuss some of these issues in the specific contexts of hypertension, diabetes and cancer drawing on the experiences of the study participants.

## 5.2.1 Hypertension

Hypertension is one of the most important public health challenges worldwide because of its high frequency and concomitant risks of cardiovascular and kidney diseases.[9] In India, there is no composite estimate on prevalence of hypertension among tribal communities, but the increasing prevalence of hypertension among tribal communities has been observed by independent researchers.[10] The NNMB Tribal Survey-2008-09 estimates the prevalence of hypertension among tribals as 24 per cent, with 25 per cent among men and 23 per cent among women.[11] Another study by Rizwan et al (2014) on the prevalence of hypertension in tribal communities, carried out a systematic review and meta-analysis of observational studies and found that the pooled estimate of hypertension prevalence was 16.1 per cent.[12] The NFHS-4 data for the states where the study was conducted, indicates significant prevalence of hypertension amongst the tribal communities is significant (Table 5.2.2.2).[13,14,15] However, awareness of hypertension was very low (8.4 per cent) among adult tribal population, according to the NFHS-4, which coincides with other studies.

**Table 5.2.2.2: Prevalence of hypertension in tribal communities**

| S. No. | Category | States | | | | | | India | |
|---|---|---|---|---|---|---|---|---|---|
| | | Chhattisgarh | | Jharkhand | | Odisha | | | |
| | | Women | Men | Women | Men | Women | Men | Women | Men |
| 1 | Scheduled Caste | 7.9 | 13 | 9.2 | 17.8 | 10.7 | 10.7 | 10.2 | 14.4 |
| 2 | Scheduled Tribe | 11.9 | 14.1 | 9.9 | 13.3 | 11.3 | 15.6 | 10.8 | 14.8 |
| 3 | Other Backward Castes | 9.1 | 12.1 | 8.5 | 11.9 | 11.9 | 13.2 | 10.5 | 14.5 |
| 4 | Other | 11.1 | 17.3 | 9.4 | 13.9 | 13.7 | 15.6 | 12.3 | 15.6 |
| 5 | Don't know | - | - | 14.0 | - | 19.0 | - | 13.0 | 10.8 |

*Source NFHS-4*

The data on hypertension counters the general perception that it is not a relevant health problem in tribal communities. According to experts with long experience in health care provision for hypertension among tribal communities in central India (Chhattisgarh),[16] two important causative factors that are especially relevant are the excess use of common salt and tobacco by tribal communities. Salt consumption of more than five grams per day is associated with increased risk of hypertension and its complications. Some studies have shown that median salt consumption among tribal communities is close to ten grams per capita per day, which is very high.[17] Efforts to reduce salt consumption to 5gm per day, as well as substantial control over the sale of salted snacks, which have found their way into tribal markets is urgent. As for tobacco use, according to the NFHS-4, the prevalence is significantly higher for the ST communities as compared to others: women (17 per cent) and men (57 per cent) from scheduled tribes are more likely to use tobacco.[18] Cessation of tobacco use is a cornerstone in management of complications of hypertension, as well as hypertension

itself. Further, the chronic stress of poverty and other deprivations are also critical factors that contribute to the high prevalence of hypertension among tribal communities.[19] To address the issue of high tobacco and alcohol consumption, SEARCH, an NGO working in Gadchiroli, Maharashtra has taken up initiatives rendering medical detoxification, along with provisions for counseling of families and individuals, group therapy and follow ups. In the year 2015-16, SEARCH furthered their attempts by setting up 'Muktipath', a project that aims at reducing tobacco and alcohol consumption within the district by 50 per cent in three years.[20]

The experience of Rajesh, a 65 year-old man from the Oraon tribal community in Pathalgaon block, Jashpur, who was diagnosed with hypertension, draws attention to some of the issues discussed here with regard to hypertension.

> *"In the year 2003, I underwent a cataract surgery at a mission hospital in Kunkuri. During the general check-up before the surgery I was diagnosed with high blood pressure. At the time, I was prescribed some medicines for it. I took the medicines for a month and then discontinued them. Over the years, I intermittently had the blood pressure medicines, usually not for more than a few months at a time. When I no longer felt any discomfort in the chest (chhaathi mein dard) or restlessness, (ghabrahat), headache (sirdard), weakness (kamzori), I discontinued the medicines.*
>
> *In October 2017, one day I felt disoriented and weak; my family got worried and took me to the CHC at Pathalgaon. The CHC is about 30 km from my village. My family called for the 108 ambulance but was told that the vehicle would take time to reach the village. They were very distressed with my condition and did not want to wait for the vehicle. So, they booked a private vehicle that cost Rs. 1,000 to take us to the hospital. At the hospital, I was examined and told that I had very high blood pressure. I was admitted in the hospital for seven days as I could not even stand up, felt very weak and disoriented. All the diagnostics were done at the CHC and I was given medicines free of cost. The RSBY card was used to pay for certain charges in the CHC.On my discharge, I was not given any medicines from the CHC; instead I was asked to buy them from private medical stores. I am taking 50 mg Atenolol. I took the same earlier too. About 12 tablets cost Rs. 15, so for a month's dose it comes to about Rs. 40."*

Rajesh's diagnosis of hypertension was incidental and became known during a cataract operation According to him, however, he was not counseled or provided information

especially with regard to the need for regular adherence to his medication. His narrative also points to the lack of availability of proximal services for regular monitoring of blood pressure and access to medicines. Since medication for hypertension has to be taken daily, the lack of regular monitoring of blood pressure and the availability of and access to free medicines at the community level or at a nearby facility also affects regular consumption of medicines.

The high prevalence of hypertension, its largely asymptomatic character, the lack of awareness about symptoms, often delays seeking of health care, and places a large number of people in rural and tribal communities at risk of the health complications due to hypertension.

### 5.5.2 Diabetes

Hemant Kumar, a 55 year old from the Gond tribal community lives in Pathalgaon block, Jashpur District; his narrative highlights his experience with diabetes.

> *"I was diagnosed with diabetes about six months ago. I had injured my leg a few months before that when the bullock butted me in my leg. My family took me to the PHC at Pharzabahar, which is about three km from my village, but no one was available there as it was a holiday. So, I went to a small private clinic-cum-medical store near the PHC. They attended to my wound and dressed it. They also gave me some injections for which I paid Rs. 3000. I returned to the clinic everyday for three weeks to get my dressing changed and for follow-up treatment. No other tests were carried out at this clinic. After a month, when the injury had not healed, I decided to go to the PHC. After examining the wound, the doctor at the PHC scolded me for the delaying the treatment. He prescribed an injection (Monocef as observed from medical records), which I had to buy from a drug store outside for Rs. 500. However, when the wound did not heal completely, the ANM in my village suggested that I should get my blood sugar tested. She had a glucometer (a mobile device to check blood sugar), which she used to carry out the test. My blood sugar was high, so she referred me to the PHC again. I went to the PHC Pharzabahar after a few days, where the doctor prescribed me some medicines for my high blood sugar. I was asked to take one pill per day. In addition to this, the doctor gave me some medicines for my injury and pain (his prescription read 'Gluconorm 2, Ofloxacin and Ibuprofen'), which I took continuously for seven months, even though my pain had subsided.*
>
> *"I got some medicines free of cost from the PHC but they asked me to buy the diabetes medicines, from the private medical store. In addition to this, the ANM was doing my glucose test every month to monitor my blood sugar. My monthly expenditure on medicines was Rs. 500 (Rs.170 for 15 days for the Gluconorm prescribed for diabetes as per prescription and bills) and the travel costs to the PHC were additional. This diabetes medicine that they prescribed was the most expensive. I had requested the PHC to give me this medicine from the PHC itself so that it could be free, but they did not do anything about it. They said they were not receiving supplies (upar se nahi aata hai). I had to*

*accept it because I did not know who else I could talk to about this. I have a valid RSBY card but I have never used it. It was not useful for me as I could not use it for my tests or medicines. I have been taking the medicines given to me regularly, and I am feeling much better. But since the injury, I have been unable to walk and have been bed ridden for most of the time. I had to give up farming. As a result, my share of the work has fallen on my son's and wife's shoulders."*

Hemant's narrative reiterates the often asymptomatic character of NCDs, including diabetes. There is also an urgent need to build awareness about NCDs, regarding their symptoms and co-morbidities and infections as well as other complications arising due to diabetes as it requires many lifestyle changes, which Hemant was not aware of. Moreover, diabetes has largely been perceived as a disease of 'lifestyle'; however, increasing evidence in the country points to a rising incidence of diabetes resulting from poverty and malnutrition.[21]

According to a study by JSS (Chhattisgarh), more than 50 per cent of the patients with diabetes from tribal communities who visited their hospital had lower BMIs than those from the non-tribal communities. The proportion of patients from tribal communities with diabetes and BMI less than 18.5 kg/m$^2$ was higher (70.69 per cent) among tribal patients, compared to percentage of patients with diabetes and BMI less than 18.5 kg/m$^2$ from other social groups – Dalits 34.74 per cent, OBCs 43.62 per cent, and general 23.68 per cent.[22] The data and the narratives indicate the prevalence of diabetes among marginalised communities including in tribal communities, and reiterate the correlationship between diabetes and malnutrition, which is common among them.

Further research is necessary to deepen understanding about the varied risk factors, especially in the context of marginalised communities, towards developing protocols for screening and treatment, enabling access to medicines, etc.

Any programme for diabetes or hypertension must therefore be cognisant of the increasing evidence about the prevalence of these health conditions among tribal communities. Given the challenges for the health system in tribal areas, especially in the context of adherence to screening and diagnosis, counselling and information towards regular monitoring and treatment, programme design and implementation for diabetes and hypertensions amongst tribal communities must incorporate their specific needs as well as address the determinants of these health conditions amongst them.

## Health System Response to NCDs

The National Programme for the Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS) was launched in 2010. The objectives of the programme are focused on risk reduction for prevention, early diagnosis and appropriate management.[23] The programme involves setting-up of NCD clinics at CHC and District Hospitals, where comprehensive examination of patients referred by lower level health facilities or health workers is carried out. The key functions of these clinics are to screen, diagnose and manage NCDs (including counseling and lifestyle management) and provide home based care for chronic bedridden patients.[24] The NPCDCS data claims the implementation of the programme in all 36 States/UTs and establishment of a total of 298 District level NCD Cells and 293 District level NCD Clinics in the country, by March 2016.


As mentioned earlier, dedicated clinics/cells were available in three of the facilities visited across the three states. Those who needed specialised care at the block level facilities were usually referred to facilities higher up like the DHs. In some of these facilities, services were available as part of the general OPD in the facilities.

However, the programme is not immune to the issues that plague the public health system. These include availability of free medicines especially for people suffering from chronic health conditions. While medicines for hypertension and diabetes are part of the list of essential drugs at the facilities, the respondents' narratives reflected their non-availability in some of facilities that they accessed. This enforced purchase of the medicines from private chemists with huge cost implications and for their continued adherence to treatment in the long term.

Where they were available and dispensed, the duration for which they were given at a time, was extremely short, requiring regular visits, which is particularly difficult for tribal communities living in remote areas bereft of transport facilities and motorable roads. Several complexities exist in the case of NCDs; towards providing long term care and treatment, especially in the remote and resource poor settings, regular screening for early diagnosis, regular and proximally accessible monitoring and treatment in the long term, access to counseling and health information are some of the imperatives of care for NCDs.

## Conclusion

The narratives clearly indicate that the lack of timely and affordable transport such as public ambulance services and the non-availability of free medicines at a proximal facility that is easily accessibly pose huge barriers particularly in the context of NCDs in tribal areas. The continuum of care required in cases of chronic conditions necessitates regular monitoring and treatment, which in the absence of availability at the community level or even at the primary level facility implies frequent visits to the secondary and tertiary health facilities, which can be huge deterrents to seeking health care. The narratives of respondents with NCDs also highlight the intersections of deprivation, poor availability and access to health care for chronic health issues, the gendered burden of care and several other issues. Women with chronic conditions are likely to have less social support, receive limited care and to have less rest as compared to men from the same communities. Additionally, the role of women as carers also becomes critical to highlight in the case of chronic conditions like NCDs as being carers means additional burden of unpaid work which the women need to undertake in families.

The risk factor framework that is often used to address NCDs, dislocate NCDs from the concern of disadvantaged communities and make it a concern of more affluent communities instead. A reorientation of the health policy and health system's perceptions about NCDs is required to understand complex, multiple deprivations that have implications for the vulnerability to NCDs, for non-adherence and inequities in accessing health care for NCDs that require long term monitoring and care. In the context of tribal populations, factors like excessive alcohol and tobacco use and other issues, such as exposure to indoor smoke, also need to be looked into as these contribute significantly to the development of chronic diseases, including NCDs. Community awareness about these and their health impact needs to be strengthened. Services for de-addiction and mental health also need to be made available in these areas. Only a comprehensive programme focused on these multiple determinants can address the growing burden of NCDs in tribal areas.

The experiences of NCDs and outcomes such as diabetes, hypertension, stroke, etc., may be varied and gendered given the complex overlaps of multiple deprivations that tribal communities face. Thus, NCDs especially amongst the poor and marginalised, here, the tribal communities, necessitate a deeper understanding regarding causal factors.

## Endnotes


1. *Non-communicable Diseases Country Profiles 2014.* (2014). World Health Organization.doi:http://www.searo.who.int/india/topics/noncommunicable_diseases/ncd_country_profile_2014.pdf
2. *NCD Global Monitoring Framework.* World Health Organization. Retrieved April 15, 2018, from http://www.who.int/nmh/global_monitoring_framework/en/
3. *India: Health of the Nation's States - The India State-Level Disease Burden Initiative* (Rep.). (2017, November 14). Retrieved February 8, 2018, from Indian Council of Medical Research, Public Health Foundation of India, Institute for Health Metrics and Evaluation, Website: http://www.healthdata.org/sites/default/files/files/policy_report/2017/India_Health_of_the_Nation's_States_Report_2017.pdf
4. Sharma, D. C. (2017, November 14). Deaths due to non-communicable diseases increased by 37 per cent since 1990. Retrieved June 20, 2018, from https://www.downtoearth.org.in/news/health/deaths-due-to-non-communicable-diseases-increased-by-37-per-cent-since-1990-59107
5. *Diet and nutritional status of tribal population and prevalence of hypertension among adults: Report on second repeat survey* (NNMB Technical Report No. 25). (2009). Hyderabad: National Institute of Nutrition, Indian Council of Medical Research. doi: http://nnmbindia.org/NNMBTribalReport.pdf
6. *India: Health of the Nation's States - The India State-Level Disease Burden Initiative* (Rep.). (2017, November 14). Retrieved February 8, 2018, from Indian Council of Medical Research, Public Health Foundation of India, Institute for Health Metrics and Evaluation, Website: http://www.healthdata.org/sites/default/files/files/policy_report/2017/India_Health_of_the_Nation's_States_Report_2017.pdf
7. *Diet and nutritional status of tribal population and prevalence of hypertension among adults: Report on second repeat survey* (NNMB Technical Report No. 25). (2009). Hyderabad: National Institute of Nutrition, Indian Council of Medical Research. doi:http://nnmbindia.org/NNMBTribalReport.pdf
8. Rizwan, S. A., Kumar, R., Singh, A. K., Kusuma, Y. S., Yadav, K., & Pandav, C. S. (2014). Prevalence of Hypertension in Indian Tribes: A Systematic Review and Meta-Analysis of Observational Studies. *PLoS ONE*, 9(5), e95896. http://doi.org/10.1371/journal.pone.0095896
9. Kumar, R. K., Tyagi, A. R., Tiwari, R., & Rai, N. (2016). A study of hypertension among tribal adults in a block of Mandla district, Madhya Pradesh, India. *International Journal of Community Medicine and Public Health,* 3(5), 1033-1037. Retrieved February 10, 2018, from www.ijcmph.com/index.php/ijcmph/article/download/843/727
10. Ibid
11. *Diet and nutritional status of tribal population and prevalence of hypertension among adults: Report on second repeat survey* (NNMB Technical Report No. 25). (2009). Hyderabad: National Institute of Nutrition, Indian Council of Medical Research. doi:http://nnmbindia.org/NNMBTribalReport.pdf
12. Rizwan, S. A., Kumar, R., Singh, A. K., Kusuma, Y. S., Yadav, K., &Pandav, C. S. (2014). Prevalence of Hypertension in Indian Tribes: A Systematic Review and Meta-Analysis of Observational Studies. *PLoS ONE,* 9(5), e95896. http://doi.org/10.1371/journal.pone.0095896
13. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16: Chhattisgarh.* Mumbai: IIPS.
14. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16: Jharkhand.* Mumbai: IIPS.
15. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16: Odisha.* Mumbai: IIPS.
16. Personal communications with Dr. Yogesh Jain, JSS, Ganiyari, Bilaspur, Chhattisgarh, (2018)
17. Ibid
18. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), 2015-16: *India*. Mumbai: IIPS.
19. BhargavaAnurag ; JAIN, Yogesh. Hypertension is falling through the gaps in primary health care. *Indian Journal of Medical Ethics,* [S.l.], v. 3, n. 4, p. 126, nov. 2016. ISSN 0975-5691. Available at: http://ijme.in/articles/hypertension-is-falling-through-the-gaps-in-primary-health-care/. Date accessed: 28 April. 2018.
20. *Society for Education Action and Research in Community Health* (SEARCH). Available at http://searchforhealth.ngo/

21. Jain, Y., Kataria, R., Patil, S., Kadam, S., Kataria, A., Jain, R., … Shinde, S. (2015). Burden & pattern of illnesses among the tribal communities in central India : a report from a community health programme. *The Indian Journal of Medical Research,* 141(5), 663–672. http://doi.org/10.4103/0971-5916.159582

22. Patil, S., Ghali, B., & Jain, Y. (January 2017). The diabetes we see: Description of a retrospective cohort of diabetes mellitus in a referral center in impoverished rural central India. *Medico Friend Circle Bulletin,* 373-374. Retrieved February 4, 2018, from http://www.mfcindia.org/mfcpdfs/MFC373-374.pdf

23. National Programme For Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS) Ministry of Health and Family Welfare | GOI. (n.d.). Retrieved May 25, 2018, from https://mohfw.gov.in/about-us/departments/departments-health-and-family-welfare/national-programme-prevention-and-control-cancer-diabetes-cardiovascular-disease-and

24. Operational Guidelines 2010: National Programme For Prevention And Control Of Cancer, Diabetes, Cardiovascular Diseases & Stroke (NPCDCS). (n.d.). Retrieved May 25, 2018, from http://health.bih.nic.in/Docs/Guidelines/Guidelines-NPCDCS.pdf

# 5.3. Mental health and well being


Chandu is a 23 year-old male who has been experiencing an undiagnosed mental health condition for the last eight years. He belongs to the Pando tribal community in Koriya district. When Chandu was in the sixth standard, he joined a residential school. After a few months he began to cry incessantly through the night. Concerned with the behaviour, the school's head master called Chandu's mother and asked her to take him home. She narrated the following incidents to us:

> *"I took him to the local faith healer but that treatment did not help him. After this, I decided to consult a 'Panda' (priest) in Salgawan (a nearby village) and took Chandu along. We both stayed in the 'dham' (shelter) in the temple run by the priest for a month-long treatment. After a few days, however, Chandu started becoming violent. He would abuse people around him, including me, and hit them. The Panda suggested that he should be restrained with ropes to prevent him from harming others. Chandu was kept tied for about a week while the Panda would recite prayers for him. After one month, Chandu showed some improvement and we returned home. He was relatively 'normal' for a year and would help with household chores, etc. As per the Panda's suggestions, I observed mannat (vows) and gifted the temple Devi (goddess) clothes, 25 kg of rice, some cereals, oils, hens, etc. over a period of three years.*
>
> *However, after a year of returning home, my son's condition gradually deteriorated. Due to the lack of any other options I took him to the same Panda, again. But when he did not*

*show any improvement, I got him back home. His condition continued to deteriorate even further – he started running away from home; he would remain missing from home for days together and return home after several days or even weeks.*

*Since Chandu's condition did not improve, one of the neighbours suggested that he should be taken to a doctor in a certain village, who gives injections for such conditions and can cure him. The neighbour also told me that she herself had been cured of her own mental health issues by that doctor's injection. I decided to take him to this doctor. A few boys and men from the community had to restrain Chandu and take him to the doctor in a private vehicle. I had to pay Rs. 3,000 for the vehicle, as the village where the doctor resided was quite a distance from our village. The doctor gave Chandu one injection, which cost about Rs. 500. Chandu felt better for a few days after the injection, but his condition soon became as bad as earlier."*

Perceptions and practices around mental illness, ranging from its assessment and diagnosis, illness behaviours as well as the help-seeking conduct of patients and caregivers, are greatly affected by cultural beliefs and rituals. These also influence expectations regarding the appropriateness of interactions that take place between a patient and a practitioner. Nearly 75 per cent of patients prefer consulting folk and religious healers before resorting to psychiatric services.[1] Often these providers are also more accessible and affordable.

Moreover, other health care options for mental health issues are either unavailable or extremely challenging to access. For example, there were no facilities for mental health problems available at the block level CHC in Sonhat, which was about 10 km from Chandu's village. The DH at Baikunthpur was another 30 km from the CHC and no services or psychiatrists were available there either. The closest facility was the Ambikapur Medical College, where some services were available; but this was about 100 km from the village. Neither were any outreach initiatives being implemented that could have facilitated Chandu's access to treatment. Further, the dearth of information and awareness at the community level regarding the availability of other health care for mental health issues is apparent from this narrative. Identification of persons with mental health issues and referral to the appropriate health care facility is largely absent at the community level. Neither the school nor community level health care providers seemed to be aware of possible health care facilities that Chandu could be taken to.

Chandu's mother, who was the primary caregiver, in the absence of any support or guidance regarding his treatment and care, was struggling with the costs of transport, treatment as well as the loss of wages. Sustained care giving, which is extremely gendered, has severe economic, social and psychological impact on caregivers, especially in the absence of adequate emotional and psychosocial care and support. Moreover, the stigma experienced by persons with mental health issues deeply affects access to health care.

The stigma often enforces silence and invisibility around mental health issues, which are huge deterrents to the care and support of persons living with mental health problems as well as their caregivers and families.

The general inadequacy of infrastructure and human resources in the country for mental health care is well-known. The substantial deficit of mental health practitioners in the country – the shortfall is of 8,500 psychiatrists, 6,750 psychologists, 22,600 psychiatric social workers and 2,100 psychiatric nurses[2] – is bound to have disproportionate implications for tribal communities and areas.

According to the National Mental Health Survey (2015-16), an estimated 150 million Indians require mental health care at any given point of time, and this includes both acute care and long term rehabilitation services. The prevalence rate for any mental morbidity, when the survey was conducted, was 13.7 per cent in a life time, and at present is 10.6 per cent. The 2011 census collated data for individuals from the ST community living with 'mental illness' across all states in the country. About 56,316 persons from scheduled tribes were reported to be suffering from mental health issues. For the three study states, this data is provided in Table 5.3.1.

**Table 5.3.1: Distribution of persons with mental illness for Scheduled Tribes**

| State | Total | Rural |
|---|---|---|
| Chhattisgarh | 6,050 | 5,628 |
| Jharkhand | 4,647 | 4,203 |
| Odisha | 7,506 | 7,123 |
| | 18,203 | 16,954 |

*Source - Census 2011*

About 93 per cent of the total ST population suffering from mental health issues were from rural areas in the study states; this flags the critical linkage between mental health and socio-economic factors. The latter are often significant determinants of stress, anxiety as well as poor access to information and care.

There is substantial evidence that points to the close association of distress, exacerbated in situations of poverty, conflict and other humanitarian crisis, and mental health issues of depression and anxiety. Several tribal communities are challenged by forced displacement and migration due to the loss of access to livelihoods, to forests, rivers and other natural habitats that are central to diverse aspects of their lives, culture, and health. In such a context, girls and women are likely to disproportionately experience compromised mental health due to their subordinate gender roles and social positions, as well as the roles of caregivers. Systematic studies that document the issues that have an impact on the mental wellbeing among tribal communities, however, are missing.

Indebtedness due to affected livelihoods, and mental health care costs place a huge burden on families and are also often causes of severe distress. Tribal communities experience distress and severe anxiety due to the onslaught of displacement, unemployment and lack of food security. The tribal communities that are displaced live under constant stress and lack of rehabilitation. The narratives from the present study exemplify how several families across the six districts experienced indebtedness, loss of savings, land, agricultural and forest produce, loss of food security, etc. due to the mounting costs of accessing health care. In some of the areas, people from tribal groups expressed being fearful and distressed due to the increasing loss of access to forest resources as well as the abusive practices and violations by forest officials and guards in their areas.

Moreover, conflict in several parts of the three study states, has had a disproportionately devastating effect on the mental wellbeing of people from tribal communities. The consequences of the conflict, largely situated in these tribal areas, on health and health care are very visible. People, including women and children often face violence at the hands of the different actors that are involved in the conflict, which causes severe trauma to those who directly experience it, as well as those who are witnesses to such violence. While direct exposure to the violence is known to have a serious impact on the mental wellbeing of people in its midst, the consequences of the conflict affects every aspect of their daily lives that has devastating effects on their mental health. These consequences, including displacement, migration, malnutrition, poor access to education, health care, livelihoods, etc., sustain the impact of the conflict on the mental health of people living in the midst of it.

People in conflict areas are known to suffer from post-traumatic stress disorders, high levels of stress, anxiety and fear given the precarious conditions as a result of conflict. Thus, conflict can have a devastating and long-term effect on mental health, and the survival and quality of the daily lives of those who face it. Most importantly, in the study areas, parts of which are designated as 'conflict zones', the state and its various institutions, including health care are functioning only marginally if at all and are not at all equipped to adequately address the needs of the people, including their mental health needs. In the absence of these services, people from tribal communities and those living in these areas, have little opportunities to access support to cope with the trauma and continuing conflict.[3] That conflict results in both immediate as well as long term consequences for the mental health of those living in these areas is now well recognised.

The poor implementation of the programme for mental health, i.e. the District Mental Health Programme (DMHP) [not particular to tribal areas] has been highlighted by the recent government reviews. Some of the key concerns highlighted by the report included the lack of community awareness about the initiative, limited screening and referrals from peripheral health facilities, the shortage of trained human resources (including specialists)

and the integration with other public health programmes. The report recommends that the outreach activities at the district and block levels need to be implemented regularly along with their integration with other programmes, so as to reach out to vulnerable groups such as children and adolescents, both in schools and in the community. Such outreach is particularly important in the context of tribal communities, given the remoteness of habitations, the poor communications and transport, difficulty in accessing health facilities and the lack of proximal functional health facilities providing services for mental health issues.[4]

The Mental Healthcare Act (2017), National Mental Health Policy (2014) as well as The Rights of Persons with Disabilities Act (2016), despite several concerns and gaps, are some of the relevant legislations and policy towards enabling access to information, support, care and treatment for persons with mental health issues. Informing future policy in the specific context of tribal communities' mental well-being is critical.

However, the recognition of mental health care as a critical part of public health care and its integration within the latter remains limited. Strengthening community-based models for care, including psychosocial counselling and support, building awareness towards strengthened peer and community support and referrals are necessary, especially in tribal communities, to manage mental health issues and prevent any negative outcomes of the same.

Substantial care can be provided at community and primary health care levels through well designed and effectively implemented outreach programmes. Specialised care for mental health issues must also be made available in proximal secondary level facilities for those who need it. Local healers and caregivers play an important role in providing care for mental health issues in the communities; programmes to address mental health should attempt to incorporate plural pathways of care and assess modalities for different care systems working in tandem for a comprehensive approach to mental health and its care and treatment. Any interventions to address mental health issues, would have to be cognisant of these factors. They should also enable minimising the potential factors that deeply affect mental health. Deepening the understanding of mental health issues and its determinants amongst tribal communities will be useful towards better designed initiatives to address mental health issues in these areas.

## Endnotes


1. Mishra, N., Nagpal S., Chadda, R. & Sood, M. (2011). Help-seeking behavior of patients with mental health problems visiting a tertiary care center in North India. *Indian Journal of Psychiatry.* 53. 234-8. doi: 10.4103/0019-5545.86814.
2. Situation Analyses - Backdrop to National Health Policy 2017, Ministry of Health & Family Welfare, Government of India. Retrieved on January 16, 2018 from https://mohfw.gov.in/sites/default/files/71275472221489753307.pdf
3. Violent Conflict and Health. (2010). *The Lancet.* Retrieved March 14, 2018, from https://www.thelancet.com/series/violent-conflict-and-health.
4. 10th Common Review Mission report (2016). National Health Systems Resource Centre (NHSRC), Ministry of Health and Family Welfare cited in Country Assessment on Human Rights in the Context of Sexual Health and Reproductive Health Rights. (2018). Sama Resource Group for Women and Health, and Partners for Law in Development.

# 5.4.1 Maternal health

A recent news item in the newspaper (Indian Express, 6th June 2018) described a pregnant tribal woman carried by her family on their shoulders, in a makeshift sling using a saree tied to a pole, to the tribal speciality hospital for delivery. There were no roads to the village and the primary health centre had informed the family that no ambulance was available.

This is the reality not just for the tribal women in Edavani village in Palakkad district, Kerala, but for most of the tribal areas in India. During the study period, a similar episode was reported by the local media (Odisha TV, 8th October, 2017) in Rayagada (Odisha).

> *"An expectant mother, resident of Tebapada village, Kalyansinghpur block had to be ferried across a river in a sling by family members for 10 km after failing to avail ambulance services. [When the woman went into labour], the family members tried frantically to call ambulance services but to no avail. The ambulance could not reach the village due to absence of motorable roads and the family members were forced to carry her to the hospital, in a sling attached to a bamboo pole, on their shoulders, wading through the river and walking some distance. Family members said that the ambulance service simply denied them the service, and even the bike ambulance did not come. The villagers also reported that this was not an isolated incident; all sick and pregnant women are being carried to the hospital in a sling and this was a perpetual problem being faced by the community."* [1]

Several such instances were reported in the media from tribal areas, particularly among the PVTGs residing in the remote forest areas, conflict areas and have also been documented by many studies previously.

While the media reports bring forth the tragic reality of the tribal communities that reside in these rural and remote areas, the recurrent narratives emphasise the absence of adequate interventions to alter them and improve access to health care, transportation, etc. for those living in these areas.

Many studies and several fact-finding reports on maternal health and maternal deaths have repeatedly highlighted[2] that maternal health indicators for women from tribal communities in India are worse compared to other social groups. A study by MAPEDIR[3] highlights the poorer maternal health outcomes in women from tribal communities; analysis of maternal deaths in four states (Odisha, Rajasthan, Jharkhand and Bihar) shows that almost two-third (63.4 per cent) of the deceased women were from backward castes, including Scheduled Tribes.[4]

This has also emerged from other inquiries into maternal deaths; a fact finding of 27 maternal deaths (of which 21 were women from tribal communities) in Barwani district in Madhya Pradesh, which has over 60 per cent tribal population, found the absence of antenatal care (despite high prevalence of anaemia), lack of skilled birth attendants and poor emergency obstetric care. Additionally, the PHC and CHC were not capable of managing even uncomplicated deliveries. At the level of the DH, there were no skilled birth attendants available for deliveries, let alone management of complications.[5]

These reports highlight the deep linkages between the poor maternal health outcomes and the abysmal socio-economic status of the women.They also establish that early marriage, early child birth, low body mass index (BMI) and high incidence of anaemia are critical reasons for the maternal deaths.[6] Similar issues are emergent from the present study as well. Since maternal health and maternal deaths have been extensively researched by both State and non-State actors, in this chapter we have focused on the key issues that emerged from the narratives as well as from the secondary data sources, which require both policy attention and community involvement.

### 5.4.1.1 Maternal deaths in tribal communities

The data (internal report) from the DH Rayagada, for example, shows the significantly higher number of maternal deaths in the April 2016 to March 2017 period amongst women from the tribal communities. Of the 47 deaths, 33 of the deaths (70 per cent) were of women from tribal communities. Eight deaths of women from Dalit communities and six of women from other backward classes (OBC) communities were the other deaths recorded during this period.[7]

### Causes of maternal deaths

Nandini Majhi was a 25 year-old woman from the Majhi tribal community from Kotem village, Khariar block in Nuapada district. She died on 21 July 2017 at the DH, Nuapada in Odisha. The cause of her death was post-partum haemorrhage (PPH) and severe anaemia. According to her Mother and Child Protection (MCP) card, she had registered her pregnancy on 13 January 2017, when she was about three months pregnant. She had received three antenatal care (ANC) check-ups before June when her Haemoglobin (Hb) was found to be 10 gm/dL initially and later 8.6 gm/dL. Her weight was 35 kg in the first ANC and 40 kg in the last one. In the month of June, she visited the DH, Nuapada, where she was found to have Hb of 7 gms/dL, for which she was prescribed iron sucrose injections. On 20 July 2017, she went into labour and delivered a male child at home; she was alive at the time. The next day, on 21 July 2017, when she experienced excessive bleeding, her family rushed her to the DH. She was admitted at the DH and died within an hour. Her Hb was 5 gm/dL.[8]


Nandini Majhi's death illustrates that anaemia and being underweight are factors that lead to maternal deaths, particularly among tribal women, not just in Odisha but also in the other study states. It also particularly draws attention to the serious gaps in ANC that led to some of the health issues not identified early and resulting in complications.

The data on maternal deaths from the DH Nuapada, where Nandini Majhi died cites some of the causes of maternal deaths during the seven month period from January to July 2017.

| Table 5.4.1.1: Cause of maternal death at the DH of Nuapada – January to July 2017 (not restricted to tribal communities) | | | | |
|---|---|---|---|---|
| **Name** | **Age** | **Admitted on** | **Died on** | **Cause of Death** |
| Kumud Boi | 27 | 25th January 2017 | 26th January 2017 | Postpartum Haemorrhage (PPH) |
| Tuli Nial | 20 | 2nd February 2017 | 3rd February 2017 | PPH, Anaemia, Septicaemia, Jaundice |
| Rukmini Hathi | 23 | 30th March 2017 | 30th March 2017 | Severe Anaemia, Jaundice, Postpartum fever |
| Chandrika Yadav | 20 | 3rd May 2017 | 4th May 2017 | Eclampsia |
| Bharati Tandi | 21 | 7th May 2017 | 15th May 2017 | Eclampsia, Septicaemia |
| Santoshi Binjhat | 20 | 22nd May 2017 | 27th May 2017 | Pregnancy-induced hypertension (PIH), Septicaemia |
| Nuadu Jal | 21 | 1st June 2017 | 3rd June 2017 | Amniotic fluid embolism, PIH, Multiple organ failure |
| Dalimba Khuwas | 22 | 8th June 2017 | 9th June 2017 | Anaemia, shock |
| Indumati Paik | 27 | 20th June 2017: 1.45pm | 20th June 2017 | Anaemia |
| Kholbaharin Satnami | 28 | 16th June 2017 | 25th June 2017 | Sickle cell disease |
| Rukmani Nag | 21 | 17th June 2017 | 28th June 2017 | PIH and anaemia |
| Nandini Majhi | 25 | 21st July 2017 | 21st July 2017 | PPH |

*Source: District Hospital, Nuapada*

The 12 women whose deaths were recorded in the DH Nuapada (Table 5.4.1.1) were between 20-28 years of age; some of them in their 2nd or 3rd gravida, which implies the risk of maternal death due to early pregnancy. The link between maternal mortality and early marriage and early pregnancy have also emerged clearly from other studies on maternal deaths amongst tribal women.[9] According to the report 'Dead Women Talking' by JSA and CommonHealth,

> *"Rita a 16 year old Adivasi woman was pregnant for the first time. Her family had been resettled because her village was in an area declared as a tiger reserve. The resettlement village was 10 km away from the road and was inaccessible during the rains. There was no ICDS centre in the village, the ANM did not visit the village and no immunisation took place. She received only one dose of tetanus toxoid during her ANC. She had multiple problems during the pregnancy – malaria, jaundice and swelling of feet and face. She delivered at home, developed post-partum haemorrhage and died before the family could get a vehicle to transport her to a facility. She died of eclampsia, (a condition that younger women are at higher risk of, which could have been prevented had the risk been identified and addressed during the antenatal period)."* [10]

The RCH in-charge in Nuapada explained that poor maternal health can also be attributed to early marriage – a large percentage of tribal women were married by the age of 16 years– leading to early pregnancy. It is well known that women who have a pregnancy at a very young age face a higher risk of morbidity and mortality.

The data also indicates the cause of death of the 12 deaths of women as being the result of post-partum haemorrhage (PPH), pregnancy-induced hypertension (PIH), sepsis, anaemia and sickle cell disease; all of these conditions are preventable or manageable with appropriate health care. However, most maternal deaths due to PPH are avoidable and are usually caused by the underestimation of blood loss, inadequate volume replacement, and delay in operative intervention, or in achieving stability results in terminal coagulopathy.[11,12] Immediate and resolute action is very critical to prevent PPH; every obstetric unit should have a protocol for the management of PPH, which every staff of the obstetric team should be familiar with.

## Location of death

According to the DH Rayagada data, the maximum number of maternal deaths took place in the health facility. During the period of April 2016 to March 2017, 47 maternal deaths were recorded in the DH Rayagada; of these, 25 deaths took place in health care facilities, followed by 14 at home and eight in transit to the health facility.

Promotion of institutional deliveries is generally premised on them being safer by virtue of being conducted by skilled and qualified personnel, as well as the availability of requisite infrastructure. However, facilities often lack the skills to pick up on complications, including not diagnosing obstructed labour, missing malpresentations, not picking up post-partum haemorrhage, etc.[13] Moreover, the lack of emergency obstetric care also implies that health facilities at various levels are poorly prepared to manage emergencies. The standard management of severe pre-eclampsia and eclampsia requires that the delivery happen as soon as possible. Delays in conducting the deliveries, however, of several hours, and even days, significantly contributed to these maternal deaths.[14]

Along with improved skills of staff at various levels of the health facilities, protocols need to be put in place for timely identification of risks and referrals for patients in life threatening situations to higher level facilities, where more advanced care is available. The data also included some maternal deaths in transit. While NFHS-4 data and studies point to women increasingly accessing institutional care, the number of deaths in transit also indicate the difficulty in geographical access and the time taken due to the terrain to reach functional health facilities. Further, the non-availability of ambulance services that are adequately

equipped to manage complications in transit is also a critical issue in tribal areas. A report by Sahayog and NAMHHR, *Chronicles of Death Foretold*[15] documented several deaths of women from tribal communities in the Godda district in Jharkhand (2016) at different locations – health facilities, homes and in transit.

The data from the DH Rayagada also indicates deaths during home deliveries. While births at institutions, including amongst tribal communities is increasing, the incidences of home births remain significant. Given the fact that infrastructure in tribal areas – both physical and human resources – still leaves much to be desired, there is a need to focus on safe deliveries, irrespective of the place of delivery. The fact is that for many tribal women, particularly those living in remote and difficult areas, home deliveries may continue to be preferred and at times, the only available option.

### Kali Bai vs Union of India, Writ Petition (PIL) No. 47 of 2015, decided on 22 September 2017

The Petitioner's daughter died during labour due to poor health facilities and mismanagement of the situations at the CHC, at Gaurela where she was admitted for institutional delivery. Acknowledging that the poor conditions at the CHC are a failure of the Government in providing medical treatment to a person in need, the High Court of Chhattisgarh held right to health includes access to public health facilities and right to a minimum standard of treatment and care through such facilities. Emphasising that right to health and reproductive rights of the mother are two among the inalienable components of basic, fundamental and human rights to life under Article 21 of the Constitution, the Court stated that identifying high-risk pregnancies and providing appropriate and prompt special care are indefeasible components of access of reproductive rights. Pointing out that the State of Chhattisgarh, has a large tribal population, including PVTGs, the Court said that these groups need special attention due to their vulnerability. Further, alluding to scheduled tribes who do not fall under the PVTGs, the Court said that they also fall into the basket which carries the homogeneous group of people who require special care.

The Court also noted that though buildings are built and health care institutions created in the form of health sub-centres, PHCs and CHCs, in tribal areas often remain dysfunctional. This situation is further compounded by inadequate monitoring, poor quality of reporting and accountability. Highlighting that the national health model/schemes and programs which is primarily designed for the non-tribal areas, the Court noted that the health needs, as well as difficulties in delivering health care in a geographically arduous, culturally different population surrounded by forests and other natural forces, require a specific attention. Pointing towards the responsibility of the Government under Article 42 in establishing a welfare state, the Court underscored that providing adequate medical facilities for the people is an inexcusable component of the obligation of governance of a welfare State. Stressing the duty of the Government under Article 42 and Article 21 in ensuring availability of doctors and good quality medical equipment and medicines, blood supplies, the Court directed the Government to take immediate steps to make available facilities, personnel and equipment, medicines and blood storage facility with three months from the judgment. The Court also directed the State Government to address the requirement of anaesthetist, gynaecologist trained in the emergency obstetric care and the need to establish blood storage facility, sonography diagnostic facility as well as the free supply of medicines at Gaurela CHC.

One of the ANMs interviewed in Odisha remarked,

> *"Tribals do not prefer institutional deliveries and their 'backwardness' poses an obstacle, which results in maternal mortality. It takes a lot of effort to convince them to go to the hospital for delivery, despite JSY. They have their own birthing practices which lead to complications, infections and maternal mortality. They are very rigid and they do not trust [the health system]."*

During the interviews with the members from community in Koriya district, respondents expressed that if services were good, free and closer to the villages, and if the medical staff were sensitive, they would access the maternal health services in health facilities.

To examine the events that lead to maternal deaths, a process of maternal death review (MDR) is important, irrespective of facility or home based deliveries. The interviews and discussions in health facilities pointed to MDRs being conducted by some of them. However, the assessment of some of the MDR documents showed that they were incomplete and a comprehensive audit of the maternal deaths had not been carried out. Further, the analysis of the MDR process and its follow up is unclear; MDRs, if conducted with due diligence can ascertain the multiple causes of death towards strengthening the quality of care so that future maternal and neonatal morbidity and mortality are prevented.

That maternal deaths are a violation of multiple human rights is well established and reinforced by the petition order below. However, this will need to translate into action to ensure that the human rights of women in the context of maternal health and health care are fulfilled.

### 5.4.1.2 Maternal health

The experiences narrated by women from the tribal communities and also the discussions with NGO representatives in the study areas revealed the inadequate availability of maternal health care; this was particularly absent in the conflict zones and migration sites. Women's narratives presented their experiences, where they had to move from facility to facility in search of diagnosis and deliveries. The quality of services were often poor and there were also some instances of gross medical negligence. The right to safe childbirth and delivery is an important aspect of reproductive rights of women; the existing gaps in maternal health care for the women from tribal communities, points to the non-fulfilment of these rights and the lack of accountability in providing essential services like emergency obstetric care.

Kusum's narrative represents a range of issues that women from tribal communities face in the course of accessing maternal health care. Kusum, a 22-year-old from the Birjiya tribe, residing in the Sirsi village of Mahuadanr block, Latehar District, was in her 9th month of pregnancy (at the time of the interview). Her first pregnancy ended in a still birth.

> *"During my first pregnancy I had undergone only one [antenatal] check-up during the village health and nutrition day (VHND). On the day of my labour, I began feeling pain in the night around 10 pm; I was having irregular pain, then the pain kept coming and going [her contractions were irregular]. We hired a vehicle and went to the PHC at Netarhat; my family members accompanied me to the hospital. I also had a cough at that time with a feeling of breathlessness and I was unable to talk. They kept me at the PHC, and one male staff made an incision in my lower part (vagina) but he did something wrong and my condition was bad; they referred me then to the CHC at Bishunpur, in Gumla district, which is located about 35 km from Netarhat. There was no ambulance at the PHC, so we hired a private vehicle for the journey. At the PHC, [health staff] they had put 'Dettol and bandage (gauze)' near the cut. We reached the CHC past midnight. At the CHC, they refused to admit me and we were further referred to the district hospital in Gumla, which was a further 84 km. The CHC provided a vehicle for us to go to the district hospital. We reached the district hospital around 4 in the morning. I became unconscious by this time. Later, when I gained consciousness, I was in the Ranchi hospital. I could not understand where I was; my mother explained to me that we were referred to this government hospital in Ranchi from the district hospital. I had stopped bleeding then but my child had died inside me. They made me do the delivery at Ranchi hospital. I was still very sick because of the bad incision and faced difficulty in urinating and defecating. The cut was till the part for passing urine (urethra). They kept me in the hospital for one month for treatment."*

The government hospital at Ranchi was about 94 kilometres from the Gumla district hospital. Kusum and her family reached the facility in Ranchi at noon. By the time she reached Ranchi, Kusum had stopped bleeding as the incision had been packed with gauze

but the baby did not survive. The episiotomy had been done extremely badly, resulting in an L-shaped cut in her perineum as well as a tear near the urethra. Kusum had to stay at the government hospital in Ranchi for a month to recover and she returned home in January 2017 after spending a month in the hospital. Kusum was using a catheter in the hospital and was advised to continue to do so for another 15 days at home as well, when she was being discharged from the hospital. Since she had to return to the hospital for the removal of the catheter and a check-up, she stayed with some relatives closer to Ranchi. She got an infection as a result of the catheter but could not go back to the hospital at Ranchi immediately. So, she had the catheter removed at a nearby private clinic.

> *"[About expenses].....we had to buy most of the medicines from a private chemist outside during my treatment, and a lot of money was also spent on the food and lodging expenses for my husband, mother in law, and other family members, who had to stay in Ranchi for the month while I was admitted in the hospital. All of these cost us a lot of money."*

These expenses caused the family very high OOPE. Further, Kusum's husband could not work for several weeks. They had to borrow money from relatives and neighbours in the village as well as from her husband's workplace in Kerala. A substantial amount was also spent on transport, especially on the return journey as they were three people travelling back to the village – her husband, mother and mother in law along with her.

Kusum's experience represents multiple gaps in the health care system in the context of maternal health. With regard to antenatal care (ANC), for both her pregnancies she received ANC during the VHND in the village. However, due to the experience of her first pregnancy, Kusum proactively sought ANC and visited the PHC at Netarhat twice – ANC was not otherwise available regularly at the community level. Even at the facility level, i.e. at the Netarhat PHC, some of the medicines were unavailable and had to be purchased. The ANC card for the second pregnancy also indicated that Kusum was registered very late in her pregnancy, in her sixth month whereas she should have been registered by her third month.

Kusum's narrative about her first pregnancy also tracks the long trajectory to the delivery, which in her case, resulted in the loss of the baby. One CHC as well as a DH refused to admit her allegedly due to inadequate facilities. While the exact reasons for denial were unknown to her, the harrowing journey and the repeated denials of care are not uncommon. In this instance, the unnecessary episiotomy by an unskilled health care provider also resulted in extremely negative health consequences for Kusum that lasted over a month.

Kusum and her family members travelled approximately 215 km for about 14 hours from home to the hospital in Ranchi in private vehicles that had to be paid for and in an ambulance in the last leg of their journey. This clearly highlights the medical negligence and gross human rights violations and the extreme apathy and unaccountability of the multiple health

care facilities that she accessed along the journey. The non-availability of health care close to their habitations, forces people to travel long distances and traverse difficult terrains; the lack of antenatal care and in the case of complications or emergency situations, the unavailability of emergency obstetric care (EmOC) largely for women from tribal areas, has extremely serious implications for their health and lives. These issues are discussed further in the following sections of the chapter.

## Antenatal care (ANC)

Given the poor maternal health context in tribal communities, the need for ANC is well established. ANC coverage for pregnant women helps in the early identification of complications, which can be treated well before further complications set in; identification and management of anaemia (low HB count), low weight, low or high blood pressure, etc., may facilitate the management of associated morbidities. ANC is also necessary as it provides a range of services towards identifying complications and monitoring women's health during pregnancy and towards preparing them for safe childbirth. Full antenatal care comprises at least four antenatal visits, at least one tetanus toxoid (TT) injection and iron folic acid tablets or syrup taken for 100 or more days.[16]

However, the present study points to the significant gaps in the provision of ANC for women from tribal communities. The ANC provided during the VHNDs was often minimal; not all of the stipulated check-ups and care were provided. Most of the tribal villages had a fixed VHND, which was scheduled on one day in a month to accommodate the ANM's visit to different hamlets that she had to cover in a given month. However, if a woman was unable to attend the VHND for any reason, she would have to wait almost an entire month to access the next one. This was particularly true for remote habitations, i.e., away from the main road or where access to health facilities was challenging.

Moreover, delays were seen in the first ANC because of late identification of pregnancy in some of the villages visited in Chhattisgarh and Jharkhand. The ANMs visiting these villages often did not have the necessary equipment; the lack of equipment or maintenance of equipment was a challenge. There was no blood pressure (BP) apparatus in the sub-centres in a few areas. Urine albumin, pregnancy test kits, fetoscope, haemoglobinometer, torch and baby blankets or warmers were not available in the kits with ASHAs and ANMs in most of the study areas.

ANMs were also challenged in accessing these areas in the absence of transport facilities provided to them. *The Nischay kit*[17] for confirming pregnancy was not available regularly with ASHAs, which also led to consequent delays in registration of pregnant woman with Anganwadis for nutritional supplements, regular ANC and monitoring of their pregnancy

and health. Some of the CHCs, for e.g. CHC Janakpur, Koriya, had initiated a fixed days approach for ANC, wherein on two fixed days of the week, ANC was provided by the doctor and women from the hamlets were mobilised by ASHAs and had to visit the facility accordingly. While this planned approach may facilitate access to a larger number of women at the facility level, it was a deterrent if women have to travel long distances at their own expense. Further, denial of ANC on other days of the week for women accessing the facility is also a serious concern, which was raised by women from tribal communities in the course of interaction with them in Badwahi village in Bharatpur block, Koriya.


Access to ultrasound diagnostics is an important component of ANC for pregnant women. The availability of ultrasounds and other diagnostic services in large parts of rural India remains a challenge. This, contrary to the Indian Public Health Standards (IPHS), according to which ultrasound sonography (USG) test should be available at the secondary and tertiary levels. They were not available at any of the eight block level CHCs across the six districts that were visited. They were, however, functional in four of the five DHs (Baikunthpur, Jashpur, Latehar, Rayagada and Nuapada) visited; in the DH Rayagada, there was no radiologist available at the time of the study due to which the service was not available and the women were referred to the private diagnostics centres. Since the USGs are not functioning and most of the patients were getting ultrasound from the neighboring private diagnostic centres. According to the NFHS-4, women from the tribal communities are also the least likely to receive ANC from a skilled provider, amongst different social groups;[18] about 72.9 per cent women from tribal communities received (at least one) ANC, which is lower than the national average of 79.3 per cent.[19] Similarly, amongst those women and girls who received ANC, less than half of the women from tribal communities were attended to by a doctor in comparison to over two-thirds of the women from other communities.

Full ANC coverage in rural areas in the study districts, which have a high proportion of tribal communities, is abysmally low, with the highest coverage in Nuapada and lowest in Latehar As per NFHS-4, full ANC coverage is 18.3 per cent (Koriya), 11.9 per cent (Jashpur), 6.3 per cent (Gumla), 2.5 per cent (Latehar), 31.7 per cent (Nuapada), 26.9 per cent (Rayagada).

| Table 5.4.1.2: Indicators for Antenatal Care (ANC) (NFHS-4: 2016) | | | | | | |
|---|---|---|---|---|---|---|
| Indicator | Chhattisgarh | | Jharkhand | | Odisha | |
| | ST | Other* | ST | Other* | ST | Other* |
| Percentage receiving ANC from a skilled provider | 87.2 | 96.3 | 58.6 | 85.6 | 76.2 | 87.7 |
| ANC from a doctor | 29.4 | 70.2 | 25.0 | 60.1 | 64.1 | 83.9 |
| ANC from an ANM/ nurse/ midwife/ LHV | 57.8 | 26.1 | 33.7 | 25.5 | 12.0** | 3.8 |
| Percentage who had four or more ANC visits | 51.3 | 69.9 | 22.3 | 47.9 | 59.9 | 64.3 |
| *Other means women/girls who do not belong to SC/ST/OBC groups. | | | | | | |
| **In Odisha, equal number of women are also receiving ANC from Anganwadi/ICDS worker, which is much lesser in Chhattisgarh and Jharkhand. | | | | | | |

*Source: NFHS 4 Chhattisgarh, Jharkhand and Odisha Reports. Data collated from tables 37, 39, and 42 in state reports*

Access to ANC from a skilled health provider is lower amongst women from tribal communities across the three states; this becomes even more stark in the context of access to care from a doctor. The data also points to care largely being provided by community health workers like ANMs, midwives, etc. This reiterates the need for strengthened provisioning of care at the community level with institutional (health facility) support, given the challenges for tribal communities to access facility based care, combined with the limited availability of doctors proximal to or at the community level in tribal area.

## Deliveries in tribal areas

In the study, during group discussions in the selected districts, women and families shared their experiences with regard to the institutional deliveries and home births. The experiences of women from tribal communities, who have undergone institutional deliveries, highlight tremendous barriers that the women have to overcome to access institutional delivery. The disproportionate focus on institutional delivery draws attention away from these other aspects that represent maternal health collectively. For example, access to food and nutrition, nutritional supplements, affordable and timely transport, health information, and care; preparedness for the birth and other aspects of ANC critically determine maternal health and care. These factors continue to remain extremely weak for women from tribal communities. The narrative (below) reiterates the need for better facilities of transport and proximal health care as well as the necessary support for home births towards improved birth outcomes.

Vijaya, a 25 year old resident of Bhaiswar village belonging to the Kherwar tribe in Sonhat block of Koriya district, narrated her experience, when she went into labour and had to go to the CHC at Sonhat.

*"I went into labour in the morning, and then my husband called the 102 ambulance (Mahtari Express). My village is around 20 kilometers away from the hospital [Sonhat CHC]. The ambulance reached the village within half an hour of the call but it came up only till the pucca road. I was required to walk from my village till the ambulance that was waiting at the main road. But, because of the pain, I could not walk for more than five minutes. So, my family members had to carry me on a cot till the ambulance. But on the way only, the birth had started taking place; I delivered the baby on the cot itself. My family members put down the cot and my mother-in-law and the ASHA then delivered the placenta. I and my child – we were taken to the hospital after that."*


Similarly, for Suparna of the same village, the ambulance did not reach in time, and she had to deliver at home despite deciding to go to the hospital and making efforts towards it. Both these women, however, were taken to the CHC for post-natal care.

However, not all women were keen on having the delivery in a facility. The experiences of women and girls during previous deliveries and interface with the health system also determined whether they accessed a facility for the delivery.

Sheila Hundadi, a 20 year-old resident of Patalamba village in Parsali gram panchayat of Kalyansinghpur block, Rayagada, belonging to the Dongria Kondh PVTG, shared her experience of her delivery:

*"Last year, I delivered a baby boy in the Kalyansinghpur CHC – it was my first child. As the baby had low birth-weight, we were referred to the Rayagada DH. The baby was admitted in the hospital for three days. My husband and mother-in-law had accompanied me as well. The doctors did not tell me what was wrong, and the baby died.*

*"[Talking about her second pregnancy] I felt during my next delivery, that it should be at home; I did not want to go to the hospital as my first child died there."*

Deaths of women or infants have caused communities to mistrust the health system, the latter perceived as negligent and abdicating its responsibility to provide the necessary care.[20] Enhancing the accountability of the health system through provisioning of quality maternal health care is an urgent need; the interface between the health system and the women from ST communities is probably the maximum in the context of maternal health care, including delivery. Given their dependence largely in the public health system, such an interface is particularly necessary in the context of the tribal community in the study

area, Sheila Hundadi, was convinced not to seek care from the public health facility and deliver at home because of her previous experiences. She had to, however, do so when she was diagnosed with a high risk pregnancy (HB count was 8 g/dL, and her blood pressure was very low as diagnosed during one of her ANC check-ups), and experienced a lot of pain during labour.

> *"I did not want to go the hospital for the delivery. I had malaria during my pregnancy and was treated for it. They [ANM/ASHA] had given me a red card during one of the ANC checkups. I was also given IFA tablets. When the pain started, it was unbearable; the ASHA and the school teacher from the village talked to my family, and they kept asking us to go to the hospital for the delivery. My pain was increasing, so we finally agreed to go to the hospital. We called the ambulance, but they refused to send the vehicle as it was raining heavily at that time and the river in our village was overflowing. So, we hired an auto in which my family members and I went till the river, then they carried me in a cloth [make shift stretcher] and crossed the river. I somehow reached the hospital and had my delivery there. I stayed in the hospital for three days."*

The dependence on the public health system for affordable care was extremely apparent in the study areas. In the context of maternal health, this was particularly so in cases where there is a need for emergency obstetric care. Although in Sheila Hundadi's case, the birth is counted as an institutional delivery, the latter is not a sufficient indicator of the quality and comprehensive maternal health care that should be available to every girl and woman, especially those from marginalised communities. An assessment of the varied barriers that confront the women and girls from tribal communities in accessing safe delivery care, and taking necessary steps to address the same, is extremely critical.

### *Home based births*

According to NFHS-4, women from tribal communities also had the highest rates of home based deliveries at almost 28 per cent, compared with 18 per cent amongst SC women, 17 per cent amongst OBC, and 14 per cent amongst women from other communities.[21] The high rates of home based deliveries may imply the availability of skilled health care providers in tribal areas – whether traditional birth attendants or dais or health care providers such as ANMs and ASHA. It could also imply the limited options available to women due to non-availability of transport, distances to health facilities that pose barriers to women from tribal communities and areas accessing them. The narratives from the study point to the latter, whereby women even when they prefer to have their delivery in a health facility, have to give birth at home due to some of the above-mentioned reasons. Home based deliveries conducted by skilled health personnel of the total deliveries in rural areas, according to NFHS-4, was 8.7 per cent in Koriya, 6.8 in Jashpur; 6 and 8.6 per cent in Gumla and Latehar respectively and 4 and 10.1 per cent in Nuapada and Rayagada.

With the increasing shift to institutional deliveries, the role of traditional birth attendants (TBAs) or dais has decreased significantly, according to the discussions and interviews in the study. Yet, they continue to play a significant role in the context of tribal communities as some women give birth at home for various reasons-including distance, non-affordability of transport or services, emergencies, poor availability and quality of services in proximal facilities, discrimination in health facilities, cultural beliefs, etc. Institutional support for skilled health care providers, including TBAs towards conduct of safe home based deliveries could improve birth outcomes significantly. The community level health workers as well as TBAs, particularly in tribal areas can play an important role in early identification of any complications, provision of health care and referrals to the most proximal health care facility towards enhancing safe delivery practices, in addition to institutional deliveries.[22] Health facilities are also perceived by some tribal communities as culturally incompatible spaces. For example, tribal communities such as the Dongria Kondh in Rayagada district prefer birthing in a squatting position. However, health facilities do not acknowledge this and enforce a single position for birthing, i.e. lying down. The squatting posture is also recognised as a facilitative position for birthing; however, the health system's narrow and hegemonic approach to health care excludes other knowledge forms, including those of various tribal communities.

To make the facilities more appropriate and friendly for tribal women, the health system should be more accepting and accommodating of the diversity in cultural practices and take necessary steps towards making these available, as long as they are not harmful for the women or newborns. While access to health facilities and quality of care including deliveries is strengthened, attention should be paid to enabling 'safe' deliveries regardless of the location – whether at home or in an institution.

The study points to inadequate ANC, which also inhibits information and awareness with regard to healthy practices for women with regard to nutrition, regular access of ANC

Home-Based Newborn Care (HBNC), an innovative approach by SEARCH, an NGO working in Gadchiroli district, Maharashtra has been accepted by the Government of India (GOI). The 11th Five Year Plan of India recommended this approach as the main strategy to reduce IMR in the country. SEARCH had conceived the innovative idea of a home based newborn health care and decided to provide neonatal care in the home of the mother and newborn. SEARCH chose 39 rural villages in Gadchiroli for active intervention. Another 47 villages were selected for comparison, where no intervention took place. They selected 39 Village Health Workers – Arogya-doots – one woman from each village, and trained them in essential newborn care including monitoring (measuring temperature, weight, breath rate, etc.) the health of the newborn during home visits on specified days, identifying high-risk infants, and providing special care for high-risk infants. The intervention also included the diagnosis and management of morbidities, including life-threatening morbidities.

*SEARCH (http://searchforhealth.ngo/)* [24]

during pregnancy, towards birth and emergency preparedness. This is particularly so for women from tribal communities whose access to health information and care is otherwise limited due to the paucity in health care in tribal areas.

## Postnatal care (PNC)

Optimal postnatal care is necessary to avert both maternal and neonatal death, as well as to prevent long-term complications associated with postnatal problems, not limited to those that arise during the birth. The postnatal period is very critical as some women may experience PPH in the first 4-6 hours after delivery, due to excessive blood loss during the labour or because of the rupture of the uterus during labour and delivery. It also poses a threat to the newborn if PPH occurs before the delivery and the baby is starved of oxygen and nutrients.[23]


Interactions with women also revealed that no system of postpartum care was in place in most of the interior villages. Though the health care providers emphasised that post-partum care is a must and has been provided through ANMs and ASHAs, this was in fact not happening on the ground. While some ASHAs, Sahiyas, Mitanins said that they visited the women in their villages following birth within a period of 42 days, most women who were interviewed or participated in group discussions, shared that they did not receive any information, or check-ups after delivery.

In the district hospitals, the case load was quite high with inadequate space and beds to accommodate everyone; very often, women were discharged soon after delivery instead of 48 hours later as mandated. Under these circumstances, families also preferred to return home as there was no space in the general wards.

Women, who delivered at home, visited the health facility or approached the ANM if they experienced any problem. The study also found that Home Based Neonatal Care (HBNC) is not effectively implemented by ASHAs, particularly in the PVTG hamlets. Although HBNC has proved to be instrumental in reducing neonatal mortality, it comprises frequent visits to all neonates, identifying problems in breathing (asphyxia) and infections in neonates as well as its management and referral.

Facility-based new born care has been a serious concern; functional Sick Newborn Care Unit (SNCUs) are supported under the NHM. SNCUs are extremely critical and are expected to have adequate availability of medical officers (MOs), which is often a major concern. Maintenance of the SNCU infrastructure, equipment should be done regularly.

The attention to institutional deliveries with minimal focus on ANC and PNC including new born care is clearly inadequate to prevent maternal deaths; a continuum of care through the process of the pregnancy, birth and after, is imperative. However, the study points to inadequate ANC, which also inhibits information and awareness with regard to healthy practices for women with regard to nutrition, regular access of ANC during pregnancy, towards birth and emergency preparedness. This is particularly so for women from tribal communities whose access to health information and care is otherwise limited due to the paucity in health care in tribal areas.

## Health system related issues

### Infrastructure and human resources

The consequences of the lack of adequate infrastructure, services and skilled human resources in public health care settings often result in poor availability of services, especially for the management of high risk pregnancies. This ultimately leads to maternal morbidity and mortality that may be otherwise avoided. As was evident from available data [Rural Health Statistics (2017)], a significant proportion of the CHCs, FRUs and other facilities continue to lack the necessary infrastructure for the management of high risk pregnancies, such as EmOC and stabilisation units for new-born children (Table 5.4.1.3).

Further, even though most CHCs are expected to have a functional operation theatre, the shortage of specialists at the facilities cause women to be referred across facilities, causing delays and heightening risks that may potentially prove fatal for the mother as well as the child. Only six out of 169 CHCs in Chhattisgarh, two out of 188 CHCs in Jharkhand and eight out of 370 CHCs in Odisha[25] have all the four specialists (paediatrician, surgeon, physician and obstetrician and gynaecologist) available.

| Table 5.4.1.3: Facilities available at Community Health Centres (CHCs) as on 31st March, 2017 | | | | | | |
|---|---|---|---|---|---|---|
| State | Number of CHCs Functioning | Number of CHCs With all four specialists | With functional O.T. | With functional Labour Room | With functioning Stabilization Units for New Born | With New Born Care Corner |
| Chhattisgarh | 169 | 6 | 133 | 155 | 94 | 150 |
| Jharkhand | 188 | 2 | 165 | 170 | 42 | 170 |
| Odisha | 370 | 8 | 327 | 370 | 26 | 349 |

*Source: RHS 2017*

None of the CHCs that were visited during the study were providing C-sections, which was primarily due to the absence of functional blood storage facilities as well as the shortfall of requisite specialists. As per the IPHS, CHCs must be staffed with several health care providers who are able to provide specialised care – including General Surgeon, Physician, Obstetrician, Gynaecologist, Paediatrician and Anaesthetist.

However, in the present study, most of the CHCs only had medical officers, while specialists were not available even at some of the district level facilities that were visited. This meant that facilities that should have been available at the CHC level were available at the distant DH or even farther.

## Unavailability of Blood

The availability of safe blood at the health facilities is a critical issue in situations of maternal morbidities such as acute anaemia or malaria. Despite the Janani Shishu Suraksha Karyakram (JSSK) mandating availability of free blood for women and children under the age of 30 days, this is frequently not available. Even though 82 per cent of the First Referral Units (FRUs) in Chhattisgarh, 59 per cent in Jharkhand and 100 per cent in Odisha reported to have blood storage facilities (Rural Health Survey 2017), the evidence from the study indicates non-availability of blood units along with other related issues.

While blood transfusion services were available at the five DHs, they were not available in seven of the eight CHCs that were visited in the study areas. Effective functioning of blood transfusion facilities is dependent on several factors, including availability of blood units, staff and infrastructure, for example, electricity amongst other things. Moreover, people are often also asked to pay for services like testing charges for the donated blood, which has to be paid out of pocket. Similarly, a stipulated quantity of blood is available free of cost, but additional units of blood are required to be purchased. Additionally, 'replacement' was seen to be the major source of procuring blood in these States.

| Table 5.4.1.4 – Availability of functional blood transfusion facilities in the study districts | | | | |
|---|---|---|---|---|
| S.No. | State | District | Facility name | Availability of functioning blood transfusion facilities |
| 1 | Chhattisgarh | Koriya | CHC, Sonhat | Not available |
| | | | CHC, Janakpur | Not available |
| | | | DH, Baikunthpur | Available |
| | | Jashpur | CHC, Pathalgaon | Not available |
| | | | DH, Jashpur | Available |
| 2 | Jharkhand | Gumla | CHC, Chainpur | Not available |
| | | Latehar | CHC, Mahuadanr | Not available |
| | | | DH, Latehar | Available |
| 3 | Odisha | Nuapada | CHC, Khariar | Available |
| | | | CHC, Komna | Not available |
| | | | DH, Nuapada | Available |
| | | R ayagada | CHC, Kalyansinghpur | Not available |
| | | | DH, Rayagada | Available |

*Source: RHS 2017*

## Ambulances and transport services

Free ambulance services are one of the most crucial aspects for assuring access to health care in these tribal areas. Their absence was a major deterrent for a large number of people in tribal communities from seeking health care. The proportion of available ambulances to the population, especially in difficult terrains and remote locations must also be higher to accommodate for the extra time that might be required in transporting people to health facilities. In the context of maternal health, the transport facilities for women till the health facility and the strengthening of services located proximally to the communities is of utmost importance.

In the study states, only 374 out of 785 (47.64 per cent) PHCs in Chhattisgarh, 128 out of 297 (43.09 per cent) PHCs in Jharkhand and 44 out of 1280 (3.43 per cent) PHCs in Odisha had referral transport.[26] The lack of adequate number of vehicles with the health facilities to provide mobility support, and the unpreparedness of the system to respond to emergencies from difficult geographical locations, emerged as major concerns during the study.

## High OOPE for pregnancy and childbirth

The data on OOPE shows high expenditure incurred with respect to pregnancy and childbirth. This is corroborated by the data from NFHS-4, which highlights that the average OOPE for women from tribal communities on accessing delivery care in a public health facility is found to be as high as Rs. 3,000. For a smaller percentage of deliveries at private facilities, the average cost is as high as Rs. 14,000.

Such expenses create inevitable cycles of indebtedness and impoverishment, impacting food consumption, health care, and other dimensions of the lives of women, children and families from these communities.

**Table 5.4.1.5: State Level data of OOP during deliveries at health facility among Scheduled Tribe population**

| Indicator | Chhattisgarh | Jharkhand | Odisha |
|---|---|---|---|
| The average out-of-pocket cost paid for delivery at public facility among the ST population | Rs. 773 | Rs. 1,033 | Rs. 3,053 |
| The average out-of-pocket cost paid for delivery at private facility among the ST population<br>(Percentage of births delivered in a private health facility) | Rs. 14,141<br>(5.6) | Rs. 12,682<br>(8.5) | Rs.14,074<br>(1.8) |

*Source: NFHS-4*

However, many of the respondents and their families shared that they spent huge amounts of money on deliveries and related costs. OOPE in the present study is significant for transport costs, for purchase of medicines and diagnostics and other incidental costs including food and accommodation for attendants, accompanying the women. The OOPE shared by the respondents indicate costs that are substantially higher than provided here (Table 5.4.1.5).

## Programmes and Policies

National level programmes like the JSSK and JSY were envisaged to promote and incentivise institutional birth, and ensure free services at the point of care. Despite these, services were inaccessible and unavailable in the study areas or families incurred high costs to avail them. The non-availability of medicines and diagnostics was a recurring concern in most of the narratives, across the study areas that were also responsible for high OOPE.

The JSSK, a flagship initiative that promised entitlement of free maternal and neonatal care and service through public health facilities meant to prevent any OOPE for those accessing maternal health care, also shows varied gaps with regard to implementation. An evaluative study of the JSSK highlights the non-availability of quality care and the high OOPE among women from marginalised communities, including tribal groups, despite JSSK in the state of Chhattisgarh.[27]

In the six districts the percentage of women who received JSY entitlements were over 60 per cent except for Latehar, where it was as low as 40 per cent. A study on high spending on maternity care in India (2016),[28] found that out of the 14,482 deliveries analysed, no costs were incurred in only 0.14 per cent of the deliveries, despite the availability of health

schemes such as JSY and JSSK.

JSY was introduced with the specific objective of reducing maternal mortality through institutional deliveries offering financial incentives to all pregnant women for institutional delivery and post-delivery care; institutional deliveries have increased all over the country, to a lesser extent in tribal areas.[29] However, maternity entitlements under JSY are not sufficient to put a check on catastrophic expenditure on maternity care. The mean spending on maternity care has been found to be ten times higher than the amount on the JSY voucher.[30] Indirect costs may typically involve wage loss of the accompanying family members, which further increases the financial burden on the family. The government's National Programme on Reproductive, Maternal, Newborn and Child Health plus Adolescents (RMNCH+A) recognises the 'hard to reach' areas and its underserved population as part of its strategic approach; it also recognises the provisions for women who cannot reach a health facility during labour.[31] However, the implementation of the strategy is extremely limited.

## Conclusion

Interventions to improve maternal health have been one of the focus areas of the public health system and holds true for tribal communities too. In fact, the policy documents state the need for a stronger focus to reduce the high maternal mortality ratio and neonatal mortality rates through the promotion of institutional births. However, the study indicates rampant morbidities in communities such as malnutrition, TB, malaria, and other factors that determine maternal health. Moreover, the status of health care for maternal health (antenatal care, pregnancy and delivery, postnatal care) reflects huge deficits. The absence of ANC during pregnancy; lack of emergency obstetric care at tertiary health care facilities; lack of skilled care during childbirth; inadequate equipment and shortage of drugs and blood banks at facilities; lack of PNC services were some of the most common problems found in many of the public health facilities visited in the course of this study. Such deficiencies inevitably lead to poor maternal health and high rates of mortality. Moreover, lack of proper roads and transportation support force women to travel great distances in difficult conditions to access care. Maternal mortality and poor maternal health is above all, a tragic outcome of the systemic deprivations and the widespread social discrimination that women from tribal communities experience. Any public health initiative, therefore, must address both these to enable improved maternal health status and access to maternal health care for girls and women from tribal communities.

# Endnotes


1. Reported by Odisha TV on October 8, 2017 – originally in Odiya, it was documented translated by the research team
2. Sri, S., Nadimpally, S., & Khanna, R. (2011). *Maternal Deaths and Denial of Maternal Care in Barwani District, Madhya Pradesh: Issues and Concerns.* Delhi: Jan Swasthya Abhiyan, CommonHealth, Sama-Resource Group for Women and Health; NAMHHR, CommonHealth, Jan Swasthya Abhiyan. (2016). Maternal and Reproductive Health: Joint Stakeholder Report to UNHRC for India's UPR-III.: Sama (unpublished) Sexual and Reproductive Health and Rights Mapping Report Draft
3. Maternal and Perinatal Death Inquiry and Response (MAPEDIR) Project was set up to investigate the social, biological and medical incidents that lead to maternal and perinatal deaths and to suggest viable solutions. It was implemented in six states during RCH-II plan, supported by UNICEF.
4. Dikid, T., Gupta, M., Kaur, M., Goel, S., Aggarwal, A. K., & Caravotta, J. (2013). Maternal and Perinatal Death Inquiry and Response Project Implementation Review in India. *Journal of Obstetrics and Gynaecology of India,* 63(2), 101–107. http://doi.org/10.1007/s13224-012-0264-3
5. Subha Sri B, Sarojini N & Renu Khanna (2012) An investigation of maternal deaths following public protests in a tribal district of Madhya Pradesh, central India, Reproductive Health Matters, 20:39, 11-20, DOI: 10.1016/S0968-8080(12)39599-2
6. Sri, S., Nadimpally, S., & Khanna, R. (2011). *Maternal Deaths and Denial of Maternal Care in Barwani District, Madhya Pradesh: Issues and Concerns.* Delhi: Jan Swasthya Abhiyan, CommonHealth, Sama-Resource Group for Women and Health.
7. Internal Reports, DH Rayagada (Odisha) provided by the facility
8. Maternal Death Review Report provided by the DH, Nuapada
9. Ibid
10. Subha Sri, B., & Khanna, R. (2014). Dead Women Talking: A civil society report on maternal deaths in India. CommonHealth and Jan Swasthya Abhiyan, 2014.
11. MoHFW, GoI. (2016). *Tenth Common Review Mission Report* (Rep.). Retrieved June 16, 2018, from MoHFW; GoI website: http://nhm.gov.in/monitoring/common-review-mission/10th-common-review-mission.html
12. Ibid
13. Subha Sri, B., & Khanna, R. (2014). Dead Women Talking : A civil society report on maternal deaths in India. CommonHealth and Jan Swasthya Abhiyan, 2014.
14. Ibid
15. Sahayog., & NAMHHR. (2016). *Chronicles of Deaths Foretold: A civil society analysis of maternal deaths In seven districts from the states of Odisha, West Bengal, Jharkhand and Uttar Pradesh, India* (Rep.). Retrieved June 15, 2018, from Sahayog website: https://cdn2.sph.harvard.edu/wp-content/uploads/sites/32/2017/02/chronicles-of-deaths-foretold.pdf
16. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16. Mumbai: IIPS.
17. Nischay is a kit is to test for pregnancy, provided free of cost to women by the Government and available with ASHAs.
18. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16. Mumbai: IIPS. Table 8.3 (Antenatal Care).
19. Ibid.
20. *Maternal Health In Tribal Communities: A Qualitative Enquiry into Local Practices and Interactions with the Health System in Rayagada District, Odisha.* (2015). National Alliance for Maternal Health and Human Rights (NAMHHR), India. Lucknow, Uttar Pradesh: SAHAYOG. doi:http://www.chsj.org/uploads/1/0/2/1/10215849/odisha_report_final_for_web.pdf
21. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16. Mumbai: IIPS. Table 8.13 (Place of Delivery).
22. Sri, S., Nadimpally, S., & Khanna, R. (2011). *Maternal Deaths and Denial of Maternal Care in Barwani District, Madhya Pradesh: Issues and Concerns.* Delhi: Jan Swasthya Abhiyan, CommonHealth, Sama-Resource Group for Women and Health.

23. Postnatal Care Module: 1. Postnatal Care at the Health Post and in the Community. (n.d.). Retrieved June 15, 2018, from http://www.open.edu/openlearncreate/mod/oucontent/view.php?id=335&printable=1
24. SEARCH- Home Based Maternal, Newborn and Child Care. Retrieved from http://searchforhealth.ngo/home-based-maternal-newborn-and-child-care/
25. Rural Health Statistics. 2017.Minisry of Health and Family Welfare.Retrieved May 3, 2018, from https://data.gov.in/catalog/rural-health-statistics-2017
26. Rural Health Statistics 2017.Ministry of Health and Family Welfare.Retrieved May 3, 2018, from https://data.gov.in/catalog/rural-health-statistics-2017
27. Sulakshana Nandi, Dipa Sinha, Deepika Joshi, Rajesh Dubey, Vandana Prasad. Evaluation of the Janani Shishu Suraksha Karyakram: Findings on Inequity In Access From Chhattisgarh, India. PHRN – Public Health Resource Network, New Delhi (Delhi NCR), India.
28. Goli, S., Moradhvaj, Rammohan, A., Shruti, & Pradhan, J. (2016). High Spending on Maternity Care in India: What Are the Factors Explaining It? *PLoS ONE,* 11(6), e0156437. http://doi.org/10.1371/journal.pone.0156437
29. International Institute for Population Sciences (IIPS) and ICF. 2017. *National Family Health Survey (NFHS-4), India, 2015-16*: Mumbai: IIPS. Retrieved from <http://rchiips.org/NFHS/factsheet_NFHS-4.shtml>
30. Opcit (29)
31. A Strategic Approach To Reproductive, Maternal, Newborn, Child And Adolescent Health (RMNCH+A) In India. (2013). Ministry of Health & Family. Retrieved March 21, 2017 from http://nhm.gov.in/nrhm-components/rmnch-a/family-planning/background.html

# 5.4.2 Uterine prolapse

Uterine prolapse[1] is one of the most common reproductive health conditions among women in India. It is caused by the weakening of the pelvic muscles and ligaments that support the uterus, usually following a stressful delivery and sometimes, even after gynaecological surgery. The weakening of the pelvic muscle causes the uterus to descend, and sometimes even to protrude out of the vagina. Further, this condition often appear after menopause, when the muscles lose their tone and ligaments begin to atrophy.[2] The condition associated with problems like urinary incontinence[3] is a direct result of decreased estrogen levels after menopause. This is often due to lack of adequate rest post-delivery, allowing healthy involution of the uterus. This condition can be extremely painful and can cause inconvenience during work and can interfere with other daily activities.

Sumani is a 50-year-old woman who belongs to the Munda tribe in Mahuadanr block in Latehar district. She has three grown-up children. She has been living with a prolapsed uterus since the birth of her last child, almost 25 years ago. All her children were born at home, and thus no one came to know about the prolapsed uterus. She also finds it difficult to sit at times. Sumani states that there are days when she cannot work because of the discomfort. Sometimes she uses a piece of cloth to push back the protrusion and keep it

in place. She disclosed that she had never told her children about her condition or thought about seeking health care.

Another interview with Helen Bakhla, a 65 year old Oraon woman from Mahuadanr underwent a hysterectomy recently at a Mission Hospital after living with a prolapsed uterus for almost 30 years. Helen, who has six children noticed the protrusion for the first time after the birth of her third child. All her children were born within two years of each other. As she had her deliveries at home, no one came to know about prolapse. She shared her experience of living with the prolapse over the last few years, before she confided in her family about her condition.

> *"Over the last ten years, I began to have discomfort during urination, experienced some protrusion when bending down as well as while just sitting. However, I did not speak to anyone and quietly suffered from this discomfort. I consulted the ASHA from my village who told me that she had no knowledge about this 'bimaari' [illness] and referred me to the CHC at Mahuadanr. At the CHC too, I did not receive the care required; the nurses suggested pushing the protrusion back, which only worked temporarily. With no relief, I visited the Holy Cross Mission Hospital in Ambikapur in Chhattisgarh as it was closer to my home. I underwent a hysterectomy at the hospital in Ambikapur, which cost us approximately Rs. 10,000. However, I also experienced many issues after the surgery. Even though it has been almost a year after surgery, I still continue to feel discomfort, but do not know how to alleviate my suffering."*

Besides being one of the most common reproductive morbidities, women in tribal areas often lack the social and financial resources that would allow them to rest and recuperate after childbirth, compelling them to resume work and to lift heavy objects soon after delivery.

Further, the ambit of women's reproductive health is often limited to only childbirth under national schemes or programmes. This limited view of women's reproductive health means that other issues like prolapsed uterus, is sidelined and ignored. It is imperative to expand the scope of these schemes and programmes to address the issues of other reproductive morbidities. The existing reproductive health schemes and programmes run by the state are ineffective and inadequate, and not sensitive enough resulting in the failure to address the problems faced by women like Sumani and Helen.

## Endnotes

1. Uterine prolapse refers to a condition in which the uterus sags down into the vagina, and may even protrude out in severe condition.
2. Ravindran, T. K. Sundari, R. Savitri, and A. Bhavani. 1999. "Women's Experiences of Utero-Vaginal Prolapse: A Qualitative Study from Tamil Nadu, India." Retrieved May 9, 2018, from https://pdfs.semanticscholar.org/ca82/a555a3a45d736d125b7abfe466757b16f551.pdf.
3. Urinary incontinence means leakage of urine while coughing, sneezing or lifting weight.

# 5.4.3 Access to abortion services

Despite abortion services being legalised in India through the Medical Termination of Pregnancy Act (MTP Act) 1971, which permitted provision of abortion services under specified conditions up to 20 weeks of pregnancy, the access to safe abortion services continues to be highly inadequate, especially in rural and tribal areas.[1] This section discusses the issue of access to abortion in the context of girls and women, particularly from tribal communities. However, in the present study, abortion related data did not emerge through primary interviews; hence, data on abortion from published resources and data sets have been analysed here through the methodology of the review of secondary data and analysis.

The following case, Amita Kujur Vs. State of Chhattisgarh & Ors (2016) illustrates the experience of a tribal woman from Chhattisgarh accessing abortion services.[2]

> *Amita Kujur, a tribal girl from Jashpur, was abducted and taken to Rajasthan, where she was subjected to rape and became pregnant. The offence of rape was registered at the Bagicha Police station, and was later transferred to Kansabel police station in Jashpur district in March 2016. She was over 12 weeks pregnant at the time and wanted to terminate her pregnancy. The District Hospital, Jashpur did not conduct termination of pregnancy due to the non-availability of trained doctors and stated that those accessing medical termination of pregnancy (MTP) were sent directly to the Chhattisgarh Institute of Medical Sciences (CIMS), Bilaspur. The doctors at CIMS informed the petitioner*

*to bring a copy of the first information report (FIR), the medico-legal case (MLC) documents and a reference letter from DH Jashpur. Amita Kujur, however, was unable to obtain these documents because of the callous attitude of the Thana in charge. Despite several representations to the authorities no adequate action was taken to facilitate the termination of her pregnancy, even after 15 days. The petitioner then approached the Hon'ble Court in Bilaspur for directions, as her pregnancy was advancing and the delay caused by the authorities may ultimately make it impossible to go through with the abortion. She filed the petition to prevent herself from the severe mental agony of carrying an unwanted pregnancy.*

Following this a direction was issued to the Dean of CIMS, Bilaspur to constitute a team of two doctors to perform a medical examination of the petitioner, to form an opinion as per the MTP Act and take suitable steps.

Amita Kujur's pregnancy was of 21 weeks gestation, which was beyond the period permitted by the Act; it would not be possible for the doctors to proceed with the termination of pregnancy without a judicial order. The court held that since it is in the interest of the victim alone, which has to be considered, the treating doctors should terminate the pregnancy.[3]

This narrative[4] illustrates a range of legal as well as operational issues that pose significant barriers to accessing safe, legal, quality abortion services. Although specific to accessing abortion in the context of rape, the narrative highlights the barriers that the MTP Act's 20-week gestation limit for termination of pregnancy creates. Moreover, in this instance, despite the law permitting termination of pregnancy that has resulted from sexual assault/rape, Amita Kujur had to face several delays at multiple levels and was left with little choice but to petition the Court. The delays were caused by the non availability of services for abortion at the hospitals that she went to. Moreover, the delays due to the denial of abortion in the absence of a FIR possessed by the woman, was in contravention to the existing protocols[5] for medico-legal care for survivors/victims of sexual violence that clearly state, "if a person has come directly to the hospital without the police requisition, the hospital is bound to provide treatment and conduct a medical examination with consent of the survivor/parent/guardian (depending on age). A police requisition is not required for this".

Since Amita Kujur had already filed an FIR, the hospital should have recorded the same and coordinated with the police or the DH Jashpur for the requisite documents instead of refusing to conduct the termination unless they were made available. This narrative further points to these unnecessary delays leading to the time period of gestation extending beyond the legally permitted time period of 20 weeks, compromising the survivor's physical and psychological health.

The MTP Act, currently permits access to medical termination of pregnancy under certain circumstances, including in case of risk to the woman's life, which may result in serious harm

to her physical or mental health, unintended pregnancy following rape, contraceptive failure in the case of married women, and in situations of foetal abnormalities. The present MTP Act, thus, does not recognise the "right" to abortion, of girls and women. For termination of pregnancy beyond 20 weeks, the Courts generally appoint a medical board to assess the case and provide an opinion.

Health care providers, as is also observed in the above narrative, largely mediate the access to abortion; the decision regarding provision of abortion services is determined by their interpretation of the situation. In several instances, this results in a limited or skewed interpretation of the conditions laid down in the MTP Act, which creates barriers and delays in the access to abortion.

Data on abortion in India indicates that in 2015, 15.6 million abortions (14.1–17.3 million) occurred in India.[6] The abortion rate was 47.0 (42.2–52.1) per 1,000 women, aged 15–49 years. About 3.4 million abortions (22 per cent) took place in health facilities, 11.5 million (73 per cent) were abortions through medication outside of health facilities, and 0.8 million (5 per cent) abortions were done outside of health facilities using methods other than medication. Overall, 12.7 million (81 per cent) abortions were medication abortions, 2.2 million (14 per cent) were surgical, and 0.8 million (5 per cent) were done through other methods.[7]

According to HMIS data for 2016-17, the total number of reported abortions was 5,63,232. Of these, 2,35,118 (41.7 per cent) were conducted in public institutions and 1,90,906 (33.8 per cent) in private health facilities, while the information on access to care for about 1,37,208 (24.3 per cent) abortions was not recorded adequately by the system.[8] The pregnancies that ended in an abortion, for women aged 15-49 years, in the study states – as per the NFHS-4 (Table 5.4.3.1) during the five years preceding the survey – indicate lower rates of abortion amongst women and girls from tribal communities.

**Table 5.4.3.1: Total abortion rate**

| | Chhattisgarh | Jharkhand | Odisha | India |
|---|---|---|---|---|
| Total abortion rate% | 2.4 | 2.6 | 4.7 | 3.4 |
| Total abortion rate% amongst scheduled tribe communities | 1.7 | 2.1 | 2.8 | 2.1 |

*Source: NFHS-4*

With regard to the place where abortion services were sought or took place in the three states, according to NFHS-4, the rate of abortion "at home" was the highest in Chhattisgarh and Odisha. However, details about the methods used – whether medication abortion (using abortifacent- allopathic or indigenous) or other methods – were unavailable in the NFHS-4 data. In Jharkhand too, the rate of abortion at home was significant, although marginally

lower than the rate of abortion at private facilities (including non government and Trust hospitals).

The rate of abortions in public health facilities was the lowest in Jharkhand, followed by Chhattisgarh; in both these states, the public health facility as the location of abortion services followed the home and private facilities. This data indicates the possibility of poor availability of abortion care in public health facilities or geographical, social barriers to access. The high rates of abortions at home may reflect access to medication abortion, or consequences of non-affordability, poor access, lack of information, stigma and lack of confidentiality in seeking care from public or private health sector.

| Table 5.4.3.2: Place of abortion | | | | |
|---|---|---|---|---|
| **Place of Abortion (Rural)** | **Chhattisgarh %** | **Jharkhand %** | **Odisha%** | **India** |
| Public Health Facility | 19.9 | 13.2 | 31.5 | 22.5 |
| Private Health Facility | 23.1 | 43.9 | 19.9 | 47.0 |
| Home | 56.9 | 41.1 | 47.5 | 30.1 |
| Other | 0.1 | 1.9 | 1.1 | 0.4 |

*Source: NFHS-4*

In Odisha, higher rate of access to abortion in public health facilities is evident from the data for the three states as well as for the country as a whole.

| Table 5.4.3.3: Who performed abortion | | | | |
|---|---|---|---|---|
| **Person who performed the abortion (%) – rural** | **Chhattisgarh** | **Jharkhand** | **Odisha** | **India** |
| Doctor | 35.3 | 29.6 | 40.3 | 48.6 |
| Nurse/ ANM/LHV | 11.4 | 27.2 | 3.1 | 18.6 |
| Dai | 3.9 | - | 0.4 | 0.6 |
| Self | 41.0 | 33.6 | 50.6 | 27.7 |
| Friend/Family/ Relative | 6.9 | 7.9 | 4.1 | 3.6 |
| Other | 1.6 | 1.7 | 1.5 | 0.8 |

*Source: NFHS-4*

Abortion by 'self' was the highest in all the three states, coinciding with the data of highest rates of abortions at home (Table 5.4.3.2). This was followed by abortions provided by doctors; in Jharkhand the rate of abortions by nurse, ANM, LHV was marginally lower than those provided by the doctors, whereas there wasn't a marked difference in Odisha and Chhattisgarh. However, in the absence of further information, it is unclear if the abortions by 'self' indicate 'medication abortions' or abortions by any other method, induced by the girl/woman. The implications of the NFHS-4 data coincide with the data emerging from

the study cited earlier, regarding the high rates of medication abortion in India. This needs deeper inquiry to understand what methods are being used by girls and women themselves and in case of medication abortion what is the source of medicines, information about their use, contraindications, etc.

A recent study amongst Baiga women in Chhattisgarh found that 31.2 per cent of the women had induced abortions multiple times.[9] The women had stated that the reasons for undergoing abortion were the number of children that they already had, or because of their last child being too young and a fear of the additional burden of having another child. These findings also point to the high unmet need for abortion as well as contraceptive services in the area. As has been discussed in the section on access to contraception, women from Baiga communities are disallowed (legally) from undergoing sterilisation; their access to other spacing methods of contraception is also probably limited. This is also reflected in the rates of induced abortions, where 10 per cent of the total number of women from the Baiga community in the study had induced abortions. Among these, a majority, i.e. 93.7 per cent used methods like 'self-medication', massaging the stomach or consuming *jadi-buti (herbs)* to induce the abortion. Significant knowledge and practices amongst tribal communities with regard to herbal abortifacents have been documented by several studies.[10,11,12]

About 24 per cent of the women in Chhattisgarh,[13] 26.2 per cent in Jharkhand[14] and 18.8 per cent in Odisha[15] stated that they experienced complications following abortions. Of these, 85.2 per cent, 65.6 per cent and 77 per cent women from the rural areas sought treatment in Chhattisgarh,[16] Jharkhand[17] and Odisha respectively.[18]

**Table 5.4.3.4: Access to health care in case of complications following abortion**

| | Chhattisgarh | Jharkhand | Odisha | India |
|---|---|---|---|---|
| Public Health Sector | 20.8 | 12.8 | 48.7 | 26.0 |
| Private Health Sector | 75.0 | 84.5 | 45.8 | 71.2 |
| At Home | 4.2 | 2.6 | 3.3 | 2.4 |
| Other | 0 | 0 | 2.1 | 0.5 |

*Source: NFHS-4*

For complications arising as a result of abortions, the percentage of women and girls who sought treatment from the private health sector or private health care providers was the highest in the states of Chhattisgarh and Jharkhand. In Odisha, those seeking treatment for post abortion complications was marginally higher in the public health sector, 48.7 per cent, followed by 45.8 per cent seeking treatment in the private sector. The high rates of women and girls seeking treatment from the private sector due to post abortion complications indicate the non availability of care in public health institutions and their poor accessibility.

The present study indicates that abortion services are mostly available only in the district hospitals in the six study districts. The distances to these facilities for women from tribal communities, in the absence of affordable transport, therefore were significant barriers to access. Only a few of the CHCs were providing abortion services at the block level. For instance, MTP services are unavailable at the CHC of Sonhat block in Chhattisgarh due to lack of trained staff. The next referral facility, which is the district hospital at Baikunthpur, is located at a distance of 30 km from the CHC. Similarly, in Odisha, abortion services are not available at the CHC at Kalyansinghpur, with the referral facility being the DH Rayagada at a distance of 46 km from the CHC. The non-availability of safe abortion services at the sub-district levels and district hospitals is a substantial gap, which has been reiterated by health review missions[19] and also by the present study.

The absence of adequate numbers of trained, legally registered health care providers throughout the country and the necessary facilities also continue to pose significant challenges to those accessing abortion care. Moreover, evidence points to the abysmal access to information and knowledge about the legal provisions of the MTP Act amongst girls and women, as well as among health care providers, often compromising access to abortion care. In addition to the lack of facilities, insufficient infrastructure and stigma, and the overlap and conflation of other laws with the MTP Act only add to the challenges. Ultimately, access to safe and quality abortion services is possible only when comprehensive health care is available at all levels of a health system devoid of any bias and discrimination.

## Endnotes


1. Iyengar K and Iyengar S (2016) Improving access to safe abortion in a rural primary care setting in India: experience of a service delivery interventionReproductive Health, 13: 54. Published online 2016 May 10..
2. Sama had been approached by the organisation that was involved in the legal proceedings to provide inputs on this case with regard to the protocols following sexual assault including access to abortion (2016).
3. Amita Kujur Vs. State of Chhattisgarh & Ors.(WP (C) 976/2016, Hon'ble High Court of Chhattisgarh. Retrieved http://hrln.org/rape-survivors-struggle-to-terminate-her-pregnancy-caused-due-the-assault/
4. Ibid.
5. Guidelines & Protocols: Medico-legal care for survivors/victims of sexual violence (2014). Ministry of Health and Family Welfare.Govt.of India. Retrieved https://mohfw.gov.in/sites/default/files/953522324.pdf
6. Singh, Susheela et al (2015).The incidence of abortion and unintended pregnancy in India.The Lancet Global Health , Volume 6, Issue 1 , e111 - e120.
7. Ibid.
8. 10th Common Review Mission report (2016).National Health Systems Resource Centre (NHSRC), Ministry of Health and Family Welfare.Government of India.
9. Lavtepatil, S., &Sijwali, H. (2017, September 23). Under Garb of 'Preservation', Chhattisgarh Is Denying Vulnerable Groups Their Reproductive Rights. The Wire. Retrieved May 25, 2018, from https://thewire.in/gender/chhattisgarh-pvtg-sterilisation-reproductive-rights

10. Ibid.
11. Rajeswari, J., & Rani, S. (2014). Medicinal Plants Used As Abortifacients. International Journal of Pharmaceutical Sciences Review and Research, 24(1), 129-133. Retrieved from http://globalresearchonline.net/journalcontents/v24-1/24.pdf,
12. Philip, A. & M. V, Krishnaraj & Prabu, Dr. &, R. Kumuthakalavalli. (2011). Ethanobotanical Exploration on Abortifacient Plants Used by Mannan Tribes of Kerala, India. International Conference on Climate Change Forest Resource and Environment. 55.
13. Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16: Chhattisgarh. Mumbai: IIPS.
14. Ibid.
15. Ibid.
16. Ibid.
17. Ibid.
18. Ibid.
19. 10th Common Review Mission report (2016). National Health Systems Resource Centre (NHSRC), Ministry of Health and Family Welfare

# 5.4.4 Contraception


The trajectory of India's family planning programme, one of the earliest such programmes in the world, has unfortunately been blotted with grave questions about the callous treatment of women, as well as violations of ethical and quality norms. Situated in the larger context of population control, it continues to be unacceptably mired in targets and disincentives, undoubtedly, a far cry from the realisation of reproductive rights and the right to the highest attainable standard of health. Moreover, the government programme continues to be extremely gendered in its approach; the iteration of girls' and women's responsibilities in using contraception towards planning families and contributing to the state's agenda of population stabilisation is palpable.

Guaranteeing access to available, acceptable, and comprehensive information and services on safe contraception, free from coercion, discrimination, and violence is not merely

linked to family planning aspects; but is also critical towards ensuring the realisation of the reproductive rights of women-tribal women in the context of this study.[1] The following section looks into some of the specific issues that emerged during the discussions with the providers, local NGOs and with communities in selected districts.

## Availability of contraceptive services

As per data from the fourth NFHS (2015-16), in Chhattisgarh, the contraceptive prevalence rate (CPR) was 58 per cent, with the rates in the districts of Koriya and Jashpur lower than the state average, at 51 per cent and 50 per cent respectively. The CPR for Odisha was slightly lower at 57 per cent with Nuapada and Rayagada indicating rates of 59 per cent and 55 per cent respectively. The CPR in Jharkhand was the lowest of the three states with a CPR of 40 per cent and Gumla and Latehar indicating rates of 26 per cent.[2,3] Of all the available contraceptive methods, female sterilisation was the most used in the three study states of Chhattisgarh, Jharkhand and Odisha. In Chhattisgarh, female sterilisation amounted to 43.6 per cent[4] of all contraceptive methods used, while in Jharkhand it was 32.7 per cent[5] and in Odisha, 25.9 percent[6]. Women continued to bear an uneven burden of a permanent contraceptive method.

Among the tribal communities in the three states, the rates of female sterilisations were higher as compared to male sterilisation or other family planning methods. According an RCH in-charge, most of the women underwent sterilisation at the government health facilities and Minilap was the common method used to perform sterilisations. In many districts we were informed that the NSV rate is very low with a declining trend. Male participation in family planning remains a challenge.

The sporadic availability of condoms and pills with ASHAs and ANMs, and the availability of IUCDs in only a few of the health facilities, were responsible for the limited contraception use in the study areas. Similar findings were reported from another study of the Baiga community in Chhattisgarh, which reflected similar trends of poor supply of Mala-D (oral contraceptive pill) and condoms at the community level, and the lack of training of ANMs on IUCD insertion.[7] Such a situation ultimately compelled people to purchase an otherwise

free service from the private sector, or not use it at all; the latter especially true of tribal communities and other poor sections of population who cannot afford to pay.

Instances of poor quality of sterilisation services, as well as the negligent attitude of medical professionals towards women from underprivileged sections, came to be widely known during the 'sterilization deaths' incident in Chhattisgarh in 2014. The tragic deaths of the 13 women, all in their 20s or 30s, and the critical condition of 70 other women, following procedures of laparoscopic sterilisation in a camp held in November, 2014 in Bilaspur district, Chhattisgarh, raised grave questions once again about the callous treatment of women, particularly the poor and the marginalised, as well as the clear violations of ethical and quality norms in the health care system. Since sterilisation camps were discontinued in 2014 following this incident, sterilisation services are primarily being provided on fixed days at the secondary and tertiary level hospitals in Chhattisgarh.[8,9]

## Denial of sterilisation to the PVTG community in Chhattisgarh

Disaggregated data at the district level was unfortunately not available in the context of tribal communities. However, a study by Jan Swasthya Sahyog (JSS), Chhattisgarh with the Baiga community[10] brought forth several important issues in this regard. It captured the impact of poor reproductive health services in the state of Chhattisgarh, where access to sterilisation was restricted for the PVTG community while the availability of other methods of contraceptives remained poor. The findings of the JSS study indicated that the mean number of pregnancies among Baiga women between the age group of 36-45 years was 5.5, while the average number of pregnancies for non-Baiga women was 3.5.[11] With regard to awareness, 11 per cent of the women knew about vasectomies, 13.6 per cent were aware of condoms, 19.4 per cent were aware of contraceptive pills and 20.7 percent of the women were aware of the IUCD. However, 97.4 per cent of the women reported that they had knowledge about female sterilisation. This indicated an extremely low awareness about contraceptive methods, other than female sterilisation. Additionally, only 1.5 per cent of the women used IUCDs, while no one reported using condoms or contraceptive pills. This points to a major gap in the availability of these services from public facilities as even the 1.5 per cent of the women who opted for IUCDs, accessed them from health centres run by JSS in the area.

In the course of the study, interactions with community leaders and NGO workers in Chhattisgarh raised the issue of a government order banning sterilisation services for specified PVTGs to ostensibly 'protect' them in the state. The government's restriction on the availability of a permanent method rendered them vulnerable to unwanted pregnancies and unsafe abortions. This order was challenged through a public interest litigation (PIL) filed by Ranichand Baiga from the Baiga tribal community in the state.[12]

Ranichand Baiga, a resident of Chhaparwa village, has five living children from seven pregnancies; two pregnancies ended in miscarriages. The eldest child is 12 years old, and the youngest is around one month old. Ranichand went to the health centre seeking a tubectomy operation, which she was denied. The primary source of income for Ranichand's family is through the making and sale of bamboo brooms, from which they earn approximately Rs. 600 per week and Rs. 2,400 per month. It is extremely difficult for the family to sustain themselves on this income. When she was denied sterilisation services, Ranichand Baiga filed an application [2015] in the Bilaspur High Court seeking dismissal of the ban.

The petition was filed under Article 226 of the Constitution of India. The challenge to the government order dated 13.12.1979 is based on the ground that such an order is arbitrary and violates the right to life and liberty of the tribal people, especially women, who have to undergo repeated pregnancies owing to the lack of contraception services and the arbitrary denial of sterilisation services. Such policies not only prevent women from marginalised tribal communities from exercising their free and informed choice on reproduction, they also violate their autonomy by thrusting the responsibility of repeatedly bearing and raising children on their shoulders. The experience of Ranichand Baiga, and many other women like her, clearly demonstrates the violation of human rights relating to reproductive health and well-being.[13] A critical reflection on a discriminatory population policy like this raises basic questions as to why only a low birth rate is seen as an important indicator, while high mortality rates among PVTGs is not considered in this approach.[14]

By limiting contraceptive services for the entire community and denying people the right to control their fertility, the government is not only being insensitive and arbitrary, it is also blatantly violating the rights and liberties of PVTGs. Thus, information and access to voluntary contraceptive services are critical in upholding the reproductive rights of women. This provides women the right to decide whether or when to have children, and to determine the number and spacing of children, thereby preventing unwanted pregnancies and minimising the adverse impact of repeated pregnancies on their health and well-being.

The non-availability of comprehensive information, informed consent, good quality services, and the inadequate assurance of follow up care in the case of side effects due to contraception, are deterrents to accessing contraception.Further, 'family planning' has

primarily been perceived in the context of marriage and procreation; thus, norms around gender and sexuality pose barriers or stigmatise access to contraception for young people and adolescents, single women and others who are outside the domain of marriage. In the context of contraception, especially for women in tribal communities, the State's position, whether in denying services (as for Baiga and other PVTG women) or in providing contraceptive services with demographic targets as the objective (as in Bilaspur), violates the reproductive autonomy and integrity of women to make informed decisions about contraception. Therefore, comprehensive contraception services necessitate a strengthened health care system that is able to provide unbiased, complete information as well as care for men and women beyond demographic targets.

## Endnotes


1. Country Assessment on Human Rights in The Context of Sexual Health and Reproductive Health Rights. (2018). Sama Resource Group for Women and Health and Partners for Law in Development
2. National Family Health Survey 2015-16 (NFHS-4), District Fact Sheet Gumla, Jharkhand. International Institute for Population Sciences
3. National Family Health Survey 2015-16 (NFHS-4), District Fact Sheet Latehar, Jharkhand. International Institute for Population Sciences
4. National Family Health Survey 2015-16 (NFHS-4), State Fact Sheet Chhattisgarh. International Institute for Population Sciences
5. National Family Health Survey 2015-16 (NFHS-4), State Fact Sheet Jharkhand. International Institute for Population Sciences
6. National Family Health Survey 2015-16 (NFHS-4), State Fact Sheet Odisha,. International Institute for Population Sciences
7. Inequity in health and nutrition and denial of services and rights: The doubly disadvantaged Baiga PVTGs of Chhattisgarh (Poster), Public Health Resource Network, Chhattisgarh
8. i) Camp of Wrongs-The Mourning Afterwards - A Fact Finding Report on Sterilisation Deaths in Bilaspur. (2014). Sama Resource Group for Women and Health, Jan Swasthya Abhiyan, National Alliance for Maternal Health and Human Rights.
9. *Robbed of Choice and Dignity: Indian Women Dead after Mass Sterilisation . Situational Assessment of Sterilisation Camps in Bilaspur District, Chhattisgarh* (Rep.). (2014). Population Foundation of India (PFI), Parivar Seva Sanstha, Family Planning Association of India, CommonHealth.
10. Lavtepatil, S., & Sijwali, H. (2017, September 23). Under Garb of 'Preservation', Chhattisgarh Is Denying Vulnerable Groups Their Reproductive Rights. Retrieved December 12, 2017, from https://thewire.in/gender/chhattisgarh-pvtg-sterilisation-reproductive-rights
11. Ibid
12. Ghose, D. (2017, April 24). Tribals want govt to scrap 1979 order denying sterilisation access. The Indian Express. Retrieved from https://indianexpress.com/article/india/baigas-tribals-want-govt-to-scrap-1979-order-denying-sterilisation-access-achanakmar-tiger-reserve-pvtg-4625607/
13. Lavtepatil, S., & Sijwali, H. (2017, September 23). Under Garb of 'Preservation', Chhattisgarh Is Denying Vulnerable Groups Their Reproductive Rights. Retrieved December 12, 2017, from https://thewire.in/gender/chhattisgarh-pvtg-sterilisation-reproductive-rights
14. Sundaraman, T., Prasad V., and Nandi S. (Ed.) (2010). Tribal Health [Module No. 15]. Public Health Resource Network

# 5.5 Undernutrition

Nutrition is considered a fundamental right by the Constitution of India[1] and the right to food and nutrition security is now encompassed within the right to life, as declared by The Supreme Court in 2001.[2] Despite this, tribal communities continue to suffer from malnutrition largely due to their poor socio-economic contexts of poverty, loss of access to forests for food, inadequate land and livelihoods, enforced migration and displacement. Cultural norms and practices during pregnancy and lactation among certain tribal communities also affect women's access to nutrition.

The study findings reiterate the high levels of undernutrition among tribal communities, particularly among the children and women, which is also the focus of this chapter.

## Undernutrition in children

The report of the High Level Committee, chaired by Prof. Virginius Xaxa states, "Malnutrition is one malaise affecting the tribal children……widespread malnutrition exposes these children to infection and infectious diseases, resulting in high mortality among them."[3] Undernutrition and micronutrient deficiency are the primary factors contributing to morbidity and mortality in children particularly under the age of five years.[4] According to a UNICEF report, around 54 per cent of children from ST communities under-5 years, are chronically undernourished.[5] According to the NFHS-4, 63.1 per cent of children (6-59 months) from ST communities in India are anaemic; 45.3 per cent of children under-5 years

are underweight (weight for age) and 16.1 per cent are 'severely underweight'. About 27 per cent of children from ST communities, under-5 years, are 'wasted' (weight for height), while 10.3 per cent are 'severely wasted'. Further, 43.8 per cent of the children from ST communities under-5 years, are 'stunted' (short for their age), while nearly 20 per cent are 'severely stunted'.[6] Stunting is considered to be the worst and most chronic form of undernutrition, whose consequences are sometimes irreversible.[7] Undernutrition is also extremely gendered with it being nearly twice as high among girls aged 6-23 months compared to boys, indicating persistent gender based discrimination in provision of food and care.[8]

Undernutrition is also closely linked to an increased risk to a range of non-communicable diseases (NCDs) such as lean diabetes, chronic lung disease, hypertension as well as infections like falciparum malaria.[9,10] Often, combined with co-morbidities such as diarrhoea, the undernutrition among children results in high fatality rates, which are otherwise preventable.[11]

The NFHS-4 indicates that a significant proportion of children in the researched States present one or more signs of undernutrition.

**Table 5.5.1: District Level Anthropometric Status of Children under 5 (Rural)**

| Indicator | Chhattisgarh | | Jharkhand | | Odisha | |
|---|---|---|---|---|---|---|
| | Koriya | Jashpur | Gumla | Latehar | Nuapada | Rayagada |
| Children under 5 years who are stunted (height-for-age) (%) | 33.8 | 35.5 | 46.5 | 44.9 | 36.4 | 46.5 |
| Children under 5 years who are wasted (weight-for-height) (%) | 29.6 | 18.8 | 32 | 29.5 | 27 | 23.3 |
| Children under 5 years who are underweight (weight-for-age) (%) | 37.9 | 36.4 | 48.6 | 45.3 | 40 | 44.4 |

*Source: NFHS-4*

Although disaggregated data for STs for all indicators are not available; the narratives that follow raise critical questions about undernutrition amongst children from these communities.

Undernutrition was extremely visible amongst children in the tribal communities in the course of the research. This was evident during the visits to villages, anganwadi centres, *ashram paathshalas* (residential schools for tribal children), and from group discussions and interactions with the respondents. While visiting a village in Nuapada district, for example, it was observed that most of the children from the Chaukhutiya Bhunjia PVTG, who were at the Anganwadi were visibly malnourished. This was confirmed by the AWW, who was also from the Bhunjia community. She explained that the mid upper arm circumference (MUAC) was regularly measured at the Anganwadi centre. Given the prevalence of malnutrition among the community, especially among the children and women, regular monitoring and

early intervention was extremely important at the community level. According to the AWW, the remoteness of the village and the lack of easy accessibility to other health care facilities demands nutritional programmes that are implemented in the community. Similarly, anaemia was a health problem in children. During visits at the *ashram paathshalas* for girls (10–14 years) in Sonbahali village, it was observed that a large number of the 150 girls who were residents there were (visibly) anemic. Undernutrition among children, especially girls, was a serious concern that emerged from the interviews, across the three states.

One-year-old Chandini, from the Pahadi Korwa PVTG in Gaybuda village, Jashpur district, had diarrhoea and vomiting when she was about seven months old. As Chandini was weaned off breastfeeding during this time, the Mitanin of the village suggested that her mother, Rajani, feed the baby a solution of water, salt, and sugar to stop the vomiting and diarrhoea. Her mother Rajani recalled:

*"Following the diarrhoeal episode, Chandini started losing weight. On the advice of the Mitanin, we took her to a Nutrition Rehabilitation Centre (NRC) in the CHC at Bagicha, 10 km from the village. Chandini was admitted at the hospital (NRC) for two weeks, during which she received regular meals and put on some weight; she gained about half a kg. The NRC team suggested that Chandini should stay in the hospital for some more time because she was still very weak and her condition was poor. However, this was not possible because I have two other children at home to look after and the distance to the CHC made it difficult for me to visit it repeatedly. We had to return to the village; after returning home, we did not receive any food from the Anganwadi for Chandini, since it had stopped functioning. At the hospital they did not provide any specific follow up feeding instructions and there was no follow-up by the ASHA or ANM in the village either."*

The narrative underlines the limited approach to enhance the nutrition of children. For instance, the ability of the NRC to provide nutritional food is limited to the stay at the centre, resulting in the lack of continuum of care to the undernourished child as well as the absence of necessary support for the caregiver and the children left behind at home.

The distance from facilities such as NRCs or hospitals, the high costs for transport in the absence of public transport, the loss of wages of caregivers due to the substantial time required to be in the NRC, care responsibilities towards the other children and family members at

home, as well as the costs of medicines, diagnostics, etc. that are frequently unavailable at public health facilities, are some of the main reasons for not accessing health and nutrition services.[12]

Another narrative from Rawatsarai village in Sonhat block, Koriya district, of the two year old Ashok Pando, illustrates similar concerns. Purnima Pando, the 25 year old mother of Ashok was pregnant at the time of the interview. She lives with her husband and two children, aged two and three years, respectively (Ashok was the second child).

> *"Our family owns only 0.25 acres of land, which is not enough to sustain the family and so we are dependent on income from MNREGA work. However, this work is irregular, and payments are usually delayed. I collect Mahua and other things like wood from the forest, which we sometimes sell. We are able to earn about Rs.2000 per month (average). We have a BPL ration card with three names; our youngest child, Ashok's name is not included in the ration card and we do not receive any rations in his name. Ashok has been falling ill and losing weight for some time. The Mitanin has suggested in the community meetings and during her visits that children whose weight is low should go to the hospital (NRC).She asked five children from the village, including Ashok, to go there. The Mitanin informed us that food would be provided there and that we would also get paid Rs.150 per day for staying at the facility. I went with the other women and children to the NRC in an auto, which we hired for Rs. 50 for each woman. We could not call the 108 ambulance because there is no mobile network in the village. The CHC is at a distance of about 30 km from the village. I did not have any money even to pay for the auto, so I had to borrow it from the Mitanin; I paid her back later after I sold a piece of wood that I had collected from the forest. I stayed with Ashok at the hospital for 15 days and we were provided all the meals.*
>
> 
>
> *All of us stayed with our children and helped in feeding them whatever food was given by the hospital. They gave Ashok and the other children cooked meals as well as fruits like oranges, bananas, and pomegranates. Two meals, milk twice a day, and fruits were given daily to the children. However, even after 15 days of having the food, Ashok did not gain any weight. So, I decided to return home. Before I left, they told me that Ashok should be fed at least six times a day in small portions at home, and that he should also be given vegetables and fruits. But I was not able to do this since I could not afford it – only if we have the money can we do it."*

Ashok used to get one packet of sattu/dry ration every two weeks from the Anganwadi centre. He used to also go to the Phulwari (community run crèche) in the village where he used to get hot meals and eggs, but it was shut down in December 2016.

The above narratives highlight important issues regarding the rehabilitation of children who are malnourished, with a particular focus on severe and acute undernutrition. The NRC is a critical initiative that provides immediate care in cases of malnutrition. The children are usually discharged when they gain 15 per cent of their initial weight. However, as the narratives indicate, several factors determine the length of the child's stay at the NRC. While the child's nutritional levels and health condition are critical, factors like the mother's loss of wages, the need to care for other children and older family members, the NRC's distance from the village as well as the distance and difficult terrain to be covered, are deterrents to regularly accessing the centres. The establishment of NRCs in 'high need areas', such as tribal districts with high under-five mortality and undernutrition rates is essential to ensure clinical management to reduce mortality among children with severe or acute malnutrition. However, narratives such as those of Rajini's and Purnima's reveal several issues in terms of NRC implementation as well as regarding the continuum of care. According to health officials who manage NRCs, "Malnourishment is the biggest issue faced by the tribal and especially the PVTG communities".

Beyond the NRCs, addressing the problem of undernutrition requires providing continuum of care even after the children return home. Rajani's experience, for example, draws attention to the disconnect between the NRCs and (absence of) care at the community level. Further, given the abysmal economic conditions, including the low levels of income among tribal communities, especially the PVTGs, any expectations that the families will be able to fulfil the requisite food and nutritional needs are misplaced.

The narratives also indicate that community level nutritional care does not materialise due to systemic issues; this includes the lack of supplies to sustain regular access to take home ration (THR), cooked food, etc. Delays in payment by NRCs to compensate for the loss of wages of the caregiver as well as the shortage in funds to sustain the effective functioning of the Anganwadis and phulwaris in the villages also contribute to the inability of parents and community level health care and AWW workers to implement the nutrition programmes.

NRCs also had issues of shortage of trained staff to take care of the dietary needs of the children, admitted at the centres.

Moreover, the mandate for Anganwadis to follow-up and provide nutritious supplementary meals is insufficient because they provide only one meal a day. In several hamlets, Anganwadis are non-functional, causing children like Chandini to be trapped in the vicious cycle of abject poverty and undernutrition. Data on the utilisation of ICDS services reveal that as many as 40 per cent of children from ST communities, between the ages of 0 and 71 months; do not receive any supplementary food at Anganwadis.[13]

The narratives also underscore the impoverishment and lack of access to regular and adequate livelihoods and incomes, rampant in these marginalised communities. Nearly 85 per cent of the children from tribal communities belong to the most impoverished families.[14] As in Ashok's narrative, his mother Purnima had no money to buy him fruits and vegetables that were recommended by the NRC. The non-payment of the daily allowance due to Purnima for the time she spent in NRC highlights the inadequate implementation of these nutritional programmes. The gaps and delays in implementation of such initiatives inevitably further the cycles of undernourishment and poverty, which they are meant to prevent among the communities.

## Malnutrition among tribal women

The endemic malnutrition among tribals was reiterated by a study from Odisha, 'Including Scheduled Tribes in Orissa's Development: Barriers and Opportunities', which found that 57 per cent of children from ST communities showed signs of long-term malnutrition (stunting or deficit in height-for-age), 28 per cent were severely stunted and 54 per cent were underweight, indicating some of the highest prevalence of malnutrition globally (Mehta, 2011:7).[15] Malnutrition persists from childhood, a consequence of the poverty and food insecurity faced by a majority of the tribal communities, and remains a significant determinant to the survival and quality of life, especially of girls and women. According to a report of the National Nutrition Monitoring Bureau (NNMB) [2000-01], food security has a critical impact on women's health. Food production among most tribal households

is never sufficient to meet their food and nutrition needs given the prevalent poverty, minimal ownership of land as well as poor access to nutrition and health care initiatives. Moreover, drought, loss of access to forests, loss of cultivable land due to mining, industry, etc., heightens the food insecurity, especially for girls and women in tribal communities.[16,17]

Meena Khadia, 28 year old woman from the Khadia tribe in Komna, Nuapada was found to be anaemic during her pregnancy, for which she had to seek treatment, including blood transfusion. Meena's anaemic condition was first discovered during one of the ANC sessions at the Village Health and Nutrition Day (VHND). The ANM on finding that Meena had a very low Hb level, suggested that she seek further diagnosis and treatment from the CHC, Komna. The ANM also gave her 100 IFA tablets and one TT injection.

> *"....The ANM during my check-up told me that I need blood as I have less of it during my pregnancy. She told us to go to CHC for better check-up and to get blood. We called for an ambulance to go to the CHC, but our request was denied the same as the ambulance was unavailable at the time. We then hired a vehicle to go to the CHC, where the doctors gave me some urine and blood tests. I had to get these tests done from the private diagnostic facility outside the CHC. After going through the test results the doctor told us that I was in need of blood. They referred me to the District Hospital (DH), Nuapada. At the CHC, they transported us in an ambulance to the DH."*

CHC Komna was around 20 km and DH Nuapada was around 65 km from her village. The doctor at the DH advised Meena to undergo some diagnostic tests - blood test and ultrasound - from a private diagnostic facility. As her Hb was 4.4 g/dL, the doctor counselled her to get admitted for blood transfusion.

> *".....[Meena] I was immediately admitted at the DH, and they gave me two units of blood. They discharged me after that. The doctor also gave me some medicines; though we had to buy most of the prescribed medicines from a private pharmacist. Two months later, I went into labour and delivered my child at CHC Belpada".*

Meena's Hb level during the delivery was 10.2 g/dL. Meena had three children previously – a seven year old daughter and two sons, who were five and one years old respectively. This was her fourth pregnancy. In the course of this pregnancy, for her anaemia and its treatment, Meena had to incur expenses of about Rs. 10,000, most of which was spent on medicines and for the payment of the diagnostic screening in private facilities, transport as well as paying 'tips' for staffs at the hospital. Given the poor economic conditions of her family, with an average monthly income of Rs.3000; she and her husband had a difficult time in managing the expenses they incurred.

> *"We had to mortgage our land (0.5 Acres) for Rs. 5000 and the rest of the amount we managed from our earlier savings. My husband had to look for extra work for some additional income to support the family".*

A study on gender disparities in nutrition, points out that the higher risk among women, especially young women from tribal communities, stems from their very low nutritional status, often experienced from childhood, that results in stunting and wasting.[18] The delayed growth and arrested development during childhood continue to manifest in their adolescence and later stages of life. Further, poor nutritional status is exacerbated in cases of early marriage, early pregnancy and childbirth, which contributes significantly to maternal morbidity and mortality. Research demonstrates that social and cultural issues such as early marriage, high rates of school drop-outs, etc., which are prevalent among tribal communities, are important causes of nutritional extremes among young women.[19] Access to nutritional and diet facilities were observed to be comparatively easy to access for men from tribal communities because they receive early and extensive social freedom to access income generating activities. Young women, on the other hand, are mostly confined to domestic and household work and kept away from most income generating activities, limiting their buying capacity and independent access to food, which eventually affects their nutrition.[20] Studies indicate that nutritional extremes increase with marginalisation in access to food.[21]

Women suffering from undernutrition are generally those in contexts of extreme poverty, low levels of literacy, gender discrimination, food insecurity, and other factors that constitute

a vicious cycle, throughout their lives. Further, undernutrition during pregnancy heightens the risks to the health of both mother and child. Women like Meena (narrative above) may be susceptible to postpartum haemorrhage and other complications. Guidelines to promote maternal health through regular monitoring and tracking throughout the pregnancy, as well as for 42 days after childbirth, have been well established.[22] However, the implementation of these guidelines is very limited as seen in Meena's narrative.

According to the NFHS-4 data, 18.3 per cent of ST women across the country were found to be 'severely thin' (BMI less than 17.0 kg/m2).[23] Within the research states, the situation is no better; in Chhattisgarh, 34 per cent of ST women were 'thin' (BMI less than 18.5 kg/m2), while 12.7 per cent were categorised as 'severely thin'. Similarly in Odisha, 34 per cent ST women were found to be 'thin' and 12.7 per cent were 'severely thin', whereas in Jharkhand, 36.5 per cent ST women were 'thin' and 14.6 per cent were 'severely thin'. The findings on anaemia paint a picture that is even more bleak: nearly 60 per cent (59.8) of ST women across India reported having 'any anaemia', compared to 31.8 per cent ST men. Within the three research states, Chhattisgarh, Jharkhand and Odisha, 55.9 per cent, 75 per cent and 63.3 per cent of ST women were anaemic respectively.[24, 25, 26]

While data for Scheduled Tribes in the study districts is unavailable, tribal communities are a significant proportion of the population in these districts; data indicates the high prevalence of anaemia and the low BMI among women here. In Koriya, Chhattisgarh 27.8 per cent of women in rural areas had below normal BMI, compared to 9.5 per cent of men. In rural Nuapada and Rayagada, Odisha and rural Gumla and Latehar, Jharkhand, the percentage of women with below average BMI was 35.1 per cent, 35.6 per cent, 28.5 per cent and 31.0 per cent, respectively. In terms of anaemia, the per cent of women suffering from anaemia in rural contexts ranged from 36.3 per cent in Jashpur, (compared to 17.8 per cent men) to 70.4 per cent in Gumla (compared to 36.2 per cent men). These statistics point to the huge gender disparities in the nutritional status of women, particularly women from ST communities. Although the data for the study districts on anaemia prevalence is not specific to women from tribal communities, it is highly likely that the situation in the latter is worse.

The levels of undernutrition are reported to be worse among the PVTGs compared to other tribal communities. A study [27] on the burden and pattern of illnesses among tribal communities in Chhattisgarh compared the nutritional level between women of non-PVTG ST and PVTG (Baiga) tribes. The study found that the Baiga PVTG women were at least 5 kg lighter in comparison to the non-Baiga tribal women from the same villages, whose median weight was recorded to be 45 kg. Approximately a quarter of the Baiga PVTG women weighed 37 kg or less. Further, other co-morbidities such as tuberculosis, pneumonia, malaria and other infectious diseases exacerbated the condition of those suffering from undernutrition. Severe anaemia, low weight, and poor BMI, which are some of the indicators of undernutrition, have extremely detrimental longterm effects over the long term on adolescent girls and women from these communities.

Other studies pertaining to maternal health of women from tribal communities have also flagged the prevalence of anaemia and under-nutrition. Mothers from tribal communities are reported to be 1.3 times more likely to be underweight and anaemic as reported by some studies.[28] One study[29] amongst the Chaukhutiya Bhunjia PVTG in Nuapada showed the prevalence of anaemia to be as high as 90 per cent among the women; 42 per cent of lactating women and 52 per cent of the pregnant women had moderate anaemia, severe anaemia was observed in 20 per cent of the lactating women and in over 14 per cent of the pregnant women.[30]

There are studies that present evidence of high undernutrition among the tribal women.[31] It is well documented that young tribal women who are suffering from undernutrition, are also at increased risk of giving birth to children who develop stunting and wasting.[32] In India, 41 per cent of moderately underweight mothers and 53 per cent of severely underweight mothers have babies who are also underweight.[33]

National level statistics reveal that merely 30.3 per cent of women consumed iron and folic acid (IFA) tablets for 100 days or more when they were pregnant, and the number was even lower among women from tribal communities, at 26.8 per cent (NFHS-4). This points to the need for programmes to assess reasons for non-consumption, initiate processes that facilitate consumption of IFA and in extending coverage of larger numbers of girls and

women. Moreover, robust monitoring and evaluation systems for low-performing states is necessary.[34]

The low socio-economic status of tribal communities, food insecurity, gendered discrimination,[35] and poor access to nutrition programmes are some of the factors that sustain the poor nutritional status of children and women. If left unaddressed, undernutrition, especially among women and children in tribal communities, may form a vicious cycle, seriously compromising their health and lives.

The need for initiatives that supplement nutrition to begin early, along with other efforts to enhance food security, especially for girls and women from marginalised communities such as STs, is reinforced by the data. The data as well as the narratives also highlight the significant rural and tribal distress around food security that needs to be addressed urgently.

## Starvation deaths in tribal areas

Starvation deaths are not uncommon among tribal communities and were flagged as a serious concern in some of the study areas; references to starvation deaths were made by the community as well as by the health care providers during interviews and discussions with them. It has been documented widely that starvation deaths are frequent occurrences in the tribal areas in India. In Odisha, 16 tribal children died due to undernutrition in 2016.[36]

In Jharkhand, 32 year old Lukhi Murmu died in January 2018 due to starvation, because the PDS dealer denied her family food grains.[37] In Chhattisgarh, the death of 52-year-old Jangal Singh in 2015 drew national attention because the post-mortem cited extreme hunger and starvation as the cause of his death.[38]

Poverty-induced food insecurity, starvation and hunger related deaths in tribal communities are frequently reported.[39] Additionally, land alienation, displacement, poor compensation and rehabilitation provisions, loss of traditional shifting cultivation and traditional crops, neglect of the tribal people and inaction by the departments of Tribal and Social Welfare and Health, the failure of the public distribution system, and the poor performance of the Mahatma Gandhi National Rural Employment Guarantee Scheme (MGNREGS),[40] are often cited as common reasons for impoverishment in tribal families, affecting their traditional food habits, purchasing power, livelihoods and overall living conditions.[41]

The tribal population also finds it difficult to access health and nutrition schemes and services as most of them are communicated in the local state official language. Comprehending written as well as verbal communication in the local state official language remains a challenge for scheduled tribes, given that each tribe has a language of its own.[42]

### Phulwari Scheme: Initiative for providing nutrition and child care

To address under-nourishment in children between the ages of six months to three years, the State Government of Chhattisgarh has introduced the 'PhulwariScheme'. The scheme provides the Zilla Panchayat grants for the food component and basic infrastructure. The Chhattisgarh State Government allocated a budget of Rs. 50,000 per Phulwari. Funds are funnelled through Zilla Panchayat to the Gram Panchayat and then to the Village Health Committee, who transfer it to the Mothers' groups running the Phulwaris.

A Phulwari is run by a woman from the village, usually selected by the mothers group, who purchases items such as hand pounded rice and pulses (dal), vegetables, eggs etc., locally. Each centre generally has one worker for every 10 children, and two workers for 15-20 children. Villages with more number of children who qualify for the benefits of this scheme, will have larger Phulwaris with a corresponding number of workers. Phulwaris also run day care centers and provide demonstrations on feeding and care related practices like the use of eggs, oil, and vegetables in the diet, frequent feeding, hand washing, handling of drinking water, use of bed-nets etc. Phulwaris are open from 8 am to 4 pm.

During the summer months when both parents go for work very early in the morning, Phulwaris are open from 3 am to 11 am. Community Health Workers (Mitanins) and their support structure play a key role in Community mobilization for Phulwaris. Mothers groups meet twice a month and this meeting provides Mitanin an opportunity to educate them around nutrition and health. In the Phulwaris, children are monitored for pneumonia, diarrhoea, fever (malaria) and any other cases detected. They are then given the required advice/treatment/referral by Mitanins. Monitoring of the height and weight of children is carried out each month and the grade (weight for age) is communicated to mothers along with the required counselling by the Mitanin. Phulwaris also engage in community based management of severely malnourished children.

*Source: The Pioneer, Centre reviews Phulwari Scheme in Surguja, 23 Feb 2015*

[The concept of "phulwari" or daycare for children less than 3 years of age was introduced by the Jan Swasthya Sahyog (JSS) in Ganiyari, Bilaspur (Chhattisgarh). The success of JSS-Phulwari inspired the Chhattisgarh Government to replicate the initiative at the panchayat level.]

## Initiatives and schemes

The public distribution system (PDS) is the biggest source of food tribal communities. All PVTGs and some others tribal groups are holders of the Antyodaya[43] card and eligible to receive 35 kg of rice per month. However, the narratives in all the three study states points to reduced rations received by a majority of people from the tribal communities. For example, they received 2 kg or 5 kg less than the stipulated quantity, a corrupt practice followed by most of the PDS dealers. Further, If the cost of rice was Re. 1 per kg, they were sometimes charged Rs. 2. People from tribal communities are unable to challenge this corruption because of their vulnerability and complete dependence on the rations, in the absence of any alternative. The quantity of rations from the PDS, moreover, according to several respondents across the study areas, is not sufficient to feed their families; sometimes lasting only half of the month. They cannot afford to buy additional rations from the market at high prices for most of the period. As a result they end up starving.

The remoteness of tribal hamlets often makes it difficult to access rations through the PDS, especially during the monsoon. Issues of geographical access and other gaps in the targeted PDS system contribute extensively to food insecurity in tribal communities.

In the present study, in some areas, rations were sometimes not transported to the Anganwadi centre because of the difficult terrain, forcing the AWW to make her own arrangements. According to an AWW in Nuapada, rations under the ICDS scheme were earlier dropped off at the panchayat headquarter, located at the top of the Sunabeda plateau. She had to go all the way there and get the rations down to the village on her own. Out of the 50 kg of rice, 10 kg was given as payment to the person who assisted her in getting the sack of rice down the hill to the Anganwadi centre. However, following repeated requests by the AWW, the rations were (at the time of the study) being dropped off at another location, which is closer to the village.

Other schemes in the states for take home rations (THR), such as the Mahtari Jatan Yojana (in Chhattisgarh), which provides pregnant women cooked meals at the Anganwadi or allows them take the food home, are important initiatives. However, they face several implementation issues. For instance, although the THR is supposed to be given on a weekly basis, the distribution is instead done altogether on a fixed day of the month.


Another state-level nutrition programme is the Phulwari scheme in which women from the community run a community kitchen to provide cooked meals and snacks to children. Phulwari centres also serve as crèches for children in the village when their mothers are out for agricultural or other labour work. This scheme caters to pre-Anganwadi children, that is, children between the age of six months and three years.

A study done by UNICEF tracked 700 children in Surguja (Chhattisgarh) District's Phulwaris for one year and found that the undernutrition rates among children had reduced by 24 per cent and the pace of reduction was higher.[44] The rate of decline in severe malnutrition among the children was even higher at 38 per cent. One-third of the children attending the Phulwaris came out of malnutrition within one year. Another study found that children attending Phulwaris were gaining weight much faster than those who were not.[45] Such persuasive evidence led the Chhattisgarh State Government to expand the scheme to all the

tribal blocks in the state. In 2014-15, the budget was doubled to Rs 20 crore. This planned to cover as many as 1,00,000 children and women in 5700 hamlets around the state.[46]

However, Phulwaris were not functioning in several of the villages that were visited in the course of the study as the VHSNCs had problems securing funds. For example, there are a total of 150 Phulwaris in Koriya district, i.e., 30 centres in each of the five blocks. Of these, nearly 20 centres in the district had been shut down due to shortage of funds, according to a Phulwari coordinator. Thus, such initiatives although perceived to be extremely beneficial to the community, are irregular and inadequate as they face shortages of funds and infrastructural and human resource support, impacting their implementation.

## Conclusion

The Census of India (2011) indicates that tribal communities, experience severe poverty and high marginalisation on the economic front.[47] Most tribal families are covered by schemes for those living 'below the poverty line' (BPL) implemented by different agencies of the Centre and States. They are supposed to receive supplies of rice and sugar at highly subsidised rates, under nutrition supplement programmes.[48] However, such initiatives do not address food diversity at all and food security (as discussed previously) only to a limited extent. Moreover, for communities who were dependent on the forests for their food, restrictions on access to forest produce due to various forest protection acts, have impacted their food security and diversity.[49] Economic trends such as inflation of food prices, have contributed to food scarcity, especially amongst marginalised communities.[50,51] The inflated prices of food pose serious barriers for tribal communities in achieving food diversity that they previously followed, as it is unaffordable to most.[52,53] Consequently, this enforces a shift

to alternative available food to cope with hunger regardless of its nutritional balance and significance.[54]This is possibly another cause of undernutrition in terms of micronutrient as well as energy supplement diets.[55]

The relationship between nutrition and migration is well-established; the incidence of migration is significant among tribal communities, given the inadequacy of livelihoods and income security. Many persons from tribal communities are forced to undertake seasonal migration to access work and supplement their income; their economic vulnerability and migration contributes to food insecurity and serious levels of malnourishment.[56] Given the marginalisation of tribal communities, any attempts to improve their nutritional status are only possible alongside a process of socio-economic development, with emphasis on gender equality.

Hence, policy planning to deal with undernutrition in a comprehensive manner needs to also address poverty, marginal land ownership, displacement, and other associated factors concomitantly while implementing the nutritional programmes.[57] For example, early marriage and pregnancy, and other forms of gendered discrimination also contribute to undernutrition among girls and women. Initiatives to enhance nutrition among girls and women from tribal communities must therefore, take these concerns into account to ensure that the cycle of undernutrition is arrested. Further, the initiatives must be cognisant of the existing culture around food amongst tribal communities and create enabling conditions to enhance communities' control over sources of food and food diversity. Thus, addressing the underlying determinants of undernutrition in specific contexts of tribal communities is extremely critical along with the effective implementation of programmes to promote access to supplementary food.

## Endnotes


1. Article 47, Constitution of India, Retrieved on April 30, 2018 from https://indiankanoon.org/doc/1551554/.
2. PUCL vs Union of India and others, Civil Writ Petition 196 of 2001.
3. *Report of The High Level Committee on Socioeconomic, Health and Educational Status of Tribal Communities of India.* (2014). Ministry of Tribal Affairs. Government of India.
4. Golden MH. Proposed recommended nutrient densities for moderately malnourished children. *Food Nutr Bull.* 2009; 30 (3 Suppl): S267-342.
5. *Nourishing India's Tribal Children* (Rep.). (2014). UNICEF. Retrieved April 12, 2018. http://unicef.in/Uploads/Resources/Tribal-low-res-for-view.pdf
6. National Family Health Survey, (NFHS-4), 2015-16: India International Institute for Population Sciences (IIPS) and ICF. 2017. Retrieved April 25, 2017. http://rchiips.org/NFHS/NFHS-4Reports/India.pdf
7. Stunting. (n.d.). Retrieved May 23, 2018. http://unicef.in/Whatwedo/10/Stunting

8. *Nourishing India's Tribal Children* (Rep.) (2014). UNICEF.Retrieved April 12, 2018. http://unicef.in/Uploads/Resources/Tribal-low-res-for-view.pdf
9. Green, R., Sutherland, J., Dangour, A. D., Shankar, B., & Webb, P. (2016). Global dietary quality, undernutrition and non-communicable disease: a longitudinal modelling study. *BMJ open*, 6(1), e009331.
10. *The Link Between Food, Nutrition, Diet And Non-Communicable Diseases* (Publication). (2014, October). Retrieved April 12, 2018. World Cancer Research Fund International : https://www.wcrf.org/sites/default/files/PPA_NCD_Alliance_Nutrition.pdf
11. Ibid.
12. *Nourishing India's Tribal Children* (Rep.). (2014). UNICEF.Retrieved April 12, 2018. http://unicef.in/Uploads/Resources/Tribal-low-res-for-view.pdf
13. National Family Health Survey, (NFHS-4), 2015-16: India. International Institute for Population Sciences (IIPS) and ICF. 2017. Retrieved April 25, 2017. http://rchiips.org/NFHS/NFHS-4Reports/India.pdf
14. *Nourishing India's Tribal Children* (Rep.). (2014). UNICEF.Retrieved April 12, 2018. http://unicef.in/Uploads/Resources/Tribal-low-res-for-view.pdf
15. Mehta, S. K. (2011). *Including Scheduled Tribes in Orissa's Development: Barriers and Opportunities* (Working paper-9). Retrieved May 24, 2018, UNICEF. http://www.ihdindia.org/pdf/saumya_kapoor.pdf
16. Hans, A. (2014, November). Scheduled Tribe Women of Odisha. *Odisha Review.* Retrieved May 20, 2018. http://magazines.odisha.gov.in/Orissareview/2014/Nov/engpdf/27-40.pdf
17. Rao, N., & Hans, A. (2018). Gender and Climate Change. *Economic & Political Weekly,* 53(17). Retrieved May 25, 2018, from https://www.epw.in/journal/2018/17/review-womens-studies/gender-and-climate-change.html,
18. Kshatriya, G. K., &Acharya, S. K. (2016). Gender Disparities in the Prevalence of Undernutrition and the Higher Risk among the Young Women of Indian Tribes. *PloS one,* 11(7), e0158308.
19. Ibid
20. Ransom EI, Elder LK. Nutrition of Women and Adolescent Girls: Why It Matters. Population Reference Bureau. Washington, DC. 2003. Retrieved 25.April 2018. http://www.prb.org/Publications/Articles/2003/NutritionofWomenandAdolescentGirlsWhyItMatters.aspx
21. Ibid
22. Kshatriya, G. K., &Acharya, S. K. (2016). Gender Disparities in the Prevalence of Undernutrition and the Higher Risk among the Young Women of Indian Tribes. *PloS one,* 11(7), e0158308.
23. MOHFW (2010) Operational Guidelines on Maternal and Newborn Health. Retrieved March 28, 2018 from http://nhsrcindia.org/sites/default/files/Operational%20Guidelines%20for%20Maternal%20%20Newborn%20Health.pdf.
24. National Family Health Survey, (NFHS-4), 2015-16: India International Institute for Population Sciences (IIPS) and ICF. 2017. Retrieved April 25, 2018, from http://rchiips.org/NFHS/NFHS-4Reports/India.pdf
25. National Family Health Survey, (NFHS-4), 2015-16: India International Institute for Population Sciences (IIPS) and ICF. 2017. Retrieved April 25, 2017, fromhttp://rchiips.org/NFHS/NFHS-4Reports/India.pdf
26. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16: *Jharkhand*. Mumbai: IIPS.
27. International Institute for Population Sciences (IIPS) and ICF. 2017. National Family Health Survey (NFHS-4), India, 2015-16: *Odisha*. Mumbai: IIPS.
28. Jain, Yogesh. "Burden and Pattern of Illnesses among the Tribal Communities in Central India: A Report from a Community Health Programme." *Indian Journal of Medical Research* 141, no. 5 (May 2015): 663–72. Accessed 3 May 2018. doi:10.4103/0971-5916.159582.
29. *Maternal Health In Tribal Communities: A Qualitative Enquiry into Local Practices and Interactions with the Health System in Rayagada District, Odisha.* (2015). National Alliance for Maternal Health and Human Rights (NAMHHR), India. Lucknow, Uttar Pradesh: SAHAYOG. doi:http://www.chsj.org/uploads/1/0/2/1/10215849/odisha_report_final_for_web.pdf.
30. Kosariya, S. S., & Chakravarty, M. (2016). Maternal Health Status of Choukhutiya Bhunjia Tribe of Gariyaband District of Chhattisgarh, India. *International Journal of Science and Research* (IJSR),5(8). Retrieved May 2, 2018, from https://www.ijsr.net/archive/v5i8/NOV164270.pdf.
31. Ibid

32. Kshatriya GK, Acharya SK (2016) Gender Disparities in the Prevalence of Undernutrition and the Higher Risk among the Young Women of Indian Tribes. *PLoS ONE* 11(7): e0158308. https://doi.org/10.1371/journal.pone.0158308
33. CHILDREN IN INDIA 2012—A Statistical Appraisal. 2012.Social Statistics Division Central Statistics Office, Ministry of Statistics and Programme Implementation-Government of India (2012)
34. Food insecurity: When people must live with hunger and fear starvation (Rep.). (2002). Retrieved May 20, 2018. Food and Agriculture Organization of the United Nations. http://www.fao.org/tempref/agl/AGLW/ESPIM/CD-ROM/documents/2A_e.pdf
35. *Country Assessment on Human Rights In The Context Of Sexual Health And Reproductive Health Rights* (2018). Sama Resource Group for Women and Health And Partners For Law In Development (PLD)
36. Kshatriya GK, Acharya SK (2016) Gender Disparities in the Prevalence of Undernutrition and the Higher Risk among the Young Women of Indian Tribes. *PLoS ONE* 11(7): e0158308. https://doi.org/10.1371/journal.pone.0158308
37. Mohanty, Debabrata. "One by One, They Died: The Forlorn Story of Tribal Children's Death in Odisha." *The Indian Express*, July 31, 2016. Retrieved Accessed May 11, 2018. http://indianexpress.com/article/india/india-news-india/odisha-tibral-children-malnutrition-deaths-government-measures-relief-and-health-centres2945156/.
38. Das, Anand. "Tribal Woman Dies from Starvation in Jharkhand as Fingerprint Mismatch Denies Her PDS Ration." *The Indian Express*, 25 January 2018. Retrieved 11 May 2018. http://www.newindianexpress.com/nation/2018/jan/25/tribal-woman-dies-from-starvation-in-jharkhand-as-fingerprint-mismatch-denies-her-pds-ration-1763397.html.
39. Hunger deaths: Chhattisgarh govt orders probe, opposition up in arms. (2015, May 31). *The Indian Express.* Retrieved May 20, 2018. https://indianexpress.com/article/india/india-others/hunger-deaths-chhattisgarh-govt-orders-probe-opposition-up-in-arms/
40. Munshi, I. (Ed.). (2012). *The Adivasi Question: Issues of Land, Forest and Livelihood (Essays from Economic & Political Weekly)*. Orient BlackSwan.
41. A.D, Manikandan. (2014). A Tragedy Unfolding. *Economic & Political Weekly*, 49(2). Retrieved May 21, 2018. https://www.epw.in/node/128891/pdf
42. Reddy, V. R., & Reddy, B. S. (2007). Land alienation and local communities: case studies in Hyderabad-Secunderabad. *Economic and Political Weekly,* 3233-3240. Retrieved on May 5 2018. http://el.doccentre.info/eldoc1/k02a/040807EPW3233.pdf;
43. The Antyodaya Anna Yojana (AAY) is a Government of India scheme whichprovides further subsidized ration from the PDS to the identified poorest of families among BPL families.
44. *Nourishing India's Tribal Children* (Rep.). (2014). UNICEF.Retrieved April 12, 2018. http://unicef.in/Uploads/Resources/Tribal-low-res-for-view.pdf
45. Xaxa. J. Dr. (2014) Problems of food security: A brief analysis of tribal areas in India. *International Journal of Scientific and Research publication,* 4(11). Retrieved April 25, 2018, from http://www.ijsrp.org/research-paper-1114/ijsrp-p3569.pdf.
46. Sharma, S. (2014, November 17). How the Chhattisgarh government is killing a scheme that's saving babies. *The Scroll.* Retrieved May 20, 2018. https://scroll.in/article/690034/how-the-chhattisgarh-government-is-killing-a-scheme-thats-saving-babies
47. Census of India 2011 .Office of the Registrar General and Census Commission.Ministry of Home Affairs, Government of India.c2010-11. Retrieved: www.censusindia.gov.in/2011-common/census_2001.html.
48. Public Distribution System.Ministry of Consumer Affairs, Food and Public Distribution. Department of Public Distribution, Government of India. c2012. Retrieved: www.pdsportal.nic.in/main.aspx.
49. Padhi S, Panigrahi N. *Tribal Movements and Livelihood: Recent Development in Orissa,* Chronic Poverty Research Center (CRPC), Indian Institute of Public Administration (IIPA), New Delhi. Working Paper No-51: 2011.
50. Census of India 2011. New Delhi: Office of the Registrar General and Census Commission. Ministry of Home Affairs, Government of India.c2010-11. Retrieved: www.censusindia.gov.in/2011-common/census_2001.html.
51. Bhattacharya R, Sen Gupta A. Food Inflation in India: Causes and Consequences. National Institute of Public Finance and Policy, New Delhi. Working Paper; 2015 June. No.: 2015–15

52. Mahapatra, R. (2013, October 15). Price of food inflation [Web log post]. Retrieved May 12, 2018, from http://www.downtoearth.org.in/blog/price-of-food-inflation-42483

53. Pons, N. (2011). *Food and Prices in India: Impact of Rising Food Prices on Welfare* (Unpublished master's thesis). Centre de Sciences Humaines (Delhi). Retrieved May 13, 2018, from https://www.isid.ac.in/~pu/conference/dec_11_conf/Papers/NathaliePons.pdf

54. Kshatriya, G. K., &Acharya, S. K. (2016). Gender Disparities in the Prevalence of Undernutrition and the Higher Risk among the Young Women of Indian Tribes. *PloS ONE*, 11(7), e015830

55. Mohapatra G. Hunger and Coping Strategies among Kondh Tribe in Kalahandi District, Odisha (Eastern India). *Transcience: a journal of global studies.* 2012; 3 (2): 51–60

56. Kshatriya, G. K., &Acharya, S. K. (2016). Gender Disparities in the Prevalence of Undernutrition and the Higher Risk among the Young Women of Indian Tribes. *PloS ONE,* 11(7), e0158308.

57. Mallavarapu, R. B. (2006). Development, Displacement and Rehabilitation: An Action Anthropological Study on Kovvada Reservoir in West Godavari Agency of Andhra Pradesh, India. *International Journal of Human and Social Sciences,* 1(1), 35-41.

# 5.6 Acute respiratory infections

Rani Bhoi is a 32 year old married woman, from the Dal tribal community from Konabira village in Nuapada, Odisha.

> *"I live with my husband and three children. We do agricultural work. We used to own about four acres of land, but we had to give it up for a water reserve project being implemented in the village. They paid us Rs. 7 lakhs as compensation. We have a BPL card, a job card under MGNREGA but we do not have any RSBY card. We earn about Rs. 2,000-3,000 per month.*
>
> *My fourth child – a son – was born in January 2016. During this pregnancy I received ANC check-ups by the ANM in the sub-centre. The ASHA and the ANM had advised me to go to the hospital for the delivery. All my previous births had taken place at home but I decided to go to the hospital for this delivery. When I went into labour, I called the 102 ambulance; but by the time it arrived, I had already given birth at home. My son received his immunisation and there were no issues with his health; he was feeding well.*
>
> *In early September 2016, he developed a cough and had fever. My husband and I took him to Komna-CHC (17 km from Konabira) in a private vehicle; it cost Rs. 500. At the CHC,*

*he was checked and referred to the Nuapada DH. We had to arrange for private transport once again which was for Rs. 1500, from the CHC to the district hospital which was about 49 km from Komna. At the Nuapada DH, after admitting him for a short while, they asked us to take him to the government hospital at Sambalpur (Veer Surendra Sai Institute of Medical Sciences and Research) because his condition was getting worse. But my husband and I were extremely distressed because the child seemed very ill, and we had been asked to go from one hospital to another. We decided to go to Raipur, Chhattisgarh (about 160 km from Nuapada) since it was closer than Sambalpur. Our family friend suggested that we take him to a private hospital in Raipur. The discharge from the Nuapada district hospital was late at night. We reached in the morning around 4 am, after travelling all night. In the private hospital my son was diagnosed with pneumonia. Our child died on 9th September 2016, despite all our efforts."*

Pneumonia is a common condition that can quickly escalate into a more serious situation as in the case of Rani's son, if the disease is not diagnosed in time and appropriate treatment not immediately provided.

Rani's narrative indicates that the family was prompt in taking the child to the CHC, despite them having to arrange and pay for the private transport. Although home based care and a robust primary health care system can prevent mortality associated with pneumonia to a large extent, for its management, in this case, services at the secondary CHC and even at the tertiary level (DH) facilities seemed to have been absent or inadequate. The child did not receive any treatment at the CHC, and instead they were then referred to the DH, although the reasons for the referral in the absence of any information cannot be clearly ascertained. The referrals caused tremendous stress for the family and it is also likely that the delay in care for the child due to the inter-facility referrals caused the child's condition to worsen.

As Rani's experience demonstrates, the lack of appropriate and adequate health services to treat the infection often exacerbates the patient's health condition. The lack of diagnostic facilities at the community level results in sole reliance on clinical symptoms and signs, such as chest in-drawing, wheezing and body temperature of more than 39°C, to determine the severity of the infection and administer empirical antibiotic treatments. Observation of clinical symptoms while extremely critical, may not be adequate to accurately diagnose the severity of the infection. Moreover, other issues such as asthma and malaria may be misdiagnosed as pneumonia.[1,2] Further, the management of severe pneumonia requires immediate administration of antibiotics intravenously. On diagnosis of severe pneumonia, the ASHAs are directed to refer the children to the nearest facility as its management is only possible at the facility level, which may have been the case of Rani's child.

In the course of the study, some of the secondary level facilities, for example, the CHC in Mahuadanr in Latehar district in Jharkhand, stated that they often provide only the first dose of gentamicin and amoxicillin and refer the patients to the DH Latehar which is about 110

kilometres away. Referrals were also justified as the only option for some of these facilities because of the shortage of skilled staff.

The lack of adequate infrastructure and human resources to manage pneumonia at facilities proximal to tribal communities encourages referrals, causing unnecessary delays. Moreover, the 108 ambulance service for inter-facility transfers with the necessary equipment and oxygen, may not always be available.

Pneumonia, which is a type of an acute respiratory infection (ARI) that affects the lungs, is a significant cause of mortality amongst children. This is particularly true in the case of undernourished children, who often lack the immunity to protect themselves against such infections[3] making severe malnutrition a key risk factor for children. Given the deprivations that several of the tribal communities experience, the determinants of ARIs including pneumonia, i.e. undernutrition, diarrhoea, poor health care, etc., are rampant.

ARIs are the most significant contributors to under-five mortality. ARIs can be classified into Upper and Lower Respiratory Tract Infections (URIs and LRIs). While URIs affect airways from the nostril to the larynx, the para-nasal sinuses and the middle ear, the LRIs affect the continuation of the airways from the trachea, the bronchi to the lungs. ARIs such as whooping cough (pertussis), measles and diphtheria, however, may affect other systems and not merely the respiratory system.[4] It is also significant that children under the age of three years, regardless of their socio-economic background, suffer from an average of three to six episodes of ARIs annually. However, the severity of the infections among children depends upon existing co-morbidities like diarrhoea, exposure to risk factors such as indoor air pollution, crowded living conditions, and the quality of health care that they receive.[5]

**Table 5.6.1: District level data on the prevalence of ARIs among children under age 5 years**

| Indicators | Chhattisgarh | | Jharkhand | | Odisha | |
|---|---|---|---|---|---|---|
| | Koriya | Jashpur | Gumla | Latehar | Nuapada | Rayagada |
| Prevalence of symptoms of acute respiratory infection (ARI) in the last 2 weeks preceding the survey (%) (Rural) | 3.4 | 5.7 | 1.5 | 5.8 | 2.1 | 3.2 |
| Percentage of children with fever or symptoms of ARI in the last 2 weeks preceding the survey taken to a health facility (Rural) | 76.6 | 57.4 | 59.8 | 66.3 | 84.9 | 74.1 |

*Source: NFHS-4*

The data in (Table 5.6.1) indicates the prevalence of ARIs in children under the age of five years in the study districts. The data captures that the prevalence of ARI among this age group varied between 1.5 per cent in Gumla to 5.7 per cent in Latehar. The data also captures

the percentage of children with symptoms of ARI taken to a health facility in the last two weeks preceding the survey, a significant per cent i.e. between 57 per cent to 84 per cent of the children were taken to a health facility for treatment.

Given the major gaps in the provisioning of health care for pneumonia and ARIs, the need for restructuring health care systems, with focus at the primary level facilities gains precedence. Along with the community level health workers – ASHAs or ANMs - being trained in diagnosis of ARIs, the supply of the requisite antibiotics must also be available at all times in tribal communities, given the high incidences of ARIs in tribal areas. Referrals to higher level facilities are not a guarantee for quality care unless they are adequately equipped with diagnostics, medicines, equipment like nebulisers as well as skilled human resources. Additionally, it is necessary to ensure timely referral and avoid delays especially in cases of severe pneumonia. All treatment and other logistics necessary to manage ARIs, including pneumonia must be provided free of cost, to prevent the escalation of the severity of the infection, which can be potentially fatal.

## Endnotes


1. Chang, A. B., Ooi, M. H., Perera, D., & Grimwood, K. (2013). Improving the Diagnosis, Management, and Outcomes of Children with Pneumonia: Where are the Gaps? *Frontiers in Pediatrics,* 1, 29. http://doi.org/10.3389/fped.2013.00029
2. Pneumonia Diagnostics: Current Outlook and Perspectives (Rep.). (2013, May). Retrieved https://www.unicef.org/supply/files/Pneumonia_Diagnostics_Aid_Devices_and_Prespective.pdf
3. Tong, Nga. Update on 2004 Background Paper, BP 6.22 Pneumonia. Report. *World Health Organisation.* May 2013. Accessed May 12, 2018.http://www.who.int/medicines/areas/priority_medicines/BP6_22Pneumo.pdf.
4. Simoes EAF, Cherian T, Chow J, et al. Acute Respiratory Infections in Children. In: Jamison DT, Breman JG, Measham AR, et al., editors. Disease Control Priorities in Developing Countries. 2nd edition. Washington (DC): The International Bank for Reconstruction and Development / The World Bank; 2006. Chapter 25. Available from: https://www.ncbi.nlm.nih.gov/books/NBK11786/ Co-published by Oxford University Press, New York.
5. Ibid.

# 5.7 Haemoglobinopathies

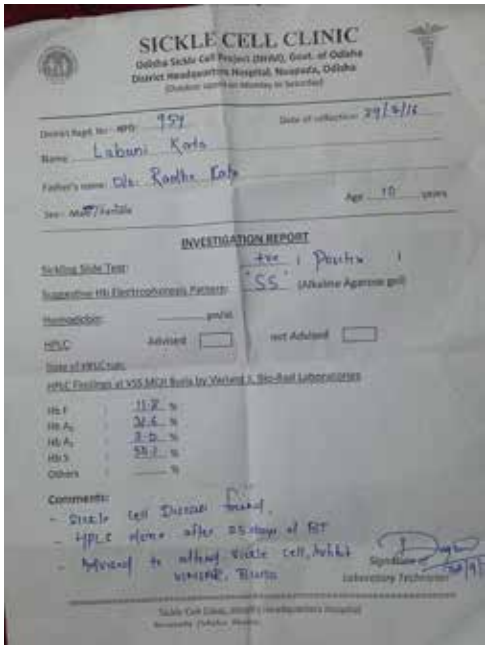
Haemoglobinopathies such as sickle cell disease (SCD) and thalassaemia are said to have a 0.028–18 per cent prevalence rate among the tribal communities, presenting a significant public health problem.[1] Yet, both these diseases have not received much attention from the policy makers in terms of diagnostics, and provision of treatment – drugs and counseling. In this section, we attempt to discuss the issues related to both the diseases, particularly in the context of tribal communities, through the narratives of the people with SCD and thalassaemia, who were part of the study.

## 5.7.1 Sickle Cell Disease

Sickle cell disease (SCD) is a genetic disease that causes abnormal haemoglobin (HbS), which is marked by sickle-shaped red blood cells.[2] It requires lifelong management and contributes heavily to infant and childhood morbidity and mortality. The most common symptoms of SCD are haemolysis, which leads to chronic anaemia and jaundice, recurrent episodes of severe body pain, and a greater susceptibility to bacterial infections. Enlargement of the

spleen and liver are also observed in patients of SCD.[3] Children and adults with SCD face both health as well as other social challenges.

SCD in India occurs predominantly in the central belt spanning eastern Gujarat, Maharashtra, Madhya Pradesh, Chhattisgarh, to western Odisha, and a smaller fraction in the Nilgiri Hills of northern Tamil Nadu and Kerala in southern India.[4] Even though tribals constitute only 8.6 per cent of the national population, the prevalence of sickle cell carriers among different tribal groups range from one to 40 per cent, in varied tribal communities.[5] Such a high prevalence of SCD in the tribal communities has motivated misperceptions that SCD is confined to the tribal population; when in reality, it affects other social groups in these areas as well.


SICKLE CELL CLINIC

INVESTIGATION REPORT

In Nuapada district, Suraj Punji, a five-year-old boy from the Gond tribal community, was diagnosed with SCD. His father recalled,

> *"Suraj has been very weak since the age of three. He used to fall ill frequently. He often complained of severe pain in his legs and arms, and at times the pain became so unbearable that it was impossible for him to play and be with other children of his age. He also missed school often. We first contacted a local medical practitioner for the fever but when Suraj did not get better, the practitioner advised us to take him to the district hospital at Nuapada. At the DH, they carried out some tests and we were then asked to take him to VIMSAR (Veer Surendra Sai Institute of Medical Sciences and Research) at Burla, Sambalpur, which is about 250 km from our village."*

The referral was made so that Suraj could undergo Hb electrophoresis[6] to confirm or rule out SCD. When the tests confirmed SCD, he was registered as a patient and provided free medicines. He was also advised to undergo blood transfusions at the DH Nuapada.

This narrative points to the gaps in the health care services to manage SCD in tribal areas. In order to ensure adequate facilities, primary, secondary and tertiary levels of health facilities should be equipped with diagnostics for screening and the necessary infrastructure and skilled human resources to provide follow up care. At the primary level, solubility tests along with provisions for further referrals to the secondary level, and Hb electrophoresis to confirm or rule out SCD, should be available at the secondary level. However, Hb electrophoresis is not available even at district levels. For example, in Nuapada, people with SCD travel all the way to VIMSAR in Sambalpur.[7] Thus in practice, this is seldom the reality.

## Medicines

Despite SCD being recognised as a public health issue, the health system is unable to provide comprehensive treatment. Even though Hydroxyurea[8] is the approved drug for the causative treatment of SCD, most state governments are still unable to provide it to patients. The drug is on the National list of Essential Medicines, 2015[9] and the Essential Drug List for Odisha[10] and Chhattisgarh,[11] but neither of the states have a sustained supply of Hydroxyurea. At present, it is only available at a few select district hospitals and in some of the Medical College Hospitals. Therefore, access to Hydroxyurea remains inaccessible to most patients from tribal communities because of the extensive distances and the difficult terrain between their habitations and these facilities.

This situation reflects the States' inability to purchase stock and distribute Hydroxyurea. SCD causes severe pain as was experienced by Suraj; the basic treatment and management for the severe pain caused by SCD relies heavily on pain medications such as analgesics, non-steroidal anti-inflammatory drugs and even opioids in rare instances. However, they are not widely and easily accessible to the people in these areas, at all times.[12]

### Writ Petition

A writ petition was filed seeking different directions in relation to PHCs and CHCs in Sukma district, Chhattisgarh. The petitioner pointed out that the blood bank in Sukma is functional at present, which comes as a huge relief to the people of the area, especially to patients of sickle cell anemia and pregnant women, who had to earlier travel to Jagdalpur for blood transfusions. The petition also demanded that the Government should be directed to ensure that the blood storage facilities be available at Chindgarh and Konta Community Health Centres. The Court held, "The question whether a particular area has been cut off from the regular stream of national life is not a matter for judicial determination through a Public Interest Litigation of the nature in hand. All the institutions of national life ought to stand guided by the fundamental principle of unity and integrity of the Nation. It would not be conducive, within the format of the Constitution, for us to presume to the contrary. It would be inadvisable for us to proceed with, in judicial process, the assumption that any part of Sukma is cut off from Governmental access on account of any challenge that could be attributed to factors which are matters to be addressed, regulated and controlled by the Governments." (Para 8)

"In the result, this writ petition is ordered directing the State Government authorities to take all requisite steps to ensure that due facilities are made available through the District Hospital Sukma as well as in CHC and PHC in that district by providing requisite Doctors, Nurses, Auxiliary Nurse Midwives and other requisite manpower. The State Government authorities shall pursue necessary steps to fill up the vacancies either by utilizing the services of persons in service or by appointing persons on contract basis. It is further directed that requisite Blood Banks shall be provided to support the facilities, as are required in that district. The availability of blood transfusion facilities, blood storage facilities and free supply of medicines shall be appropriately maintained……." (Para 10)

*Source: http://cg.nic.in/hcbspjudgement/judgements_web/WP%28PIL%2911_16%2826.09.17%29.pdf*

## Blood transfusions

Blood transfusions can correct anaemia by increasing the number of normal red blood cells in the body. They can also be used to treat spleen enlargement as a consequence of SCD in children, before the condition becomes life threatening. Moreover, regular transfusion therapy can prevent strokes from recurring in children with SCD. However, access to blood transfusion facilities are still extremely limited; they are generally available at the District Hospital level with most block-level CHCs having no blood storage and transfusion facilities. Given this, even in emergencies, persons with SCD have to often arrange for replacement units of blood. This, despite guidelines and policies, which clearly state that replacement units should not be asked, especially in case of emergency transfusions.[13,14]

Families also have to spend extensively on private transport, despite the 108 emergency response vehicles in these states, especially given the repeated visits to health facilities that may be required for persons with SCD. The poor availability of emergency response vehicles is iterated by Suraj's father,

> *"I bring my son for blood transfusion regularly. Sometimes, we have to collect blood from relatives for transfusion and sometimes, blood is provided by the hospital. Every time we come to the hospital, we have to spend a few days here. For every visit, we spend almost Rs. 1,000 for transport and food. We come from a very poor family and my only source of income is through wage work."*

Despite such judicial orders given in the Box, and other treatment guidelines and health policies, there was a significant absence of adequate facilities for people with SCD in the study areas. This pushed patients and their families to seek alternative treatment. According to one respondent,

> *"We took our daughter, who is a patient of sickle cell disease, to a private hospital Raipur when she became weak and could no longer walk. We were told that the hospital would treat her under the RSBY scheme; she was admitted there for ten days and given three units of blood. However, before her discharge, they told us that the hospital would neither subsidise the treatment nor accept our RSBY card. They gave us a bill of almost Rs. 3,00,000 (Three Lakh rupees) and demanded that the entire amount be paid immediately. We had to frantically arrange for the money; we had to ask our extended family and take a huge loan, which we have still not been able to repay. Later, we came to know about an ayurvedic medicine available in Bhilai (Chhattisgarh), which was cheap*

*and was said to be able to "cure" the disease. We have started giving this medicine to our daughter after we heard that many SCD patients have been taking the medicine for the past one year and were actually feeling better".*

The narrative emphasises the urgent need for free and accessible treatment for people with SCD; in the absence of availability of such treatment, families and caregivers are often left with little choice but to follow treatment pathways that are available and accessible to them regardless of their efficacy. This could eventually cause further harm to the persons with SCD and distress to the families, as a result of delayed treatment.


## 5.7.2 Thalassaemia

Runi Paekra, a two year old girl from the Paekra tribal community from Tarekela village, Pathalgaon, Jashpur is the youngest of three siblings. When she was six months old, Runi was diagnosed with thalassaemia. According to Runi's mother,

*"We initially took her to a private hospital called the Community Welfare Society Hospital in Jagda, Rourkela where she was tested. We were informed that she has thalassaemia, a hereditary disease and that even if the parents do not show any symptoms, they can still carry the trait (negative) and pass it on to their children. They asked all of us to get tested for thalassaemia at the hospital. The doctor also told us that Runi cannot be cured and that she would require regular blood transfusions, throughout her life. He suggested that we take her to a government hospital where we can get free blood easily. We had already spent a large sum of money at the hospital. The testing for the entire family alone cost Rs. 35,000.*

*After we returned home, we took Runi seven times to the Holy Cross Hospital in Kunkuri, for blood transfusions. After that, we went to the Ambikapur district hospital three times. We had to donate one unit of blood for every unit given to Runi, so we had to take another person with us for the blood donation. The total cost for each such visit would be Rs. 3,500–3,800. While the medical expenses were covered through our RSBY card, we still had to spend on travel and accommodation. This was a very heavy burden on us. We had no choice and had to borrow money from relatives and take loans with high interest rates. Whenever we were unable to arrange for enough money at the right time, we had to delay the transfusion for up to two months; because of this, at times, Runi's haemoglobin levels would fall to as low as 3-4 gm /dL".*

Thalassaemia and other haemoglobinopathies cause varying degrees of anaemia, that may range from being insignificant to being life threatening.[15] Every year 10,000 children with thalassaemia major are born in India, which constitutes 10 per cent of the total number of persons with thalassaemia globally.[16] Moreover, people with thalassaemia, who access health care from government facilities are mostly from the socio-economically marginalised communities. Diagnosis of thalassaemia, necessitates lifelong care; management includes regular blood transfusions, chelation therapy for iron overload as well as management of complications caused by thallassaemia such as osteoporosis, cardiac dysfunction, endocrine problems, Hepatitis B & C, HIV infection, CMV (cytomegalovirus) infection, etc.

However, costs of optimal treatment for thalassaemia is extremely prohibitive for those who want to access it.[17] The cost of transfusing and chelating a child whose weight is 30 kg for one year was estimated at Rs. 2,00,000 (Two Lakh rupees) in 2008.[18] Thus, less than 5–10 per cent of children in India with thalassaemia receive optimal treatment.[19] In addition to bearing the high costs of treatment, the patients and their families also have to deal with tremendous psychological stress.[20]

Currently, persons with thalassaemia, especially from remote rural areas, are unable to access adequate treatment, with a substantial number unable to even reach a health care facility that provides the necessary services.

## Conclusion

Programmes to manage SCD and thalassaemia should focus on strengthening the primary, secondary and tertiary levels of health care facilities. In the case of SCDs at the primary level, there should be provision of solubility tests, along with protocols for referrals to secondary level facilities. Diagnostic facilities, including Hb electrophoresis, to confirm or rule out sickle cell anaemia (SCA) should be available at the CHCs and DH is critical, along with the availability of requisite drugs in health care facilities at all levels of the health system.

However, as is evident from the narratives above, the access to treatment for persons with SCD and thalassaemia is abysmal, with patients and their caregivers having to manage the consequences of these health conditions as well as the tremendous burden of catastrophic expenditure on treatment.

Recent observations regarding the unchanged rates of mortality, in the last 20 years, for older children with SCD indicate the need for new approaches and therapeutic interventions for disease management. Psychosocial counseling and support groups for patients and caregivers are other critical initiatives for patients of SCD and thalassaemia. The glaring gaps in knowledge regarding the disease necessitate wide and regular dissemination of health information and education to dispense with myths and inaccurate information about SCD and thalassaemia. A comprehensive, integrated approach instead, that focuses on the multiple issues of access to drugs, blood, and other health care, to health information and education as well as transport is critical.

The Guidelines for "Prevention and Control of Haemoglobinopathies in India" (2015) by the MoHFW includes various strategies to address various aspects of health care in the context of haemoglobinopathies. The guidelines also proposed collaborative efforts to build awareness on these issues.[21] While the study indicates the situation with regard to facilities for haemoglobinopathies in the study areas, a systematic assessment of the implementation of the guidelines will provide insights into any changes or improvements in access to health care for persons with SCD and thalassaemia.

## Endnotes


1. Sengupta, M. (2008). Thalassaemia among the tribal communities of India. Internet Journal of Biological Anthropology. 1.
2. It occurs in two forms. The first form is a condition called sickle cell trait (also called Heterozygous, because the sickle gene is received only from one parent), which is often an asymptomatic or a mildly symptomatic condition wherein the person carries the 'S' gene and transmits it to the offspring. The second form is Sickle Cell Disease (SCD) or Sickle Cell Anaemia (SCA), also called homozygous as the offspring receives the 'S' gene from both the parents. The sickle-shaped red blood cell results in often a severe and chronic condition.
3. Sickle Cell Disease - What Are the Signs and Symptoms of Sickle Cell Disease? (n.d.). Retrieved March 19, 2018, from https://www.nhlbi.nih.gov/node/4179
4. Serjeant, G. (2017). World Sickle Cell Day: Lessons for India. *The Indian Journal of Medical Research*, 145(6), 705–707. http://doi.org/10.4103/ijmr.IJMR_1208_17
5. Colah, R. B., Mukherjee, M. B., Martin, S., & Ghosh, K. (2015). Sickle cell disease in tribal populations in India. *The Indian Journal of Medical Research,* 141(5), 509–515. http://doi.org/10.4103/0971-5916.159492
6. Hb electrophoresis is a test for SCD
7. *Prevention And Control Of Hemoglobinopathies In India - Thalassemias, Sickle Cell Disease And Other Variant Hemoglobins.* (2016). National Health Mission. Ministry of Health and Family Welfare. Govt. of India.

8. A type of chemotherapy, which is known to be highly beneficial for people with SCD because it alleviates many common symptoms of the disease.
9. *National List of Essential Medicine.* (2015). Central Drugs Standard Control Organization. Director General Of Health Services, Ministry Of Health And Family Welfare, Government Of India.
10. *Essential Drug List.* (2014). Directorate of Health Services, Department Of Health And Family Welfare, Government of Odisha.
11. *Essential Drug List.* (2016). Department of Health & Family Welfare, Government of Chhattisgarh.
12. *Prevention And Control Of Hemoglobinopathies In India - Thalassemias, Sickle Cell Disease And Other Variant Hemoglobins* (pp. 60-61). (2015). National Health Mission.
13. *National Blood Policy.* (2007). National AIDS Control Organisation, Ministry of Health and Family Welfare, Government of India.
14. *Prevention And Control Of Hemoglobinopathies In India - Thalassemias, Sickle Cell Disease And Other Variant Hemoglobins.* (2015).National Health Mission. Ministry of Health and Family Welfare. Govt. of India.
15. Sengupta, M. (2008). Thalassemia among the tribal communities of India. Internet Journal of Biological Anthropology.
16. Varawalla NY., Old JM., Venkateshanz SR., Weatherall DJ. (1991) The spectrum of beta thalas-semia mutations on the Indian subcontinent the basis of prenatal diagnosis. Brit J Hematol, 78: 242-247.
17. Mallik, S., Chatterjee, C., Mandal, P. K., Sardar, J. C., Ghosh, P., & Manna, N. (2010). Expenditure to Treat Thalassaemia: An Experience at a Tertiary Care Hospital in India. *Iranian Journal of Public Health,* 39(1), 78–84.
18. *Prevention and Control Of Hemoglobinopathies In India - Thalassemias, Sickle Cell Disease and Other Variant Hemoglobins* (pp. 60-61). (2015). National Health Mission.
19. Petrou, M. (2010). Screening for beta thalassaemia. *Indian Journal of Human Genetics,* 16(1). doi:10.4103/0971-6866.64934
20. Mallik, S., Chatterjee, C., Mandal, P. K., Sardar, J. C., Ghosh, P., & Manna, N. (2010). Expenditure to Treat Thalassaemia: An Experience at a Tertiary Care Hospital in India. *Iranian Journal of Public Health,* 39(1), 78–84.
21. Ibid.

# 5.8 Epilepsy


*Jaya Rupuli, a 50-year-old woman from the Dongria Kondh tribal community in Rayagada district, had been experiencing fits for a year. Her family was extremely poor, landless and dependent on wages from seasonal agricultural labour. Her husband had passed away several years ago and she was living with her brother's family. About a year before the interview, Jaya Rupuli had mirgi (fits)[1] while working in the field but was unable to understand what had happened. Thereafter, she began experiencing them frequently. Family members and neighbours had to inform her when she had fits, and they believed it was caused because Rupuli used to eat mud. The fits usually lasted about 30-60 minutes and she sometimes had four to five fits in a day. She also experienced stiffness in her body before the fits. Jaya Rupuli did not know what was causing them or what was wrong with her. She went to the beju (healer) in Kalahandi, who performed jhaad phoonk (sorcery). The healer gave her some herbal medicines. She continued to have the herbal medicines for a couple of months. However, even two days before the interview, Jaya Rupuli had fits. She had not been to a doctor because she was afraid she might get fits on the way to the health facility. Her family was reluctant to accompany her and she did not want to go alone. She had also stopped going to work because of the fear that she may experience a seizure anytime. She had already sustained some injuries– she had bruised her knees from a bad fall during one of the episodes. Gradually her health deteriorated further*

*– she was experiencing loss of memory and getting uncontrollably violent and abusive (verbally). She had approached the ASHA but did not receive any help as, according to Rupuli, the ASHA only took care of women who were pregnant in the village.*

In another case, Pradeep Bakhla, 25 years old, from the Oraon tribal community in Mahuadanr, Latehar, was living with his parents at the time of the interview. He had been undergoing treatment for TB for the last one year. He started getting fits about four years ago. According to Pradeep,

*"Generally before a fit, my body stiffens up, I get a headache and I fall down. Once I fell down while having a fit and injured my head. I did not disclose to the doctors who are treating me for TB at the CHC in Mahuadanr that I am experiencing fits. I'm not sure whether I should tell them, as I am already on TB treatment."*

Jaya Rupuli's and Pradeep Bhakla's narratives, although from two different locations draw attention to several common concerns. There is a complete absence of awareness and information around neurological disorders like seizures and epilepsy.

That epilepsy is not a rare disease, is reinforced by the available estimates of more than 10 million persons living with epilepsy (PWE) in India, with a prevalence of about one per cent. The prevalence is higher in the rural (1.9 per cent) compared to urban population (0.6 per cent). There are close to 1.5 million women with epilepsy (WWE) in the reproductive age in India.[2]

Patients and caregivers are generally aware that epilepsy is a health issue with a possible treatment. They resort to *jhaad phoonk* like Rupuli, not so much out of ignorance as much as due to the unavailability and inaccessibility of other health care facilities. Persons with epilepsy (PWE), as was seen in the narratives, were not even able to get a diagnosis despite having experienced fits for a number of years. Pradeep Bhakla's narrative also referred to other persons in the area suffering from seizures and possibly, epilepsy. This points to the possible lack of space and opportunity or inhibition to discuss the seizures, which led to the lack of diagnosis and care, despite his regular interface with the health system for the TB treatment. The trepidation about the seizures and consequent injuries, along with the lack of knowledge on its prevention and management, may affect the ability of PWE to work, earn or seek health care, as in the case of Jaya Rupuli, thus sustaining a cycle of ill health and vulnerability. People living with such morbidities, in the absence of immediate and long term intervention, face serious economic and psychosocial consequences.

The magnitude of epilepsy treatment gap in India ranges from 22 per cent among urban, middle-income people to 90 per cent in villages.[3] The need for comprehensive, accessible services for prevention, care and rehabilitation for such neurological conditions is urgent and necessitates a comprehensive programme for their prevention and management,

especially at the community level, in tribal areas. Interventions to address this could be through intensive health awareness campaigns, counselling, training of doctors and other health care providers, free supply of Antiepileptic drugs (AEDs), follow-ups to monitor adherence to treatment, side-effects if any, etc. Unless, case identification and confirmation of diagnosis is done and treatment is started within rural communities by the primary care providers (including AYUSH or ANMs / nurses and other community level health care providers), patients will continue to remain untreated.[4] Other studies have also pointed to the treatment gaps in India for epilepsy as ranging between 22 per cent and 95 per cent, with the latter estimate from a study of tribal communities in Jharkhand. The treatment deficit, according to a study, was higher in rural areas and amongst women.[5]

Since epilepsy is recognised as a public health issue, albeit to a limited extent, some steps have been initiated by the Ministry of Health and Family Welfare (MoHFW) towards building awareness, screening and treatment. Epilepsy is one of the NCDs that finds mention in the Operational Guidelines for the Prevention, Screening and Control of Common NCDs, under the National Health Mission (NHM), for which early identification and referral from the home, community as well as the facility levels is being promoted.[6] Other efforts include public events such as the annual National Epilepsy Day, to build public awareness amongst the people. However, the findings indicate a complete absence of any information or health care amongst the tribal communities in the study areas. The State also needs to proactively address the huge shortfall of neurologists in the country – there are fewer than 2,500 neurologists for the 1.3 billion population of the country.

The diagnosis of epilepsy has far-reaching consequences, not only for PWEs but also for their families. However, several misconceptions persist among health care providers as well as in communities, that often pose barriers to the identification and treatment of epilepsy, and also lead to discrimination against PWEs.[7] There is considerable stigma attached to epilepsy and this is worse when patients remain untreated and distressed due to seizures. While it is established that epilepsy can be prevented and treated, the situation as per the present study is a far cry from this. It remains a significant public health issue due to the stigma, a

big treatment gap, and the inadequate health care system. This requires a multidisciplinary approach that encompasses the psychosocial and economic impact of epilepsy, beyond the mere epidemiological aspects.

The importance of diagnosis and instituting treatment, as early as possible, lies in the fact that most epilepsy patients, other than the occasional seizure, can otherwise lead 'normal' lives. However epilepsy, even in such patients, is extremely disabling due to the unpredictability of the seizures and the fact that most patients lose awareness during the seizures. Very often, untreated PWEs, as children, may have to drop out from schools and as adults are not able to live life to its full potential. Medical treatment of epilepsy in most patients is extremely effective and relatively inexpensive, ranging approximately Rs. 300-500 per month. Since the treatment is usually long-term, public health programmes to address epilepsy should incorporate initiatives to ensure regular and long-term supply of drugs, along with efforts to motivate PWEs to continue their treatment on a regular basis. A comprehensive public health initiative, that brings together a range of health care providers, for the prevention, care, as well as the rehabilitation of PWEs, is therefore necessary in India.

## Endnotes

1. Mirgi refers to fits or seizures due to epilepsy in lay person's language.
2. Santhosh, N. S., Sinha, S., & Satishchandra, P. (2014). Epilepsy: Indian perspective. *Annals of Indian Academy of Neurology,* 17(Suppl 1), S3–S11. http://doi.org/10.4103/0972-2327.128643
3. Sinha, S., & Satishchandra, P. (2014). Epilepsy: Indian perspective. *Annals of Indian Academy of Neurology,* 17(Suppl 1), S3–S11. http://doi.org/10.4103/0972-2327.128643
4. Personal communications with Dr. Mamta Bhushan Singh, (AIIMS), 2018
5. Amudhan, S., Gururaj, G., & Satishchandra, P. (2015). Epilepsy in India II: Impact, burden, and need for a multisectoral public health response. *Annals of Indian Academy of Neurology,* 18(4), 369–381. http://doi.org/10.4103/0972-2327.165483
6. Operational Guidelines Prevention, Screening and Control of Common Non–Communicable Diseases: Hypertension, Diabetes, and Common Cancers (Oral, Breast, Cervix). (n.d.). Retrieved http://nhsrcindia.org/sites/default/files/Operational Guideline Comprehensive Primary Health Care.pdf
7. Srinivas H V. Epilepsy management-beyond prescription. Neurol India [serial online] 2017; 65, Suppl S1:2-3. Retrieved http://www.neurologyindia.com/text.asp?2017/65/7/2/201677

# 5.9 Snakebites, dog bites and other animal attacks

Snakebites and animal bites are a significant cause of morbidity and mortality in the studied districts in Jharkhand, Chhattisgarh and Odisha. Poor access to health care services and scarcity of antivenom increases the severity of the injuries and their outcomes.[1] In this section we will discuss snakebites and other rabid animal bites as narrated by the respondents.

## 5.9.1 Snakebites

Padma, a resident of Majhartola village in Koriya district, belonged to the Gond tribal community. She died after a snakebite in August 2017. We visited her family two days after her death. Her husband narrated what had transpired.

> *"Padma was in the forest collecting firewood when she probably stepped on, or got very close to, a snake and was bitten by it. Others who were with her brought her home. I tried to call an ambulance from the closest health facility. However, due to poor connectivity in the village, I was unable to contact [the facility]. My uncle and I walked three km from the*

*village to the main road from where we were able to get in touch with the Mitanin. She tried to call the ambulance (108), but it was unavailable because a patient from another village needed to be transported to the health facility. We brought Padma to the main road so that we could get on to any private transport, but unfortunately, we could not get any. The closest primary health centre, Kathgodi, where medicine is available is 35 km away from the village. By the time the ambulance arrived to transport her to the health facility, my wife had died."*

Anita, from the Oraon tribe of Jharkhand, described the events leading to her brother's death from snakebite:

*"During harvesting time [katai ka samay] a lot of rats come to the field, and snakes are also very common at that time. One day, when my brother was working in the field, he stepped on a snake and was bitten. When he came home, my mother placed a small sacred stone on the wound. We believe that this particular stone absorbs the poison. However, the wound was very painful and he began to feel giddy. My family rushed him to the vaid. But that did not help and the situation became worse. Next morning, we moved him to Ranchi hospital the next morning. He was given injections, but it was too late and he died."*

Our group discussions and interviews clearly revealed that many people visit the *Gunia* (local healer) or an unqualified medical practitioner after a snakebite. Many spoke about their faith in the gunia/local healer. "We first seek treatment from traditional healers and only then go to the health facility. Sometimes the chanting and the potions help."

During a FGD in Gumla, a respondent narrated that her aunt was in the forest during the monsoon season collecting wild mushrooms for consumption. She was bitten by a snake, but she realised this much later. The family took her to the local healer. However, it did not help her and she died the next day. This clearly indicates the reliance on ineffective local interventions and faith healing, which delays treatment and results in death.

Snakebite is a common medical emergency for which timely treatment can reduce mortality and save lives. India is reported to have the highest number of snakebites (81,000) and deaths from snakebites (11,000) per year.[2] Yet the problem remains invisible and unrecognised. However, snakebite morbidity and mortality are generally considered to be under-reported, largely because not all victims are treated in hospitals.[3,4,5,6]

Another respondent in the group discussion said that her neighbour had suffered from a snakebite and experienced severe pain and swelling. The chanting of the healer did not help and the family had to rush the woman to a private clinic for treatment. "In our area, we find a variety of snakes some are extremely poisonous. The health centres are very far from our place. It gets very difficult in the rainy season to travel so far without any transport facility if there is a snake bite," said a respondent from Jashpur district in Chhattisgarh.

The provision of public transport is critical to enable snake bite victims, especially those living in remote rural areas and forested areas where people are more exposed to the risk of snakebite, to reach health facilities without delay. Delay in treatment is one of the most serious causes of death due to snakebite, and can be disastrous, as with the passage of time, more venom binds to the tissue and becomes less manageable for neutralisation by the anti-snake venom (ASV).[7] The other reason for these delays is lack of knowledge about health facilities where treatment for snakebite is available. A respondent from Odisha said that five years ago a snakebite patient from his village had visited the CHC, but ASV was not available. The patient was instead referred to the DH. The doctor told the family that there was a shortage of ASV and suggested that they should buy ASV from a private pharmacy.

The peripheral public health care facilities are most often poorly equipped. There is a shortage of ASV, other emergency medicines, ventilators, etc., thus necessitating access to care in private tertiary-care hospitals, where treatment may be unaffordable for most victims from rural areas. Distressed families, without knowing where to go for immediate treatment, rush victims to private hospitals where also ASV is not easily available.

Despite the large number of deaths resulting from snakebite every year, only one government institute produces ASV in India—the Haffkine Institute for Training, Research and Testing, Mumbai. Other public sector companies and institutes that earlier manufactured the bulk of ASV have stopped production. Consequently, there is a perpetual shortage of ASV, especially in rural and tribal areas. Some studies have highlighted the acute shortage of ASV at most government hospitals below the district headquarter level. While ASV is supposed to be supplied free of cost in government-run hospitals, its availability is irregular. PHCs, which are generally the first point when a patient seeks medical care in rural and tribal areas, are rarely stocked.[8] Further, when it can be procured in the open market, it costs between Rs. 350 to Rs. 900 per 10 ml vial.

| Table 5.9.1.1: Anti-Snake Venom: Manufacture and Cost | | | | | |
|---|---|---|---|---|---|
| **Drug** | **Manufacturer** | **Quantity** | **Dose** | **Cost per unit** | **Source** |
| Snake venom antiserum | Premium Serums & Vaccines Pvt. Ltd. | 1 vial | 10 ml | Rs. 350 | India Mart (wholesale) |
| Snake venom antiserum | Premium Serums & Vaccines Pvt. Ltd. | 1 vial | 10 ml | Rs. 992.4 | 1 MG (retail) |
| Snake venom antiserum | Biological E Ltd. | 1 vial | 10 ml | Rs. 556.24 | 1 MG (retail) |

*Source: 1MG and India Mart* [11]

ASVs also require refrigeration and should be administered only by trained staff. This is also a major challenge, where many of the staff are not trained. Medical Officers at PHCs, and CHCs should be trained for snakebite management as per the standard treatment guidelines for the management of snakebite by Government of India (GoI), 2016.[9] All health facilities in tribal areas, particularly those reporting a high incidence of snakebite cases, should be well stocked with anti-venom injections. In the absence of this, the situation is particularly dangerous for people living in remote areas, where the numbers of snakebite cases are the highest.[10]


ASHAs, ANMs and other frontline workers play a critical role in providing first aid treatment and timely referrals. They can also discourage people from resorting to local treatments or practitioners, which may not be equipped to address the emergency. In addition, counselling is crucial for patients under treatment to help them deal with the trauma and fear of death.

## 5.9.2 Dog bites

Dog bites were common in the study areas. Health care providers in all the three states perceived dog bites as a key public health issue. The standard treatment for dog bites includes washing of the wound, followed by the administration of anti-rabies vaccine. Additionally, in the case of severe wounds, anti-rabies serum is also administered. As per the IPHS guidelines, and as per the list of essential drugs, the anti-rabies vaccine should be available at PHCs,[12] while both anti-rabies vaccine and anti-rabies serum should be available at CHCs.[13]

However, several factors affected the availability of these two essential drugs in health facilities in the study areas. Anti-rabies vaccine could not be stocked, for example, in PHCs

where there was intermittent supply of electricity. One of the PHCs in Koriya district, used solar power as it did not have electricity. Here, the facility did not have an Ice Lined Refrigerator to stock the vaccines and hence, was not able to stock and make available the anti-rabies vaccine. For those who accessed this PHC, in the case of non-availability of the vaccine, the referral facility was the CHC at Sonhat at a distance of 20 km, through the Guru Ghasidas (Sanjay) National park in Koriya district. The CHC had the anti-rabies vaccine in stock but not the anti-rabies serum. Hence, the patients were mostly referred to the District Hospital at Baikunthpur, about 30 km from the CHC at Sonhat. Similarly, in Latehar district, Jharkhand, the PHC at Durup did not have the anti-rabies vaccine and referred patients to the CHC at Mahuadanr, about 13 km away. This facility also did not have an ambulance and the persons coming to the PHC following dog bites were expected to hire private vehicles to the CHC. Though the CHC, similar to the CHC at Sonhat, had only the anti-rabies vaccine in stock. Therefore, people were referred to the DH at Latehar, which another 110 km, and three hours away.

These are some examples that point to the non-availability of essential drugs at the primary and secondary level facilities. Non availability of the vaccine to patients from tribal communities, at proximal facilities, creates a huge burden for them and their families as they experience delays, are forced to cover long distances and to expend substantial costs to access essential medicines. Non-compliance with the IPHS norms to access post exposure prophylaxis – rabies vaccines and serum – is a serious violation of the rights of persons with dog bites to be able to access the requisite services in public health facilities.

### 5.9.3 Other animal attacks

Suganti Kerketta, a 55-year-old woman from the Oraon tribe from Aigu village in Netarhat, Latehar district, Jharkhand is an Anganwadi worker. On 18 August 2017, around 5.30 PM, she was returning home after a meeting when two bears attacked her and mauled both her legs. She somehow managed to reach home, despite suffering from great pain and shock. Her narrative was as follows:

*"My family members applied a paste of raw turmeric and tied a cloth around the wounds. Since it was late in the evening, they did not get any means of transport to take me for treatment to the nearest health facility. The next day they took me in a private vehicle to the Carmel Missionary Hospital in Mahuadanr and got me admitted there. My family said they spent around Rs.12,000–13,000 on medicines and transport.*

*The District Forest Officer visited my family on 21st August and enquired about the bear attack. He assured us that we would receive assistance but asked us to provide some documents first. We had also lodged a first information report (FIR). My wounds did not heal, and the doctor at the hospital asked my family to shift me to another health facility. On 27th August, my family decided to move me to Ranchi, hired a private vehicle after spending approximately Rs. 4,000 and got me admitted in Sadar Hospital, a government facility. The doctors at Sadar Hospital said that treatment was not possible at the hospital and advised my family to take me immediately to the Rajendra Institute of Medical Sciences (RIMS) in Ranchi. The doctors at RIMS asked me to visit the hospital to get the injections over the next few months. At RIMS, the injections were provided free of cost. We initially stayed in a rented place in Ranchi so that we could go to the hospital to get the injections regularly. However, we returned to our village as staying in Ranchi was very expensive."*

Recovery from a bear attack depends on the extent of damage suffered, like the depth and extent of the wound and the extent of tissue loss, and often involves long-term medical treatment. During the research period, a four-year-old boy was reportedly mauled to death by a leopard in Nuapada district after the animal dragged him into the forest while he was sleeping beside his parents. Forest officials caught the leopard and shifted it to the Nandankanan Zoo in Bhubaneswar.

## Conclusion

Forests often surround tribal areas, and animal attacks (from bears and leopards) and bites (from dogs, snakes and scorpions) are very common and require an urgent response from the health system. The long distances between interior habitations and health centres, the arduous terrains of tribal areas and the minimal availability of public transport, however, often cause long delays in the reception of treatment. This is often coupled with local beliefs and practices, caused by a lack of access to information regarding such incidents, leading patients and their families to turn to folk healers or traditional rituals, first. Moreover, the unavailability of essentials drugs, vaccines and services at public health facilities, be it PHCs,

CHCs or DHs, drives patients to seek treatment in expensive private clinics/hospitals or go from one facility to another, which takes a further toll on their financial situations. In this way, the overall lack of awareness around appropriate first-aid measures, poor access to health care services, poor accessibility to transport and the consequent systemic delays, especially in remote, rural areas, end up having adverse effects on the wellbeing of those who live in these areas. It is, therefore, imperative that these shortcomings are addressed so that these communities can overcome what has become a significant public health hazard.

## Endnotes


1. Snake bites. (2018, February 5). Retrieved March 21, 2018, from http://www.who.int/news-room/fact-sheets/detail/animal-bites
2. Kasturiratne, A., Wickremasinghe, A. R., de Silva, N., Gunawardena, N. K., Pathmeswaran, A., Premaratna, R., … de Silva, H. J. (2008). The Global Burden of Snakebite: A Literature Analysis and Modelling Based on Regional Estimates of Envenoming and Deaths. *PLoS Medicine,* 5(11), e218. http://doi.org/10.1371/journal.pmed.0050218
3. Vaiyapuri, S., Vaiyapuri, R., Ashokan, R., Ramasamy, K., Nattamaisundar, K., Jeyaraj, A., Hutchinson, E. G. (2013). Snakebite and Its Socio-Economic Impact on the Rural Population of Tamil Nadu, India. *PLoS ONE*, 8(11).doi:10.1371/journal.pone.0080090
4. Kasturiratne A, Wickremasinghe AR, de Silva N, Gunawardena NK, Pathmeswaran A, et al. (2008) The global burden of snakebite: a literature analysis and modelling based on regional estimates of envenoming and deaths. *PLoS Med 5*: e218. Retrieved June 15, 2017, from http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0050218
5. Fox S, Rathuwithana AC, Kasturiratne A, Lalloo DG, de Silva HJ (2006) *Underestimation of snakebite mortality by hospital statistics in the Monaragala District of Sri Lanka.* Trans R Soc Trop Med Hyg 100: 693–695. Retrieved June 15, 2017, from https://academic.oup.com/trstmh/article-abstract/100/7/693/1885852
6. Mohapatra, B., Warrell, D.A., Suraweera, W., Bhatia, P., Dhingra,N., et al. (2011) Snakebite mortality in India: a nationally representative mortality survey. *PLoSNegl Trop Dis 5*: e1018. Retrieved June 15, 2017, from http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0001018
7. Gupta YK, Peshin SS (2014) Snake Bite in India: Current Scenario of an Old Problem. J ClinToxicol 4:182. doi: 10.4172/2161-0495.1000182
8. Bhaumik, S. (2018, June 8). Snake Bite Envenomation – the Public Health Problem That Is Also a Silent Killer. *The Wire.* Retrieved June 8, 2018, from https://thewire.in/health/snake-bite-envenomation-the-public-health-problem-that-is-also-a-silent-killer
9. Standard Treatment Guidelines. Management Of Snake Bite. Quick Reference Guide (Publication). (2016). Ministry of Health and Family Welfare. Govt. of India. Retrieved February 11, 2018, from http://www.nhm.gov.in/images/pdf/guidelines/nrhm-guidelines/stg/Snakebite_QRG.pdf
10. Pradhan, A. (2012, July 20). Anti-venom shortage stings remote areas. The Times of India. Retrieved January 27, 2018, from https://timesofindia.indiatimes.com/city/bhubaneswar/Anti-venom-shortage-stings-remote-areas/articleshow/15061768.cms
11. IndiaMART is an online marketplace, connecting buyers with suppliers. https://my.indiamart.com/1 mg is an e-commerce health care company, https://www.1mg.com/
12. Indian Public Health Standards (IPHS), Guidelines for Primary Health Centres (Revised 2012), Directorate General of Health Services, Ministry of Health & Family Welfare, List of essential drugs at PHC, Annexure 4 of the IPHS guidelines for Primary Health Centres. Retrieved January 27, 2018, from http://www.nhm.gov.in/images/pdf/guidelines/iphs/iphs-revised-guidlines-2012/primay-health-centres.pdf
13. Ibid

Chapter 6

# Availability and utilisation of health services

The public health infrastructure and services in a country are an important determinant of the health of the people.[1] In this chapter, the shortfalls in health care facilities, including human resources and other critical gaps with regard to the health system in the study states, are discussed. This is based primarily based on the secondary data such as National Health Profile, RHS, , NFHS-4 and the records of NSSO 71st round, interspersed with some primary data from the study.

## 6.1 Shortfall in facilities and services

The organisation of the public health system in India organised at three levels – primary, secondary and tertiary levels – was envisioned to ensure the availability of health services as proximally as possible to the people. SCs and PHCs are the core units for the provision of health care at the primary level, with the CHCs, Sub-Divisional Hospitals (SDH) and DHs envisaged to provide secondary level of health care. Medical College Hospitals are the facilities at the tertiary facility and provide specialised care following referrals from the primary and secondary health care facilities. In tribal areas, a similar structure of the

public health system exists with the only exception of relaxed population norms for hilly and remote areas, i.e. the health care facilities at all levels are expected to provide services for a smaller proportion of the population in tribal areas.

In the course of the study, the key informant interviews, visits to health care facilities revealed the facilities available to the tribal population, shortfalls in these facilities, as well as barriers to accessibility that were experienced by tribal communities.

There are considerable variations in the availability of facilities in the study states. As Table 6.1 suggests, Chhattisgarh has the required number of SCs and PHCs, while there is a 12 per cent shortfall in CHCs. In contrast, Jharkhand has a considerable shortfall in all three levels of care, while the shortage of PHCs is higher (69 per cent). In Odisha, the shortfall is most pronounced at the SC level.

**Table 6.1: Shortfall in public facilities in study states (%)**

| State/ UT | Sub Centres | | | PHCs | | | CHCs | | |
|---|---|---|---|---|---|---|---|---|---|
| | R | P | % Short-fall | R | P | % Short-fall | R | P | % Short-fall |
| Chhattisgarh | 4,885 | 5,186 | 0 | 774 | 785 | 0 | 193 | 169 | 12 |
| Jharkhand | 6,060 | 3,848 | 37 | 966 | 297 | 69 | 241 | 188 | 22 |
| Odisha | 8,193 | 6,688 | 18 | 1,315 | 1,280 | 3 | 328 | 370 | 0 |
| All India/ Total | 1,79,240 | 1,56,231 | 19 | 29,337 | 25,650 | 22 | 7,322 | 5,624 | 30 |

*Source: RHS 2017*

R – Required, P – In position; Note: Shortfall is calculated based on 2011 Census population numbers.

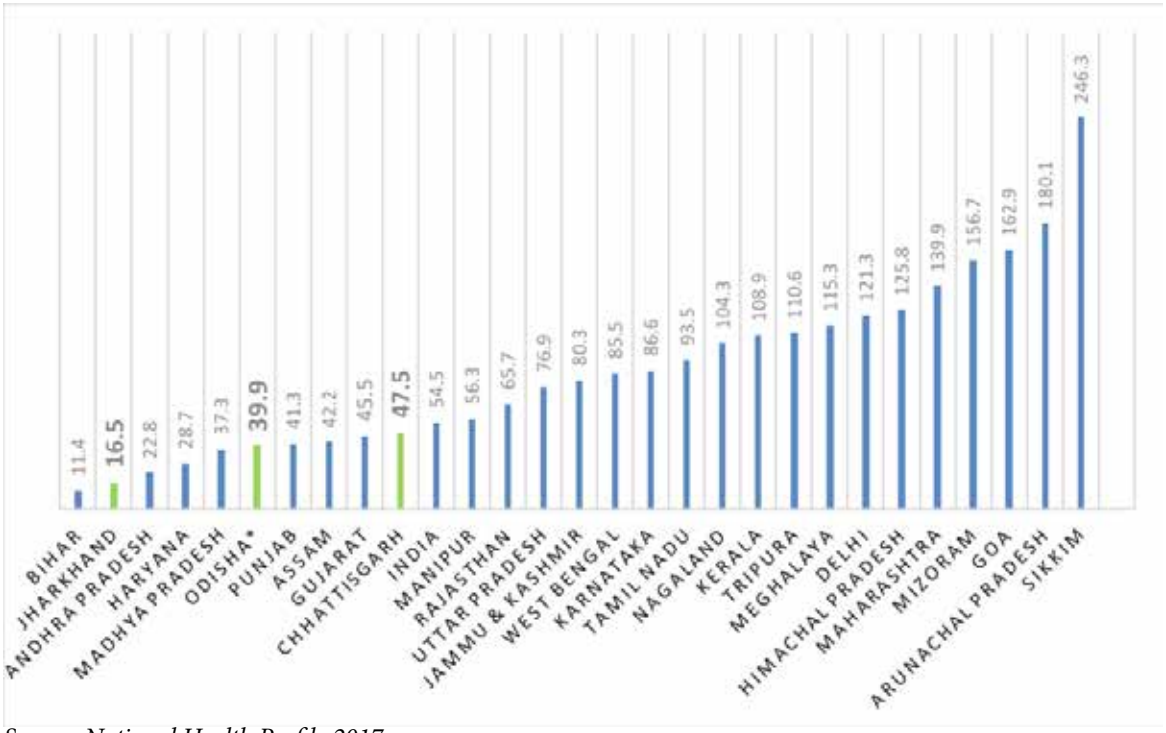
Despite the relaxation of norms to enhance access to health care by the tribal population, the distance from facilities, the terrain and other logistical issues are substantial barriers to accessibility. The facilities proximal to the tribal communities, especially the SCs, PHCs need to be better equipped and functional to provide a range of services.

**Table 6.2: Number of facilities available in sample districts (as on 31 March 2017)**

| | | Sub Centres | PHCs | CHCs | Sub Divisional Hospital | District Hospital |
|---|---|---|---|---|---|---|
| Chhattisgarh | Koriya | 189 | 29 | 5 | 0 | 1 |
| | Jashpur | 258 | 35 | 8 | 2 | 1 |
| Jharkhand | Gumla | 243 | 1 | 11 | 0 | 1 |
| | Latehar | 97 | 7 | 7 | 0 | 1 |
| Odisha | Nuapada | 95 | 17 | 6 | 0 | 1 |
| | Rayagada | 235 | 38 | 11 | 1 | 1 |

*Source: RHS 2017*

**Figure 6.1: Govt. hospital bed/ 100,000 persons in Indian states**




*Source: National Health Profile 2017*

Presence of beds is a key indicator of the availability of public health services in the state. As illustrated by Figure 6.1, all the three states have low bed-population ratios, depicting significant shortages. For instance, Jharkhand has only 16.5 beds per lakh population compared to the national average of 54.5. In contrast, states like Maharashtra (139.9) and Delhi (121.3) have 8.5 and 7.3 times more beds compared to Jharkhand. This clearly depicts the disparities between better-off states and major urban centres of the country and other states.

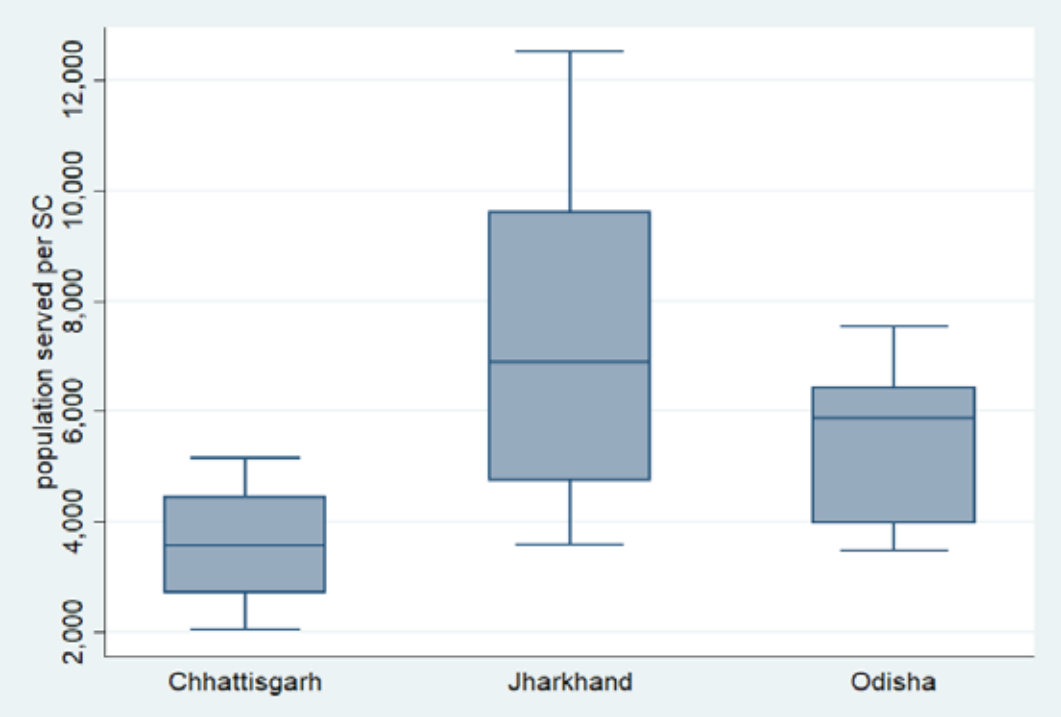
## The Sub-Centre (SC)


The SC is the first point of interface of the community with the health system. In tribal areas, a functional SC is often the only facility or public health care available to tribal communities, especially in remote habitations and difficult to reach areas. Each SC is proposed for a population of 3000 in hilly and tribal areas as compared with a population of 5000 in the plains and non-tribal areas. However, the Indian Public Health Standards (IPHS)[2] recommends that SCs must be organised as per the density of population and the 'case load' in a particular facility

rather than a universal sub-centre to population ratio. Table 6.1 depicts that Jharkhand has a 37 per cent shortfall of SCs, while Odisha has an 18 per cent deficit.

One of key indicators to assess shortfall is the proportion of population covered per SC. Figure 6.2 and Table 6.3 clearly point out that there are significant variations across districts and states. For instance, there are districts in Jharkhand where the average population served by a SC is 12,500 people. On the other hand, there are districts in Chhattisgarh where one SC serves 2,030 people, which is well within the prescribed norms for tribal and hilly areas.

**Figure 6.2: Population served per Sub Centre across districts**




*Source: RHS 2017*

**Table 6.3: Summary statistics related to population served per Sub Centre in districts**

| Variable | No of districts | Min | Max | Quartile 1 | Median | Quartile 3 | Mean | Standard deviation |
|---|---|---|---|---|---|---|---|---|
| Chhattisgarh | 18 | 2,030 | 5,146 | 2,700.0 | 3,553.5 | 4,449.0 | 3,573.2 | 995.7 |
| Jharkhand | 24 | 3,591 | 12,500 | 4,736.5 | 6,892.5 | 9,602.0 | 7,101.5 | 2,645.6 |
| Odisha | 30 | 3,475 | 7,517 | 3,950.0 | 5,864.0 | 6,423.0 | 5,425.1 | 1,246.2 |

*Source: RHS 2017*

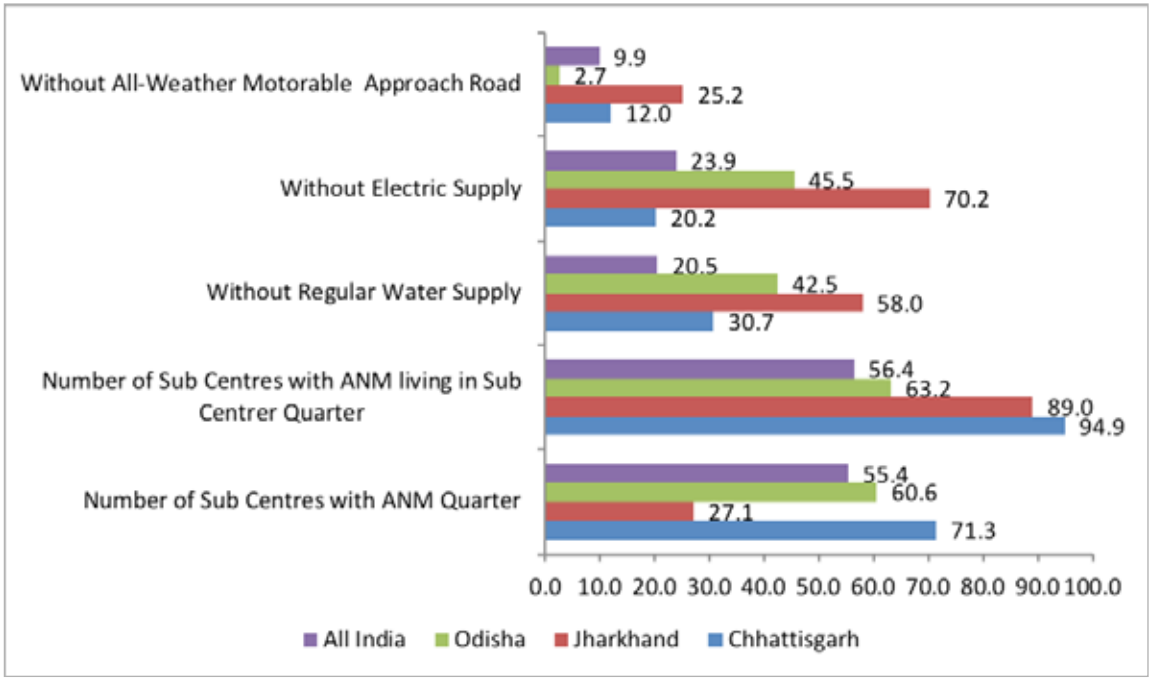
*Note: In Chhattisgarh some of the districts are further bifurcated. In order to get reliable population estimates we have used the undivided districts and made the estimations based on the combined number of facilities*

SCs are supposed to provide a range of preventive services required by the community, and identify health issues early so that they can be screened and treated at the community level.

The SC is expected to provide care for maternal and child health, contraception, nutrition, immunisation, diarrhoea and for communicable diseases. It is also expected to identify persons with non-communicable diseases so that they can be counselled and referred to the PHC for screening, diagnosis, and treatment. However, there are considerable lacunae in the basic amenities available at SCs, which has implications for provisioning of services.

Providing ANMs with accommodation in the SC premises is an important requisite. In Jharkhand, merely 27 per cent of the SCs have ANM quarters. Whereas, 60 per cent of SCs in Odisha and 70 per cent in Chhattisgarh have attached ANM quarters. Almost 20 per cent in Chhattisgarh and 70 per cent of SCs in Jharkhand do not have electricity supply (Figure 6.3).

**Figure 6.3 Status of facilities at Sub Centres (%)**




*(Source RHS 2017)*

The human resources for each SC should include at least one ANM and MHW. They work with the ASHAs/Sahiyas/Mitanins from the communities for strengthened outreach. For a functional Type-A SC, two ANMs (one essential and one desirable) are the minimum requirement. For a Type-B SC, two ANMs are the minimum requirement. However this norm was not implemented in the study areas.

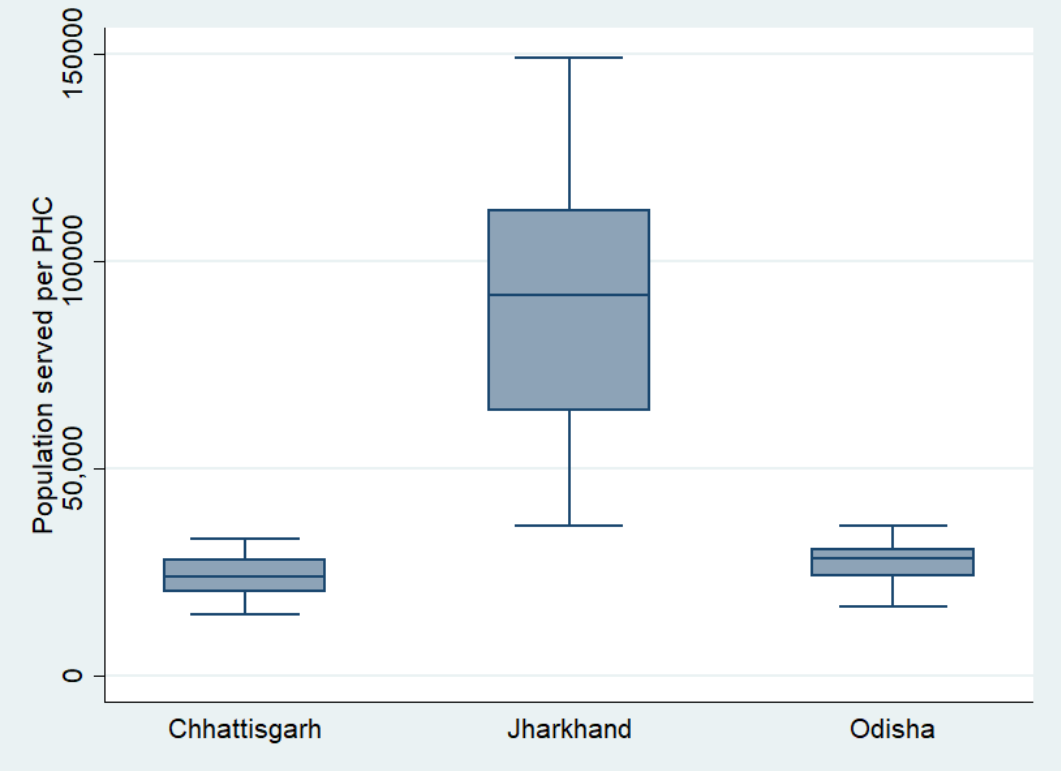
As per the 2012 IPHS guidelines, SCs are expected to be involved in many outreach and curative services. However, at present, even those SCs that can be considered functional are only providing a part of the range of services envisaged. In a majority of instances, they are largely providing maternal and child health care.

## Primary Health Centres (PHC)


The PHCs are the next point of access to health care in rural areas. PHCs are planned at the ratio of one PHC for every 20,000 population in hilly, tribal and desert areas, as compared to the norm of one PHC for every 30,000 population elsewhere. This reorganisation of PHCs on the basis of population was proposed in the sixth five year plan (1983-88), which was important for tribal areas, where the population is scattered with hamlets/houses located at considerable distances from each other, and the public health facilities located at great distances.

As observed in Table 6.1 earlier, however, there are critical gaps in the number of PHCs at the state level. Variations in the availability of PHCs become more pronounced when their availability is considered at the district level. As depicted in Figure 6.4 and Table 6.4, the shortfall is quite high in Jharkhand compared to Odisha and Chhattisgarh. The state average in Jharkhand, represented by both median and mean, is more than 92,000 people per PHC. Compared to Jharkhand, the averages for Chhattisgarh and Odisha are 23,800 and 28,170 respectively, closer to the prescribed norms.

**Figure 6.4: Population served per PHC**




*Source: RHS 2017*

| Table 6.4: District level variations in population served per PHC: Summary statistics | | | |
|---|---|---|---|
| Population served per PHC | | | |
| States | Chhattisgarh | Jharkhand | Odisha |
| No. of Districts | 18 | 24 | 30 |
| Min | 14,714 | 36,214 | 16,521 |
| Max | 33,084 | 1,76,245 | 36,266 |
| Quartile 1 | 19,995 | 65,573 | 23,866 |
| Median | 23,805 | 92,141 | 28,173 |
| Quartile 3 | 27,826 | 1,16,985 | 30,401 |
| Mean | 23,923.8 | 92,384.2 | 27,558.7 |
| Standard Deviation | 5,359.7 | 35,401.0 | 4,808.6 |

*Source: RHS 2017*

*Note: In Chhattisgarh some of the districts are further bifurcated. In order to get reliable population estimates we have used the undivided districts and made the estimations based on the combined number of facilities*

Table 6.5 on existing health facilities in the study districts depicts the present status of facilities in these areas. The figures from Jharkhand are especially striking as the two districts covered, Gumla and Latehar, each have very few functional PHCs, i.e. one in Gumla and seven in the entire district of Latehar. Among the study districts, Koriya has the least population served by a PHC (15,642), while Latehar has the most (96,446). The rest of the districts serve between 20,000-30,000 people served by a single PHC.

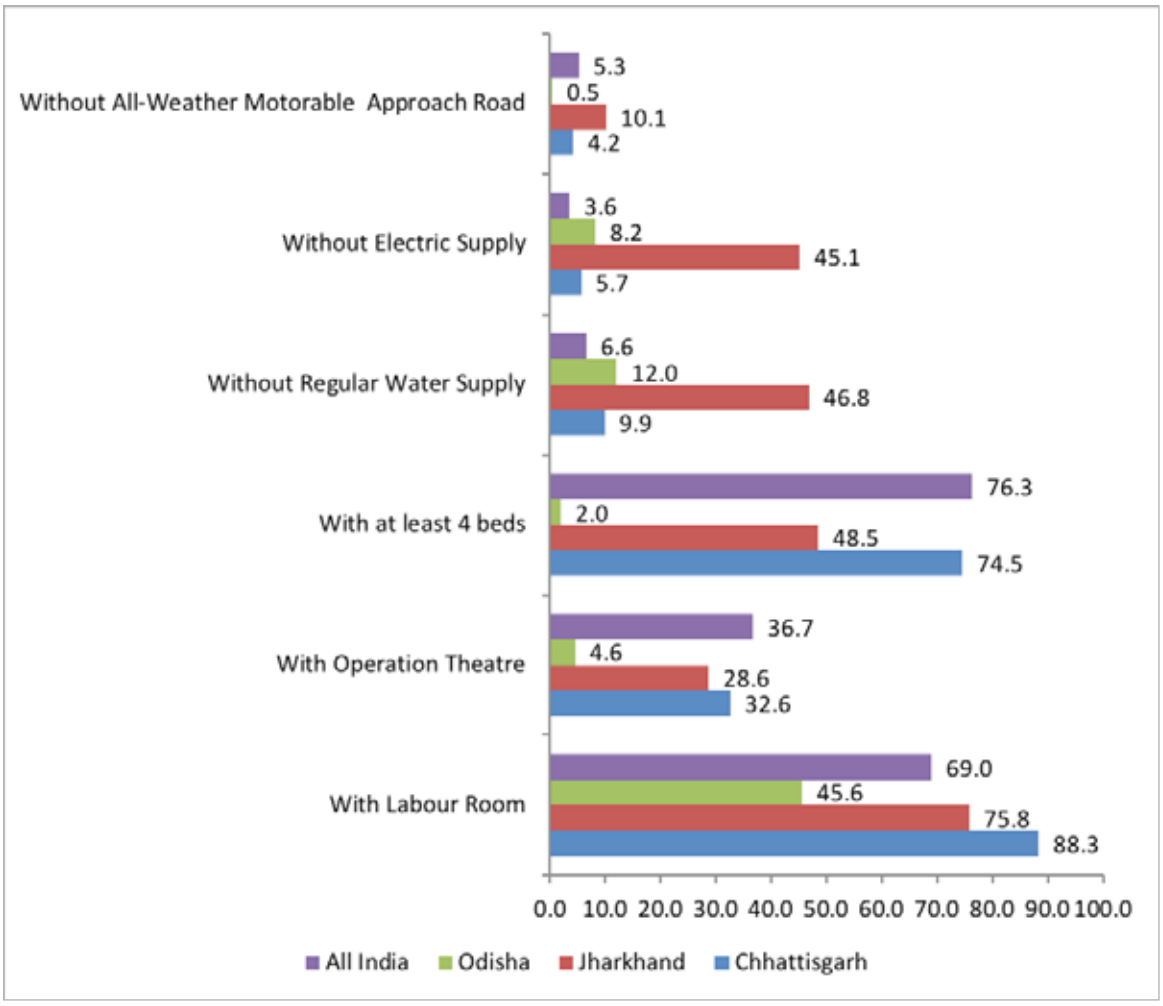
| Table 6.5: Number of PHCs in sample districts | | |
|---|---|---|
| States/Union Territory | Name of the District | Number of PHCs in study districts (As on 31st March, 2017) |
| Chhattisgarh | Koriya | 29 |
| | Jashpur | 35 |
| Jharkhand | Gumla | 1 |
| | Latehar | 7 |
| Odisha | Nuapada | 17 |
| | Rayagada | 38 |

*Source: RHS 2017*

IPHS guidelines[3] for PHCs suggest the discontinuation of this population-based setup and instead propose that the number of PHCs should depend upon the case load of the facilities. In addition to this, the guidelines also propose that PHCs should be able to provide 24 hour nursing facilities and emergency care especially in areas with a scattered population, where the secondary level facilities or CHCs are more than an hour away.

In the Indian public health system, PHCs are an essential point of care. They are the first facility, where a patient is able to access a doctor, and are also an important point in the referral chain. Despite this critical location of the PHCs, the availability of services is affected by myriad issues. Some of the key issues pertain to round-the-clock availability of doctors, insufficient physical infrastructure and facilities, lack of diagnostic facilities and drugs, amongst others. Figure 6.5 provides a comparison of the study states in terms of the lack of some of the basic amenities like electricity, water supply, road connectivity, minimum number of beds, absence of labour rooms and operation theatres (OTs), all of which are among the most elementary requirements for the proper functioning of a PHC.

**Figure 6.5: Status of Facilities at Primary Health Centres (%)**




*Source: RHS 2017*

Merely two per cent of PHCs in Odisha have four functional beds; and only 4.6 per cent have a functional OT, and less than half of the PHCs have a labour room (45 per cent). The lack of PHCs in Jharkhand has been highlighted earlier. In tribal areas, these issues are heightened due to the remoteness and the difficult terrain. This trend has also been captured in tribal areas by the RHS 2017.

## Community Health Centres (CHCs)

CHCs are secondary level facilities in the Indian public health system. They are a level above the SCs and PHCs, and are expected to function as block public health units and referral centres. The population norm for CHCs is one CHC for a population of 1,20,000, while it is one CHC for a population of 80,000 in hilly and tribal areas. CHCs also offer out-patient department (OPD) services and in-patient department (IPD) services. There are considerable gaps at the CHC level in all the study states, with it being highest in Jharkhand (Table 6.6).

**Table 6.6: District level variations in population served per CHC: Summary statistics**

| State | Chhattisgarh | Jharkhand | Odisha |
|---|---|---|---|
| No. of Districts | 18 | 24 | 30 |
| Min | 45,126 | 79,519 | 47,202 |
| Max | 182,520 | 9,60,132 | 1,88,643 |
| Quartile 1 | 9,07,24.0 | 1,12,596.0 | 73,588.0 |
| Median | 1,20,118.0 | 1,36,827.0 | 95,145.0 |
| Quartile 3 | 1,29,029.0 | 1,70,697.5 | 1,07,531.0 |
| Mean | 1,16,390.1 | 1,70,875.1 | 96,641.8 |
| Standard Deviation | 36,609.5 | 1,72,135.3 | 29,927.9 |

*Source: RHS 2017*

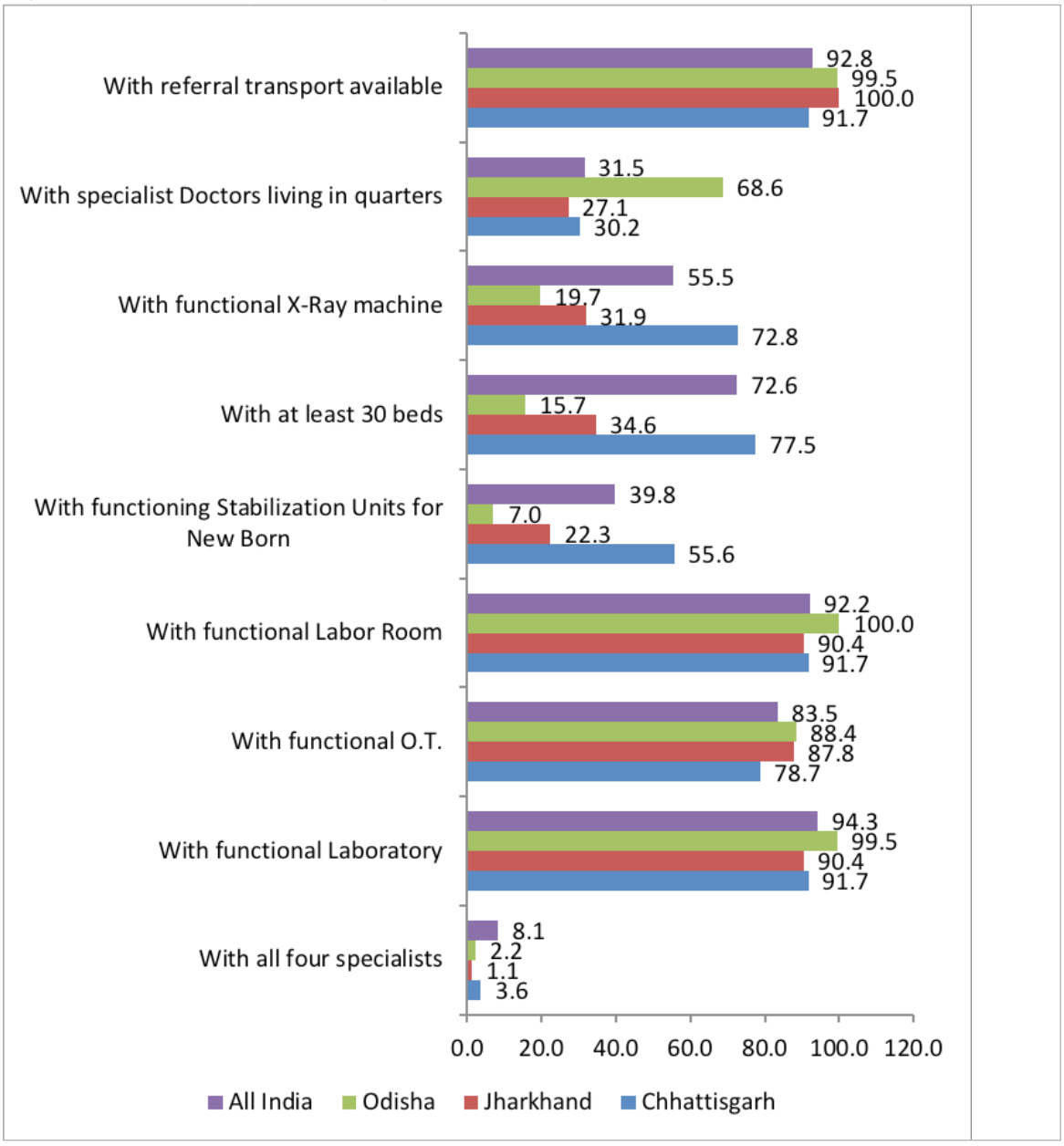
CHCs are the first contact points for patients who need specialised care. Figure 6.6 shows that there is a huge shortage of specialists in CHCs across the three study states. Almost none of the CHCs in these states have all the four specialists that are prescribed by the IPHS. The issue of lack of specialists has been dealt with separately later in the chapter. Most CHCs in Odisha and Jharkhand function without 30 beds. From Figure 6.6, it emerges that CHCs in Chhattisgarh have better infrastructure and facilities compared to the other two states. In all the three states, CHCs seem to be the first point where functional labour rooms and OTs are present, indicating that these are key facilities for institutional deliveries. However, the lack of new-born stabilisation units point towards the inability of CHCs in dealing with complications during the neo-natal period.

### *Diagnostics at CHC*

The IPHS[4] lists the diagnostic services that CHCs need to provide. For radiology, the IPHS norms list x-ray for the chest, skull, spine, abdomen, bones and dental problems as essential, and ultrasonography as desirable services. However, according to the RHS 2017, only 123 out of 169 functional CHCs in Chhattisgarh, 60 out of 188 CHCs in Jharkhand and 73 out of 370 CHCs in Odisha have functioning x-ray machines. Unavailability of free diagnostics at government facilities contributes heavily to the OOPE of patients leading to long-term

indebtedness. The MoHFW states that in 2013-14, the total out of pocket expenditure for health care across the country amounted to 2,90,932 crore, out of which 9.61 per cent was spent on medical and diagnostic purposes, and 6.21 per cent on patient transportation.

**Figure 6.6: Availability of some key facilities at CHCs (%)**




*Source: RHS 2017*

## District hospital (DH)

The DH is envisioned as the secondary level of health care service providing curative, preventive and promotive healthcare services to the people in the district.[5] DHs are linked to public hospitals and health centres at the Sub-district/Sub-divisional level, CHCs at the block level and PHCs and SCs at the community level. A major issue facing the DHs is

the distance of the hospitals from the tribal blocks and villages. Often, DHs in tribal areas, as a consequence of inadequately functioning PHCs and CHCs, provide services that the latter are supposed to provide. This is extremely difficult and distressing for patients as they are forced to spend large amounts of time and money to seek the care and services that should be available to them closer to their villages.

In some of the study areas, the unavailability of services in the public health sector virtually implies that the treatment, including medicines, diagnostics and other facilities are inaccessible to the patients. With very few quality private sector health facilities in some of the areas, as well as the high costs of care, the options for patients from tribal areas are extremely limited, pushing them to delay treatment, or seek health care at distant locations, often incurring catastrophic OOPE.

## Human resources for health care

The retention of doctors at the PHCs is one of the most common issues that affects the functioning of the PHCs in these areas.

**Table 6.7: Doctors at PHCs in Tribal Areas (as on 31st March, 2017)**

| States | Required [R] | Sanctioned [S] | In Position [P] | Vacant [S-P] | Shortfall [R-P] | Shortfall in per cent |
|---|---|---|---|---|---|---|
| Chhattisgarh | 392 | 409 | 157 | 252 | 235 | 60% |
| Jharkhand | 165 | 290 | 177 | 113 | Surplus | 0% |
| Odisha | 425 | 425 | 335 | 90 | 90 | 21% |

*Source: RHS 2017*

As visible from the Table 6.7, the shortfall of doctors is a major gap in PHCs in the tribal areas of the study states. As per the IPHS norms,[6] it is essential to have one MBBS doctor in each PHC (for both category A and category B). However, only two of the five PHCs that were visited during the study had MBBS doctors, one of whom was posted at the block level CHC, as the block level in charge.

CHCs, like the PHCs are also affected by a severe shortage of doctors and specialists,

especially in tribal areas. The Table 6.8 provides the details of the shortfall for key health care providers at the CHC level in the three states. As per the IPHS guidelines,[7] it is essential for CHCs to have one General Surgeon, one Physician, one Obstetrician and Gynaecologist, one Paediatrician and one Anaesthetist. Though the shortfall of doctors and especially specialists is apparent across most of the rural parts of the country, this shortfall is often most pronounced in tribal areas. The data from RHS 2017 also indicates the severe shortage in the availability of specialists at the CHCs. This shortfall has serious implications for distant areas from referral facilities such as DHs, as was the case in the study districts. These shortfalls in human resources limit the range of services available to patients at the secondary level of the health care system. Not only are specialist services not available, but even minor surgical procedures become difficult to access in such situations. Thus, despite a three tier structure, the public health system in these areas is heavily dependent on DHs.

**Table 6.8: Shortfall of Specialists at CHCs in Tribal Areas (as on 31st March, 2017)**

| States | Chhattisgarh | | Jharkhand | | Odisha | |
|---|---|---|---|---|---|---|
| **Specialists** | **No** | **% shortfall** | **No** | **% shortfall** | **No** | **% shortfall** |
| Surgeons | 76 | 95% | 104 | 100% | 123 | 93% |
| Obstetricians & Gynecologists | 72 | 90% | 89 | 86% | 107 | 81% |
| Paediatricians | 73 | 91% | 96 | 92% | 118 | 89% |
| Physicians | 75 | 94% | 102 | 98% | 125 | 95% |

*Source: RHS 2017* **Percentage calculated against required number of specialists.*

As per the IPHS guidelines,[8] DHs must also have specialists like a surgeon, physician, obstetrician and gynaecologist, paediatrician, orthopaedic surgeon, ophthalmologist, anaesthetist, ENT specialist and dentist in addition to the specialists placed at the block level CHC. The DHs cater to the people living in urban district headquarter towns, from adjoining areas and the rural population of the district. However, the DHs are still plagued by the unavailability of doctors and services, issues of accessibility for the tribal community and the poor quality of the services provided.

### *The Accredited Social Health Activists (ASHAs)*

ASHAs/Mitanins/Sahiyas are community health workers, who play a critical role in strengthening the community's linkages with the public health system. One of the key components of the National Health Mission (NHM), the ASHA/Mitanin/Sahiya is a woman selected by the community, resides in the community and is trained and supported to function in her own village or hamlet to improve the health status through enabling access to health care information and services. This role, despite its voluntary nature, is crucial as ASHAs often form the first link between the community and the larger public health system. Despite this role as a link worker, her accountability is towards the community and its members who chose her and whom she represents. An evaluation of the ASHAs was commissioned by the National ASHA Mentoring Group and coordinated by National Health System Resource Centre (NHSRC) in 16 States, in three rounds, between 2010-2014. The evaluation was conducted in the states of Assam, Bihar, Odisha, Rajasthan, Jharkhand, Andhra Pradesh, Kerala and West Bengal in phase one, in 2010-2011.[9] The evaluation included 2 districts from each of these states and included two of the states, i.e., Jharkhand and Odisha, from the present study. In terms of the support that the ASHAs require performing better, over 70 per cent of all ASHAs articulated the need for better training as the single greatest requirement. Monetary support and timely replenishment of the drug kit was a close second. As per the NHM, every ASHA is to be provided with a drug kit

containing a set of drugs, equipment and products. The kit enables her to provide basic level care to the community.[10] These include disposable delivery kits, pregnancy kit, paracetamol tablets, IFA tablets, ORS packets, deworming pills, condoms, etc. and basic equipment such as thermometer, BP monitor, weighing scale (for newborn), baby blanket, etc. The evaluation (2010) also highlighted that the ASHA programme had been successful in terms of the promotion of institutional deliveries. In the context of immunisation, however, it concluded that there were gaps in coverage of the marginalised; an estimated 15 per cent to 50 per cent of women, in some districts (across all assessment states) had not been reached.[11] Despite this, the evaluation concluded that the ASHA is not as effective in influencing critical health behaviours such as three ANCs, breastfeeding, adequacy in complementary feeding, which undermines her effectiveness in bringing about changes in health outcomes. The evaluation argued for greater support for ASHAs to implement health care services through engagement with NGOs, provision of competency based training, adequate drug supplies, and mentoring and motivation (beyond cash incentives). In tribal areas ASHAs have a very crucial role to play in mobilisation and linking the community to the public health system but the fact that health facilities remain distant and poorly equipped undermines their role and impedes mobilisation in seeking health care. Thus, provision of quality health care by the public health system is very important, without which ASHAs role in mobilisation is devalued. Moreover, the lack of adequate health facility support, of regular supply of medicines and other equipment as well as inadequate remuneration devalues her work, undermining the important role of ASHAs in the health system.

## 6.2 Availability and utilisation of drugs, diagnostics and other services

### Ambulance and referrals

As per the IPHS guidelines,[12] ambulance services are not essential for PHCs, but are mentioned as desirable. Free public transport or ambulance facilities for transport of patients ensure timely referrals to functional first referral units (FRUs), in case of complications during pregnancy and childbirth and other medical emergencies. Ambulance facilities are extremely critical in tribal areas due to poor connectivity and long distances between villages and health facilities as well as for inter- facility referrals at all health facility levels. Often, PHCs are linked to the secondary facilities though the National Ambulance Services but in areas, which are interior and the CHCs are located at substantial distances, emergency transport is essential. Well-equipped ambulances are necessary to transport patients from villages to the PHCs as the hamlets are often located away from motorable roads, in hilly and difficult terrain that require patients to walk or to be carried long distances to the road to access these services.


To ensure referral transportation during childbirth, the Governments of Odisha and Jharkhand have initiated schemes, wherein vehicles at local levels are arranged by the Government through contracts. In Odisha, the State Government has initiated the 'Janani 201 Express' programme for pregnant woman and sick neonates; 4-wheel vehicles are hired locally on contractual basis for a period of one year.[13] Four hundred and sixty two Janani Express Vehicles have been engaged at various levels in health facilities.[14] In Rayagada, provisions for additional Janani Expresses were created under the IMR MMR Mission in the year 2016-17. The Mamta Vahan programme in Jharkhand, although created for the same purpose as Janani Express, works under a different structure. 24*7 call centres to access Mamta Vahans have been established in the DHs. Further, the vehicles have been arranged at the Panchayat level and all vehicle owners have a written agreement with the State Government.[15] However, the functioning of these two schemes needs further review and improvement. For instance, weak phone connectivity to Mamta Vahan call centres hinders access to the facility. Moreover, difficult terrain and poor road

conditions in some areas as well as the poor maintenance of the vehicles, which is the responsibility of the private vehicle owners, prevent the vehicles from reaching the location on time. In some districts, very few vehicles are available. In terms of coverage, some of the Janani Express vehicles have not reached 60 per cent of the time and even the drop back rate is as low as 40 per cent. The average patient transport for some Janani Express continues to be less than 20 per month.[16,17] Jharkhand is in the process of rolling out the National Ambulance Programme. Ambulance vehicles have been purchased and infrastructure procurement is under process.[18]

Transport is a major issue in most of the tribal areas, particularly in the hilly, forested and conflict areas, which makes it very difficult for patients to reach health services from their villages. Poor communication systems in these areas also make it challenging to contact the ambulance services during emergencies. During the interviews the respondents repeatedly shared the hardships they faced to reach health facilities. In the absence of timely availability of ambulances, a substantial number of the respondents had to spend large sums of money on alternative modes of transport. Transport for patients from the PVTG habitations to the nearest health facility is particularly critical; a mapping of the PVTG hamlets to ensure easy access to emergency transport and a functional communications system is urgently required.

Further, Mobile Medical Units (MMU) can be used effectively to cover remote PVTG hamlets, through a roster system, whereby they cover all the hamlets on specified dates; the dates/days of visit are well publicised so that the communities are able to access the services.

Jharkhand has 94 MMUs operational across the state, covering all 24 districts. There are three MMUs in each of the districts that are managed under Public Private Partnership (PPP) mode, wherein they provide services of OPD, drug dispensing and basic laboratory services. Chhattisgarh does not provide services through MMUs but proposes to provide mobile medical services through the 108 vehicles, which are unutilised.

Referrals necessitate an appropriate ambulance with oxygen facility and other equipment for the patient during inter-facility transfer. A protocol is critical so that referrals from one institution to the next are medically justified, reasons for which are mentioned clearly in a referral form addressed to a specific person in the institution that the patient is being referred to. The protocol must ensure that the onus of coordination of the referral, including

provision of the equipped ambulance, and communications with the institution to which the patient is being referred to, should be on the referring institution and not on the patients and their families. On completion of the referral, the institution that has been referred to should revert back with a record of the treatment provided to the referred patient. Referrals should be accompanied, especially in emergencies, i.e. a trained health worker should accompany patients, who have been referred to distant secondary or tertiary level facilities for treatment.

Referrals should not be premised on denial of care and refusal of treatment at primary and secondary level facilities, causing delays in treatment and consequent health complications for the patients.

## Dialysis services

With respect to dialysis services, the Central Government launched the Pradhan Mantri National Dialysis Programme, under which BPL populations have been exempt from user charges for availing dialysis services across all States.[19] The state governments of Jharkhand and Odisha are in the process of setting up services under the PPP model. In Jharkhand, the government is planning to set up modern dialysis units under the PPP at 18 district hospitals of the state on a priority basis. The process has already been initiated in eight sadar (district) hospitals in Ranchi, Dhanbad, Jamshedpur, Bokaro, Hazaribag, Dumka, Palamu and Giridih.[20] The Government of Odisha has developed the Sahay Programme under which as many as 127 dialysis machines will be installed in the PPP mode at 25 district headquarter hospitals and one community health centre at Narasinghpur in Cuttack.[21]

## Availability of medicines including blood

Most of the study respondents had to buy medicines from private pharmacies at considerable OOPE. This raises questions about the factors that contribute to the high prices of medicines and the inability of the central and state governments to provide free medicines as per existing policy mandates. These issues are particularly pertinent in the context of their availability, accessibility and affordability for the tribal communities, one of most impoverished populations in India. The study revealed that availability of medicines in the public health facilities in tribal areas is severely affected by poor supply, distribution and storage systems.

The PHCs and CHCs in the tribal areas frequently experience shortage of essential medicines such as iron folic acid, vaccines, zinc tablets, anti-rabies, antiserum for snakebites, etc.[22] This section attempts to analyse the policies and schemes of the Central Government as well as the State Governments of Chhattisgarh, Jharkhand and Odisha regarding the supply of free medicines in the public health system.

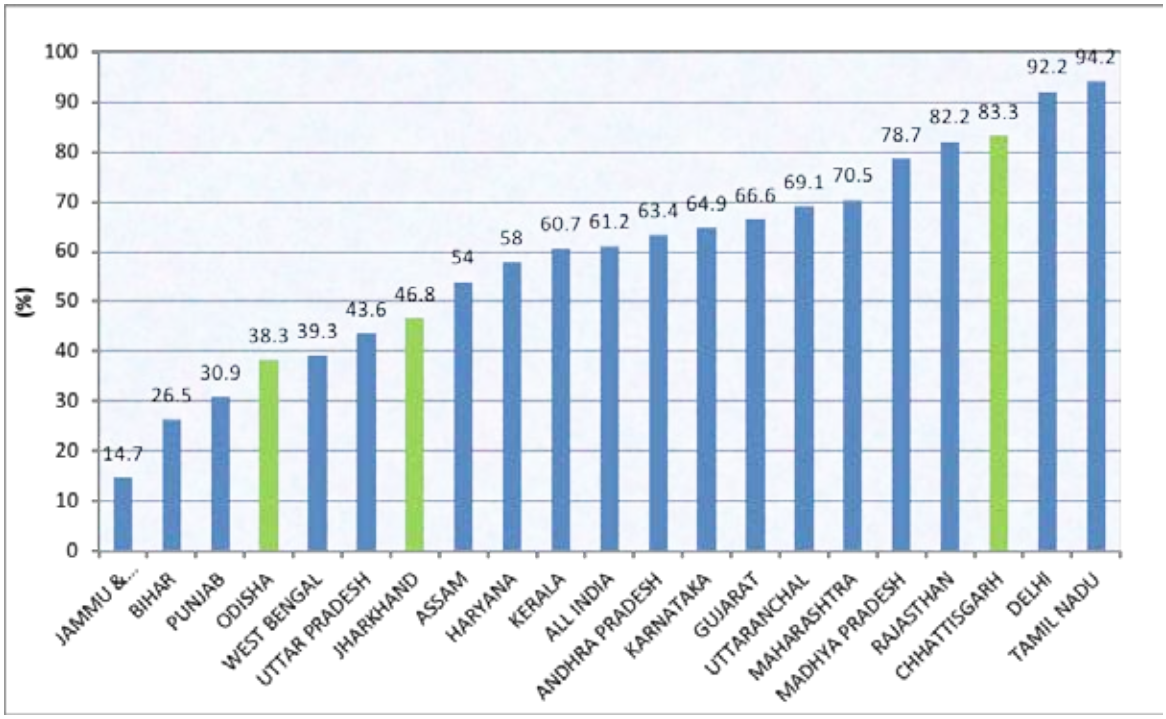
### *Free medicines schemes of the State Governments*

The governments of Odisha and Chhattisgarh have established free medicines schemes in their respective States. An autonomous corporation has been constituted to procure, supply and distribute medicines in Odisha and Chhattisgarh.[23] However, in Jharkhand the medicines are procured by the State Department of Health.[24] According to RHS data, among the study states, Chhattisgarh is ahead of other two states in terms of providing free medicines to patients at its public health facilities. The situation is quite different for states like Jharkhand and Odisha, where a substantial number of the people do not receive free medicines; merely 46.8 per cent people in Jharkhand and 38.3 per cent in Odisha respectively (Figure 6.7).

#### Free medicines schemes in Odisha

On 29 April 2015, the Government of Odisha announced the launch of 'Niramaya', a scheme for the free distribution of essential medicines to all patients, who approach the public health facilities. The Niramaya Scheme has laudable objectives – improving accessibility to essential medicines, reducing the financial burden and in the process reducing mortality and morbidity. As per the operational guidelines, patients can avail of 570 types of drugs out of

**Figure 6.7: Patients receiving free medicines in public facilities: 2014**




*Source: Unit records of NSSO 71st round: Morbidity and Health Care*

the essential drugs list, decided by the state, at district headquarter hospitals, health facilities below district level and medical colleges.[25] However, 50 per cent of these medicines are not found in these public facilities.[26] The scheme proposed 1,102 Drug Distribution Centres in 2013, but only 350 had been established by 2016.[27] The facilities required to distribute the medicines for the scheme to function effectively, are not in place in many CHCs and DHs. For instance, some hospitals do not have fully-automated drug distribution counters, while some drug distribution centres are not in a position to go online.[28] The transactions are not updated on the e-Niramaya portal on time. Drug stock-outs have been reported in various districts.[29] In some cases, the ANMs have found the storage facility to be insufficient. In certain districts, the health facilities have no storage facilities such as racks, shelves, etc., for drugs.


### Free medicines schemes in Chhattisgarh

In 2013, the Government of Chhattisgarh announced a policy guaranteeing access to free generic medicines in all its public health facilities. Earlier, Chhattisgarh had a decentralised model for the procurement of drug and medicines at the district level, but this model failed. In order to ensure availability of free generic medicines, the Chhattisgarh Government constituted the Chhattisgarh Medical Services Corporation Limited (CMSCL) for centralised procurement of drugs, improvement of supply chain management, and prevention of stock-outs and expiry of medicines.[30] The primary responsibility of CGMSCL is to procure, test, store and supply all kinds and varieties of generic drugs, suture and surgical items for the various health facilities.[31] It also engages in procurement, distribution, installation and maintenance of all types of medical equipment and instruments required in various health facilities in the state, along with designing and constructing hospitals and other buildings for the Department of Health, Government of Chhattisgarh.[32] With the establishment of the scheme for free medicines, modelled on the schemes in the states of Tamil Nadu and Rajasthan, Chhattisgarh also allocates funds to support and manage the scheme. A study by Tripathi et al., reports that Chhattisgarh has made considerable progress in increasing the access of patients to generic medicines at public health facilities.[33] The study revealed that 58 per cent of the patients surveyed had access to generic drugs at the public health facilities. About 35 per cent of the total medicines (both branded and generic) were purchased from private pharmacies. However, the study notes that there is a need to increase the financial resources for generic medicines, improve the supply chain and logistics for better

distribution, and mandate that physicians in these facilities prescribe generic medicines.[34] Though the Chhattisgarh and Odisha state governments have launched schemes for free medicines, which are run by autonomous corporations, medicines are still out of reach for the tribal population. For instance, hydroxyurea is essential for treatment of SCD. There are directives which require these States to make this medicine available at CHCs and DHs. The Essential Drug List (EDL) enlists this medicine as essential for the treatment of sickle cell anaemia. Despite this, the present study found that hydroxyurea was not available in the CHCs and DHs that were visited in both the States.

### Free medicines schemes in Jharkhand

In Jharkhand, the medicines are distributed through the state sponsored public scheme. The CAG report found that drugs such as paracetamol, B-complex and albendazole, were not available as per IPHS recommendations and the State essential list. Further it was also revealed that essential medicines/consumables required for RCH services, such as Vitamin-A, contraceptive pills, ORS packets, RTI/STI drugs, essential obstetric kits, etc., were not available in some of the health facilities.[35]

In 2016, the state announced a free cervical and breast cancer screening scheme for women in the state.[36] As per the scheme, the state government provides free screening for cervical and breast cancer patients as well as subsidised cancer treatment. The scheme was for women from households with a gross annual income of less than Rs 72,000. It also aimed to reach out to women across various socio-economic strata within two years. The government also announced that it would provide medical assistance of up to Rs 4 lakh for treatment under the Mukhyamantri Gambhir Bimaari Sahayata Yojana.[37] However, the details of the functioning of the scheme are not yet available.

The tenth Common Review Mission of NHM (2017), reports that in Jharkhand, all the facilities are providing free drugs to patients and the mandate of generic prescription is in place, but prescription auditing is not in practice, apart from the district hospitals.[38] Standard treatment guidelines are not available at the facilities other than district hospitals. District drug warehouse, Godda has a shortfall of drugs, in spite of having sufficient storage space and human resources.[39] It is not clear how the system of quality assurance for the supplies delivered at the health facilities is ensured. Finally, there is no mechanism in place to manage expired drugs, reagents and vaccines across the facilities in the district.[40]

### *National List of Essential Medicines (NLEM)*[41]

NLEM is a list of medicines prepared by the MoHFW based on essentiality. States like Odisha[42] and Chhattisgarh[43] have devised their own EDL containing drugs suited to state specific health needs. The Chhattisgarh EDL does not list fixed dose needs. The Chhattisgarh

EDL does not list fixed dose combinations and new drugs. It appears that this category of medicines will be introduced only when they are proven to be effective compared to the existing medicines.[44] While commenting on the EDL in Odisha, some of the doctors felt that the EDL was inadequate and not useful for treating certain conditions. They felt that patients were comfortable taking combination drugs and the EDL does not have those.[45] Prescribing drugs listed in EDL would increase the number of drugs that patients have to take, which they may find difficult to adhere to.[46] However, Jharkhand seems to be following the NLEM and has not developed any separate EDL.

To reduce the health expenditure on medicines, the state governments should take steps to ensure that medicines listed in the EDL are available free of cost in public health facilities, along with a cap on the price of essential medicines in the private market. In this regard, pricing and regulation of the cost of retail medicines becomes absolutely crucial for their affordability and for reducing the OOPE on medicines. Several concerted policy initiatives and interventions are required to reduce the individual spending on medicines in India. Evidence regarding insurance schemes introduced by the government indicates that despite the increased access to hospitals, health care expenses have not reduced.[47] Some states such as Tamil Nadu and Rajasthan exemplify efficient and reliable medicines supply chain models, which have been fundamental in improving access to medicines in frontline facilities, in these two states.[48]

## Public private partnerships for diagnostics and other services

To bridge the existing gaps in diagnostics and referral transportation, two of the study states have established programmes in the PPP model. In Jharkhand, the state government has outsourced its pathology diagnostic services to Medall and SRL diagnostics under the PPP model. In this model, Medall and SRL conduct tests that are not available at the facility where they are situated. Medall has been operating since August 2015 in 12 districts, namely, Lohardaga, Gumla, Khunti, Simdega, Palamau, Garhwa, Latehar, East Singhbhum, West Singhbhum, Seraikela and Kharswan, along with the MGM Hospital, Jamshedpur and Rajendra Institute of Medical Sciences (RIMS), Ranchi. The state government has signed the MoU with SRL diagnostics for the other remaining districts.[49] The diagnostic services are provided free to people living below the poverty line. For others, the rates are set to not exceed the CGHS rate fixed by the central government. In Odisha, the government initiated the 'Nidaan' programme to provide identified diagnostic services free of cost to all patients in the public health facilities of the state from 1 January 2018. Further, additional diagnostic services such as high-end pathology tests, digital X-rays, CT scans and MRIs were to be provided free of cost in government facilities in PPP mode by March, 2018.[50]

### *Analysing the efficacy of PPPs*

However, the efficacy of PPPs needs more debate and discussion. Concerns regarding the functioning of private parties in terms of their motives to maximize profit, the lack of concern towards public health goals, non-sharing of clinical information, and poor regulatory control have often been raised.[51] The argument in favour of PPPs states that the private sector is an 'untapped resource' with the skills, innovation and efficiency required to compete in the market.[52]

Adoption of PPPs with corporate social responsibility (CSR), voluntary services and pro-bono services in the underserved areas is projected by the National Health Policy (NHP) 2017 as an innovative, short term measure to cover critical gaps in health care delivery. However, these measures generally diminish the financial responsibility and the accountability of the State in providing the adequate budget as well as public health care services.[53] Despite the NHP 2017 proposal to increases state sector health spending to more than 8 per cent of their budget by 2020, the current budget does not allocate enough to improve the public sector and fails to incorporate costs that will emerge through contracts and purchase of services from PPPs.[54] Further, the use of 'short term' to define the duration of the partnerships remains unspecified.


Adoption of such partnerships at primary health care facilities has resulted in the reintroduction of user charges, to avail the services, albeit largely for those who are not in the BPL group.[55] However, both user fees as well as conditionalities for access are known to create barriers to health care. For instance, in 2016, the PPP between the diagnostic service provider, Medall and RIMS Ranchi faced a dispute of over Rs. 2.5 crores, which the hospital was due to pay to the service provider pertaining to the tests conducted. A report by The Telegraph, dated 8th July 2016 stated that three patients from underprivileged communities, who were eligible for the tests free of cost, had to provide a No Objection Certificate (NOC) from the Deputy Superintendent of the hospital on their prescriptions, to receive the medicines free of cost. Any pathological test conducted without the approval of the deputy superintendent was unauthorised and, thus, not free. Additionally, a second clause mentioned that the tests provided by Medall should not be available at the hospital. Thus, flouting of these norms delayed the procedure of payment and resulted in a dispute between the two parties.[56]

In terms of monitoring and evaluation mechanisms, the contractual workers in PPPs are subject to lower pay and poor working conditions. The implications of the lack of a proper monitoring mechanism also reflect in terms of quality control of services such as diet services and occupation safety standards of the sanitary workers, making it imperative to build the capacity and expertise of the government at various levels in designing and managing partnerships, especially in terms of the MIS, incentives and penalties.[57,58] Studies have also provided insights into the lack of experience in formulating PPPs on the part of the public sector, whereby the loopholes in contracts have led to distorted cost sharing models, with the private partners garnering big gains over a long period of time.[59] Further, studies have also demonstrated how private players initially accept the stringent terms of the PPPs while bidding, and later recover by demanding a renegotiation of the contract.[60] Even though the PPPs today are evolving faster than ever, with the government encouraging private investment in health care, the evidence points to several concerns especially with regard to the quality of care and the accountability of private service providers in PPPs. Thus, increased investment by the State in strengthening the overall public health sector is of utmost priority and should not be replaced by PPPs.

## 6.3 Private practice

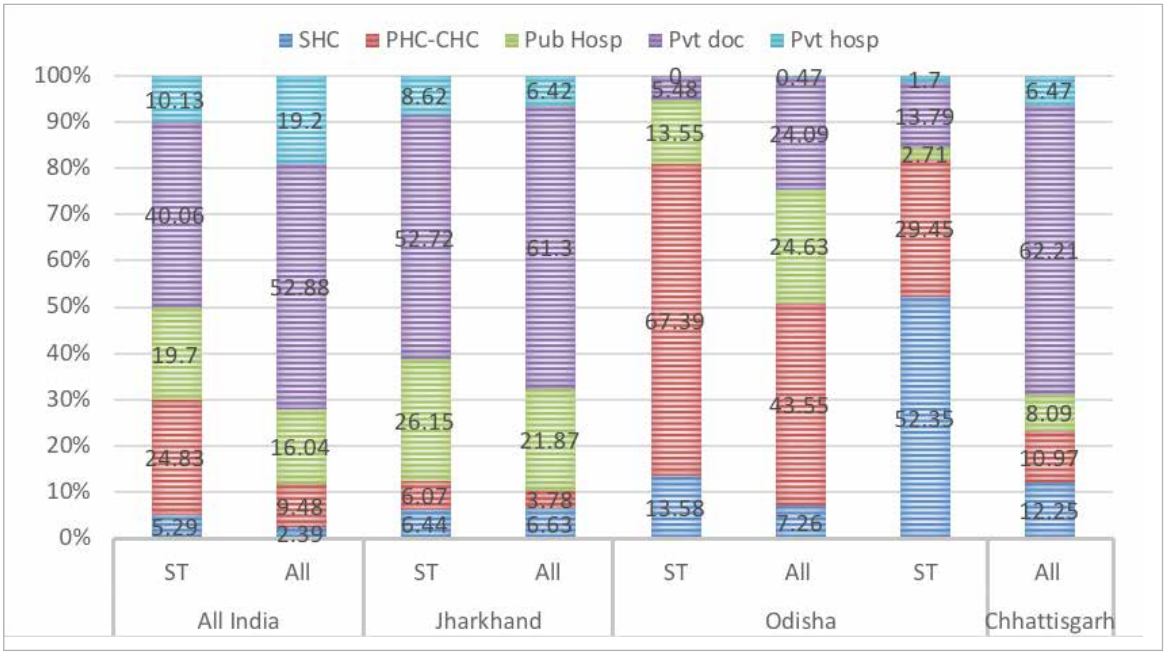
In a few districts, it was observed that the doctors attached to government health facilities referred patients to their private practice or clinics. Some states are following the central norm and giving their doctors (in government facilities) Non-practicing Allowance (NPA), whereas some states allow their doctors to practice after duty hours. However, in certain states, those doctors working on a contract basis are not paid any NPA, and hence allowed to carry on private practice after their duty hours. Given the paucity of doctors in the tribal areas as well as the several concerns and malpractices that it leads to, private practice should be discouraged for doctors in permanent posts in government health facilities. In 2017, the National Human Rights Commission (NHRC) asked the Odisha Human Rights Commission (OHRC) to initiate action as per a petition filed against illegal private practice of Government medical officers during duty hours.[61]

## 6.4 Utilisation and access to health services

Out-patient care of various kinds is commonly used by people and constitutes the major burden of health care. For this analysis, unit records of NSSO 71st round have been used, which categorises facilities into SCs, PHCs and CHCs, public hospitals, private doctors or clinics and private hospitals – the latter two being private and the rest being public. Figure 6.8 depicts the place of seeking outpatient care services for tribal population in rural areas, compared with all other social groups.

As is the case with the all-India level, use of public facilities is much higher among the tribal population compared to all groups; the study states are no different. In Odisha, where dependence on public facilities is generally higher compared to other states, tribal people avail public services for almost 94 per cent of OP care. Use of private doctors is the most common practice (53 per cent) for seeking OP care in the country. The proportion is much higher in Chhattisgarh (62.2 per cent) and Jharkhand (61.3 per cent). It is important to note that compared to all social groups, tribal people depend very little on private doctors in Chhattisgarh (14 per cent). The situation is very different in the case of Jharkhand, where

**Figure 6.8: Utilisation of OP care by type of provider in rural areas (%): 2014**




*Source: Unit records of NSSO 71st round: Morbidity and Health care*

more than half of the tribal people go to private doctors for OP care. One of the factors responsible for greater use of private doctors could be the sheer lack of public facilities in Jharkhand, which we have highlighted repeatedly in the previous sections.

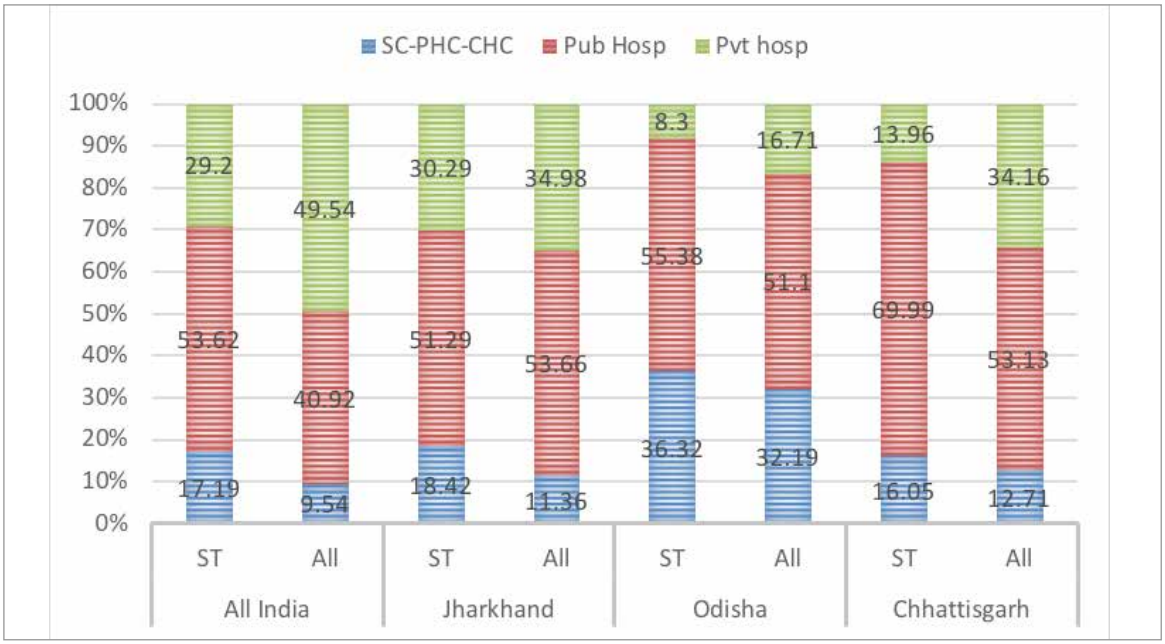
The use of public facilities is much more for hospitalisation care, compared to OP care. More than 70 per cent of hospitalisation needs of tribal people are taken care of in public facilities at the national level. Almost 6 out of every 7 hospitalisation cases for tribal people happen in public hospitals in Chhattisgarh and 11 out of 12 in Odisha (Figure 6.9). This higher dependence of tribal people on public services for both OP and hospitalisation care, despite the poor state of affairs calls for the need to improve public facilities in tribal areas.

## Institutional deliveries

Several authors have pointed to increasing institutional deliveries under NRHM in states. Data from the study states also suggest that the majority of the deliveries are happening in

institutions. However, dependence on home delivery among tribal women is significant. For instance, more than half of the deliveries in Jharkhand happen at home. However, those who choose to go to institutions prefer public facilities over private ones. In Odisha, 97 per cent

**Figure 6.9: Utilisation of hospital services by type of provider in Rural areas (%)**

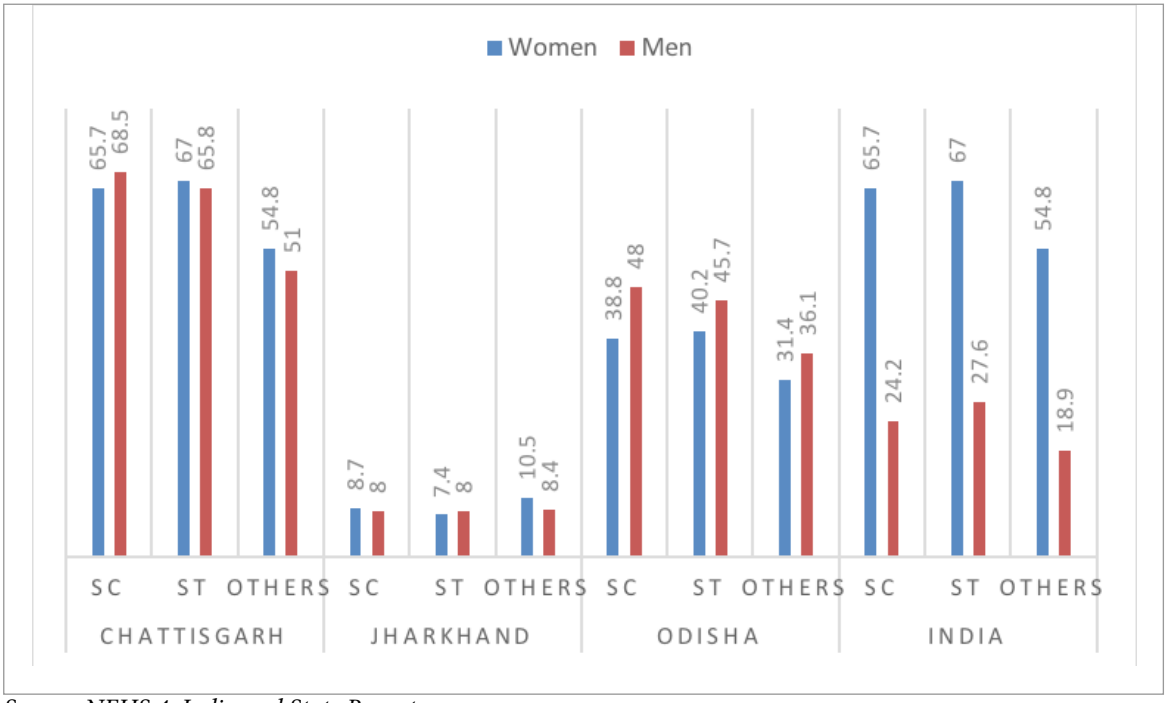



*Source: Unit records of NSSO 71st round: Morbidity and Health care*

of all institutional deliveries and 71 per cent of all deliveries for tribal women take place in public hospitals. In Chhattisgarh the ratios are 90 per cent and 56.5 per cent respectively. State sponsored health insurance programmes have been initiated by the central and state governments in the last decade or so as a means to improve access to hospitalisation services, particularly in the private sector and to ensure financial protection. Several authors have pointed out the limitations of these schemes in ensuring financial protection, including creating several layers of exclusion. There remain significant variations across states in terms of coverage. For instance, in Jharkhand coverage of insurance and other government schemes is as low as 8 per cent for ST men and 7.4 per cent for ST women (Figure 6.10). Coverage of these schemes is quite high in Chhattisgarh, in fact higher than the national average. In Odisha a third to half of the people are covered under insurance, depending upon their gender and caste differences.

Despite claims of ensuring cashless hospitalisation for the poor in private facilities, the state sponsored insurance schemes have failed to protect people from the high expenses of hospitalisation care in private facilities. Latest data from NSSO suggest that there is very little reduction in OOPE while accessing private facilities with insurance protection. As depicted in Figure 6.11, both in the case of Jharkhand there is actually an increase

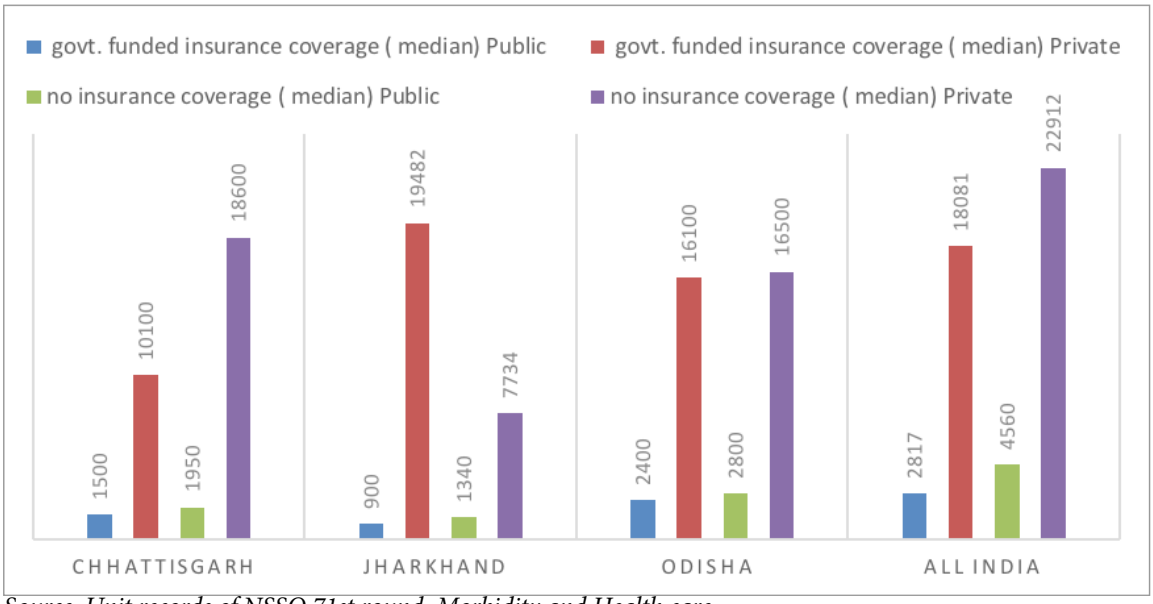
**Figure 6.10: Coverage of health insurance and other government schemes among SC, ST men and women: 2015-16**




*Source: NFHS 4, India and State Reports*

in OOPE per hospitalisation episode, if one accesses private facilities with insurance (Rs. 19,482) compared to those without insurance, (Rs. 7,734). In case of Odisha, the reduction in OOPE is only marginal – from Rs. 16,500 to Rs. 16,100. If a poor person does not possess insurance, s/he is more likely to go to a public facility. In all the three states, as is the case with the national average, hospitalisation costs in public facilities are significantly lower without insurance compared to a situation where they access care in private facilities

**Figure 6.11: Out-of-pocket expenditure per hospitalisation episode: 2014**




*Source: Unit records of NSSO 71st round: Morbidity and Health care*

with insurance. Across all the three states, a patient spends the least on hospitalisation when s/he has insurance and is able to access care in public facilities. Even though public health facilities in the study states are not adequately equipped, it remains the most trusted among tribal people. Hence, investment in creating the necessary infrastructure and services in public facilities is critical rather than expending financial resources settling insurance claims for private sector hospitals.

## 6.5 Community involvement and patient-centric health care

The Declaration of Alma Ata in 1978 recognised the significance of community participation in deciding and planning and implementing health care. In keeping with the vision, the NHM envisages increased spaces for community participation in the form of public participation in the management of district health societies, hospital development societies and village health committees. But in most situations the community representative is not appropriately selected, the powers provided are inadequate, and there is no effort to build their capacities. NGOs, patient groups are almost completely excluded from processes of programme development, implementation, monitoring and evaluation.[62]

Further, the community monitoring system is often tokenistic and has been rolled out in less than five per cent of the blocks across the country.[63] There lies a significant gap in involving the community in the health system and this is particularly true for tribal communities. It is thus important to ensure engagement of the community members, their representatives and the community based organisations in developing policies, schemes, district plans to ensure the incorporation of the requirements of local communities. Involving them in planning and monitoring as equal stakeholders rather than mere passive recipients without any agency is vital.

## Conclusion

Health is a state subject and the state governments have the power to make laws on issues relating to health. Each state, therefore, has its own health care delivery system. While states are responsible for the functioning of their respective health

care systems, certain responsibilities also fall on the central government, namely aspects of policy making, planning, guiding, assisting, evaluating and coordinating the work of various provincial health authorities and providing funding to implement national programmes. This chapter points to the huge shortfalls in health infrastructure, human resources, across the three states that is established by demographic data analysis. The situation on the ground evident from the present study, appears to be worse, especially in the context of tribal areas and population. Moreover, the latter are disproportionately impacted by the weak infrastructure and services of the public health system as well as privatisation initiatives, given their huge reliance on the public health system.

## Endnotes


1. Kumar, A., & Gupta, S. (2012). *Health Infrastructure in India: Critical Analysis of Policy Gaps in the Indian Healthcare Delivery.* Vivekananda International Foundation. Retrieved April 17, 2018, from https://www.vifindia.org/sites/default/files/health-infrastructure-in-india-critical-analysis-of-policy-gaps-in-the-indian-healthcare-delivery.pdf.
2. *Indian Public Health Standards (IPHS); Guidelines for Sub-Centres; Revised 2012.* (2012). Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
3. *Indian Public Health Standards (IPHS); Guidelines for Primary Health Centres; Revised 2012.* (2012). Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
4. *Indian Public Health Standards (IPHS); Guidelines for Community Health Centres; Revised 2012.* (2012). Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
5. *Indian Public Health Standards (IPHS); Guidelines for District Hospital (101 to 500 bedded); Revised 2012.* (2012). Retrieved May 28, 2018, from Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
6. *Indian Public Health Standards (IPHS); Guidelines for Primary Health Centres; Revised 2012.* (2012). Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
7. *Indian Public Health Standards (IPHS); Guidelines for Community Health Centres; Revised 2012.* (2012). Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
8. *Indian Public Health Standards (IPHS); Guidelines for District Hospital (101 to 500 bedded); Revised 2012.* (2012). Retrieved May 28, 2018, from Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
9. *Evaluation of Accredited Social Health Activists (ASHA),* NHSRC and ASHA monitoring group, Ministry of Health and Family Welfare, Press Information Bureau , Government of India, 27-February-2015 12:14 IST, Link - http://pib.nic.in/newsite/PrintRelease.aspx?relid=116029
10. List of Drugs being provided in ASHA Kit. (n.d.). Retrieved from http://nhm.gov.in/communitisation/asha/list-of-drugs-being-provided-in-asha-kit.html
11. *Evaluation of Accredited Social Health Activists (ASHA),* NHSRC and ASHA monitoring group, Ministry of Health and Family Welfare, Press Information Bureau , Government of India, 27-February-2015 12:14 IST, Link - http://pib.nic.in/newsite/PrintRelease.aspx?relid=116029

12. *Indian Public Health Standards (IPHS); Guidelines for Primary Health Centres; Revised 2012.* (2012). Directorate General of Health Services. Ministry of Health & Family Welfare. Government of India.
13. 102 Services; National Health Mission. Department of Health and Family Welfare. Government of Odisha. (n.d.). Retrieved May 24, 2018, from http://www.nrhmorissa.gov.in/frm102Services.aspx
14. Ibid.
15. *Mamata Vahan, Jharkhand.* (n.d.). Centre for Innovations in Public Systems - Health. Retrieved from http://www.cips.org.in/documents/DownloadPDF/downloadpdf.php?id=287&category=Health
16. 102 Services; National Health Mission. Department of Health and Family Welfare. Government of Odisha. (n.d.). Retrieved May 24, 2018, from http://www.nrhmorissa.gov.in/frm102Services.aspx
17. *Mamata Vahan: Reducing the delay of reach.* (n.d.). India: National Health Systems Resource Centre. Retrieved from http://nhsrcindia.org/sites/default/files/Mamata Vahan - Reducing delay in reach Jharkhand.pdf
18. 329 ambulances to hit Jharkhand streets before March. (2017, November 20). The Free Press Journal. Retrieved from http://www.freepressjournal.in/business/329-ambulances-to-hit-jharkhand-streets-before-march/1173341
19. *9th Common Review Mission* (Rep.). (2015). Retrieved May 28, 2018, from Ministry of Health and Family Welfare. Government of India. Website: http://nhm.gov.in/images/pdf/monitoring/crm/9th-crm/Report/9th_CRM_Main_Report.pdf
20. CM pushes for dialysis units in 18 sadar hospitals. (2016, April 6). *The Times of India*. Retrieved May 28, 2018, from https://timesofindia.indiatimes.com/city/ranchi/CM-pushes-for-dialysis-units-in-18-sadar-hospitals/articleshow/51708774.cms
21. Odisha govt launches 4 new health schemes. Here are benefits. (2017, December 19). *Odisha Sun Times*. Retrieved May 28, 2018, from http://odishasuntimes.com/odisha-govt-launches-4-new-health-schemes-here-are-benefits/
22. *Report on visit of the Districts Gumla and Simdega of Jharkhand by a team of the Commission from 7th to 10th July, 2015 to oversee the Implementation of various Flagship Programmes of the Central and the State Government.* Available at http://nhrc.nic.in/Documents/Reports/misl_gumla_simgeda_flagship_7-10july2015.pdf
23. *Chhattisgarh Drugs and Medical Supplies Policy.* (n.d.). Chhattisgarh: State Health Resource Centre. Retrieved from http://www.shsrc.org/webupload/PUBLICATION/POLICY_HEALTH_SYSYTEM/CG_DRUG_AND_MEDICAL_POLICY.pdf
24. Department of Health, Medical Education & Family Welfare. Jharkhand (n.d.). Retrieved from http://www.jharkhand.gov.in/health-department#;file:///C:/Users/User/Downloads/e- Procurement Tender Notice for Medicines (1).pdf;
25. Niramaya headache for Odisha. (2017, December 17). *The Telegraph.* Retrieved from https://www.telegraphindia.com/states/odisha/niramaya-headache-for-odisha-194079
26. Ibid.
27. Gouranga Ch. Mohapatra, *Free medicine "NIRAMAYA" scheme in Odisha: Field reality.,* Presentation at Short Course on Challenges to Access to Medicines by Sama-Resource Group for Women and Health on 17 August 2017.
28. Ibid.
29. Draft Drug Stock Out Assessment. Department Of Health & Family Welfare Government Of Odisha. (2014, November). Retrieved from http://www.nrhmorissa.gov.in/writereaddata/Upload/Documents/12.
30. Chhattisgarh Medical Services Corporation Limited (CGMSCL). (n.d.). Retrieved May 28, 2018, from http://cgmsc.gov.in/Home/HomePage.aspx
31. Ibid.
32. Ibid.
33. Tripathi, N., Kerketta, F., Chatterjee, P., Raman, V. R., John, D., &Jain, K. (2018). Access and availability of essential medicines in Chhattisgarh: Situation in public health facilities. *Journal of Family Medicine and Primary Care,* 7(1), 152.
34. Ibid.

35. Performance Audit of Reproductive and Child Health under National Rural Health Mission(Vol. 25, Rep.). (2017). Retrieved May 27, 2018, from https://cag.gov.in/sites/default/files/audit_report_files/Chapter_4_-_Availability_of_medicine_and_equipment_of_Report_No.25_of_2017_-_Performance_audit_Union_Government_Reproductive_and_Child_Health_under_National_Rural_Health_Mission_Reports_of_Ministry_of_.pdf
36. Ranchi: Free cancer check, subsidized treatment for BPL women. (2016, February 6). *Health World from The Economic Times.* Retrieved from https://health.economictimes.indiatimes.com/news/policy/ranchi-free-cancer-check-subsidized-treatment-for-bpl-women/50834839
37. Ibid.
38. 10th Common Review Mission report (2016). National Health Mission. Ministry of Health and Family Welfare, Government of India.
39. Ibid.
40. Ibid.
41. The NLEM is a powerful tool in the actualisation of highest standard of health and reducing the irrational usage of drugs. The medicines are selected with due regard to the public health relevance, evidence of efficacy and safety and comparative cost-effectiveness. . There are 209 medicine formulations listed which should be available in all levels of health care (primary, secondary and tertiary), 115 medicine formulations for secondary and tertiary levels and 79 medicine formulations for the tertiary level. Though, these medicines ought to be available free of cost in public health systems, in reality it is not so. For instance, Trastuzumab, anti-cancer drug (breast cancer) is not available in all public health systems, even though it is listed under the NLEM. Moreover, certain important essential drugs, such as bedaquilin and delamanid for second line TB, are not listed under the NLEM. Although these medicines may be available in private health facilities and private retail pharmacies, they are often unaffordable due to their exorbitant costs, acting as a barrier for affordable healthcare.
42. *Essential Drug List - 2014.* (n.d.). Odisha State Medical Corporation Limited. Retrieved May 28, 2018, from http://osmcl.nic.in/sites/default/files/Essential Drug List 2014.pdf
43. *Essential Drug List - 2013.* (n.d.). Chhattisgarh: Deaprtment of Health and Family Welfare. Retrieved May 28, 2018, from http://cghealth.nic.in/ehealth/2013/miscellaneous/EDL-2013Final.pdf
44. Chhattisgarh Drugs and Medical Supplies Policy. (n.d.). Chhattisgarh: State Health Resource Centre. Retrieved from http://www.shsrc.org/webupload/PUBLICATION/POLICY_HEALTH_SYSYTEM/CG_DRUG_AND_MEDICAL_POLICY.pdf
45. Rapid Assessment of Drug Availability and Stock-out at Government Health Facilities,http://www.nrhmorissa.gov.in/writereaddata/Upload/Documents/12.%20Draft%20Drug%20Stock%20Out%20Assessment,%20including%20recommendations%20for%20the%20procurement%20system,%20identification%20of%20issues%20arising%20and%20mitigation%20plan,%20agreed%20with%20DHFW.pdf
46. Draft Drug Stock Out Assessment. Department Of Health & Family Welfare Government Of Odisha. (2014, November). Retrieved from http://www.nrhmorissa.gov.in/writereaddata/Upload/Documents/12
47. Prinja, S., Chauhan, A. S., Karan, A., Kaur, G., & Kumar, R. (2017). Impact of publicly financed health insurance schemes on healthcare utilization and financial risk protection in India: a systematic review. *PloS one,* 12(2), e0170996.
48. Singh, P. V., Tatambhotla, A., Kalvakuntla, R., & Chokshi, M. (2013). Understanding public drug procurement in India: a comparative qualitative study of five Indian states. *BMJ open, 3(2),* e001987.
49. State Govt Inks MoU With Medall Healthcare. (2015, May 9). *The Pioneer.* Retrieved May 28, 2018, from http://www.dailypioneer.com/state-editions/ranchi/state-govt-inks-mou-with-medall-healthcare.html
50. Odisha govt launches 4 new health schemes. Here are benefits. (2017, December 19). *Odisha Sun Times.* Retrieved May 28, 2018, from http://odishasuntimes.com/odisha-govt-launches-4-new-health-schemes-here-are-benefits/
51. Raman A.V., Björkman J.W. (2015) Public-Private Partnerships in Healthcare. In: Kuhlmann E., Blank R.H., Bourgeault I.L., Wendt C. (eds) The Palgrave International Handbook of Healthcare Policy and Governance. Palgrave Macmillan, London.
52. Ibid.
53. Roy, B. (2017, March 20). Why Public-Private Collaboration is Bad News For Healthcare in India. *The Wire.* Retrieved May 30, 2018, from https://thewire.in/health/ppp-healthcare-health-policy

55. Ibid.
56. Private lab in RIMS bill mess - Norms flouted for tests for the poor, Rs 4 crore stuck. (2016, July 8). *The Telegraph.* Retrieved May 30, 2018, from https://www.telegraphindia.com/1160708/jsp/jharkhand/story_95371.jsp
57. Roy, B. (2017, March 20). Why Public-Private Collaboration is Bad News For Healthcare in India. *The Wire.* Retrieved May 30, 2018, from https://thewire.in/health/ppp-healthcare-health-policy
58. Raman A.V., Björkman J.W. (2015) Public-Private Partnerships in Healthcare. In: Kuhlmann E., Blank R.H., Bourgeault I.L., Wendt C. (eds) The Palgrave International Handbook of Healthcare Policy and Governance. Palgrave Macmillan, London.
59. Kishore, R. (2016, June 3). The dangers of relying on PPP; Public-private partnerships have had a chequered record across the world. *Live mint.* Retrieved May 30, 2018, from https://www.livemint.com/Sundayapp/TIkphu70hpPwV6QifPxbjO/The-dangers-of-relying-on-PPP.html
60. Ibid.
61. National Human Rights Commission direction on private practice by Government doctors in duty hours. (2017, July 31). *The New Indian Express*. Retrieved March 7, 2018, from http://www.newindianexpress.com/states/odisha/2017/jul/31/national-human-rights-commission-direction-on-private-practice-by-government-doctors-in-duty-hours-1636024.html
62. *Realising the Right to Healthcare: A Policy Brief*. (2014). Jan Swashtya Abhiyan.
63. Ibid.

## Chapter 7

# Conclusion and Recommendations

The Constitution of India envisages that equality before the law, equal protection of the law and the right to life,[1] including the right to live with dignity, which are the fundamental tenets underpinning effective governance by the State.[2] The right to live with dignity includes the right to be free from hunger; to receive health care; to obtain free public education; to liberty; to freedom of movement; to a fair, public and speedy trial; to privacy, etc. The Directive Principles of State Policy (DPSP) also oblige the state to take steps progressively to improve the social and economic conditions of citizens by facilitating the right to earn a living by working, to have safe and healthy working conditions, to social security and to have adequate housing etc. In the context of tribal communities, the State is particularly obliged to ensure the fulfillment of their rights.[3]

Starting from the Bhuria Commission (2002), which elucidated its expert thoughts on the issues of tribal health and medical services in its report,[4] several Committees that looked into tribal issues have highlighted substantial concerns with regard to the situation of the tribal people in the country.[5,6,7] The Xaxa Committee report of the High Level Commission (HLC) by the Government of India (GOI, 2014) made an important observation that "although numerically only about 8.6 per cent, they disproportionately represent the people living below the poverty line, are illiterate and suffer from extremely poor physical health". The suboptimal health status of tribal communities and the health inequalities between tribal and non-tribal populations are also inevitable and reflect a fundamental failure to ensure the freedom of tribal people to fully realise their human, social, economic, and political capabilities.

While the National Health Mission (NHM) seeks to provide universal access to health care, the situation of tribal communities continues to be very distant from this reality. Despite the efforts made by the NRHM and thereafter by the NHM, the present study by Sama, commissioned by the National Human Rights Commission (NHRC) reinforces this. The tribal people are amongst the poorest and most marginalised, experiencing extreme deprivations, including poverty and ill-health. The non-availability of essential diagnostics, drugs, inadequate infrastructure, human resources, the lack of transport and communications facilities are rampant and impact the health and health care of these communities. In the tribal areas, the local indigenous practitioners, as well as (often) unqualified, medical practitioners, who are available in or near tribal habitations are the first points of contact for health care. Moreover, amongst the PVTGs, there was notable reliance on local knowledge

and practices for health care, as was seen in the course of the study. While the acceptance of modern medicine has increased in the recent years among the tribal communities, access to quality care continues to be a major issue. The non-availability of health care closer to the tribal people continues to persist, denying timely access to quality care. Ideally, communities residing in remote or arduous locations should be able to access health services within their villages or in accessible proximity to avoid delays or expenses caused by the need to travel long distances. Infrastructure development should, therefore, reflect the needs and the accessibility of the population in a particular region. Further, an improved understanding of the epidemiology of tribal areas and communities is necessary to delineate the health needs of the tribal population. The participation of the tribal populations in processes of planning and in decisions regarding their health and health care is also core to a robust public health programme.

Currently, however, the budget allocation towards providing accessible, affordable and equitable quality health care to all, is abysmal. The Union government's allocation for the health sector, as a share of the GDP, has seen only a marginal increase from 0.26 per cent in 2016-17 to 0.30 per cent in 2017-18. This has not only fallen short of meeting the long-standing demand of increasing the allocation for the health sector to 2.5 per cent of the GDP, articulated in the National Health Policy (NHP) 2017, but also reflects the government's stance on health care in general. In order to bring about any significant change in the health situation in the country, the government must, therefore, prioritise the health system, and ensure adequate budget allocation towards its strengthening. Moreover, an increase in the allocation of financial resources to improve the health of tribal communities is an urgent priority.

As the Xaxa report concludes, "Tribal communities face disregard for their values and culture, breach of protective legislations, serious material and social deprivation, and aggressive resource alienation" and recommends, "Any solution, therefore, should begin with confidence-building measures through the redress of past wrongs and the guarantee of justice. This is necessary in order to restore the trust of the tribals in the government" (pg 32, ibid).[8] Government must tak cognisance of tribal communities right to health, as enshrined in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). The State has the responsibility to prioritise health of the tribal communities particularly of PVTGs while formulating laws and policies on factors that affect health and health care.

## 8.1. Recommendations

The recommendations are primarily based on the respondents narratives of their experiences in accessing health care. Within the domain of health problems, the recommendations have covered only those that emerged from the study and a few which were drawn from the

secondary sources that were also reviewed during the study. Although the recommendations are specific to health system, a few of the social determinants that emerged from the study are also included. However, the scope of the study objectives did not include an in-depth inquiry into many of these social determinants such as conflict, migration and displacement, which have a crucial impact on the health status of tribal communities. Each of them as well as their inter-sections requires further in-depth inquiry.

The health system generally reinforces the power asymmetry between providers and 'patients'; the persistent inaccess to comprehensive information about their health (symptoms, prevention, treatment, etc.), the lack of proactive processes to enhance the knowledge about their entitlements, denies people their agency and often renders them passive, within the health system. The providers, given the biomedical character/orientation of the health system, may have a limited understanding of local ecologies and contexts. They are often ill equipped to sensitively deal with the issues of patients who come from distinct socio-cultural backgrounds, including tribal communities.

For health programmes and policies to be effective, especially for tribal and other marginalised communities, it is imperative to take into account the perspectives, experiences and opinions of those who will be impacted by them. Communities and particularly the affected/'patients' should be invited to join the debates and discussions around health facilities, at the district level and upwards. Bridging the lay-expert divide and involving the voices of the last mile, will the policies and programmes be truly effective.

Since the focus of the study is on health and health care, the primary recommendations, are directed towards the Union Ministry of Health and Family Welfare (MoHFW), and also to the State health ministries of Chhattisgarh, Jharkhand and Odisha. Some of recommendations are also directed to the Ministry of Tribal Affairs (MoTA), the Ministry of Women and Child Development (MWCD), the Ministry of Roads, Transport and Highways, Ministry of Mines and Geology, Ministry / Department of Environment, Forest and Climate Change, given the multi-sectoral response required for tribal health issues.

The recommendations have been organised under the following sections:

8.a. Health system issues – both infrastructural and human resources

8.b. Specific health problems and illnesses

8.c. Monitoring and Data for Accountability of health care services

8.d. Social determinants of health

8.f. Policy directives, planning, and convergence

8.g. General Recommendations

## 8.a. Health systems issues – infrastructure and human resources

The first part of the section provides recommendations for SCs, PHCs, CHCs and DHs, many of which are common to all the facilities while some pertain to specific facilities such as transport, free diagnostics, medicines, infrastructure and population norm flexibilities, etc. The second part provides recommendations for frontline health care workers, primarily ASHAs, AWWs and ANMs.

### *Sub Centre and the Health and Wellness Centres (wherever rolled out)*

1) Implement the current relaxed population norms for tribal, forest or geographically arduous areas, particularly in areas where PVTG live.

2) Establish norms for the location of SCs, not merely based on population norms but also determined by their proximity to the communities.

3) Upgrade SCs to Health and Wellness Centres to provide comprehensive primary health care at the community level or proximal to the community.

4) Strengthen the physical infrastructure of the SCs: provide government buildings, regular water and electricity supply, drugs, appropriate diagnostics (for e.g. RD kits) etc.

5) Address all shortfalls in skilled human resources; train and recruit mid- level managers for health care delivery.

6) Establish and implement clear protocols for referral to a primary, secondary or tertiary level health care facility; develop systems to make referrals accountable, including provision of free ambulance and continuity of care through 'accompanied transfers' (by skilled paramedical or health care provider), especially in emergency health situations.

7) Ensure availability of well-equipped ambulance services (with oxygen, and other emergency care equipment, and essential medicines), to manage health complications in transit, given the distances and terrain in tribal areas,

8) Disseminate widely the schedules of the MMUs and any other services proposed to be provided through health workers as well as other means so that the communities are able to access services being provided in the community.

9) Ensure that the SCs/Health and Wellness Centres are resourced and their capacities are built to offer a broad range of health care services:

   (a) Health education;
   (b) Care during pregnancy and child birth;

(c) Neonatal and child health care services, including immunisation and management of sick infant;
(d) Adolescent health care services;
(e) Reproductive Health Care services, including contraceptive services;
(f) Management of common communicable diseases and general out-patient care for simple illnesses and minor ailments;
(g) Management of Communicable diseases: National Health Programmes;
(h) Screening and Management of Non-Communicable diseases;
(i) Counselling, particularly with respect to substance abuse and nutrition;
(j) Care for Common Ophthalmic and ENT problems;
(k) Basic Dental health care;
(l) Geriatric and palliative health care services;
(m) Trauma Care (that can be managed at this level) and Emergency Medical services;
(n) Referral;

10) Provide free public transport from panchayat/village level in tribal areas for accessing health facilities, with regular maintenance and functioning of the to be coordinated by the gram panchayat committee in collaboration with the health department.

11) Recruit and train local ST/PVTG girls/women and boys/men as multi-purpose male/female health workers; each district must have a training institute for male and female multi-purpose health workers exclusively for the needs of tribal areas.

## Primary Health Centres (PHCs)

1) Ensure further relaxation of the existing population norm (current: one per 20,000 population in tribal areas) given the scattered nature of villages and habitations in tribal areas; ensure strict implementation of the norm.

2) Recruit and train health care staff from the tribal communities; towards this end provide additional incentives and relaxation of the recruitment norms.

3) Fill vacancies on a priority basis in the tribal areas, given the significant reliance of communities on public health facilities proximal to the tribal areas.

4) Establish and implement a cadre of a mid-level providers to address the acute shortage of human resources, especially doctors, both MBBS and specialists in PHCs and CHCs.

5) Ensure accommodation for all the staff working in remote hamlets in hilly terrains and forest areas, from where daily commuting to block/district headquarters is challenging.

6) Ensure PHCs in tribal areas are functional with qualified MBBS doctor/s.

7) Ensure services by gynaecologists in the PHCs at least three days in a week (desirable all five days) to provide services to pregnant and lactating women.

8) Provide adequate transportation and ensure resources for maintenance of vehicles and equipped ambulances (for transportation of patients to other health care facilities) in PHCs in tribal areas as they have to cover vast areas and difficult terrains.

9) Dedicated vehicles should be attached to each PHC for transport or outreach of health care providers; male health workers and female health assistants should be provided with two wheelers, so, that they can move in the tribal area with ease and implement/supervise various health programmes, vaccination, immunisation, etc.

10) Extend and reschedule the working hours of the PHCs in the tribal hamlets to ensure services in the morning and evening so as to facilitate access as well as prevent loss of work and wages in the areas.

11) Medical Officers in the PHCs should be adequately compensated by allowances and other facilities and incentives, like out of turn promotion, preference in PG admission and after a fixed tenure (service) in a tribal area, a posting of his/her convenience.

## Community Health Centres (CHCs)

1) Ensure that specialists are available at the CHC through relaxation of eligibility criteria for the posting of specialists. Short-term arrangements can be made where MBBS doctors who have received short-term training or have relevant experience of at least two years in the particular speciality can be recruited to fill the vacancies for specialists.

2) Ensure that each CHC has adequate ambulances and vehicles based on population covered / case load to transport patients to facilities and for further referrals if required.

3) Ensure that all CHCs in the tribal areas provide services like X-ray, dental X-ray and ultrasonography (USG), electrocardiogram (ECG) with the necessary technicians.

4) Ensure that solubility tests and electrophoresis for SCD diagnosis is available in CHCs in tribal areas, along with free medicines, appropriate storage and blood transfusion facilities.

5) Ensure that all services, including diagnostics for all, especially patients from tribal communities are provided free, without any user charges.

6) Ensure that all CHCs in tribal areas have functional blood storage units with the minimum requirement of blood (which should be double the number of units that of the average daily requirement) available at all times.

7) Ensure that user charges and replacement is not imposed as a condition for blood transfusion services for maternal and other conditions, such as haemoglobinopathies.

8) Ensure that services like minor surgeries and c-sections are available at the CHCs around the clock; ensure that a roster is maintained (resource pooling can be carried out) for doctors from neighbouring areas /blocks to provide these services regularly wherever this is not possible due to shortage of human resources.

9) Ensure that PHCs and CHCs have decentralised budgetary allocations to purchase medicines locally, especially in case of emergencies.

10) Facilitate involvement of the local unlicensed practitioners in provision of health care information and referrals; provide training in standard treatment protocols for common illnesses in tribal areas like malaria, TB, pneumonia and other bacterial infections and conditions that require immediate referrals to facilities.

11) Address health system shortfalls with regard to human resources in health through the creation of opportunities for young people from tribal communities to train as nurses, doctors, paramedical personnel, or to access courses such as BSc (Community Health), the six month Indira Gandhi National Open University (IGNOU) Bridge course for mid-level care providers, for example.

## District Hospital (DH)

1) Ensure that the infrastructure and services at the DH fulfills all the criteria in the IPHS. Critical shortfalls of doctors and other human resources in tribal areas must be immediately dealt with and addressed (particularly for specialists – obstetrician & gynaecologist, surgeon, pediatrician, oncologist, opthamologist, anaesthetist, radiologist, pathologist, etc.)

2) Organise health facilities in a district as a cluster, and ensure the presence of a team of specialists in each cluster, to manage the current paucity of specialists and doctors in tribal areas.

3) Ensure the provision of emergency obstetric and trauma care. DHs serving tribal areas-must operationalise as a fully functional FRU equipped to provide round-the-clock services for emergency obstetric and new born care, in addition to all/other emergencies/trauma cases.

4) Ensure adequate blood and storage facilities are available, so that blood can also be supplied to CHCs regularly. Ensure that user charges and replacement is not posed as a requirement for providing blood transfusion.

5) Provide at least three equipped ambulances at each DH serving in tribal areas in addition to the centralised ambulance services.

6) Ensure adequate availability of all essential medicines. Ensure that the inventory of medicines at the DH factors in the emergency need of medicines by the sub-divisional health facilities under it.

7) Ensure the availability, regular maintenance and replacement of all diagnostic services like X-ray, CT scan, ultrasound, etc.

8) Ensure budgetary and financial administration by the DH to incur expenditures pertaining to any infrastructure building, or maintenance requirement on an annual basis.

9) DH must report/make a requisition for any shortfall in its facility/equipment/services/human resources to the district administration, to be addressed immediately.

10) Establish a district level team and formulate a plan for preparedness and response to an epidemic or emergency, to assist the CHCs/PHCs in addressing any community outbreak of any diseases like malaria, diarrhoea, etc.

11) Ensure that any further referral must follow protocols – referral formats with complete details of the patient and reasons for referral to the tertiary level facility; provide ambulance/vehicle to the patient to travel to the referred facility, and ensure that s/he is accompanied by a para-medical staff or health care provider from the hospital to ensure management of complications in transit.

12) Ensure robust monitoring of referral cases at the DH – those that are referred to the DH as well as those that are referred from the DH – with a clear database for the type of cases, treatment/services provided etc. This data must be incorporated within the HMIS.

13) District hospital management along with district administration must ensure the MDRs of all the maternal deaths that take place at the facility, at the peripheral facilities; the hamlets within its jurisdiction are carried out without delays. The MDR should be carried out in a systematic and thorough manner and details should be made available for each district on a regular basis, along with follow up action that has been initiated in this regard.

14) Ensure that DHs comply with the bio-medical waste disposal and management system.

15) Strengthen the role of Rogi Kalyan Samiti (RKS) in overall hospital management and ensure adequate representation of tribal communities in RKS and other similar bodies towards enabling improved accountability of health care facilities to the communities.

16) Display publicly the Charter of Patients' Rights in the DHs and ensure its thorough implementation. DHs should also disseminate information on patients' rights to all the sub-divisional health facilities and health centres under its administration.

17) Help desks should be stationed in the district hospital near the registration area to enable/facilitate any help that may be required by patients including those coming from far off areas, in emergency situations etc.

18) Strengthen the grievance redressal mechanism for the patients utilising the services at government facilities. Also the name contact details of the MO and other staff in facility must be displayed inside the facility along with details of the numbers to address the grievance.

## Frontline Health Workers – ASHA, AWW and ANM

- Develop clear, demarcated roles and responsibilities for the frontline workers – ANM, ASHA, AWW – in tribal areas to facilitate coordinated care and activities at the community level, as well as referrals to health facilities.
- Ensure regular disbursement of salaries/remuneration to all the frontline health workers without any delays.
- Special attention should be paid towards ensuring the safety of frontline health workers posted in remote hamlets, in and around forest areas as well as in conflict areas.
- Ensure that adequate travel support is provided to frontline workers in tribal areas to prevent barriers to their mobility.
- Ensure a conducive and safe working environment for frontline workers and establish mechanisms for grievances particularly related to abuse and sexual harassment.

### *Accredited Social Health Activist (ASHA)*

1) Relax population norms for ASHAs in tribal areas such that they are hamlet based rather than for a population of 1000. Identify and recruit local women to be trained as ASHAs.

2) Initiate regular training for ASHAs who have been inducted, by ASHA facilitators. A separate training module (mainly pictorial) should be developed for ASHAs from PVTGs.

3) Ensure flexibility in educational criteria for recruitment, particularly for ASHAs from PVTG communities.

4) Ensure a regular monthly salary for ASHAs, as well as other benefits (including extra remuneration for transport, and other costs given in the contexts of tribal areas). Salary and remunernations should not be based on incentives.

5) Strengthen and implement regular trainings for ASHAs to enhance skills of human resources; in tribal areas enhance the capacities of ASHAs through refresher trainings using ASHA Modules to manage, antenatal and postnatal care, home based neonatal care and other illnesses like pneumonia, diarrhoea, etc.

6) Ensure that the ASHA kit is equipped regularly with medicines for common ailments; ensure regular supply of diagnostic aids like slides, RD kits, Pregnancy Test kits, thermometers and weighing scale, torch and baby blankets as part of ASHA kits.

7) Ensure ASHAs have regular supply of paracetamol syrup & tablets, Iron Folic Acid (L), punarvadu candur (ISM preparation of Iron), dicyclomine, tetracycline ointment, Zinc tablets, covidine ointment tube, G.V. paint, cotrimoxazole syrup, paediatric cotrimoxazole tablets, ORS Packets, condoms, oral contraceptive pills, spirit, soap, sterilised cotton, bandages, emergency contraceptive pill and sanitary napkins, in their kits.

8) Ensure travel/mobility support for ANM to visit all the assigned areas in a timely and convenient manner.

9) Ensure that the District ASHA coordinator/Programme Coordinator should conduct regular meetings with the ASHAs in the area and review their work.

10) Reactivate the functioning of the ASHA Mentoring Group (AMG) constituted by the MoHFW to serve as a technical and advisory body for the ASHA Programme and to extend support to the Centre and State Governments in overall implementation, mentoring and monitoring of the programme.

### *Anganwadi Worker (AWW)*

1) Ensure that all Anganwadi workers and helpers are from tribal or PVTG communities, even if it requires a relaxation of qualifications and age norms.

2) Ensure adequate supplies for provision of hot cooked meals to children under three years of age and pregnant and lactating women, daily, though ICDS or community run crèches.

3) Ensure that the ration for the AWC is dropped at the AWC as commuting in the interior forest and hilly areas is extremely challenging.

4) Relax population norms for opening ICDS centres, especially for PVTG habitations, as they are often more located in the interiors. Anganwadi centres and Mini Anganwadi centres should be opened as per the availability of children.

5) Equip AWW to provide referrals of children in the community to facilities like District Early Intervention Centres, Malnutrition Treatment Centres or public health facilities, if needed.

6) Ensure a designated building for AWC with water, toilet and electricity facilities for effective implementation. Provide health information and assessment tools for promoting, and monitoring the physical and mental development of children. Ensure resources for appropriate play materials for the AWC.

### *Auxiliary Nurse Midewifery (ANM)*

1) Relax population norms for ANMs in tribal areas such that an ANM is available for a cluster of hamlets in remote and difficult locations.

2) Ensure flexibility in educational criteria for recruitment to facilitate the selection of ANMs from the ST/PVTG communities. Position 2nd ANM to subcentres in the interior and conflict affected areas.

3) Ensure that vacant positions for ANMs are filled in all the SCs in the tribal areas; increase the number of ANMs per SC, in the tribal areas.

4) Train and equip ANMs to manage acute illnesses and provide follow up care for at least the most common of the chronic illnesses. Conduct needs assessments for trainings of ANMs to ascertain skills and identify gaps for training.

5) Ensure training of ANM on skilled birth delivery, Intra uterine copper device (IUCD) insertion, managing new born, stabilisation of severe malaria, infection management, first aid for snake bites etc. to be given.

6) Equip ANMs in tribal areas with regular supply of essential drugs and diagnostic aids like slides, RD kits, thermometers, weighing machine, BP measurement

apparatus, glucometer, haemoglobinometre, pregnancy test kit, fetoscope, urine test kits, MVA kits, solubility kits, etc. Ensure regular maintenance of equipment and timely replacement as per requirement.

7) Ensure that ANMs maintain checklist of antenatal services and care regularly

   a) Registration of pregnancy in first three months (with the support from ASHA)
   b) Providing mother and child health card to pregnant women
   c) Blood Pressure (BP) taken in all ANC visits
   d) Two TT injections
   e) Weight checked in all ANC visits
   f) Blood test for Hb in all ANC visits
   g) Abdomen examination in all ANC visits
   h) Iron and Folic Acid tablets (IFA) (90 tablets or 3 strips)
   i) Urine test (at least once)
   j) Counselling for institutional delivery
   k) Enquiry about any danger signs like - swelling, blurring of vision and severe headache or fever with chills etc.

8) Ensure the availability of IFA tablets at subcentre with ANM, without any failure as its absence hinders the work of ANM.

9) Monitor the availability of all equipment required at the subcentre/with ANM-weighing machines, BP machine, examination table in working conditions etc.

10) Ensure travel/mobility support for ANM to visit all the assigned areas in a timely and convenient manner.

## 8.b. Specific Health Problems and Illnesses

### *Malaria*

1) Ensure strict implementation of Tribal malaria sub plan - National Framework for Malaria Elimination in India (2016–2030). Hamlet/village level plans should be made in consultation with Gram Sabhas, PRIs, VHSNCs, ANMs, ASHAs as well as the MO of the nearest PHC.

2) Train ASHAs to carry out primary testing and treatment of malaria, in accordance with the NHM Training Module for ASHAs on Malarialogy.

3) Ensure availability of Rapid Diagnostics Kits (RD kits) and slides for testing with ASHAs and ANMs; provide clear protocols for the transfer of slides to the nearest PHC/ CHC from where results are obtainable within 24 hours.

4) Ensure adequate and regular supply of chloroquine, primaquine and artemisinin-based combination therapy (ACT) with ASHAs and ANMs.

5) Ensure high bed-net coverage in malaria endemic tribal areas. Budget sufficient resources in the Project Implementation Plans (PIPs) for adequate supply of bed-nets for free distribution in these areas.

6) Implement appropriate treatment protocols for severe malaria in all PHCs/ CHCs.

### *Tuberculosis*

1) Ensure full range of diagnostic facilities for TB: sputum microscopy in PHCs, X-rays at CHC and CB-NAAT at DH.

2) Provide the full range of treatment options, including medicines to cope with side-effects, supplements for TB care, etc., for free.

3) Ensure adequate supply of free, quality TB medicines, including drugs for MDR-TB, bedaquiline and delaminid, are made easily available and affordable by issuing compulsory licenses to local manufacturers under the Patents Act.

4) Ensure the transfer of technology so that local manufacturers can make machinery for tests like CBNAAT or Genexpert, which are rapid and efficacious but expensive and difficult to access, at cheaper rates.

5) Evaluate the utility, acceptability and sustainability of the DOTS strategy, given that TB is a chronic issue.

6) Availability of medicines, treatment, supplementary nutrition should be continuous and uninterrupted. Linkages need to be made intra and interstate for people who migrate to other places for work and other reasons.

7) Ensure that treatment for TB is accompanied by the provision of supplementary nutrition. Implement the Food Security Act with vigour and political will and make amendments in relation to TB, by expanding the sort of food covered under it, including food grains, cereals and proteins.

8) Link schemes such as PDS, rations, etc. with TB nutritional support in order ensure that food assurance is guaranteed throughout life, beyond those dealing with undernourishment and TB.

9) Withdraw immediately the mandatory Aadhar link to TB treatment under RNTCP. Enable access to information about TB, and counseling on treatment adherence, side effects, prevention of infection, and available schemes and entitlements such as nutritional supplements, etc.

10) Implement campaigns to build public awareness to reduce the stigma and misinformation that exists about TB.

### *Leprosy*

1) Strengthen patient and community awareness about leprosy on a priority basis.

2) Strengthen services for leprosy, particularly in high prevalence tribal areas, remote locations that are difficult to access; intensify case detection and MDT coverage and provide services through the mobile Leprosy Treatment Unit.

3) Ensure availability of diagnostic services for leprosy detection in PHCs and CHCs.

4) Implement special surveillance systems for monitoring trends and prevalence of leprosy in tribal areas.

5) Ensure corrective surgery and rehabilitation of people affected by leprosy in tribal areas.

6) Provide accurate information and counseling on leprosy to persons with leprosy about side effects and self-care measures to ensure adherence to treatment, and enable timely health seeking, towards recovery from leprosy.

7) Follow up support from the health system, to address adverse effects, deformities or disabilities is critical. Long term follow up and support may also be necessary, in terms of protective eye-gear (sunglasses), micro cellular rubber (MCR) footwear as well as with self-care techniques, for the prevention of disability.

8) Provide counselling and also create public awareness campaigns related to stigma and discrimination of people with leprosy.

### *Non-Communicable Diseases (NCDs)*

1) Ensure the effective operationalisation of the NHM guidelines on prevention, screening and control of common NCDs in all tribal areas.

2) States should operationalise the revised National Programme for the Prevention and Control of Cancer, Diabetes, Cardiovascular disease and Stroke (NPCDCS) guidelines by MOHFW by strengthening and expanding risk assessment, screening, early detection and management of Hypertension and Diabetes Mellitus including referral and follow up.

3) Ensure implementation of the Community Based Assessment Checklist (CBAC) for early identification of NCDs by ASHAs.

4) Equip ASHAs with BP apparatus and glucometers to undertake regular examinations at the village level. The ANMs should also conduct regular home visits and ensure adherence to treatment.

5) Facilitate community level participation through meetings in tribal hamlets on the issues of NCDs, presided over by BMO/MO/CDMO.

6) Expand the operationalisation of district NCD clinics, particularly in the tribal areas and districts.

7) Undertake collection of disaggregated data on the prevalence of NCDs amongst tribal population.

8) Undertake focused research on the prevalence of NCDs amongst tribal populations; assess risk factors of NCDs in the context of the lives and ecology of tribal population. Train frontline workers to perform hypertension management in the field.

9) Build the capacities and competence of the ANMs and other paramedical staff to check blood pressure, document blood pressure values, and refer patients to the health facilities.

10) Continuum of care and community based patient support for NCDS should be ensured.

### *Cancer*

1) Establish infrastructure for regular screenings in remote tribal areas, including cervical cancer screening with VIA (Visual inspection with Acetic Acid), along with appropriate referral protocols and systems for treatments.

2) Train ASHAs and ANMs to conduct cervical cancer screenings through visualisation with acetic acid (VIA) method.

3) While hypertension, diabetes, oral and breast cancer screening can be offered in the outreach services at the village level, since the processes are relatively simple, ensure there is a space for cervical cancer screenings where speculum examinations and VIA can be done, including facilities for sterilising of equipment at the Sc and PHC levels.

4) Create robust systems for registration of cases of cancer for an accurate picture of prevalence/incidence in tribal areas, towards the development of facilities in tandem with the need of the population.

5) Build awareness programmes regarding cancer and methods of self-diagnosis (in case of breast cancer) among tribal communities.

6) Consider undertaking screenings at SCs and PHCs. They should offer screening facilities, additional investments in terms of equipment and skill building

7) Ensure follow up of screenings with treatment. Ensure free treatment, including access to free medicines, chemotherapy and provide counseling for cancer 'patients'.

8) Implement public awareness campaigns about the health consequences of alcohol, tobacco, and other substance abuse; enable linkages of the health system with allied service providers for counseling, de-addiction, and other support services, including community based strategies, such as support groups, etc.

### *Reproductive health services*

1) Assure comprehensive services for maternal health, abortion, contraception and other reproductive and sexual health services to women and adolescent girls from the tribal areas.

2) Ensure ANC and PNC care safe deliveries regardless of the location of the delivery – whether home based delivery or institutional delivery.

3) Ensure the availability of free and equipped ambulance or emergency response vehicles in tribal areas for transportation of patients from habitations to health facilities and for inter-facility transfer, accompanied by a health care worker.

4) Make sure that PHC/CHC/ are staffed with efficiently trained providers who can manage any obstetric complications. Referrals to district hospitals should be made an exception and not the rule.

5) Ensure availability of blood at the CHC and DH levels free of cost. Block-level CHCs must have blood storage and transfusion facilities. In case of emergency transfusions, families must not be made responsible for arranging replacement units of blood.

6) Ensure proper check up of women after they have given birth at home, to screen for any post-natal complications and for any consequent need for referral.

7) Ensure that maternal health outcome indicators go beyond JSY disbursements and that the numbers of institutional deliveries include indicators of safety, like completeness of ANC, technical aspects of care like active management of the third stage of labour, and the provision of postpartum care.

8) While the Janani Shishu Suraksha Karyakram (JSSK) is a step towards universal maternity care, make sure it is monitored rigorously, both from within the system and from outside – through communities – to ensure that no OOPE is being incurred.

9) Newer initiatives such as Pradhan Mantri Surakshit Matritva Abhiyan (PMSMA), Mothers Absolute Affection (MAA) etc. must be better planned and implemented, along with the strengthening of earlier initiatives for RMNCH+A health outcomes.

10) The data entry of ANC, PNC, maternal deaths should be disaggregated on the basis of social groups and particularly the data from the PVTGs. Maternal death reviews should be done regularly for both facility and community based maternal deaths.

11) Ensure that both home based and facility based maternal deaths are documented and reviewed. Maternal death audits to be conducted periodically and analysis of maternal should emphasis on social causes and should highlight implementation gaps and move beyond clinical causes.

12) Shift the current policy focus on institutional Deliveries and Janani Suraksha Yojana to safe deliveries – continuum of care including quality ANC, intranatal care and PNC – done by skilled birth attendants.

13) Indicators for maternal health should to move beyond number of JSY and number of Institutional Deliveries to include some of the UN Process Indicators described earlier (Amount of EmOC services, proportion of births in EmOC facilities, Met need for EmOC services, C-sections as a percentage of all births, Case Fatality Rate).

14) Indicators for assessing governance in the health sector need to be developed and institutionalised.

15) JSY amounts should be paid to women without any delay and should not be linked to Aadhaar.

16) Ensure that maternity benefits programmes are accessible to women without any conditionalities like the order of birth, age or institutional birth (which are conditionalities under Pradhan Mantri Matritva Vandana Yojana [PMMVY]).

17) Develop a strong referral network from community to facility and back to ensure better follow up of children discharged from SNCUs and NRC/MTC.

18) Sensitise health workers and staff at health towards the cultural practices of the tribal communities. Ensure that the space within the health system is comfortable and acceptable for women from tribal communities, and provisions are made for women to choose birthing positions, like squatting etc.

19) Develop special responses and policies to address malnutrition among women and girls during pregnancy. Ensure that pregnant women with low BMI are identified during antenatal check-ups provided with food for daily intake, in

addition to Take Home Ration being given from the anganwadi centres.

20) Ensure the availability of services including screening, follow-up, and treatment, to address non-obstetric conditions and diseases such as TB, malaria, HIV/ AIDS, reproductive and other cancers, NCDs, infertility, uterine prolapse, RTIs, STIs, menstrual disorders, etc.

21) Ensure free of cost Anti-Retroviral Therapy (ART) to all people living with HIV (PLHIV) in tribal areas. HIV related counselling should be ensured at the facility level.

22) Implement the HIV and AIDS (Prevention and Control) Act, 2017 and ensure non-discrimination and equal participation of persons suffering from sexually transmitted diseases including HIV in all spheres of life

23) Build awareness and enable access to information in tribal communities on the range of health issues; ensure that persons particularly with health issues that are stigmatized such as HIV, abortion, infertility, STIs, etc. are able to access counseling. Enable processes in the communities that reduce stigma around these issues.

24) Remove restriction on sterilisation services for PVTGs and recognise the right and autonomy of the members of PVTGs to take make informed decisions regarding reproduction, contraception and family planning.

25) Adhere to Supreme Court (Civil Writ Petition No. 95/2012 (Devika Biswas v/s Union of India) specific directions in its order dated 14.9.2016, to be strictly followed by the Government of India, the State Governments and Union Territories for delivering quality family planning services in the country.

26) Fixed day sterilisation services need to be operationalised at CHCs and DHs following the standard operating procedures and Supreme Court directive.

27) States should work out innovative approaches to promote male participation in family welfare programme including NSV.

28) No PPIUCD or PPIACD should be inserted without any informed consent of the woman. All the risks associated with each method should be explained before the insertion.

29) Guarantee robust implementation of relevant programs such as Rashtriya Kishor Swasthya Karyakaram (RKSK) so that young people from tribal communities have access to safe and youth-friendly reproductive health services in the public health sector. Trained counsellers should be posted at all the adolescent friendly health clinics / Shraddha clinics.

30) Ensure the distribution of deworming tablets and IFA (Blue) Tablets to all the children and young people-both school going and otherwise.

31) Monthly meetings with adolescent girls in the tribal villages should be held by ASHA.

32) Ensure the distribution of sanitary napkins to the young girls by ASHA, along with timely sessions on menstrual health and other aspects of sexual and reproductive health (SRH).

33) Implement a comprehensive sexuality education program for adolescents to have access to correct and safe information regarding their SRH.

34) Skills and competencies of ASHA and ANM should be built to enable discussion with young people/adolescents about their health and well-being issues.

35) Ensure special focus on health conditions of tribal children/adolescents in ashramshalas or residential schools.

36) Ashram schools and hostels should become a point of convergence and delivery for several priority actions including-provision of first aid for fever, diarrhoea, fall, snake bite, injuries etc.

37) Each Ashram school/hostel should be attached to a trained medical practitioner along with essential medicines, including anti venom etc.

### *Hemoglobinopathies : Thalassemia, Sickle Cell Disease (SCD)*

1) Ensure the proper management of haemoglobinopathies at the primary, secondary and tertiary levels of health care facilities; ensure availability of solubility tests at the primary level with protocols for referrals to secondary level facilities.

2) Provide diagnostic facilities for Hb electrophoresis to confirm or rule out SCA at the block levels and district levels.

3) Ensure the availability and accessibility of requisite drugs such as hydroxyurea, pain killers across different facilities free of cost.

4) Ensure blood transfusion for persons with SCD and thalassaemia free of cost.

5) Create awareness, education and screening programmes for SCDs and thalassaemia.

6) Develop and implement a strategy for controlling thalassaemia among the tribal populations including effective and targeted measures for prevention and treatment.

### *Snakebites, dog bites and animal attacks*

1) Train MOs at PHCs, and CHCs for the management of snakebites and the administration of Anti-snake Venom (ASV) as per the National Snakebite Management Protocol of the Government of India.

2) Guarantee regular stock and storage of ASV at the PHC level as per IPHS guidelines, particularly those reporting a high incidence of snakebite cases.

3) Ensure the provision of ASV and anti-rabies vaccine free of cost. Ensure functional refrigerators and deep freezer at each PHC for proper storage of anti-rabies vaccine, anti- snake venom, etc.

4) Ensure counselling for 'victims' under treatment to help them deal with the trauma resulting from the fear of death.

5) Build awareness among communities regarding snakebites and build the capacities of ASHAs, ANMs and other frontline workers to administer first aid and ensure timely referrals to health facilities for necessary treatment.

## 8.c. Monitoring and data for accountability of health care services

1) Data collection and entry should be disaggregated on the basis of social groups, particularly for STs and PVTGs in all health records and surveys.

2) Ensure the systematic management of data entry points/ sources – HMIS/MCTS/ RCH. Give adequate attention to data emerging from tribal communities.

3) Address the issue of under reporting of illnesses such as malaria, TB, HIV and other morbidities through multi-site data collection, i.e. at the community as well as the facility levels to ensure inclusion of many patients who may not have visited health facilities for these illnesses.

4) Digitise and incorporate baseline studies by micro agencies around the health indicators of PVTGs, as per CCD plan/scheme, within larger databases.

5) Institutionalise grievance redressal mechanisms, particularly those related to negligence or discrimination by health care providers against persons from tribal communities, on the basis of their identity.

6) Strengthen the system for the reporting and review of maternal deaths. Broaden the composition of the district and state MDR committees to include civil society representatives, PRI representatives (including from tribal communities), and independent technical experts.

7) Ensure that common reviews of health programmes focus in tribal areas, to document the particular issues and challenges that the communities face in the

context of health as well as health care.

8) Strengthen institutional mechanisms for regular cross validation, verification, and authentication of data, before uploading them to the portal in the states.

## 8.d. Social Determinants

1) Strengthen access to determinants of health such as nutrition and sanitation, through convergence between different ministries and departments.

2) Any coercive or punitive measures for open defecation must immediately be discontinued as such mechanisms further marginalise and lead to the harassment of already deprived families in tribal areas.

3) Ensure access to safe drinking water in all the tribal areas, particularly in remote tribal habitations.

4) Ensure access to nutritional services and strengthen food security and food diversity amongst tribal population through the promotion, universalisation and expansion of the PDS.

5) Establish a well-functioning PDS in tribal areas; ensure regular supply of quality provisions in the ration.

6) Implement community level nutrition crèches-cum-centres, for children between six months to three years of age, steered through VHSNC in the village, in order to enable and encourage community participation.

7) Provide hot cooked meals to pregnant and lactating women in the community, through the Anganwadi centres.

8) Guarantee the effective implementation of nutrition schemes/programmes for all pregnant women and nursing mothers in tribal areas, and for all children, including additional supplements to malnourished children.

9) Guarantee that all the PVTG households across the states are covered under the Antyodaya scheme (AAY), in compliance with the Supreme Court judgment on the 'right to food case' in May 2003.

10) Improve the management of under-nutrition among children under 5, at the community level, through improved provisioning and regular supply of quality food at the Anganwadis.

11) Ensure that Aadhaar is not mandatory for availing treatments or accessing any government schemes or programmes.

12) Provide sufficient educational opportunities to tribal communities and ensure minimum dropouts. Ensure that schools are located close to tribal hamlets so that children from tribal communities do not find it difficult to reach them.

13) In the absence of schools that can be accessed easily, put in place residential schools.

14) Ensure that school buildings, in conflict areas, are not occupied by the CRPF or state armed forces.

15) Motivate teachers and a ensure security to encourage them to continue teaching in schools in and around tribal areas.

### *Migration*

1) Ensure that inter-state and intra-state migration does not pose barriers to accessing health care.

2) Ensure the continuity of treatment for illnesses like TB, NCDs and SCD, as well as antenatal and postnatal care.

3) Ensure that tribal migrant women are able to access entitlements such as JSY, JSSK even if they give birth outside their home states.

4) Aadhaar should not be made mandatory for people on migration for accessing health services and availing other benefits.

5) Direct States to strengthen the process of safe mobility for women who wish to migrate by setting up 'safe spaces', both virtual [mobile numbers, websites, whatsapp groups they can join] and physical [addresses, wall advertisements] for them to contact in times of crisis.

6) Carry out extensive public education programmes to help women access safe spaces in both space of origin and destination.

7) Enable sustainable livelihoods in tribal areas to reduce the need for migration.

8) Address issues of sexual violence and sexual harassment against women travelling with children at the workplace, and provide counselling and support for the same.

9) Address the issue of trafficking by providing safe mobility counselling and information to young and vulnerable women both in health care facilities and at the gram panchayat.

10) Prevent routinised testing for women rescued from trafficking. Ensure informed and voluntary consent for women who are rescued from trafficking. Protect their confidentiality in health care services.

### *Conflict and displacement*

1) Develop a specific health plan for conflict-affected areas, to ensure the availability of health infrastructure and services.

2) Ensure comprehensive health care in conflict areas by reaching out to villages and providing doorstep delivery of services.

3) Motivate health functionaries to work in conflict areas by providing adequate incentives and ensuring security.

4) In areas where health workers are concerned about travelling to their work areas individually due to security threats, create teams of health personnel to enable travelling in groups.

5) Initiate broad-based consultations in districts that are particularly affected by conflict. Involve tribal communities, government departments like the police, health, women and child development, tribal welfare, water and sanitation, food, transport, etc., as well as health groups, experts and civil society members, to develop a health plan, gain insights into the status of health and health care in specific contexts and address the gaps and barriers to accessing health care for tribal communities.

6) Ensure availability of fully equipped ambulances and MMUs in these areas. Ensure that all the emergency care and transport is available 24 hours.

7) Address mental health issues caused by the constant threat of violence and ensure accessible counselling facilities for those facing these issues.

8) Ensure that all new development projects in tribal areas/villages/hamlets comply with tribal land rights, guaranteed under the constitution as well as the law, to ensure that no tribal family is reduced landless due to any development project - whether government or private/corporate.

## 8.e. Decentralised governance of health/community interface

1) Decentralise local health planning; strengthen the capacities of VHSNCs in tribal areas to plan and implement health and nutrition programmes and facilitate institutional interface with the public health system. Ensure availability of untied funds to VHSNC for improved functioning.

2) Institutionalise grievance redressal mechanisms at health facilities in tribal areas.

3) Ensure effective functioning of the RKS and VHSNCs. Communitisation of health delivery system - VHSNC must include representation from various tribal communities present in the village.

4) Ensure that VHND is implemented regularly in tribal areas. Increase the frequency of VHNDs as well as the number of health care workers present at the VHND for timely and improved coverage of immunisation and other health services in the village.

5) Ensure inclusion of PVTGs within communitisation of health by focusing on strengthening VHSNC in PVTG villages and by ensuring their participation in all community level meetings.

6) Special focus should be given to having 'health volunteers' from PVTG community, who can participate in various training programmes meant for community level or frontline workers.

7) Initiate the formation of peer support groups within various disease control programmes, especially for chronic diseases.

8) Involve local Non Governmental Organisations (NGOs) working with tribal populations, in planning and monitoring processes.

9) Engage local media proactively in raising awareness on health issues, widely covering the health problems in the areas.

## 8.f. Policy directives, planning, and convergence

### Need for convergence

There is need for convergence between health and other departments relevant to tribal communities' health and welfare. Departments of Tribal Affairs, Women and Child Development, Education, Water and Sanitation, Forest and Environment, etc., should aid in comprehensive planning at State/UT and district level for better health service delivery.

#### *Ministry of Tribal Affairs (MoTA)*

1) MoTA should work towards finalising the National Tribal Policy, within a limited timeframe. Health should be an essential component within such a policy and the traditional healers and trained dais should be an integral part of it.

2) Systematically document indigenous knowledge about medicinal/ herbal plants; accord recognition to it as an independent system of medicine. Develop systems for the practice of indigenous medicine and its links with other existing health care systems.

3) Ensure particular focus on PVTGs and communities living in remote habitations in tribal areas, to enable access to health care.

4) Assign a mandatory component of primary health care within the Conservation cum Development (CCD) plan for PVTGs; ensure last mile connectivity beyond NHM, for gaps in the existing facilities.

5) Prioritise the health component when allocating special grants to states to formulate their TSP, and make sure the state governments ensure the timely approval and implementation of the TSP.

6) Create a separate post for Schedule Area Health Officer at each TSP project office, to work with the health department, and to supervise, monitor, and manage the medical and health care system in the Scheduled Areas.

### *Ministry of Women and Child Development (MWCD)*

1) Adopt a liberal approach regarding the population norm for setting up Anganwadi / mini Anganwadi centres, especially in PVTG hamlets. Given the distances between tribal hamlets and difficult terrains, each hamlet should have access to its own centre.

2) Ensure regular and adequate supply of THR and monitor their timely disbursement.

3) Salaries of AWWs should be paid on time, without delays.

4) Formulate state specific plans to ensure the safety and protection of women and children, on migration, from sexual exploitation, harassment at workplace, abuse and trafficking etc.

5) Hold specific consultations focusing on the needs of tribal communities, in the context of their vulnerability to trafficking and exploitation during migration for work/livelihood.

6) Ensure that all the hospitals/medical institutions have constituted an Internal Complaints Committee (ICC), as per the mandatory requirement under section 4(1) of the Sexual Harassment of Women at Workplace (Prevention, Prohibition and Redressal) Act, 2013, to provide efficient and timely grievance redressal and to look into the complaints of sexual harassment.

7) Direct States to strengthen the process of safe mobility for women who wish to migrate by setting up 'safe spaces' both virtual [mobile numbers, websites, whatsapp groups they can join] and physical [addresses, wall advertisements], for them to contact in times of crisis.

8) Undertake extensive public education programmes to help women access safe spaces in both space of origin and destination.

9. Address the issue of trafficking by providing safe mobility counselling and information to young and vulnerable women both in health care facilities and at the gram panchayat.

## 8.g. Research and Data collection

1) Ensure research on social determinants of health focusing on conflict, displacement and migration, and their impact on health for ST and PVTGS.

2) Invest in more epidemiological studies to further understand the disease burden among tribal communities.

3) Undertake specific research highlighting the gender inequities in the health status and health care within tribal communities.

## 8.h. General

1) Increase budget allocations for public health to 2.5 per cent of the GDP as articulated in the NHP 2017.

2) Increase the allocation of financial resources to improve the health of tribal communities.

3) Increase of investment by the State in strengthening the overall public health sector is of utmost priority and should not be replaced by PPPs. Further, state-specific PPPs in tribal areas should be monitored and regulated for transparency, accountability and quality.

4) Discourage private practice by government doctors in tribal areas. Send strict guidelines to hospitals to ensure that no government doctor is involved in private practice during duty hours at the public health facility.

5) Recognise and promote the traditional knowledge and healing systems, including safe home-based birthing practices.

6) Ensure that both public and the private sector implements the provisions of the Charter of Patient's Rights.

7) Address the issues of current widespread violation of patient's rights, irrational and overcharged care.

8) Regulate the commercialised private sector across the country, as per the Clinical Establishments (Registration and Regulation) Act, 2010 and Code of Medical Ethics Regulations, Medical Council of India, etc.

9) Establish systems for regular audits of prescriptions and inpatient records, death audits etc., in private health facilities as well.

10) Examine the status of current regulation of the private sector and develop frameworks for much more effective and responsive regulations.

11) Strengthen and re-orient public health systems including diverse experiences of community monitoring and participation of communities towards a people oriented accountability of health services.

## Endnotes


1. Article 21, Constitution of India.
2. Nandini Sundar & ors v State of Chhattisgarh, https://indiankanoon.org/doc/920448/
3. Article 244(1), Constitution of India.
4. Report of the Scheduled Area and Scheduled Tribes Commission, Government of India. Volume I. (2002-04) https://tribal.nic.in/writereaddata/AnnualReport/BhuriaReportFinal.pdf
5. Development Challenges in Extremist Affected Areas — Report of an Expert Group. Government of India. 2008-available at https://tribal.nic.in/writereaddata/AnnualReport/DevelopmentChallengesinExtremistAffectedAreas.pdf;
6. 3rd Report of the Standing Committee on Inter-sectoral issues relating to Tribal Development. GoI (2009)-available at https://tribal.nic.in/writereaddata/AnnualReport/Mungekar3rdreport2.pdf.;
7. Recommendations of the National Advisory Council (NAC)-Development Challenges Specific to Particularly Vulnerable Tribal Groups (PVTGs)-available at https://tribal.nic.in/writereaddata/AnnualReport/NACRecommendationsforPVTGs.pdf.
8. Report of the High Level Committee on Socio-Economic, Health and Educational Status of Tribal Communities of India. Ministry of Tribal Affairs, Government of India, May 2014.

*Annexure 1*

# Format for In-depth Interviews with Individual Respondents

## Section 1: Demographic profile of respondent

Date of the interview: _____

Name of the Respondent: _____

Address: _____

_____

| | | | | | |
|---|---|---|---|---|---|
| 1.1 | District | | 1.2 | Block | |
| 1.3 | Village | | 1.4 | Panchayat | |
| 1.5 | Hamlet / Pada | | | | |
| 1.6 | Age | | 1.7 | Sex | |
| 1.8 | Caste | | 1.9 | Tribe | |
| 1.10 | Religion | | 1.11 | Literacy level | |
| 1.12 | Marital Status | | 1.13 | Occupation (last 12 months) | |
| 1.14 | Average income of household (Monthly) | | 1.15 | Number of members in family | |
| 1.16 | Main source of livelihood (Service/ Own cultivator/ farm labour/ non farm labour/ any other, specify | | | | |
| 1.17 | Land holding (Yes/No) | | 1.18 | If "Yes", Acres | |
| 1.19 | Patta Land | | 1.20 | D Patta Land | |
| 1.21 | BPL Card Holder (Yes/ No) | | 1.22 | If yes, Card Number | |

| | | | | | |
|---|---|---|---|---|---|
| 1.23 | Ration Card holder (Yes/ No) | | 1.24 | If yes, Card Number | |
| 1.25 | Beneficiary under any government scheme (Yes/ No) | | 1.26 | If yes, which one ? (eg. Indira Awas Yojana, Antyodaya/ Annapurna card holder, pension scheme, RSBY, any other specify etc.) | |

## Section 2: Household profile

### 2.1 Profile of family members

| Name | Relation to Respondent | Sex | Age | Marital Status | Education | Occupation Main \| Subsidiary | | Current Monthly Income | Any skill possessed |
|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |
| | | | | | | | | | |

### 2.2 Household assets

| | |
|---|---|
| Cycle, any other vehicle, TV, refrigerator, bed, water purifier, hand pump, telephone, mobile, any other specify etc. | |

## 2.3 Household type

| | | | | | |
|---|---|---|---|---|---|
| 2.3.1 | Owned/rented | | 2.3.2 | If owned, (patta land/ encores/ under FRA/any | |
| 2.3.3 | Pucca/Kutcha | | 2.3.4 | Roof: thatched/tiled/ cemented/any other specify | |
| 2.3.5 | Whether any govt. housing scheme/ funds availed (Yes /No) If yes, mention the scheme | | | | |
| 2.4 | Ownership of Livestock (poultry, cattle, goat, pig, sheep, buffalo, plough bullocks etc.). Specify. | | | | |

## 2.5 Household facilities

| | | | | | |
|---|---|---|---|---|---|
| 2.5.1 | Toilet (Yes, No) | | 2.5.2 | If yes, then type (Flush toilet, Public/ Shared flush toilet, pit toilet, Public/ Shared pit toilet, Other (specify) | |
| 2.5.3 | Whether water is available or not (Yes/No) | | 2.5.4 | Whether used or not (Yes/ No) | |
| 2.5.5 | Kitchen room (Yes/No) | | 2.5.6 | Separate/ Attached | |
| 2.5.7 | Cowshed (Yes/ No) | | 2.5.8 | Separate/ Attached | |
| 2.5.9 | Main cooking fuel (Wood, charcoal, kerosene, cow dung, smokeless chulha, LPG) | | | | |
| 2.5.10 | Main source of Drinking Water (Hand Pump, Pond, River, Open well, Tube well, Piped water, Public tap, any other | | | | |

| | | | | | |
|---|---|---|---|---|---|
| 2.5.11 | Availability of Electricity (Yes/No) | | 2.5.12 | Regular electricity (Yes/No) | |
| 2.5.13 | Solar electricity (Yes/No) | | | | |

## Section 3: Household income

### 3.1 Annual income of household

### 3.2 Sources of household income

| S. No. | Sources of work | Number of family members engaged | Nature of work: Continuous / Seasonal | Duration of work (number of days in a year) | Annual income in Rupees |
|---|---|---|---|---|---|
| 1. | Agriculture | | | | |
| 2. | Forest Resources | | | | |
| 3. | Wage Labour | | | | |
| 4. | Skilled Labour | | | | |
| 5. | Migrant Labour | | | | |
| 6. | Employment (govt) | | | | |
| 7. | Employment (Pvt) | | | | |
| 8. | Common Property Resources | | | | |
| 9. | Artisan | | | | |
| 10. | Business | | | | |
| 11. | Fishery | | | | |
| 12. | Goat rearing | | | | |
| 13. | Pig rearing | | | | |
| 14. | Sheep rearing | | | | |
| 15. | Poultry | | | | |
| 16. | Income from household rent | | | | |
| 17. | Any other | | | | |
| | | | | | |
| | Total | | | | |

## Section 4: Health status of the respondent

4.1 Are you currently suffering from any illness, or suffered from any illness recently?

Yes/No _____

4.2 If yes, what illness or illnesses?

_____

_____

_____

4.3 For how long you have been experiencing this health condition?

_____

_____

4.4 What were the symptoms that you experienced?

_____

_____

_____

_____

_____

_____

4.5 What did you do to address these symptoms? (Did not seek treatment, self treatment, home remedies, seek treatment)

_____

_____

_____

_____

_____

4.6 Has the treatment given you any relief? Did it cause any further health problems?

_____

_____

_____

_____

_____

_____

## Section 5: Health seeking behavior of the respondent

5.1 Where did you go to seek the treatment from?

a) Public Health facility: Research Centres, Sub centre; Primary health centre; Community health centre; Sub division hospital, District hospital, Medical college hospital, Anganwadi centre;

b) Private Health facility: Private hospital / health centre / dispensary / NGO operated hospital / Missionary Hospital.

5.2 Whom did you consult for these symptoms? (Please Tick)

a) ASHA

b) ANM

c) Medical Doctor

d) AYUSH practitioners

e) Local private practitioner

f) Traditional healers

g) Faith healers

h) Any other indigenous practitioner (specify):

_____

_____

_____

5.3 Reason for visiting particular health facility or practitioner? (Please Tick)

a) Accessible (distance/safety-security/timing)

b) Affordable (free, inexpensive/cheap)

c) Available (Practice nor/ test/ medicine)

d) Quality of care

e) Behavior

f) Previous positive experience of treatment/Trust

g) Relative/ friends recommended

h) Culture/tradition/belief/faith

i) Any other (specify)

_____

_____

_____

5.4 Details of treatment seeking and trajectory throughout the experience of this illness.

5.5 If visited health facilities, then tick mark the Level of facility (sub centre/ PHC/ CHC/ hospital). What was the location of the facility, distance from village.

5.6 Mode of transport: ambulance/ private vehicle/ walking, cycle, bus, any other, specify.

5.7 Expenses incurred towards transport:

Approximate time taken to reach the health facility from the village/hamlet:

5.8 Human resources at the facility (availability of doctor / nurse / Pharmacist / health provider); diagnostics; medicines; blood, etc. Note down respondent's experience in detail.

5.9 About the treatment:

Were any diagnostics or tests conducted? If yes, share the details (probe for ECG, X-ray, blood tests, urine, stool, eye, pregnancy, ultrasound or any other test)

Where were the diagnostic tests conducted? Government facility or private? If private, what was the cost?

5.10 Were any medicines given/prescribed? Where did you get the medicines from? Did you receive a regular supply (as per relevance to be asked)? Were they provided free or did you have to buy? Which medicines were free and which medicines you had to buy?

(Please collect the prescriptions, reports photocopy etc.) Write in detail.

5.11 Were you given any counseling about the treatment? Were you told about any possible side effects of the medicine prescribed? Did you experience any side effects because of the medicines? If yes, please provide the details.

5.12 Was there any change in your condition after medication? If yes, was it good or bad and after how long?

Note: Researcher should explore all referrals as part of the trajectory of treatment, and details of each referred facility/provider (Timing, duration, mode of transport, support service, cost). Any other detail or observation.

## Section 6 : Healthcare utilization

6.1 What was the cost of the complete treatment (monthly in case of chronic illnesses)?

6.2 Do you have RSBY /government insurance scheme? Did you use the RSBY (card) for this treatment? Did you face any difficulty in using the insurance card? Who did you approach for assistance? Was the issue resolved?

Do you have any other health insurance? If yes, which one? Did you use it?

6.3 Did you have to spend money for the treatment: (e.g. towards costs of transport, food, doctor's fees, any tip or money charged by hospital staffs, diagnostics, surgical procedures, medicines etc)? If yes, how much money was spent? (can be asked at every point of the trajectory of treatment / or as a whole)

6.4 Did you have to take a loan/ sell any assets/ do extra work, etc. to pay for the treatment? If yes, probe detail.

6.5 Current status of the illness and treatment (Whether cured or not, any continued symptoms/pain if any).

6.6 How did the illness affect/impact work, daily lives, health, household, relationships, social engagements/interactions, etc. (Write down the narrative)

6.7 Do you feel satisfied with the treatment you received?

6.8 What are the reasons for satisfaction or dissatisfaction? (to be explored for the varied levels/nature of treatment: Counseling, information, accessibility w.r.t timings/waiting time, behavior/attitude of health providers, cleanliness, availability of toilets, water, beds, food, cost of expenses etc).

## Section 7: Grievance redressal mechanism

7.1 Are you aware about the Rogi Kalyan Samiti, VHSNC, Gaon Kalyan Samiti (GKS) or any other committees in your village?

7.2 If yes, do you know where these committees sit? Have you ever approached them with any health service related concern/complaints?

7.3 In case of lack of adequate services, do you know whom to contact for registering a grievance?

7.4 Probe any other issue respondent wants to share with the interviewer.

## Probing points for additional information collection on specific health condition

### Malaria

- Stocks of Cloroquine, ACT and Primaquine and RD kits with the ASHAs and ANMs;
- Referrals for severe symptoms;
- Malaria related deaths in the villages/panchayat;

### Sickle Cell

- Screening facilities, procedure, availability;
- Drug availability (Hydroxy urea);
- Facilities for blood transfusions;
- Referrals;

### Tuberclosis (TB)

- Testing facility-availability;
- DOTS administration process;
- MDR TB cases;
- Reasons for discontinuation of treatment in relevant cases;

### Anemia

- Supply and distribution of IFA tablets
- Availability of Iron Sucrose injections
- Nutritional programmes being implemented in the village

### Antenatal and postnatal care

- Availability of pregnancy testing kits;
- Reasons for delay in registration of pregnancies/seeking ANC in relevant cases;
- Availability of Take Home Ration (THR) for pregnant women from anganwadi;
- Number of ANC;
- Identification of high risk pregnancy;
- Postnatal care- availability of ambulance services on discharge from hospital after delivery;
- Home visits by ASHAS in cases of home based deliveries;

## Newborn child care

- Immunisation services availability and gaps;
- Monitoring of malntrution status;
- Nutrition supplements from Anganwadi;
- Home visits by ASHAs and ANMs for new born care;

***Annexure 2***

# Checklist for District Hospital - Interaction with Chief Medical Officer

Name of the State: _____

Name of the District: _____

Name of the District Hospital: _____

Name of the CMO: _____

Date of Data Collection: _____

1. Professional details
   a) For how many years have you been working/ practicing medicine in the state?
   b) Before being posted here as CMO/SMO, how many years have you worked as a MO and in which districts of the state?
   c) Have you ever been posted in a PHC/CHC in tribal population dominated area?
   d) If yes, what were the challenges you faced in those areas? How did you solve those challenges? Have you made any efforts to address those challenges for your MOs now?
2. Since when are you working as a CMO/MO? For how long have you been working in the district? Has the demographics of the patients visiting this health facility changed over years? Do you think the location of DH is accessible from all the parts of the district?
3. Can you please share with us the endemic health problems/diseases prevalent in this district? Has this disease spectrum shown any changes over the years or it still by far remains the same?
4. Will you be able to categorize your patients in percentage of people from different castes and regions? Do you think people from far flung tribal areas come to seek treatment and care to DH? If yes, are there any specific health problems faced by tribal communities for which they visit DH?
9. Can you let us know about the public health facilities available for treatment of these health problems at district level? Do you think it is sufficient to address health issues of your district population? Do you think it is sufficient to address health issues of the tribal population in your district?
10. Are there any special provisions made by the state for addressing various tribal health issues in your district? If yes, what are these provisions? Can you explain the different levels of community that they are present and the manner in which these are implemented?

Is there any provision to monitor these activities? If yes, how are they monitored?

11. Do you have a dedicated human resource to look into the problems of tribal communities?
12. What are the IEC provisions that you make to let tribal people know about the services available in different public health facilities?
13. Have you organized a health awareness and screening camp in your district esp for tribal communities and tried to address their health issues?
14. What are the various public health interventions run by DH in district/ tribal area and how are they implemented? Is there any provision to monitor the same? If yes, then what?
15. Can you please let me know the last time that monitoring process was undertaken? Who are the persons involved in monitoring? Where does this report goes? Is the report available in public forum?
16. Can you elaborate provisions planned for following specific diseases?

| Health Problems | Public health intervention and its implementation for tribals, esp. PVTGs | Monitoring and evaluation mechanism – human resource involved, Forms and Surveys used, How are they monitored |
|---|---|---|
| TB | Special provision of Execution of DOTS program among tribal population, if any? | |
| Malaria | | |
| Severe anemia | | |
| Sickle cell anemia | | |
| Leprosy | | |
| Others | | |
| Water borne diseases | | |
| STDs | | |
| Hypertension | | |
| Diabetes | | |
| Cancer | | |
| Others | | |

12. Are there any special provisions to enable or facilitate tribal's access to health facilities? If yes, what are these provisions and how are they working currently? (Probe on geographical access- Transport provision, ambulance, mobile medical units, social access- outreach services, IEC provisions, screening camps, health camps, financial access- free medicines and diagnostics, facilitate treatment in private health facilities eligible under any govt health scheme if treatment not available in public sector)
13. What is the strength of doctors and nurses in your DH? Do you think you have sufficient human resource to address health concerns of your district? Is there any provision to have a separate department in the hospital to look primarily into tribal health issues?

14. What do you think about the functioning of DH? Is it overburdened or is able to meet the health needs of the district population?
15. What do you think about the work stress on yourself and your staff? Are they doing fine with current strength or need more helping hands?
16. When was the last time that you visited a PHC or CHC in the district for inspection? What were the major issues you witnessed and what were the steps you took to address the same?
17. What other steps you would like to take to address the health needs of his district esp the tribal community, if given a chance to? Do you think the provisions under NHM have helped address tribal health issues in your district?

**Health services and National and State level program facilities available at the DH**
**Infrastructure check / Quality check**

18. What is the condition of infrastructural cleanliness, water, electricity in different facilities at the DH?

| Rooms and Facilities available at the DH | Present/ not present and number | Cleanliness and Ventilation | Water supply - Regular / intermittent/ storage facility available | Electricity supply- Regular/ intermittent/ no supply | Presence of generator |
|---|---|---|---|---|---|
| Operation Theatre | | | | | |
| Pre operative room | | | | | |
| Post operative room | | | | | |
| Emergency room / Casualty | | | | | |
| OPD Rooms | | | | | |
| Waiting Spaces adjacent to each consultation and treatment room | | | | | |
| Accommodation for family of admitted patients (number) | | | | | |
| Administrative Block | | | | | |
| Entrance Area | | | | | |
| Ambulatory Care Area (OPD) | | | | | |
| Registration Counter | | | | | |
| Assistance and Enquiry Counter | | | | | |

| *Rooms and Facilities available at the DH* | *Present/ not present and number* | *Cleanliness and Ventilation* | *Water supply - Regular / intermittent/ storage facility available* | *Electricity supply- Regular/ intermittent/ no supply* | *Presence of generator* |
|---|---|---|---|---|---|
| X ray room | | | | | |
| Ultrasound room | | | | | |
| Sample collection for tests separate room | | | | | |
| Separate laboratory room | | | | | |
| Residential Quarters for staff | | | | | |

19. What is the condition of sewerage and garbage disposal at the DH? (Based on observation and interview)

| Type of | Present/ absent reasons given for current form used | Any details |
|---|---|---|
| Waste disposal system in CHC<br>Segregation of waste is followed or not?<br>Needles are disposed properly? | | |
| Needle cutter present in every OPD?<br>Gloves disposed after single use or not?<br>Provision for collecting waste?<br>In-patients room cleaned frequently or not? | | |
| Provisions for separate Disposal of medical waste | | |
| Presence of incinerator | | |
| Type of sewerage system ( 1- Soak pit; 2- Connected to Municipal Sewerage) | | |

**If connected, whether water disposed is treated before letting out in the common sewage? Washing facility available for bedding and gowns etc.?**

20. What types of health services are currently available at the DH? What are the various departments that are currently present and functional (Both OPD and IPD services)? (Can be based on observation and interview).

| Services | Availability and service type | Building condition and availability of separate area | Cleanliness, water and electricity supply | Type of staff available currently | Availability of facilities – medicines and diagnostics |
|---|---|---|---|---|---|
| General Medicine | | | | | |
| TB testing and DOT centre | | | | | |
| Malaria/Filaria treatment | | | | | |
| Leprosy | | | | | |
| Others | | | | | |
| General Surgery | | | | | |
| (Type of surgery available) | | | | | |
| Obstetric & Gynaecology Services | | | | | |
| Delivery-Normal and C section | | | | | |
| Intra and post partum Complications – Eclampsia, PPH, Sepsis, obstructed labour | | | | | |
| PPIUCD | | | | | |
| MTP services | | | | | |
| PAIUCD | | | | | |
| Family Planning services like Counseling, Tubectomy (Both Laparoscopic LTTand Minilap), NSV, IUCD, OCPs, Condoms, ECPs, Follow up services | | | | | |
| Paediatrics including Neonatology, Neonatal ICU present or not? | | | | | |
| Immunization and treatment of deficiencies like Anemia, Vitamins etc | | | | | |
| Emergency (Accident & other emergency) | | | | | |
| Critical care/ Intensive Care (ICU) | | | | | |
| Anesthesia | | | | | |

| *Services* | *Availability and service type* | *Building condition and availability of separate area* | *Cleanliness, water and electricity supply* | *Type of staff available currently* | *Availability of facilities – medicines and diagnostics* |
|---|---|---|---|---|---|
| Ophthalmology | | | | | |
| Radiotherapy Allergy | | | | | |
| Otorhinolaryngology (ENT) | | | | | |
| Orthopaedics | | | | | |
| Radiology including Imaging | | | | | |
| Psychiatry | | | | | |
| Geriatric Services | | | | | |
| Dental care | | | | | |
| STI Clinic; ART Centre | | | | | |
| Screening and treatment of cancer – eg Cervical and breast cancer | | | | | |
| Counseling Services for Domestic Violence, Gender Violence, Adolescents, etc. | | | | | |
| General Specialties Dermatology and Venerology (Skin & VD) | | | | | |
| Blood storage Unit | | | | | |
| Blood bank Blood transfusion facility | | | | | |
| Diagnostic facilities available | | | | | |
| Blood test, urine test, USG, CT scan, X ray etc. | | | | | |

11. What is the current in-patient capacity at the hospital? Can you tell us on a monthly average based on region and caste? Can you give a number for how many people from tribal areas access these services and for which ailment predominantly?

| **IPD services available for** | **Average number of patients** | **Average tribal and PVTG people who accessed in last 3 months** |
|---|---|---|
| Delivery | | |
| Geriatric services | | |
| Specific health problems( list them) | | |

| *IPD services available for* | *Average number of patients* | *Average tribal and PVTG people who accessed in last 3 months* |
|---|---|---|
| Male wards | | |
| Female wards | | |
| Neonatal care unit | | |
| Paediatric ward | | |
| Isolation ward | | |

12. What diagnostic services are available? (Ask about the specific services and their status- Some parts can be filled in through researcher observation too).

| **Type of Diagnostic Facility** | **Availability status** | | | |
|---|---|---|---|---|
| | **Available at the DH/near DH** | **Timing of operation and days they are operating and charges if any** | **Referred to other providers- (If yes fill next box )** | **Information on provider- Distance from the hospital, timings & charges. Who arranges transport for people to these facilities?** |
| Laboratory services including Pathology and Microbiology | | | | |
| Designated Microscopy centre X-Ray | | | | |
| ECG | | | | |
| Sonography | | | | |
| Endoscopy | | | | |
| Blood Bank and Transfusion | | | | |
| Physiotherapy | | | | |
| Biopsy services | | | | |
| Screening for cancer | | | | |
| Dialysis | | | | |
| Dental Technology (Dental Hygiene) | | | | |
| Any other | | | | |

(Note these are essential services that should be available at a DH as per IPHS norms)

13. Is there a pharmacy for drugs recommended at the district hospital? What drugs are currently/usually available? How many drugs form the listed ones under NHM are available? For those not available, how much time does it take to replenish the stocks? How do you compensate to patients for the same? Does your staff prescribe outside drugs if the listed drug not available in the DH?

14. Do you face any problems with respect to drug availability, stock maintenance or any other? What type of problems do you face and what do you do in such situations?

15. Other facilities available at the DH?

| Other Facilities | Current status- what is the average cases in last month/ 3 months | Barriers faced in these services |
|---|---|---|
| Integrated Disease surveillance, epidemic investigation and emergency response | | |
| Medico-legal/post mortem, Transport of dead bodies from DH to native place | | |
| Ambulance services and other Transport facilities | | |
| Referral Facilities | | |
| Health promotion and Counseling Services | | |
| AYUSH centre | | |
| NRC centre | | |

16. What is the Current status of health services under national and state programs at the District Hospital?

| Programs | Current programs and activities that are ongoing | Staff availability and training levels for these programs | Coverage among tribal population (average monthly figures) | Barriers faced |
|---|---|---|---|---|
| **Communicable & Vaccine Preventable Diseases** | | | | |
| TB RNTCP - DOTS | | | | |
| Malaria-NMEP | | | | |
| Leprosy-NLEP | | | | |
| Kala Azhar | | | | |
| JE | | | | |
| Dengue | | | | |
| chickengunya | | | | |
| Elephantytis | | | | |
| Sickle Cell Anemia | | | | |
| Hepatitis | | | | |
| Jaundice | | | | |
| Diahhroea | | | | |
| HIV and ART | | | | |
| **Non-communicable Diseases (Programs on specific diseases)** | | | | |
| Diabetes | | | | |
| Cancer | | | | |

| *Programs* | *Current programs and activities that are ongoing* | *Staff availability and training levels for these programs* | *Coverage among tribal population (average monthly figures)* | *Barriers faced* |
|---|---|---|---|---|
| Hypertension | | | | |
| Epidemiological Health Investigation, Promotion & Counseling | | | | |
| Disease profiling at the district level | | | | |
| **RMNCH+A** | | | | |
| ANC facilities outreach | | | | |
| Early registration | | | | |
| JSY | | | | |
| JSSK | | | | |
| Referral Transport for delivery/ post partum complication/ child health problem | | | | |
| VHND | | | | |
| Maternal and Child tracking (MCTS) | | | | |
| Maternal Death reviews | | | | |
| Family Planning services –fixed day ( options given OCP, Condom, NSV, LTT, ECP,IUCD, others) | | | | |
| Family Planning camps ( options given OCP, Condom, NSV, LTT, ECP,IUCD others) | | | | |
| Family Planning counseling | | | | |
| Sterilization death reviews | | | | |
| HIV/AIDS | | | | |

| *Programs* | *Current programs and activities that are ongoing* | *Staff availability and training levels for these programs* | *Coverage among tribal population (average monthly figures)* | *Barriers faced* |
|---|---|---|---|---|
| Pradhan Mantri Surakshit Matritva Yojana | | | | |
| JYS | | | | |
| JSSK | | | | |
| Iron + initiative (NIPI) | | | | |
| WIFS | | | | |
| De worming | | | | |
| Iron Supplementation for adolescents | | | | |
| IFA for PW | | | | |
| RKSK | | | | |
| **IMNCI (Diseases covered)** | | | | |
| Diahhroea management | | | | |
| Jaundice | | | | |
| Others | | | | |
| RBSK | | | | |
| Vitamin A supplementation | | | | |
| Adolescent & School Health (Adolescent & school health promotional activities) | | | | |
| PNDT tracking cell | | | | |
| Pradhan Mantri Dialysys scheme | | | | |
| State Level initiatives and innovations undertaken (from PIP) | | | | |
| Health Kiosks for diagnostic tests | | | | |

17. Quality Control factors and their availability at the District Hospital?

| Particular | Whether functional / available | Barriers to functioning |
|---|---|---|
| Is the Citizen's charter displayed (Yes/No) | | |
| Constitution of Rogi Kalyan Samiti (Yes/No) (give a list of office order notifying the members) | | |
| Internal monitoring (Social audit through Panchayati Raj Institution / Rogi Kalyan Samitis, medical audit, technical audit, economic audit, disaster preparedness audit, monitoring of accessibility and equity issues, information exchange etc. (Specify) | | |
| External monitoring (Monitoring by PRI (Zila Parishad)/ Rogi Kalyan Samitis, service / performance evaluation by independent agencies | | |
| Monitoring of Laboratory (Internal & External Quality Assessment Scheme | | |
| Record Maintenance (Use of computers with connectivity to District Health System, State and National Level | | |

18. What do you see as the current barriers for provision of quality health services at the DH? What are your suggestions, thoughts on overcoming the same?

19. Are there any provisions for CME of your staff? Do you conduct in house training for the same? Do you have sensitization sessions for your medical and nursing staff to deal with cases related to gender based violence, violence against tribal communities or how to deal with patients coming from marginalized communities?

    Do you provide your staff with good practices training to be followed during labour, abortion, MDR etc.?

20. What do you see as the barrier to access to health for marginalized tribal communities? What are your suggestions to improve the access to healthcare and health facilities for people from remote areas esp. from marginalised tribal communities?

***Annexure 3***

# Checklist for CHC/Block PHC/BMO/MO

Name of the State _____

District _____

Tehsil/Taluk/Block _____

Location (near village/block center/ isolated area) and Name of CHC/BPHC

_____

_____

Is the facility designated as an FRU? _____

Type of Building of CHC/BPHC (Govt/ Private) _____

Condition of building (Describe)

_____

_____

_____

_____

Date of Data Collection (DD/MM/YY) _____

Name and Signature of the Person Collecting Data

_____ _____

1. Since when are you working in this district?

_____

2. Since when are you working as BMO/MO/other managerial staff? Duration of work at this CHC?

_____

3. Can you tell us a little about the endemic health problems/diseases in the area covered by this CHC?

_____

_____

_____

4. Are there any specific health problems faced by tribal communities including PVTG's?

5. What is your perception of the public health facilities that are available for these health problems especially for tribals?

6. Are there any special provisions made by the state for addressing tribal health at the CHC level? What are these provisions and at what level are they present and how are they executed? How are they monitored?

| Health problems | Public health intervention and its execution for tribals (especially PVTGs ) | How are they monitored |
|---|---|---|
| TB | | |
| Malaria | | |
| Severe Anemia | | |
| Sickle Cell anemia | | |
| Leprosy | | |
| Others | | |
| Adolescent health related (Write all problems) | | |
| Maternal health related (write all provisions) | | |
| ANC | | |
| PNC | | |
| Delivery normal/complicated | | |
| PPIUCD | | |
| Child health related (write all problems) | | |
| Hypertension | | |
| Diabetes | | |
| Cancer | | |
| Mental Health | | |
| HIV | | |

7. Have any special provisions been made to enable or facilitate tribal population's access to health facilities? What are these provisions and how are they working currently? (Probe on geographical access- Transport provision, social access- outreach services, financial access- free medicines and diagnostics).

**Health services and National and State level program facilities available at the CHC.**

8. What is the condition of infrastructural cleanliness, water, electricity in different facilities at the CHC?

| Rooms and facilities available at the CHC | Present/ not present and number | Cleanliness and Ventilation | Water supply Regular/ intermittent/ storage facility available | Electricity supply Regular/ intermittent/ no supply | Presence of generator |
|---|---|---|---|---|---|
| Operation Theatre | | | | | |
| Family Welfare room | | | | | |
| Emergency room/ Casualty | | | | | |
| Waiting room for patients | | | | | |
| OPD rooms | | | | | |
| Accommoda-tion for family of admitted patients | | | | | |

9. What is the condition of sewerage and garbage disposal at the CHC?

| Type of | Present/ absent reasons given for current form used | Any details |
|---|---|---|
| Waste disposal system in CHC | | |
| Provisions for separate Disposal of medical waste | | |
| Incinerator | | |
| Sewerage system | | |
| 1) Soak pit; | | |
| 2) Connected to Municipal Sewerage | | |

10. What types of health services are currently available at the CHC?

(Can be based on observation and interview)

| Service | Availability of service/ If not available reason | Building condition and availability of separate area | Cleanliness, water and electricity supply | Type of staff available currently | Availability of facilities, medicines and diagnostics free of cost |
|---|---|---|---|---|---|
| Ante-natal care | | | | | |
| Intranatal care (24 hour delivery services both normal and assisted) | | | | | |
| Is treatment for anemia given to both pregnant as well as non-pregnant women? | | | | | |
| Emergency Obstetric Care including surgical interventions like Caesarean Sections and other medical interventions | | | | | |
| PPH care | | | | | |
| Pre eclampsia care | | | | | |
| Other complications | | | | | |
| Post-natal care | | | | | |
| New born Care | | | | | |
| Are the low birth weight babies managed at the PHC? | | | | | |
| Emergency care of sick children | | | | | |
| Is BCG and Measles vaccine given regularly in the PHC? | | | | | |

| *Service* | *Availability of service/ If not available reason* | *Building condition and availability of separate area* | *Cleanliness, water and electricity supply* | *Type of staff available currently* | *Availability of facilities, medicines and diagnostics free of cost* |
|---|---|---|---|---|---|
| Cold chain maintenance from PHC to sub centre during immunization camps | | | | | |
| Is the treatment of children with pneumonia available at the PHC? | | | | | |
| Is the management of children suffering from diarrhea with severe dehydration done at the PHC? | | | | | |
| Treatment of deficiencies like Anemia, Vitamins etc | | | | | |
| Is treatment for anemia given to both pregnant as well as non-pregnant women? | | | | | |
| PPIUCD and incentives | | | | | |
| Family Planning services | | | | | |
| Is the facility for tubectomy and vasectomy available at the CHC? | | | | | |
| NSV | | | | | |
| Minilap/ LTT | | | | | |
| IUD | | | | | |
| ECPs | | | | | |

| *Service* | *Availability of service/ If not available reason* | *Building condition and availability of separate area* | *Cleanliness, water and electricity supply* | *Type of staff available currently* | *Availability of facilities, medicines and diagnostics free of cost* |
|---|---|---|---|---|---|
| Availability of MTP services | | | | | |
| Any precondition for doing MTP such as enforced use of contraceptives after MTP or asking for husband's consent for MTP? | | | | | |
| PAIUCD and incentives | | | | | |
| Management of RTI / STI | | | | | |
| Facility for internal examination for gynaecological conditions RTI/ STI/Infertility available at the CHC? | | | | | |
| Is the treatment for gynecological disorders like leucorrhoea, menstrual disorders available at the CHC? | | | | | |
| Operation Theatre for surgeries | | | | | |
| Operation Theatre for obstetric and gynecological use | | | | | |
| Labour room for deliveries | | | | | |

| *Service* | *Availability of service/ If not available reason* | *Building condition and availability of separate area* | *Cleanliness, water and electricity supply* | *Type of staff available currently* | *Availability of facilities, medicines and diagnostics free of cost* |
|---|---|---|---|---|---|
| Food provision for inpatient services- especially for deliveries | | | | | |
| Others | | | | | |

11. What is the current in-patient capacity at the CHC ? Can you tell us on a monthly average, how many people from tribal communities access these services?

| IPD services available for | Average no of patients | Average tribal and PVTG people who accessed in last 3 months/if not why? |
|---|---|---|
| Delivery | | |
| Delivery with complications | | |
| Neonatal care | | |
| Specific health problems for which IPD treatment is taken (list them) | | |
| Malaria | | |
| TB | | |
| Others | | |
| Male Wards/ Female wards are separate- how many of each | | |
| Others | | |

12. What diagnostic services are available? (Ask about the specific services and their status- Some parts can be filled in through researcher observation too.

| Type of Diagnostic Facility | Availability of services | | | |
|---|---|---|---|---|
| | Available at the PHC /near PHC | Timing of operation and days they are operating and charges if any | Referred to other providers- (If yes fill next box ) | Private provider- Distance from the PHC- what are their timings- what are their charges? |
| Blood Bank and Transfusion | | | | |
| Blood storage unit | | | | |
| Concept of e-raktkosh | | | | |
| Dialysis services | | | | |

(Note these are essential services that should be available at a PHC as per IPHS norms)

13. Is there a pharmacy for drugs recommended at the CHC? What drugs are currently/ usually available?

14. Do you face any problems with respect to drug availability, stock maintenance or any other? What type of problems do you face and what do you do in such situations?

15. Other facilities at the CHC?

| Facilties | Status of these services | staff needed and working/involved for service provision | Coverage of Tribal areas (average in 3 months) | Barriers faced in these services |
|---|---|---|---|---|
| Transport facilities to CHC from villages-free | | | | |
| Referral Facilities | | | | |
| Health promotion and Counseling Services | | | | |
| Disease surveillance and control of epidemics | | | | |
| AYUSH services as per local preference | | | | |
| Rehabilitation services (please specify) | | | | |
| Data operator and data entry for HMIS | | | | |

16. What is the Current status of health services under national and state programs at the District?

| Programs | Current programs and activities that are ongoing | Staff availability and training levels for these programs | Coverage among tribal population (average monthly figures) | Barriers faced |
|---|---|---|---|---|
| **Communicable & Vaccine Preventable Diseases** | | | | |
| TB RNTCP - DOTS | | | | |
| Malaria-NMEP | | | | |
| Leprosy-NLEP | | | | |
| Kala Azhar | | | | |
| JE | | | | |
| Dengue | | | | |
| Chickengunya | | | | |
| Elephantytis | | | | |
| Sickle Cell Anemia | | | | |
| Hepatitis | | | | |
| Jaundice | | | | |
| Diahhroea | | | | |
| HIV and ART | | | | |
| **Non-communicable Diseases (Programs on specific diseases)** | | | | |
| NPCDCS | | | | |
| Diabetes | | | | |
| Cancer | | | | |
| Hypertension | | | | |
| NMHP/DMHP | | | | |
| NPCB | | | | |
| NPHCE | | | | |
| Epidemiological Health Investigation, Promotion & Counseling | | | | |
| Disease profiling at the district level | | | | |
| **RMNCH+A** | | | | |
| ANC facilities outreach | | | | |
| Early registration | | | | |
| JSY | | | | |
| JSSK | | | | |
| Referral Transport for delivery/ post partum complication/ child health problem | | | | |
| VHND | | | | |

| *Programs* | *Current programs and activities that are ongoing* | *Staff availability and training levels for these programs* | *Coverage among tribal population (average monthly figures)* | *Barriers faced* |
|---|---|---|---|---|
| Maternal and Child tracking (MCTS) | | | | |
| Maternal Death reviews | | | | |
| Family Planning services –fixed day ( options given OCP, Condom, NSV, LTT, ECP,IUCD, others) | | | | |
| Family Planning camps ( options given OCP, Condom, NSV, LTT, ECP,IUCD others) | | | | |
| Family Planning counseling | | | | |
| Sterilization death reviews | | | | |
| HIV/AIDS | | | | |
| Pradhan Mantri Surakshit Matritva Yojana | | | | |
| JYS | | | | |
| JSSK | | | | |
| Iron + initiative (NIPI) | | | | |
| WIFS | | | | |
| De worming | | | | |
| Iron Supplementation for adolescents | | | | |
| IFA for PW | | | | |
| RKSK | | | | |
| **IMNCI (Diseases covered)** | | | | |
| Diarrhoea management | | | | |
| Jaundice | | | | |
| Others | | | | |
| RBSK | | | | |
| Vitamin A supplementation | | | | |

| *Programs* | *Current programs and activities that are ongoing* | *Staff availability and training levels for these programs* | *Coverage among tribal population (average monthly figures)* | *Barriers faced* |
|---|---|---|---|---|
| Adolescent & School Health (Adolescent & school health promotional activities) | | | | |
| Pradhan Mantri Dialysis scheme | | | | |
| State Level initiatives and innovations undertaken (from PIP) | | | | |
| Health Kiosks for diagnostic tests | | | | |
| District level activities under national tobacco program NTCP | | | | |

17. Quality Control factors and their availability at the CHC?

| S. No. | Particular | Whether functional / available | Barriers to functioning |
|---|---|---|---|
| 17.1 | Is the Citizen's charter displayed (Yes/No) | | |
| 17.2 | Constitution of Rogi Kalyan Samiti (Yes/No) (give a list of office order notifying the members) | | |
| 17.3 | Internal monitoring (Social audit through Panchayati Raj Institution / Rogi Kalyan Samitis, medical audit, technical audit, economic audit, disaster preparedness audit, monitoring of accessibility and equity issues, information exchange etc. (Specify) | | |
| 17.4 | External monitoring (Monitoring by PRI (Zila Parishad)/ Rogi Kalyan Samitis, service / performance evaluation by independent agencies | | |

| S. No. | Particular | Whether functional / available | Barriers to functioning |
|---|---|---|---|
| 17.5 | Availability of Standard Operating Procedures (SOP) / Standard Treatment Protocols (STP)/ Guidelines | | |

18. What do you see as the current barriers for provision of quality health services at the CHC ? What are your suggestions, thoughts on overcoming the same?

***Annexure 4***

# Guide for Focus Group Discussion (FGD)

Date: _____

FGD Starting Time _____ End Time _____

## Instruction for FGD Moderator

Ensure that the FGD is conducted with men, women or adolescents. Include about 10-12 participants in each FGD and ensure varied representation from the community. The FGDs can be conducted in discrete groups of similar respondents, for example, FGD comprising women participants only, as well as in mixed groups.

Explain to the participants the background, purpose and objectives of the study.

Take their consent for the discussion, documentation and use of the information/data.

Write down the names of all the participants and their brief background profiles as per the format before asking the questions.

Ask participants to speak one person at a time but allow discussion and interaction among them.

Ask all the sub-set of questions and note down the responses for each question.

At the end of discussion, thank members for their valuable responses.

## Section I: Background Information of the FGD Participants

Village _____ Panchayat _____ Block _____

District _____ State _____

Location of FGD _____

Date of FGD _____

Discuss the background of the hamlet / village, community – housing, food, water, sanitation, occupation, education, etc.

Note down the profile of participants who attend the FGD in the following format.

| Sl. No. | Name | Tribal Group | Age | Literacy / Education | Marital Status | Occupation |
|---|---|---|---|---|---|---|
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |
| | | | | | | |

## Section II: Overall Health Context

Discuss the background of the hamlet / village, community – housing, food, water, sanitation, occupation, education, etc.

What are the prevalent health problems, diseases/illnesses in the village, among tribal and non tribal communities?

Are these seasonal?

Are they specific to certain communities?

Where do they go for treatment? Explore the different providers/facilities they access for different health issues.

Who do they seek advice from locally before going to the health facility? – ASHA/ANM/ AWW/ any traditional healer/ private service provider, any other.

Which health care facility is preferred and frequented? Reasons for the same – distance/ cost/ behaviour/ effective treatment/ availability of facilities/services, trust, any other.

Which is/are the government health facilities (Sub Centre, Primary Health Centre, Community Health Centre, Sub-district hospital, District hospital) do they go to at different levels – panchayat, block or district? Reasons for the same?

What is the distance from the village to the nearest motorable road point? How are persons who are unwell transported/ taken to the health facility/hospital. What is the road availability and condition of the road from the village to the health facility?

Is there any transport facility available in the village? What are the usual transport facilities to the health care facilities? Details (self-owned/ borrowed/ private service/ public service, cost, reliability)

Are they aware about the 108/102/ambulance facility? What has been their experience about the cost, punctuality, attitude of driver, availability of equipment? What difficulties do they face in using the service?

What services do they generally access from the government health system and what services from the private hospitals? Reasons?

Experience of the health care facilities that they go to in terms of cost, behaviour of employees of the facilities, follow-up care, any other.

What do they feel about expenses related to health care? Are they affordable or expensive? Is there a difference between the public and private facilities? How do you they cover these expenses (from savings, borrowing from some one, credit, sale of assets?)?

For the most recent incidence of illness in their village, how much was the direct expenditure of illness (Transportation, Medicines, Diagnosis, Doctor's fee, OPD charges)? And how much was the indirect expenses of illness (Escort, Food, Logistic, Man-days loss, tips)?

Where do they get the medicines? Are medicines available free of cost in the government health institutions?

What about screening, treatment and follow up for malaria, sickle cell disease, anemia etc?

What is the First aid and Treatment available for snake bites and animal attacks? Where do they go for such incidents?

Do the women have access to antenatal care (ANC), postnatal care (PNC) and contraceptives? Supply of condoms?

Are sterilisation services available for both men and women?

Have there been any child deaths in the village within last one year (Infant death, Neonatal death, still birth, child below 5 year)? What were the causes of death?

Discuss the prevalent practices regarding feeding practices for children (breastfeeding, colostrum feeding, complementary feeding, etc.) Are issues of malnutrition common? What are the reasons for the same? Available government programmes / schemes to address it?

What is the source of drinking water?

Is there ASHA/Mitanin in their village? What all do they do in the village/area? What services does she provide?

Does the ANM visit regularly visit their village? What services do they get from her?

Is there any committee in their village for health (GKS/VHSNC)? What does the committee do? How are they involved in the committee's activities?

What are the health schemes/programmes that they are aware of? What services do they receive through the schemes and programmes. (ICDS, JSY, JSSK, others specific to tribal areas). Discuss in detail.

Are they aware of untied grants given to the VHSNC? How are such funds utilised?

Are Monthly Village Health and Nutrition Days (VHND) being organised? Do they participate in such events? What are the activities usually undertaken during the VHNDs?

Are Mobile Medical Units (MMUs) available in the area? What services are provided by MMUs?

Do they have RSBY (Rashtriya Swasthya Bima Yojana) cards? Have they used them? Discuss what they used it for, their experience in doing so, and problems faced if any.

Do they have any suggestions for the improvement of health services in their area?

Any other observation or comment.

Overall remarks by FGD Moderator

**Signature of the Moderator/s**

Name: _____

Date: _____

Place: _____

*Annexure 5*

# Summary of Recommendations

1. **Remove restriction on sterilisation services** for **PVTGs in Chhattisgarh** (order dated 13.12. 1979 issued by the Public Health and Family Welfare Department, Madhya Pradesh government) and recognise **the right and autonomy** of the members of PVTGs to make informed decisions regarding reproduction, contraception and family planning.
2. Ensure that all CHCs in tribal areas have **functional blood storage units** with the minimum requirement of blood (which should be double the number of units that of the average daily requirement) available at all times.
3. Ensure that **no user charges are collected for blood transfusions and replacement is not imposed for blood transfusions**.
4. Ensure the **availability of requisite drugs for Haemoglobinopathies like Sickle Cell Disease (SCD) and Thalassemia, such as Hydroxyurea, iron chelation therapy and pain killers across different facilities free of cost**.
5. Ensure the **availability of diagnostic facilities like solubility tests** at **Sub-centre** and **PHCs,** and **Hb electrophoresis at CHC and DH to confirm or rule out Sickle cell anaemia.**
6. Ensure the **availability, regular maintenance and replacement of diagnostic services as per the Indian Public Health Standards like radiology services including X-Ray (for Chest, Skull, Spine, Abdomen, bones),** Dental **X-Ray and Ultrasonography (USG**) in all CHCs and District Hospitals without user charges.
7. Ensure all essential drugs as per the Essential Drug List (EDL) and IPHS are available for free in all government facilities. Ensure **regular audits of prescriptions** to ascertain prescription of generic medicines from the facilities.
8. Ensure that both **community based and facility based maternal deaths are documented and reviewed**. Maternal death audits should be conducted periodically and the analysis of maternal deaths should not focus on clinical causes alone. Emphasis should be on social causes and should highlight implementation gaps.
9. The **data entry of ANC, PNC, maternal deaths should be disaggregated on the basis of social groups and particularly the data from the PVTGs.**
10. Guarantee **regular stock and storage of Anti Snake Venom (ASV) at PHCs** as per IPHS guidelines, particularly in areas reporting a high incidence of **snakebite cases**.

11. Ensure adequate **supply of free, quality TB medicines, including drugs for MDR-TB, Bedaquiline and Delamanid**, are made easily available and affordable by **issuing compulsory licenses** to local manufacturers under the Patents Act.

12. Immediately **withdraw the mandatory requirement of Aadhar for TB treatment and nutritional support for TB under RNTCP**. Further, revoke the requirements for **mandatory Aadhar card as conditionality** for other social welfare services like PDS, pension and for seeking treatment in private and public sector hospitals.

13. Ensure that ASHAs and ANMs in malaria endemic districts have regular supply of **Rapid Diagnostic Tests, Chloroquine, Artemisinin-based Combination Therapy (ACT) and primaquine, with** them all year around. Ensure regular monitoring and refill of these in their drug kits.

14. Ensure that **maternity benefits programmes** are accessible to women without any conditionalities like the order of birth, age or institutional birth (which are conditionalities under Pradhan Mantri Matritva Vandana Yojana [PMMVY])

15. **Adhere to Supreme Court (Civil Writ Petition No. 95/2012 (Devika Biswas v/s Union of India) specific directions in its order dated 14.9.2016, to be strictly followed** by the Government of India, the State Governments and Union Territories for delivering quality family planning services in the country.

16. Guarantee **that all the PVTG households across the states are covered under the Antyodaya scheme (AAY)**, in compliance with the Supreme Court judgment on the 'right to food case' in May 2003.

17. Ensure that all **PHCs in tribal areas (which are identified and mapped as geographically challenging by District or Block level administration) are equipped with an ambulance with Basic Life Saving (BLS) devices**. Ensure that CHCs in tribal areas with areas identified as geographically challenging are equipped with **additional vehicles by the health department**. While patients who book their own vehicles to reach health facilities are reimbursed from RKS funds against actuals.

18. Ensure PHCs are set up according to the norm in the tribal populated districts.

19. Prioritise the health component when allocating special grants to **states to formulate their TSP (Tribal Sub Plan),** and make sure the state governments ensure the timely approval and implementation of the TSP.

20. Create a **separate post for Schedule Area Health Officer at each TSP project office**, to work with the health department, and to supervise, monitor, and manage the medical and health care system in the Scheduled Areas.