EndMMNow

No Time to Lose: Fighting Maternal and Infant Mortality through Community Reporting

EndMMNow is a project by:

with the generous support of:

Acknowledgments

Through the generous support of the ISIF Asia, Nazdeek, PAJHRA and ICAAD have developed the "End MM Now" project to empower Adivasi women to identify and report cases of health violations in their communities. Through legal empowerment, community monitoring and technology, we're working to combat preventable maternal and infant mortality in Sonitpur District, Assam.

The End MM Now Project would not be possible without the tireless support of its 40 community volunteers. We thank each of them for pursuing this cause of justice, and are honored to work by their side.

Nazdeek is a legal capacity building organization committed to bringing access to justice closer to marginalized communities in India. Nazdeek partners with grassroots activists and lawyers to build community-based legal networks to increase accountability in the protection of social and economic rights. Leveraging the power of local and transnational networking, we work with communities in developing tools to demand justice.
www.nazdeek.org

PAJHRA, which in Adivasia language means "life spring" stands for the Promotion and Advancement of Justice, Harmony and Rights of Adivasis. A community-based organization in Assam, India, PAJHRA's mission is to empower members of the Adivasi community and their institutions by building their capacity, self esteem and advocating for their rights.
www.pajhra.org

International Center for Advocates Against Discrimination (ICAAD) combats structural discrimination and promotes human rights norms consistent with public international law. Structural discrimination refers to systems of inequality that provide a social, political, cultural, or economic advantage to dominant groups while furthering barriers of exclusion that marginalize communities and expose them to violence or indignity. To address this problem, ICAAD brings together passionate teams of multi-disciplinary partners in law, data, and design to improve access to justice and strengthen the capacity of civil society on behalf of women, girls, and other vulnerable groups.
www.icaadglobal.org

Report Photo Credit: Rajan Zaveri, Multimedia
Report Layout & Design: Jaspreet K. Singh, Joseph R. Wheeler

Executive Summary

Context

With the highest number of maternal deaths[1] in the world, India leads a quiet war against women. Ninety percent of these deaths are preventable, often caused by fatal delays in seeking and obtaining care.

The North Eastern state of Assam leads the country with the highest maternal mortality ratio (MMR),[2] and one of the highest infant mortality ratios (IMR) in India.[3]

These health indicators persist, despite the right to safe motherhood protected by the Indian Constitution and guaranteed under national laws and policies. Insufficient budget allocation, weak implementation of policies and poor monitoring and oversight contribute to a tragically high number of maternal and infant deaths.

These human rights violations are particularly prevalent for women hailing from Adivasi (tribal) communities who live and work in the tea gardens of Assam. Forcibly brought to work on the gardens more than 150 years ago, over 25 lakhs (2,500,000) families in Assam live in a state of 'generational servitude' and lack access to services and facilities necessary to ensure safe motherhood.

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1 Maternal death is the death of a woman while pregnant or within 42 days of termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management but not from accidental or incidental causes, available at: www.who.int/healthinfo/statistics/indmaternalmortality/en/, last accessed on 5th February 2015.

2 The Maternal Mortality Ratio is the number of maternal deaths per every 100,000 live births, available at http://www.maternalmortalitydata.org/definitions.html, last accessed on 5th February 2015.

3 The Infant Mortality Rate is the number of infant deaths per every 1,000. Infant death is the death of a child less than one year of age, available at http://data.worldbank.org/indicator/SP.DYN.IMRT.IN/countries, last accessed on 5th February 2015.

"End Maternal Mortality Now" Project Report

The lack of data on the Adivasi community makes it particularly difficult to address some of the gaps in the implementation of maternal and infant health policies. Unlike other Indian States, Adivasi communities living in Assam do not enjoy Scheduled Tribes status. As a result, the Government does not collect disaggregated data on the Adivasi community, the large majority of whom are tea garden workers. This condition is further exacerbated by low literacy and awareness of health rights among Adivasi women, which affects their ability to report and monitor violations.

For this reason, Nazdeek, PAJHRA (Promotion, and Advancement of Justice, Harmony and Human Rights of Adivasi) and ICAAD (International Center for Advocates Against Discrimination), have developed an innovative project, to empower Adivasi women to identify and report cases of health rights violations. "End Maternal Mortality Now" fuses legal empowerment, community monitoring and technology to combat preventable maternal and infant mortality in Sonitpur district, Assam.

Through the Project, 40 women volunteers have reported almost 70 cases of violations between May and November 2014 in tea gardens and rural areas in Sonitpur District. Reports, sent through codified SMSs, are mapped on an online platform and database and made publicly available at the End MM Now Project website (www.EndMMNow.org).

The data collected, backed with field research and interviews with patients and health workers, reveals vital insights on a forgotten community's struggle. The ambition of this Report is to bring light to the challenges that Adivasi women face in navigating the health system, and give voice to those who are left out of the system's path. Through this process we hope a sustained dialogue begins between community members and health authorities in a joint effort to save mother and infant lives.

Findings

Across 68 reports received, the most common violation reported (47% of total cases), was **undue payment**, or informal fees, for medical services that should be provided free of cost.

After undue payment, the 3 most heavily reported issues were:

- **lack of medical care** – for example, no doctor or nurse being present at a clinic/hospital (29% of total cases)
- **ambulance unavailability** – for example, patients often having to hire private taxis (28% of total cases)
- **undue hospital referrals** – for example, patients being referred to 4 different hospitals while in labor (25% of total cases)

There were 11 reports of newborn deaths or stillbirths, and 4 reports of maternal deaths. Within these, the most commonly associated violations were:

- **lack of medical care** – in 55% of newborn death or stillbirth cases, and 50% of maternal death cases
- **undue hospital referrals** – in 45% of newborn death or stillbirth cases, and 50% of maternal death cases

The reports also highlighted **blood unavailability** and **inadequate hygiene and overcrowding** as issues hindering access to adequate treatment.

In-depth case studies revealed the tragic outcome of delay, with patients such as *Patient M* shuffled between 4 hospitals in 2 days due to a lack of services, and ultimately dying on her way to a 5th hospital, more than 160 kms away. Other stories, such as *Patient R* underscore how devastating it is to be poor, with women forced to sleep on the dirty corridors of hospitals for weeks, unable to pay the illegal fees required to receive basic medical care.

Common among all reports is the urgent need to reduce delay in every step of the health care chain: from the moment women decide to seek care, to their journey in reaching the facility, to obtaining care at the hospital. For this reason, the 'Three Delay Model' has been applied to analyze the findings.

Recommendations

The Project reveals the everyday challenges that marginalized women and their families face in accessing basic health care. These insights offer tangible opportunities for health authorities and tea garden managers to improve the delivery of health care consistent with legal obligations.

Quantitative and qualitative analysis of the data allowed for the development of key recommendations to health authorities at State, District and Block level, as well as to tea garden managers. The recommendations span issues of availability of services and quality of care, as well as monitoring and accountability of Government scheme implementation. Specific recommendations have been crafted for facilities covered under the Project, with concrete and feasible actions, if implemented, leading to an improvement in the delivery of health services.

Some of the most urgent recommendations address the blood emergency unfolding in Assam, with a demand for a functioning blood bank at the Dhekiajuli Community Health Center (CHC), which critically requires the appointment of a hematologist. Another key recommendation concerns the need to establish a transparent and responsive grievance mechanism resulting in increased community awareness of rights and entitlements and a more accountable health system. The mechanism would include quarterly meetings between Block health officials and community representatives, with issues such as undue payment, discrimination, or lack of services brought to the attention of government officials with a request for time-bound action.

Other recommendations address the need for a more efficient transportation and referral system, such as strengthening the use of alternative forms of transport suitable for rural areas, and increasing the number of ambulances in specific facilities within the Project area.

This Report is the first community-driven effort to bridge the gap between what the law says and what Adivasi women in Sonitpur experience during pregnancy and childbirth. In doing so, community members seek to work with health authorities towards a common goal of ensuring safe motherhood for all women living in Assam.

Photo: Community members attending a meeting on End MM Now Project

Introduction

Maternal and infant health in Assam

Ninety percent of maternal deaths are preventable. India leads the world with the highest number of maternal deaths, where according to the United Nations around 50,000 women per year die from pregnancy-related causes. Assam leads the country with the highest maternal mortality ratio (MMR) - 328 deaths per 100,000 live births against 178 deaths per 100,000 live births in the rest of the country.[4] The infant mortality rate (IMR) is 54 - far above the national IMR of 40.[5]

Based on national and international obligations, the Central Government and the Assam State government have enacted policies and programs to curb maternal and infant mortality rates while guaranteeing universal health care. The main umbrella health scheme, launched by the Central Government in 2005, is the National Rural Health Mission (hereafter NRHM), a sub-mission of the overarching National Health Mission. The aim of NRHM is to improve availability of and access to quality health care by people, especially for those residing in rural areas, the poor, women, and children. These goals are in line with the Millennium Development Goals (MDGs) and the Sustainable Development Goals (SDGs) – for instance, reduction of child mortality, improve Maternal Health and combat HIV/AIDS, Malaria and TB (Development Goals States of India Report, 2010).

One of the flagship programs under the NRHM is the Janani Suraksha Yojana (JSY), which provides for services such as post-delivery cash benefits, supplementary nutrition, and medical check-ups.

4 Registrar General of India, *Special Bulletin on Maternal Mortality in India 2010-12*, Sample Registration System

5 *Id.*

The right to safe motherhood in Indian Law

Relevant Laws:

- Article 21 of the Indian Constitution (right to life which includes right to health, food and freedom from cruel and inhuman treatment)
- Articles 14 and 15 of the Indian Constitution (right to equality and non-discrimination)
- Article 2 of the International Covenant on Economic, Social and Cultural Rights
- Article 12 and 14 of the Convention on the Elimination of Discrimination Against Women

Key Caselaw:

- Chameli Singh v. State of UP (1996): "the right to life in any civilized society implies the right to food, water, shelter, education, medical care and a decent environment. These are basic human rights known to any civilized society..."
- Laxmi Mandal v. Deen Dayal Harinagar Hospital & Ors (2010): an 'inalienable" component of the right to life is "the right to health, which would include the right to access government (public) health facilities," including "the reproductive rights of the mother and the right to nutrition and medical care of the newly born child.'"

Despite these Government programs health outcomes remain poor.

Insufficient budget allocation, weak implementation of policies and poor monitoring and oversight contribute to the high number of maternal and infant deaths. These human rights violations are particularly prevalent for women hailing from Adivasi communities who live and work in the tea gardens of Assam.

India's Universal Periodic Review

India accepted and noted the following recommendations during its second cycle assessment at the UN Universal Periodic Review (UPR):

Yellow = Accepted Green = Noted

Recommendation	Recommending State
Address the inequities based on rural-urban divide and gender imbalance	Botswana
Take further practical steps to reduce the high level of maternal and child mortality, inter alia, through better access to maternal health services	Austria
Further efforts towards addressing the challenge of maternal and child mortality	Egypt
Strengthen its efforts to improve maternal health and acts to effectively balance the skewed sex-ratio among children, including by combating female foeticide	Norway
Take further measures to ensure all women without any discrimination access to adequate obstetric delivery services and sexual and reproductive health services, including safe abortion and gender-sensitive comprehensive contraceptive services	Finland
Ensure that laws are fully and consistently enforced to provide adequate protections for members of religious minorities, scheduled castes, and adivasi groups, as well as, women, trafficking victims, and LGBT citizens	United States
Implement the recommendations made by the Special Rapporteur on the rights of human right defenders following her visit in 2011, with particular emphasis on recommendations that concern defenders of women's and children's rights, defenders of minorities rights, including Dalits and Adavasi, and right to information activists	Norway

See UPR-Info, available at: http://www.upr-info.org/

Maternal health in tea gardens

With more than 1.2 million permanent workers, and hundreds of thousands of seasonal workers, the tea industry is the largest private sector employer in India.[6] One of out of every 7 workers in India's organized sector is a tea plantation worker.[7] More than 50 percent of these workers are women.[8] The tea garden workers, mostly Adivasi and lower castes, are fourth generation descendants of indentured immigrants brought by the colonial planters 150 years back from the tribal tracts of Bengal, Bihar, Orissa and Madhya Pradesh. Today, workers remain isolated from Assam's mainstream, both physically and in terms of economic development. Decades of "generational servitude" resulted in workers being dependent on tea management for their livelihoods, and their families' housing, health, food, education, and cultural life. Factors such as low wage and barriers to free association contribute towards a sustained state of exclusion and marginalization.

As a result, over 25 lakh (2,500,000) families[9] living in Assam's tea gardens lack access to services and facilities guaranteed under the Constitution of India, the Plantation Labor Act, 1951, and other relevant statutes and policies.[10] The Plantation Labor Act, 1951 (PLA) and the Assam Plantation Labor Rules, 2010 (APLR) are the main legal instruments regulating living and working conditions in the gardens,

6 D. Mishra et. al, *Unfolding Crisis in Assam's Tea Plantations: Employment and Occupational Mobility*, Routledge, (2012), p. 3.

7 Tea Board of India, Tea Statistics 2003-04 (31 Dec., 2004 total number of tea workers estimated at 1,257,610 and number of dependents of resident workers estimated at 1,229,730).

8 http://labourbureau.nic.in/SECOWW_Plantation_200809.pdf.

9 *Report of the one man enquiry Committee on the implementation of the Plantation Labor Act 1951*, Government of Assam, 2014.

10 Other relevant statutes include, but are not limited to, Minimum Wages Act, 1948, Maternity Benefits Act, Provident Fund Scheme Act, 1952, Payment of Bonus Act, 1965.

including minimum requirements of health facilities. However, implementation of the PLA across the State is alarmingly poor,[11] with only 32% of tea gardens in the State meeting at least 80% of the PLA requirements. For instance, tea garden hospitals lack equipment, skilled medical personnel and referral systems necessary to protect women and infants' lives.

The State Government has tried to address the dire state of health services by extending NRHM services to tea gardens through public-private partnerships set forth in Memorandum of Understandings (MOUs). Under the MOU, health services must be provided free of cost for workers and residents. In addition, the Government provides funds for ambulances as well as salaries for a Medical Officer and an Auxiliary Nurse Midwife (ANM).

The terms of the MOU include requirements to:

- Build a labor room equipped with appropriate facilities;
- Hire ANM/doctor;
- Display signage regarding the NRHM scheme in the hospital;
- Establish a NRHM Management Committee to monitor implementation of the MOU and address grievances raised by stakeholders (the committee must include a TE Manager, TE Welfare Officer, TE Doctor, two Permanent Workers, a Medical Officer, a Block Programme Manager and District Medical Office).[12]

However, as analysed in this Report, mismanagement of funds and lack of transparency on funding allocation by tea gardens has hindered the Government's effort to improve access to healthcare in tea gardens.

The right to access health care in tea gardens

- The Plantation Labor Act, 1951, and the Assam Plantation Labor Rules, 2010, Section 35 – 37, guarantee workers and their families rights including access to:
  - A doctor;
  - A labor room; and
  - 24-hour-per-day 'normal delivery service.'
- A recent Government report has found that PLA is poorly implemented in the gardens. For instance:
  - There is a shortfall of 280 garden hospitals in the State;
  - Not a single group hospital has been established in the State;
  - The number of doctors, midwives and nurses is often below legal requirements.

Report of the one man enquiry Committee on the implementation of the Plantation Labor Act 1951, Government of Assam, 2014

Gap between healthcare providers and patients

There is a sizeable gap between health care providers and patients, especially those belonging to tea gardens and rural areas. This gap results in significant delays in seeking and receiving care, and therefore jeopardizes the effectiveness of the treatment provided. Such factors, explored in Chapter 2 of this report, include lack of awareness over rights and entitlements, corruption, lack of services and poor quality of treatment available in public and private hospitals. Indeed, according to a 2009 study by the University of Guwahati (Assam) only 21% of health

11 *Supra* n 6

12 The committee must include a TE Manager, TE Welfare Officer, TE Doctor, two Permanent Workers, a Medical Officer, a Block Programme Manager and District Medical Office.

facilities in the District of Sonitpur offer 24-hour delivery service, only 39% have a labor room and only 17% have inpatient service.[13]

In tea gardens, additional factor contributing to high rates of maternal and infant death is the failure to ensure access to non-medical services. For example, workers often do not receive food rations allocated by the Central Government through the Public Distribution Scheme. This gap contributes to the widespread malnutrition and anemia. According to a 2006 survey, the average rate of anemia among tea garden workers is 70%.[14] Medical staff interviewed during this Project indicated that 90% of women living in tea gardens are anemic.[15]

The "End Maternal Mortality Now" Project: Closing the Gap

To address some of the abovementioned gaps, Nazdeek, PAJHRA (Promotion, and Advancement of Justice, Harmony and Human Rights of Adivasi) and ICAAD (International Centre for Advocates Against Discrimination),[16] developed and implemented the "End Maternity Mortality Now" Project ("End MM Now Project" or "Project"), which combines social accountability, legal empowerment and technology.

The project seeks to empower patients and their communities to monitor and report instances of lack of access to health services.

13 *Rapid appraisal of National Rural Health Mission Implementation*, University of Guwahati, Department of Statistics, Population Research Centre, 2009

14 T. Mahanta et al., *Effect of Directly Observed Iron Therapy in Anaemia and Productivity – A Community Based Intervention Study in Dibrugarh, Assam*, Indian Journal of Applied Res., Apr. 2013, at 24.

15 Interview conducted by Project team with Sonitpur district health officials dated Dec. 19, 2015.

16 Collectively referred to as "Partner Organizations"

Basanti T., Joshila S., Rumila S. – fearless members of the End MM Now team

Project Goals:

- Map and report gaps in the delivery of maternal and infant health services
- Serve as a bridge between communities and government health system
- Raise awareness on the government schemes and how to avail of them

Aim of Report:

- To visualize and analyze the data collected during the duration of the pilot project
- To offer health authorities and civil society a ground-level perspective on the delivery of health services in Balipara and Dhekiajuli Blocks of Sonitpur District.
- To give a voice to those who are left out of the health care system, exposing the challenges encountered in ensuring access to lifesaving treatment essential for safe motherhood.
- To establish a dialogue between community members and health authorities, towards the common goal of improving the delivery of health services in the state.

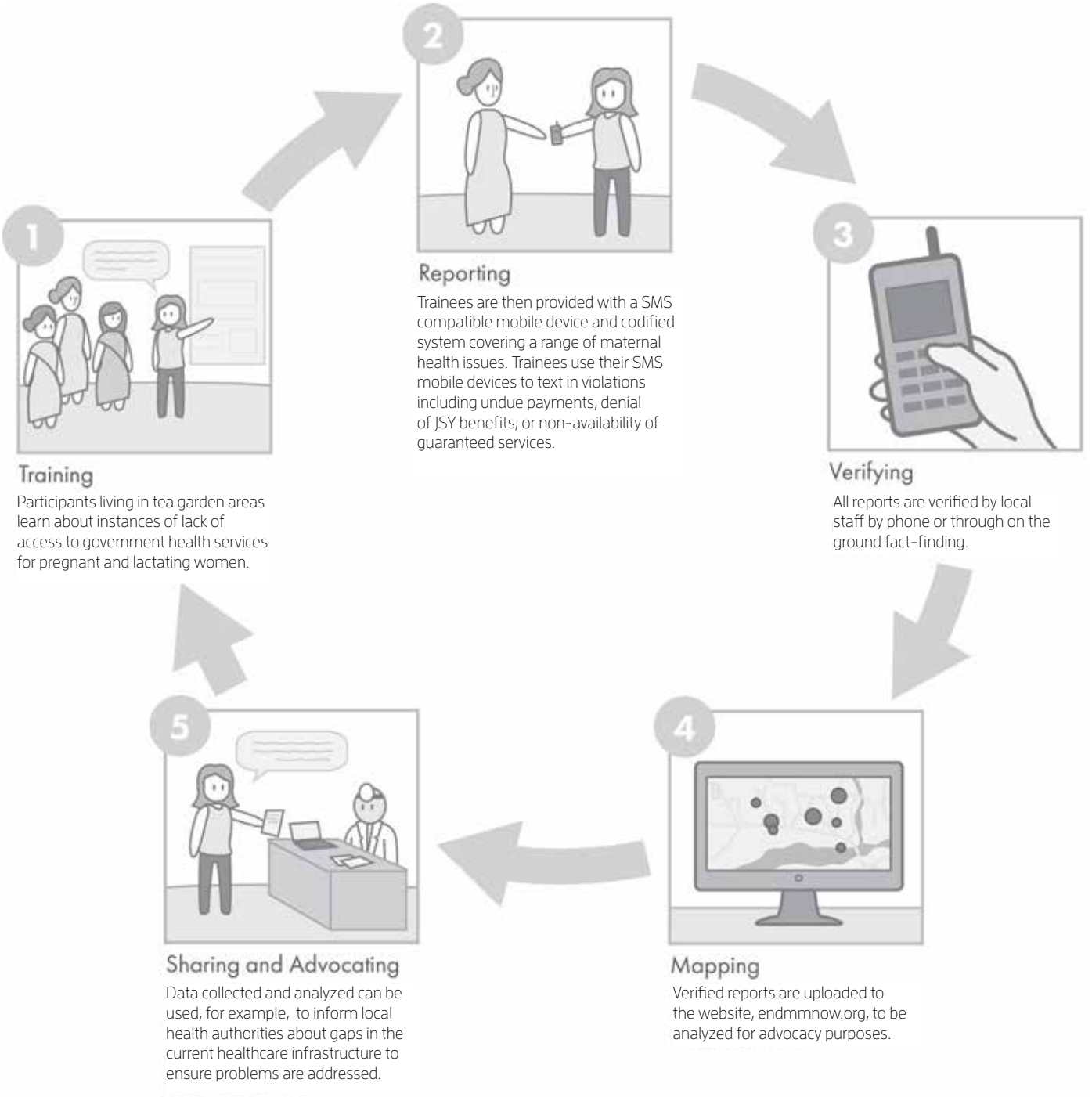
Methodology

This Report is based on the data collected in the End MM Now Project. Launched in April 2014, the Project identified and trained a group of 40 women volunteers living in Balipara and Dhekiajuli Blocks in the Sonitpur District of Assam.

Project volunteers attended a series of training sessions on issues of maternal and infant health and rights and entitlements under the NRHM. From May to November 2014, volunteers collected and reported incidents when pregnant and lactating women could not access health and nutrition services and benefits required by the NRHM, the PLA, , the Public Distribution System (PDS), and MOUs between the Central Government and tea gardens. Through a coding system, the volunteers reported the incidents via SMSs to the Project team based in Tezpur.

The veracity of all reports received has been systematically assessed, either by phone or through field visits. Verified reports were mapped on an online platform and database and made publicly available at the End MM Now Project website (endmmnow.org).

In December 2014, Nazdeek and PAJHRA conducted surveys and fact-finding



investigations with victims, volunteers and health staff in several government and tea garden facilities located in Balipara and Dhekiajuli Blocks. They selected eight case studies and conducted in-depth field research to illustrate key challenges Adivasi women face in accessing the public health system.

The partner organizations chose to work in the Sonitpur District for a number of reasons, including the: (I) key role played by the District at State level; (2) sizeable number of tea gardens and high Adivasi population; and (3) presence of strong grassroots groups which allowed for an effective Project implementation, specifically, PAJHRA in Tezpur and Dhekiajuli, and PNJSS (Pragati Nari Jagaran Sangram Samity) in Balipara. For this reason, findings and recommendations illustrated in this Report are limited in scope to the area covered.

End MM Now volunteers given phones to report cases

The coding system

The Partner Organizations developed a system for coding over 30 different violations of the NRHM, the PLA, MOUs, and PDS. Categories of codes include: availability of services, conditions of facilities, JSY entitlements, and undue payment. In addition, recognizing the correlation between right to safe motherhood and right to food, the coding system also includes five codes specific to the availability of quality food rations through the PDS. A complete list of codes is found at Appendix I.

Based on this categorization, the End MM Now Project online platform allows users to filter reports based on these categories of codes. However, the findings presented in this Report do not necessarily reflect this categorization.
Data was collected at a number of different locations and types of health facilities to ensure a more nuanced understanding of ground conditions. Codes have been assigned to the eighteen facilities present on the Project area, which can be found at Appendix 2.

Volunteers applied different the relevant standards for the various health facilities. For example, volunteers applied the NRHM Service Guarantees when they analyzed potential violations in Primary Health Centers, Community Health Centers and higher facilities. Volunteers referred to Section 35-37 of the APLR when evaluating complaints at tea garden hospitals. However, volunteers applied the terms of the MOU when evaluating complaints at tea gardens that receive NRHM funding, namely: Sapoi, Panbari, and Narayanpur (Dhekiajuli Block).

Volunteers also reported violations that occurred at government-run nutrition centers (Anganwadi Centers) and PDS ration shops by the

village where the concerned facility is located. In addition, volunteers reported violations occurred in villages (e.g., failure to register pregnancies or to provide JSY cash benefits after home deliveries) based on the location of the health center covering the area where the instance occurred.

Volunteers and affected families

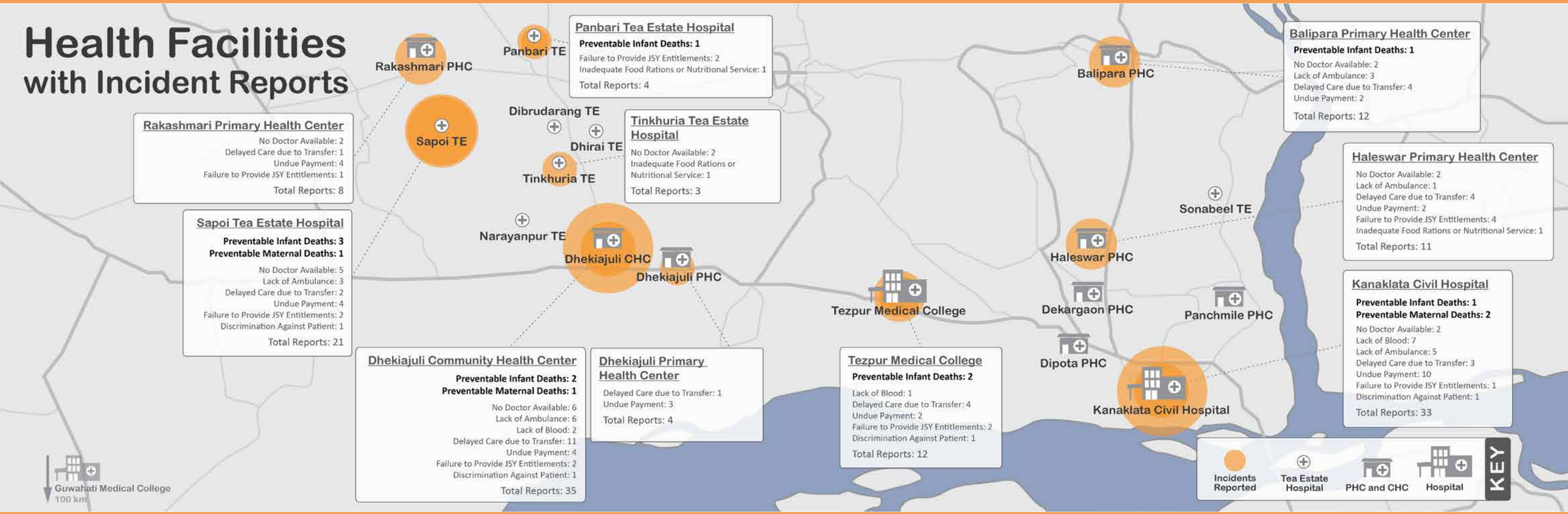
Project partners selected End MM Now volunteers from different backgrounds and diverse geographic locations throughout the region. For instance, 54.5% of the volunteers live in a village, while the other 45.5% volunteers live in the tea gardens. Their occupations also vary; half of the participants work as housewives, 18.2% are employed as Government workers (Accredited Social Health Assistant or Anganwadi Worker), 22.7% serve as teachers or social workers, and the remaining 9.1% work in another profession.

Volunteers had varying education level as well; most volunteers have a class VI-X education level (54.5%); 27.3% have a class I-V level; and 18.2% have earned their Bachelors of Art. 40.9% of volunteers are Hindus, and 54.5% are Christians. As to the age group, about 35% volunteers are between 24-35 years of age, while 35% of the volunteers are older than 35 years of age. The youngest volunteer is 19 years old and the oldest 48 years old.

While the data collection also tracked names of the victims and their family members, these are not published in this Report to protect the privacy of affected women and children. Similarly, only few names of Project volunteers have been made public. All individuals cited in the Report provided written consent to use their name for the purpose of this publication.

Photo on Right: Training for volunteers in Balipara Block on maternal health entitlements, May 2014

Health Facilities
with Incident Reports



Rakashmari Primary Health Center
No Doctor Available: 2
Delayed Care due to Transfer: 1
Undue Payment: 4
Failure to Provide JSY Entitlements: 1
Total Reports: 8

Panbari Tea Estate Hospital
Preventable Infant Deaths: 1
Failure to Provide JSY Entitlements: 2
Inadequate Food Rations or Nutritional Service: 1
Total Reports: 4

Tinkhuria Tea Estate Hospital
No Doctor Available: 2
Inadequate Food Rations or Nutritional Service: 1
Total Reports: 3

Sapoi Tea Estate Hospital
Preventable Infant Deaths: 3
Preventable Maternal Deaths: 1
No Doctor Available: 5
Lack of Ambulance: 3
Delayed Care due to Transfer: 2
Undue Payment: 4
Failure to Provide JSY Entitlements: 2
Discrimination Against Patient: 1
Total Reports: 21

Dhekiajuli Community Health Center
Preventable Infant Deaths: 2
Preventable Maternal Deaths: 1
No Doctor Available: 6
Lack of Ambulance: 6
Lack of Blood: 2
Delayed Care due to Transfer: 11
Undue Payment: 4
Failure to Provide JSY Entitlements: 2
Discrimination Against Patient: 1
Total Reports: 35

Dhekiajuli Primary Health Center
Delayed Care due to Transfer: 1
Undue Payment: 3
Total Reports: 4

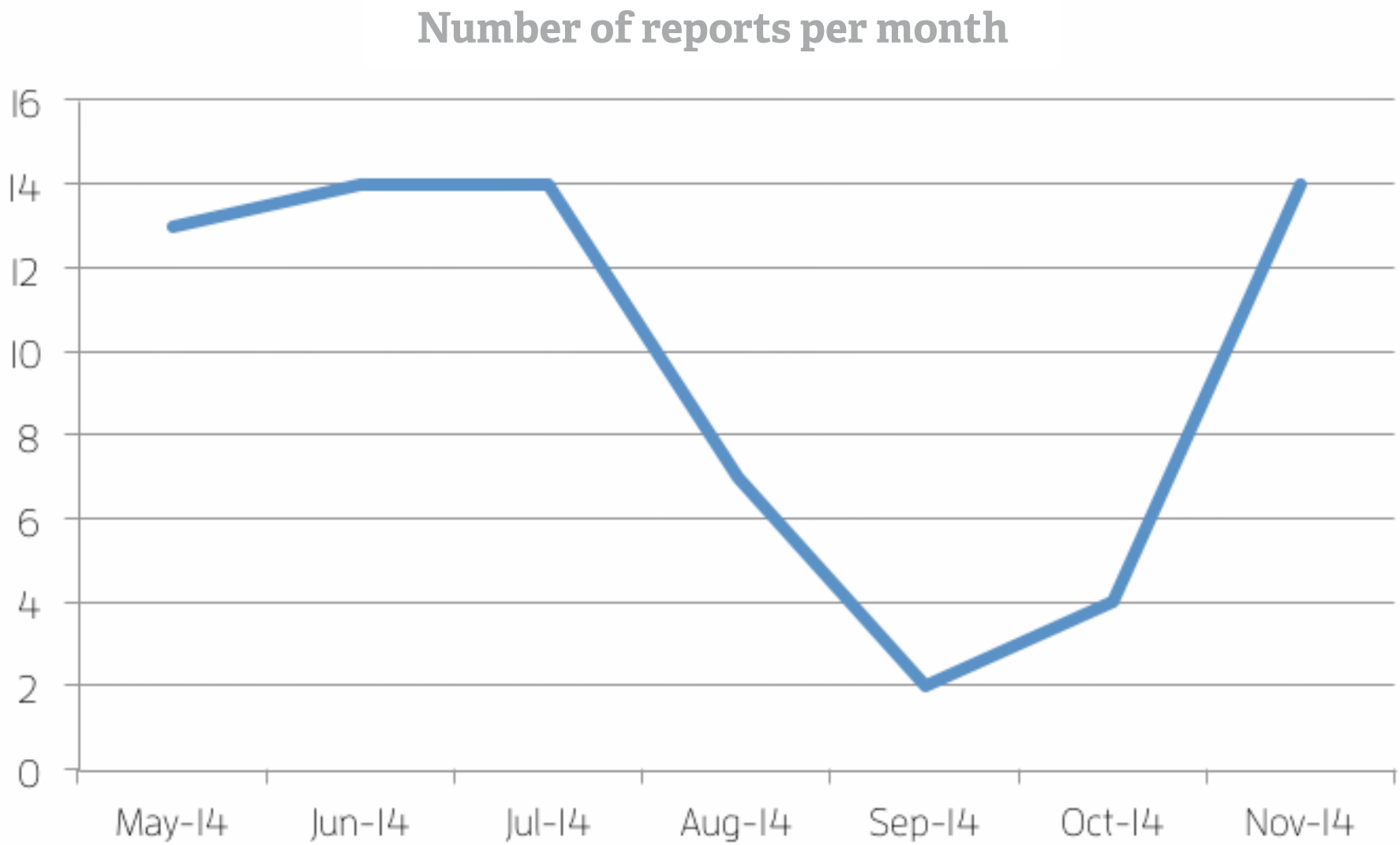
Tezpur Medical College
Preventable Infant Deaths: 2
Lack of Blood: 1
Delayed Care due to Transfer: 4
Undue Payment: 2
Failure to Provide JSY Entitlements: 2
Discrimination Against Patient: 1
Total Reports: 12

Balipara Primary Health Center
Preventable Infant Deaths: 1
No Doctor Available: 2
Lack of Ambulance: 3
Delayed Care due to Transfer: 4
Undue Payment: 2
Total Reports: 12

Haleswar Primary Health Center
No Doctor Available: 2
Lack of Ambulance: 1
Delayed Care due to Transfer: 4
Undue Payment: 2
Failure to Provide JSY Entitlements: 4
Inadequate Food Rations or Nutritional Service: 1
Total Reports: 11

Kanaklata Civil Hospital
Preventable Infant Deaths: 1
Preventable Maternal Deaths: 2
No Doctor Available: 2
Lack of Blood: 7
Lack of Ambulance: 5
Delayed Care due to Transfer: 3
Undue Payment: 10
Failure to Provide JSY Entitlements: 1
Discrimination Against Patient: 1
Total Reports: 33

Overview of Results



A total of 68 cases have been captured through SMS reports across 7 months, from May until November 2014. This equates to approximately 10 reports per month.

Photo (left): Meeting with volunteers to discuss reported cases, July 2014

Photo : Tea Garden Hospital

Most commonly reported issues

While some reports could be categorized as type of violation, most reports involve multiple abuses or concerns.

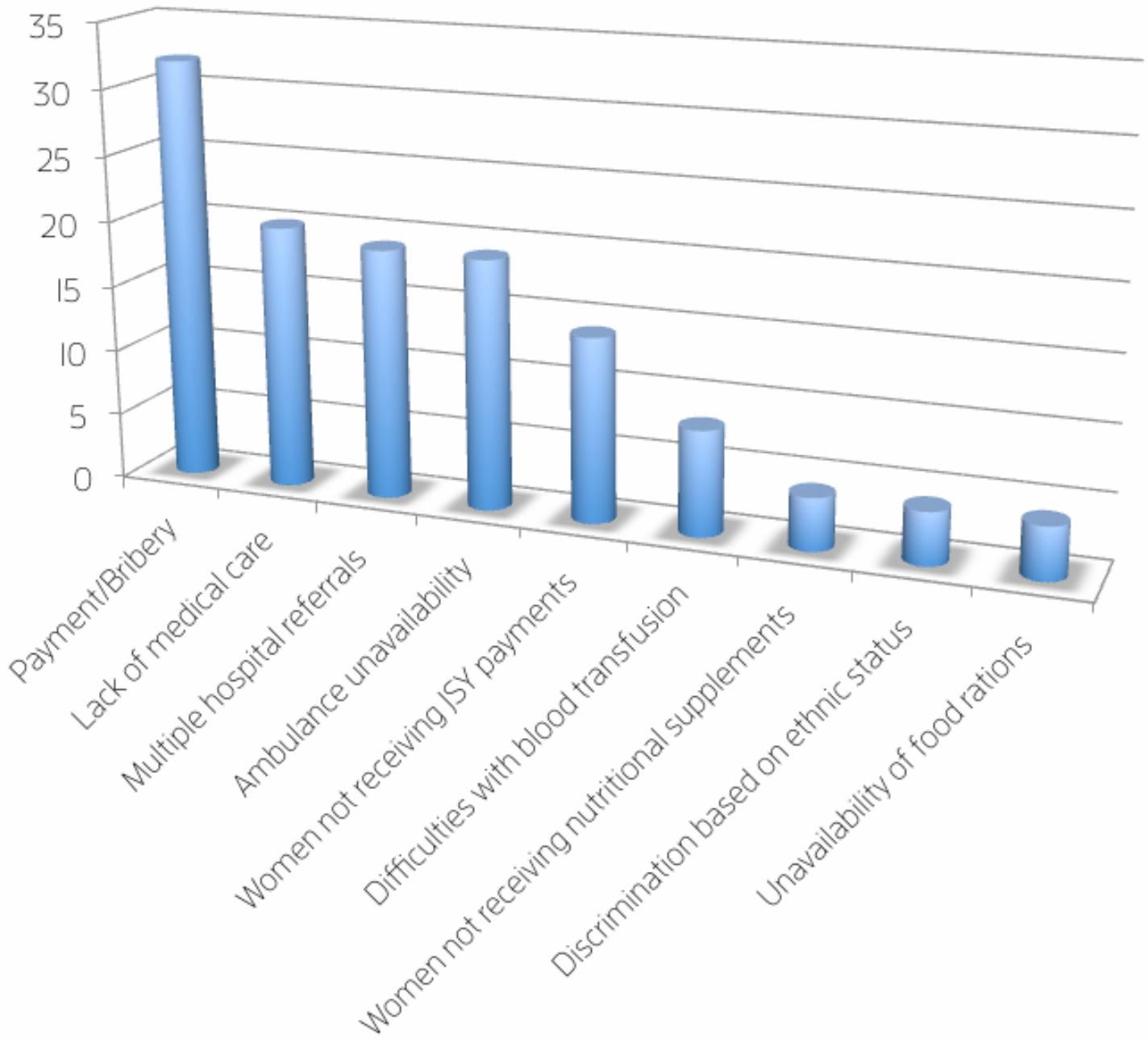
The most commonly reported violation was **undue payment**, or informal fees for medical services that should be provided for free to pregnant women. 32 of the 68 reports (47%) involve undue payment violations.

After undue payment, the three most commonly reported violations were:

- **Lack of medical care** (e.g., no doctor or nurse was present at a clinic/hospital) – 20 cases
- **Ambulance unavailability** (e.g., patients hired private taxis because the ambulance was not available) – 19 cases
- **Undue hospital referrals** (e.g., patients were referred to 4 different hospitals while in labor) – 17 cases

Issue	Number of mentions across all cases
Undue payment	32
Lack of medical care	20
Multiple hospital referrals	19
Ambulance unavailability	19
Women not receiving JSY (Government maternal healthcare assistance) cash payments	14
Difficulties with blood transfusion	8
Pregnant not receiving nutritional supplements	4
Discrimination based on ethnic status.	4
Unavailability of food rations	4

Most frequently reported issues

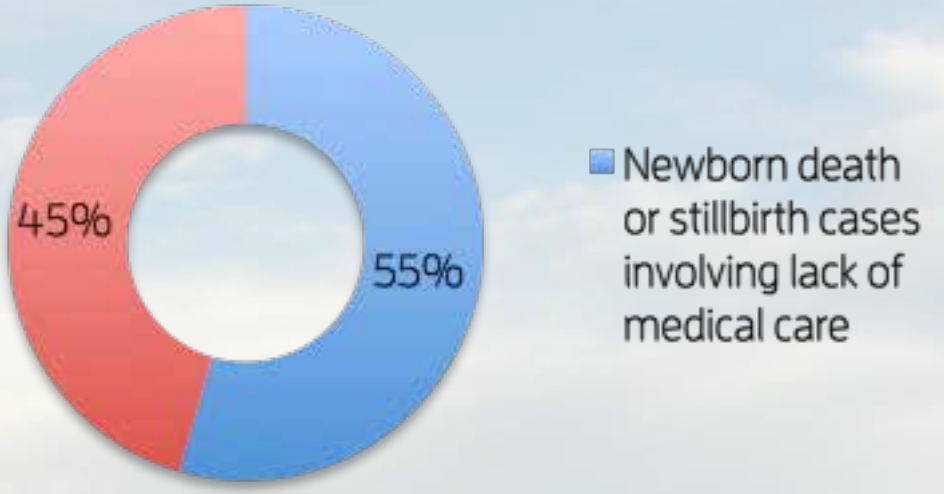


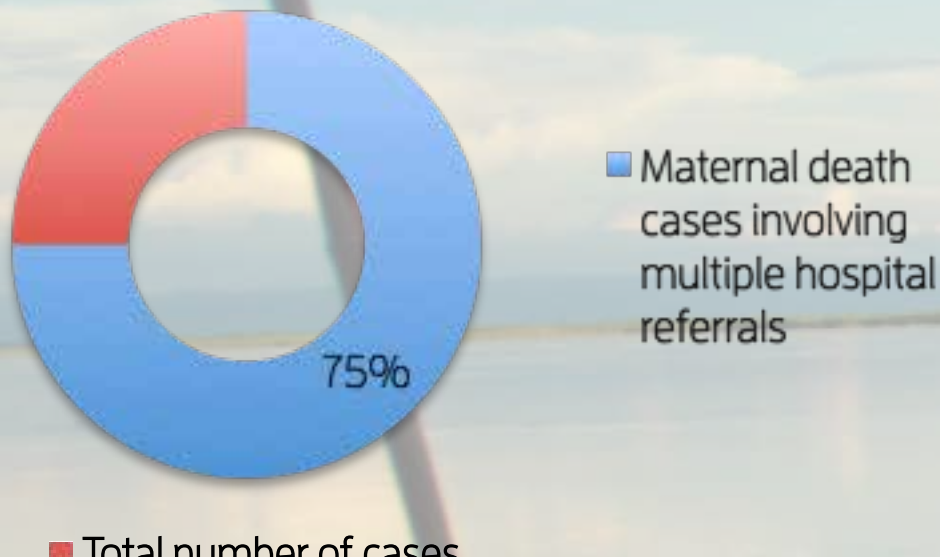
Reports of deaths

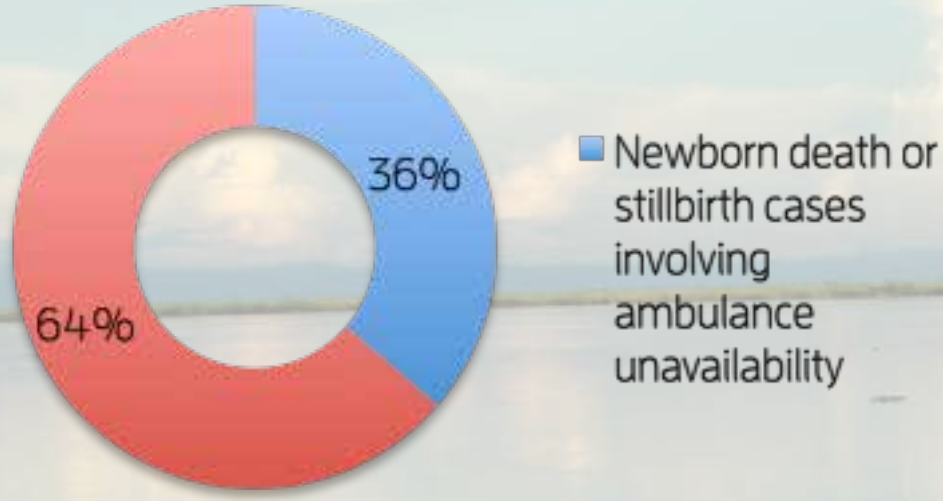
Across 68 cases, there were **11 reports of newborn deaths or stillbirths**, and **4 reports of maternal deaths.** A familiar pattern can be found when analyzing each case based upon the reported violations.

Of the 11 cases[17] that resulted in **newborn deaths or stillbirths**:

- 6 (55%) cases involved **multiple hospital referrals**
- 6 (55%) cases involved **lack of access to medical care**
- 4 (36%) cases involved **ambulance unavailability**
- Other newborn death or stillbirth cases involved blood transfusion, undue payments, not receiving nutritional supplements, and not receiving JSY payments.

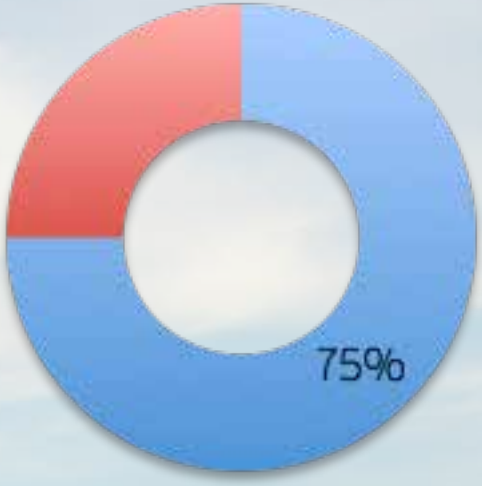




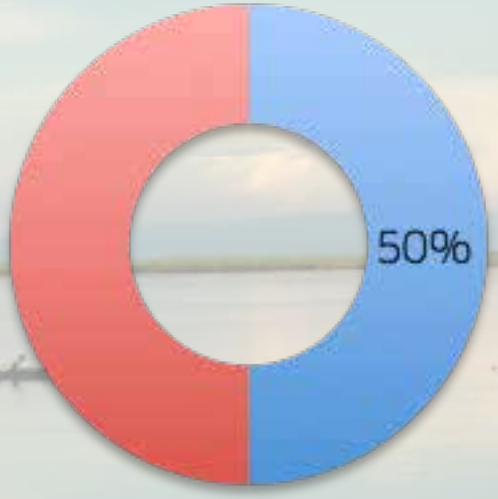


17 Please note that many of these cases involve multiple violations.

Maternal death cases involving multiple hospital referrals

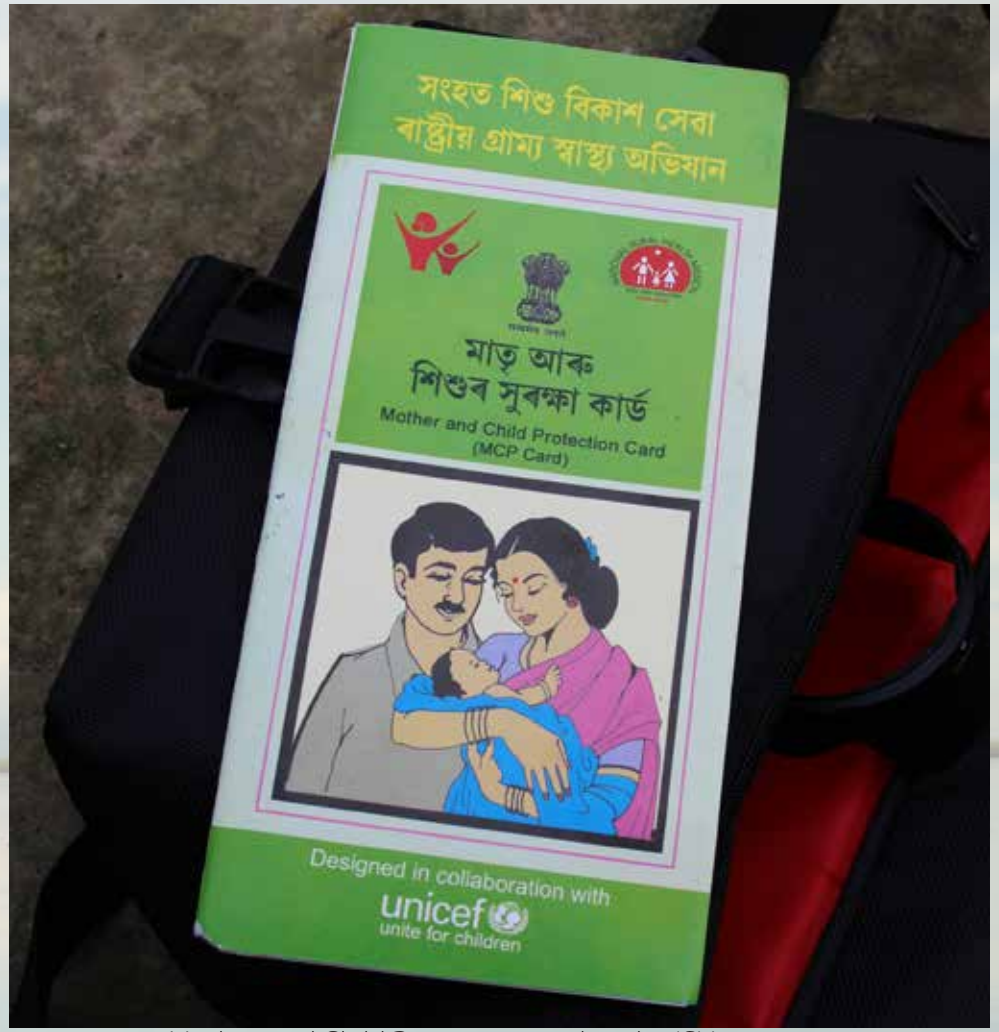


Maternal death cases involving lack of medical care



Of the 4 cases which involved a **maternal death**:

- 2 (50%) cases involved **multiple hospital referrals**
- 2 (50%) cases involved **"lack of access to medical care"**
- I (25%) case involved reports of **not receiving nutritional supplements**
- I (25%) case involved **undue payment**



Mother and Child Protection card under JSY program

End MM Now
Case Studies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Rakashmari PHC
Panbari TE
Dibrugarang TE
Sapoi TE
Dhirai TE
Tinkhuria TE
Narayanpur TE
Dhekiajuli CHC
Dhekiajuli PHC
Tezpur Medical College
Balipara PHC
Sonabeel TE
Haleswar PHC
Dekargaon PHC
Panchmile PHC
Dipota PHC
Kanaklata Civil Hospital
Guwahati Medical College
100 km

KEY
Case Study
Tea Estate Hospital
PHC and CHC
Hospital

Findings

The "Three Delays Model"

The 'three delays model' has been widely by the UN,[18] by NGOs,[19] and academics,[20] and is considered a comprehensive approach to understand the causes surrounding maternal and infant deaths.[21] For this reason, the model – summarized below – has been utilized to assess the delivery of health services in light of the cases reported through the End MM Now Project. The model is summarized in the box on the right.

The Three Day Delay Model

1. Delay in deciding to seek care:
   Are women aware of the need for care and the danger signs of pregnancy?
2. Delay in reaching a health-care facility:
   Are services inaccessible because they are not available, because of distance and/or cost of services?
3. Delay in receiving care after getting to a health-care facility:
   Is the care received at the facility timely and effective?

Adapted from: Van Den Broek, Nynke and Falconer, A.D. (2011) "Maternal Mortality and Millennium Development Goal 5," British Medical Bulletin, Vol 99, Issue 1, pp. 25-38.

Delay #1: Deciding to seek care

The delay in seeking care centers largely on a patient's decision to avail herself of services from health facilities or staff. Many of the health authorities interviewed for this Project reported a gap between frontline health workers and patients, a gap which they believe contributes significantly to Delay #1 – seeking care. This gap relates to the socioeconomic context in which women live and on various factors surrounding the accessibility of health services. Indeed, there is strong consensus among doctors interviewed in government and private facilities in the Sonitpur district that women often reach the facility too late, when the health issue has become serious. At this stage, medical interventions are more difficult and the patient's life is in considerable risk.

Socioeconomic factors that contribute to the delay in seeking care include: (1) geographic isolation and social marginalization of women living in tea gardens; (2) gender inequality entrenched in the society; and (3) unawareness of rights and entitlements available to women.[22] There are a number of factors that influence access to medical services, including undue payment, poor hygiene and lack of adequate services.

This Report analyzes the data collected from patients, health workers and officials to explore some of the most significant issues underlying the delay in seeking care.

18 *Setting standards for emergency obstetric and newborn care*, UNFPA 2010, available at http://www.unfpa.org/resources/setting-standards-emergency-obstetric-and-newborn-care (last accessed 26th January 2015).

19 *Applying the three delays model*, Save the Children, 2013, available at http://www.healthynewbornnetwork.org/sites/default/files/resources/Applying the three delays model_Final.pdf (last accessed 26th January 2015).

20 Waiswa P., Kallander K., Peterson S., Tomson G., Pariyo GW. *Using the three delays model to understand why newborn babies die in eastern Uganda*, Trop Med Int Health 15: 964-972, 2010.

21 Maine, D., Safe Motherhood Programs: Options and Issues, New York: Center for Population and Family Health, Columbia University, 1991, available at www.amddprogram.org/vl/resources/SMProgOptionsandIssuesEN.pdf, last accessed on 25th January 2015.

22 Assam Tribune (2010), Most Women Still Unaware of Their Rights, http://www.assamtribune.com/scripts/detailsnew.asp?id=may1010/city05.

Undue payments

There is a widespread belief that patients are required to pay money for treatment at a government hospital. This belief is a significant factor in Delay #1. Indeed, undue payment, or informal fees, was the most commonly reported violation. This issue was mentioned in 32 reports out of 68 (47%). The case studies shed light on a startling range of costs, from instances where nursing staff demand bribes, to patients who were forced to buy their own hypodermic needles.

Many patients and their families enter into debt to pay for care at government hospitals, despite the fact that these charges violate NRHM guidelines on treatment of pregnant women, which specifically exempt women from any charges during pregnancy and childbirth. Such charges discourage poor patients from seeking care and reduce their chance of a healthy delivery.

"There is a widespread belief that patients are required to pay money for treatment at a government hospital. This belief is a significant factor in Delay #1."

Entitlements for Pregnant Women:

- Free and zero expense Delivery and Caesarean Section
- Free Drugs and Consumables
- Free Essential Diagnostics (Blood, Urine tests and Ultra-sonography etc)
- Free Diet during stay in the health institutions (up to 3 days for normal delivery & 7 days for caesarean section)
- Free Provision of Blood
- Free Transport from Home to Health Institutions
- Free Transport between facilities in case of referral
- Drop Back from Institutions to home after 48hrs stay
- Exemption from all kinds of User Charges

Case study 1 - July 2014

M, a 25 year old pregnant woman, went into labor and was taken to Dhekiajuli CHC. After M gave birth, the hospital cleaner demanded a bribe of INR 100 to sweep around her bed. Later, a group of nurses demanded INR 500 to look after her. After being discharged from the CHC, the ambulance driver charged her INR 100 to take her home. The family survives on the income of M's husband, a delivery driver who earns INR 175/day. They spent INR 700 in illegal charges – around four days of wage.

According to the ASHA assigned to this case, illegal charges are commonplace. The ASHA stated that if one of her patients refuses to pay at the CHC, the next patient the ASHA brings to the facility would be denied treatment.

Patient M and her child

Poor hygiene and overcrowding

Inadequate hygiene and overcrowding at most of the public hospitals also contributes to patients' delay in seeking care. At times, patients are forced to wait for days while sleeping on the hospital stairs or in corridors of dirty facilities, often without access to toilets, food or drinking water. In some instances, patients feel that a home delivery would be safer and cleaner than the conditions at government hospitals.

An illustrative example is Kanaklata Civil Hospital, Tezpur, the district hospital in Sonitpur where many patients are referred for secondary care treatment because such treatment is often not available at lower level facilities. Here women are often forced to lie on unhygienic pavements and staircases, and at times outdoors, to receive basic treatment.

Photos (above and left): Women patients awaiting treatment at Tezpur Kanaklata Civil Hospital

"Come here any day and you will always find pregnant women in the corridor awaiting treatment. The maternity ward only has 40 beds, and on a typical day we have 160 patients. What are we supposed to do?"

"Yes, sometimes a patient will have to pay for syringes, needles or other goods. **They always find a way to pay.**" - Health professional testimony: Doctor, Tezpur Kanaklata Civil Hospital

Case study 2 - June 2014

R – an anaemic mother of a newborn – was referred to Tezpur Kanaklata Civil Hospital. For 20 days, while waiting for a blood transfusion, she had to sleep on the floor in the corridor. During this time, the hospital provided no food. The staff also informed her that she would have to provide her own syringes and needles.

Hungry, and knowing that she could not afford to buy the medical goods in any case, she gave up and left without the blood she needed. R today remains very weak and malnourished.

Patient R and her child

Discriminatory treatment

Patients belonging to tea garden areas, the large majority of whom are from the Adivasi community, have reported that they feel mistreated by health workers in government hospitals as they belong to "lower" sectors of society. Additionally, interviews revealed a stark difference in perception between the quality of treatment received by Adivasi patients in public and private hospitals. Patients reported that they were treated with more dignity and received better care in private facilities; however, the high cost of care at such facilities make it's difficult for the women to access such services.

Among the cases reported, four women reported being mistreated because they belong to the Adivasi community. The term "mistreatment" encompasses a lack of attendance by nurses and doctors, a refusal to admit patients to a hospital, verbal abuse, and the demand of undue payments.

Lack of awareness of rights

Most of the patients, especially those belonging to tea garden areas, lack awareness of rights and entitlements available to pregnant and lactating women. There is little or no available information about reproductive health entitlements at the tea gardens.

For instance, women lack awareness about entitlements under JSY. Even when they are aware of some of the benefits provided under the scheme -- such as the post-partum cash assistance – the process to avail of these benefits remains largely unclear. The Project tracked 14 cases of women who did not access JSY cash benefits. ASHA workers who were interviewed attribute this to various practical barriers to accessing cash benefits; for example, women must have a bank account to receive the payment but often live far from bank branches and/or lack basic documentation needed to open a bank account.

Lack of rights awareness also contributes to poor medical treatment. For example, many of the women do not feel confident to ask the health staff for the services to which they are entitled. The women also struggle to see these services as entitlements protected by the law.

Delay #2: Reaching a healthcare facility

Even when a patient decides to seek care, there are multiple obstacles that prevent her from accessing care at a health facility. It is widely acknowledged that reducing delay #2 would dramatically reduce maternal mortality.[23]

A review of studies in India[24] revealed that between 42 and 74% of reported deaths occurred at home or on the way to a health facility. According to that review, there are two pathways pregnant women may take to reach emergency obstetric care, which reflect the findings of this Report. For example, delays can occur when: (i) travelling directly from home to a facility with capacity for comprehensive care of obstetric complications, or (ii) attempting to receive care from a first line clinic and the patient being referred to a comprehensive care facility.

Delays on either of these pathways can be fatal. The table, depicted below, provides estimates of the average time before death after onset

23 Holmes, W., Kennedy, M., Reaching emergency obstetric care: overcoming the second delay, Compass, the women's and children's health knowledge hut, Briefing Paper, 2010, available at http://www.wchknowledgehub.com.au/sites/default/files/pdf/mnrh_1_2_briefingpaper_Reaching_emergency_obstetric_care_2009.pdf, last accessed on 25th January 2015, p. vii.

24 Ibid, p. 5.

of the most common complications faced by pregnant women:

Complication	Time (hours) before death
Hemorrhage (postpartum)	2
Hemorrhage (antepartum)	12
Ruptured uterus	24
Eclampsia	48
Obstructed labor	72

Source: Maine, D., Safe Motherhood Programs: Options and Issues. Center for Population and Family Health, Columbia University

The barriers to reaching emergency care are multifaceted. Here, we focus on the three most common issues in Balipara and Dhekiajuli Blocks: (1) the unavailability of ambulances; (2) the costs of alternative transportation; and (3) the inefficient system of referrals. All of these have a particularly high impact on tea garden workers who often live in rural communities far from the nearest hospital. Most of the case studies featured in this Report demonstrate more than one of these barriers.

Unavailability of ambulances

In 19 out of 68 cases (28%), there were reports of difficulties in finding an ambulance. Among cases of newborn death or stillbirth, this rises to 36%, demonstrating the critical impact of this delay on the outcomes of these cases.

There is a wide range of violations related to the unavailability of ambulances. In some cases, patients waited for hours for an ambulance to arrive, delays that caused fatalities. In other cases, hospitals told patients that ambulances were not available, or patients were forced to pay for the ambulance even though this service is free of cost.

The lack of ambulance coverage is often due to:

- Insufficient number of ambulances
- Poor road infrastructure, which makes it difficult for an ambulance to reach remote areas
- In tea gardens: low number of ambulances and avoidable delays due to permissions required by the manager to utilize the ambulance

Findings in this Report have been confirmed in other sources. For example, a 2012 report by Comptroller Auditor General of India on Sonitpur District found a shortage of 40% of ambulances at PHC level and of 33% at CHC level during the period 2007-12 (Ch. 5 p.20).[25] Indeed, Dhekiajuli CHC does not have a 108 Ambulance. In Balipara Block, at least 3 out of the 5 PHCs covered under this Project do not have an ambulance, namely Haleswar, Dipota and Panchmile.

In tea gardens, the situation is further complicated by the fact that patients must obtain permission by the garden manager to use an ambulance. This leads to fatal delays, and is contrary to the tea gardens' legal obligation to provide emergency care to garden workers.

Even worse, some tea gardens have no adequate means of transportation. For instance, in Tinkurria tea garden, pregnant women are transported to the hospital by a tractor, despite the garden purchasing an ambulance with the NRHM funding allocated by the State Government in 2007.

25 Comptroller Auditor General of India, Audit Report on District of Sonitpur for the year ended 31 March 2012, Chapter 5: Social Services, page 20.

Case study 3 - December 2013

M, a permanent worker at Sapoi Tea Estate, went into labor at her home, at midnight. Her father and uncle repeatedly called for the ambulance to come from Sapoi Tea Estate hospital to no avail. Finally, four hours later, the ambulance driver was woken up and came to pick up the patient at 4am .

M was referred to 4 different hospitals during that day – Dhekiajuli CHC, Tezpur Kanaklata Civil Hospital, Tezpur Medical College, and Guwahati Medical College. She also visited Nath private hospital. M died later that day, while trying to reach Guwahati Medical College.

Widower of Patient M

Case study 4 - May 2014

B is a 20-year-old pregnant woman, living at Dibrudarrang Tea Estate. She felt a lot of pain in her womb one evening. After speaking to her on the phone, staff at Dhekiajuli CHC referred her to Tezpur Medical College.

B asked her ASHA to call an ambulance. The ASHA told her that none was available. Worried, B's husband called the tea estate management to ask for an ambulance with urgency, but the management also told them there was none available. In desperation, they booked a taxi costing INR 1200. However, while waiting for the taxi, B delivered a very small and weak baby at home

B's family survives on the salary of her husband, a tea garden security guard. At this salary (INR 94), it will take B's husband six days to earn the INR 1200 cost of this taxi.

Patient B with her child

Inefficient referral system

Referrals to multiple facilities contribute to significant delays in accessing care. In 17 out of 68 cases (25%), medical problems were exacerbated by multiple referrals (i.e., women referred from clinics to hospitals, or from one hospital to another hospital, etc.). The data suggests that there is a correlation between multiple referrals and infant and maternal deaths; there were reports of multiple referrals in 55% of infant stillbirths and 75% of the maternal death cases.

While referral may be necessary to ensure prompt and adequate treatment, the data illustrates an extremely inefficient and often counterproductive referral system. Patients were often refused entry to one health facility and sent to another facility, without examination by a health professional. In some cases, patients were referred for reasons of hospital overcrowding, the lack of adequate equipment and services, or the unwillingness of staff to deal with the case. In other cases, patients were referred to a hospital even though it did not provide the service they urgently required.

The system of referrals appears to be dangerously inefficient, risking mothers and infants' lives, and wasting the time and resources of health professionals.

Case study 5 - June 2014

B, a 21-year-old woman, visited Balipara PHC on her due date, but the staff refused to admit her. A month later, B was in a lot of pain, and her ASHA took her back to Balipara PHC. This time a doctor told her that the baby had passed feces in the womb, and referred B to Kanaklata Civil Hospital.

B arrived at Kanaklata Hospital by ambulance, and went into labour when she arrived. There, B was not attended to for a few hours, and was eventually referred again to Tezpur Medical College. No ambulance was available this time, so she had to be taken in an auto rickshaw. On arrival at the Tezpur Medical College – three hospitals and many hours after originally seeking help - B delivered a stillborn baby.

Patient B

Fatal Referrals
Timeline of Case 3

Delay #3: Deciding to seek care

Even after a pregnant woman overcomes all the potential obstacles of delay #1 and #2, and manages to reach a healthcare facility, her struggle to delivery a healthy baby is often just beginning.

Delay #3, the time spent waiting for adequate treatment after reaching a healthcare facility, can often be the difference between life and death. Indeed, according to a study[26] carried out in Tanzania, third-type delays occurred in 72.5% of newborn deaths or stillbirths.

In this section we focus on two broad categories of factors that contribute to delay #3: the lack of blood banks and adequate blood supplies, and the lack of attendance by trained medical staff.

Unavailability of blood

Assam has a blood emergency on its hands. According to the Chief Minister's Vision for Women and Children (2012) 72% of pregnant women in Assam are anemic.[27] The lack of disaggregated data on the tea gardens population makes it particularly difficult to estimate the number of anemic women living there. A poor diet based on an erratic supply of rations, and a lack of nutritional supplements, contribute to a situation where, according to one doctor interviewed, "90% of women" on tea gardens are anemic.

Maternal mortality is related to high levels of anemia, which is in turn directly linked the availability of free blood.

26 Mbaruku G, van Roosmalen J, Kimondo I, Bilango F, Bergstrom S (2009) Perinatal audit using the 3-delays model in western Tanzania. Int J Gynaecol Obstet 106: 85-88.

27 http://online.assam.gov.in/documents/218378/2d2df305-bfd4-46f5-86aa-10fcec046fa7

"We often have to collect blood from the blood bank at Karnaklata Civil Hospital to use for transfusions at this hospital. When a patient requires blood, even a pregnant woman, they always have to find someone willing to exchange blood to get the donation. **Not only do they have to find (and usually pay) a donor, they also get charged INR 250 for testing each donor's blood.**"
- Health professional testimony: Manager, Private Hospital, Tezpur

The NRHM Service Guarantees require all CHCs to have a functioning blood bank that provides free supplies of blood units to pregnant and lactating women.

Despite this requirement, the data confirms that most facilities do not provide blood transfusions or impose financial and logistical obstacles to receiving needed transfusions. In the area covered by the Project, only Tezpur Kanaklata Civil Hospital has a functioning blood bank. In Dhekiajuli CHC, which caters to a high number of patients coming from tea gardens, the existing blood bank is defunct due to the lack of a hematologist. There is no blood bank in Balipara Block PHC even though a Block PHC has the same requirements as a CHC. Even worse, blood is not available in Tezpur Medical College, a recently inaugurated tertiary level facility.

This serious crisis in blood availability places a huge burden on Tezpur Kanaklata Hospital, which does not have the capacity to care for all of the patients referred to this hospital. As a result, patients are forced to pay for blood units and to arrange for blood donors even in cases requiring emergency obstetric care.

Alarmingly, as found from our interviews with government officials, there is a widespread belief, even among senior staff, that patients or their families are required to bring donors to replace blood needed for a transfusion, even when the patient is pregnant.

Blood bank vehicle, Kanaklata Civil Hospital

Case study 4 - May 2014 (see also Delay #2)

B is a 20-year-old pregnant woman, living at Dibrudarrang Tea Estate. When she was 5 months pregnant, she was suffering from anemia, and swollen feet. When she went for a checkup at Dibrudarrang Tea Garden Hospital, she was referred to Dhekajuli CHC for a blood transfusion. At Dhekiajuli CHC she found that there was no blood bank at the facility and was then sent to Tezpur Medical College. At the Tezpur Medical College, no blood was available either, so she was referred to Tezpur Kanaklata Hospital.

At the Civil Hospital, B's family was told that they would need to find blood donors to exchange blood, if B was to receive a blood transfusion. Even when they found 3 people to give a unit of blood each, they had to pay INR 4,000 for the blood to be tested, and for transportation costs for donors.

"90% of the tea garden women I see are anemic, they are malnourished, and they are either not provided with iron supplements or they don't take them. **Anemia is the main cause of pregnancy complications here. Certainly, the Dhekiajuli CHC should have a blood bank; it's essential.**"

- Health professional testimony: Doctor, Private Hospital, Tezpur

Undue Payments

As noted above, inappropriate charges for treatment deter patients from seeking medical treatment in the first place (see Delay #1). Moreover, demands for payment further delay treatment and often make cause women to refuse treatment because it is unaffordable.

Patient R and her child

Case study 6 - December 2013

R, a 30-year-old pregnant woman, lives in Sapoi Line in Dibrudarrang Tea Estate. When she was nine-months pregnant, on 28th May 2014, she experienced pain and went to the tea garden hospital in Dibrudarrang Tea Estate at around 8 am. As there was no doctor at that time, she was referred to Dhekiajuli CHC. After the CHC, she was referred twice more, to the Tezpur Medical College and then to the Kanaklata Civil Hospital.

There, on 29th May at 9 pm she went into labour and she was taken to the delivery room. She was left by herself, with no water, food or attendance until the next morning. On 30th May at about 10 am she had a normal delivery assisted by a nurse. To facilitate the delivery, a cut was performed. Two hours passed before her placenta was taken out, and during this time she kept on bleeding until she became unconscious.

At that point her sister-in-law begged the hospital staff to assist her. The nurses responded: "Show us how much you want her to survive.", and demanded a bribe. While R was bleeding to death, her family were forced to pay INR 100 to all the five nurses present, who finally stitched her cut.

"It is common that the nurses ask for payment before they will do any stitching. It's not only at the Civil Hospital (Kanaklata). At Dhekhajuli CHC they also demand money, a minimum of INR 200. If a patient won't pay, the nurses won't do the stitching properly; **there's no choice but to pay up.** Last year another ASHA tried to make a complaint. But after that complaint, any patient she brought there would be sent away."

- Health professional testimony: An ASHA at Sapoi Tea Estate

Lack of medical care

A lack of medical care – for example, when there is no doctor or nurse present at a clinic/hospital – is reported in 20 (29%) of the 68 cases documented in this Project. This violation is more prevalent among cases of newborn death or stillbirth cases and maternal death cases; this violation was reported in 55% of infant death cases, and 50% of maternal death cases.

This category of violations includes reports that doctors were not available to attend a patient as well as medical negligence – willful or otherwise – by the hospital staff. In addition, in some cases, ASHAs and nurses were not trained to provide basic assistance to pregnant women.

Want of trained medical staff is particularly acute in tea garden hospitals, most of which do not have a permanent doctor, despite legal obligations to ensure access to health care. The Government has sought to address the staff shortage by requiring newly graduated medical officers to serve in tea garden hospitals for at least one year. This effort, while commendable, is not enough to address the problem.

Indeed, at least 4 out of 7 tea gardens covered in this Project do not employ have a resident doctor. This is also true for gardens receiving NRHM funds, such as Sapoi and Panbari. Some gardens, namely Dibrudarrang, Panbari and Dhirai, do not even have a visiting doctor.

In tea gardens with no permanent doctor, it is very difficult for workers to access basic medical services. Visiting doctors are only available two times per week for two hours each time, and only during working hours. Barriers to access are exacerbated by the fact that most of tea garden hospitals are closed on Sundays, the only day off for most workers.

Case study 7 - July 2014

S was taken to Sapoi TE hospital on the morning of July 13th 2014, as she went into labour. It was her first child. She was taken in an ambulance from Sapoi TE to Tezpur Kanaklata Hospital, as she needed blood. She was told to find a man from her village to donate blood so she could get the blood she needed in exchange, which her family managed to do.

Having received blood, a nurse and doctor examined her, and said it wasn't time for her to deliver yet. By evening she had still not delivered, and although she was too weak to push out the baby, a Cesarean section was not offered.

During the evening S was given an injection by a nurse. The family do not know what the injection was for, but they were told it was to "warm her body." Within 10 minutes of the injection, she died at the hospital.

The hospital gave the family 1000 rupees and sent them away in an ambulance. The cause of death is written in English on a discharge certificate as "cardiac respiratory failure," but neither her family nor the ASHA are aware of this being the cause of death.

Sister in law of patient S

Case study 8 - September 2014

J, 25, is a housewife. On her third checkup at Dhekiajuli CHC, she was admitted for four days due to high blood pressure. During this time she needed an ultrasound scan, and was referred to a private clinic, as she was told no ultrasound facility was available at the CHC, nor at Kanaklata Civil Hospital. She had to pay for both the scan (INR 900) and a taxi to the private hospital (INR 1000).

Upon returning to the CHC, she went into labor and delivered her premature baby in the toilet, as she was not being properly attended to. No doctor was available after the delivery either, so a nurse attended to her and cut the umbilical cord.

Later that day, J began to experience a lot of pain in her womb area. The nurse said there was nothing to worry about, but J kept screaming, and eventually she was referred to Tezpur Medical College. The family had heard that the service at Tezpur Medical College was terrible. They decided first to try Tezpur Mission Hospital – where she was told there was no Doctor available – and then Sukhada Private Hospital.

At Sukhada, a nurse helped clean the remainder of the placenta that had not been properly cleaned at CHC. This had left her in a dangerous condition but, following treatment at the private hospital, she has recovered.

"The Civil Hospital does have an ultrasound machine. However we do not have a radiologist here. Right now, the Gynecologist carries out the ultrasound scans when he is available. The salary for radiologists is too low, they can't be recruited." - Health professional testimony: Doctor at Kanaklata Civil Hospital

Patient J and her child

Poor health infrastructure & services

Lack of services and the lack of access to needed equipment and medicine also contribute to delays in accessing health care.

The case studies expose a widespread lack of essential services and resources. We have seen cases of women denied services outright, or forced to pay for private providers out of desperation. The reports show that facilities lack a range of equipment and services, including basic essential equipment such as scissors to cut the umbilical cord at a tea garden hospital, to more costly but vital services such as ultrasound scans at Kanaklata Civil hospital.

Importantly, lack of services is the primary reason for the high number of referrals occurring from lower level facilities to higher facilities, most notably to Tezpur Kanaklata Hospital.

Lack of services and appalling hospital conditions are particularly unacceptable in light of the large amount of unutilized funds across the District. The Comptroller Auditor General report found that in regards to implementation of health services, "20 to 54 per cent of the fund available remained unutilized at the end of the financial years during 2007-12."[28] The Comptroller Auditor General report reveals severe shortfalls, both in terms of health infrastructure, with 11 CHCs (80% of the required number) not constructed, and of essential services, such as newborn care (shortfall of 54% in PHCs), 24x7 deliveries (shortfall of 48% in PHCs) and obstetric services (shortfall of 77% in PHCs).[29] See Case study 8 above.

28 *Supra* n. 23.
29 *Id.*

Further factors delaying access to healthcare

Although this Project collected reports on specific instances of health rights violations, the data exposed two systemic barriers underpinning poor access to health care for women in Assam. These barriers have a ripple effect on the problems illustrated above, and further aggravate health infrastructure conditions, particularly in tea gardens.

The analysis stems from an overall assessment of the reports, and is supported by field research undertaken by the project team.

"We have very little resources, we don't even have a delivery kit to deal with the most basic births. Nowadays, we just use whatever tools we can find, to cut the umbilical cord and deliver the baby as safely as we can.

We don't have a permanent doctor, he visits on Tuesdays and Fridays, for two hours each day. The hospital is open from 7-12 daily*, except Sundays.

Today is vaccination day. 54 children need their Diptheria, Pertussis and Tetanus vaccines, but we only have 10 doses." - Health Professional Testimony: ANM Nurse, Tea Garden Hospital


VACCINE

Lack of transparency over NRHM funding allocation in tea gardens

The Government of Assam has signed a series of MOUs with tea plantations to address the dire state of maternal and infant health in the gardens. As noted in the Introduction, under the MOUs, tea gardens receive public funds to implement specific maternal and infant health services.

The MOUs require establishment of a NRHM Committee to oversee budget allocation and the implementation of health services. However, NRHM Committees are often in the hands of tea garden management, who are not made accountable to budget expenditures. Workers and the public know very little about allocation of NRHM funds.[30] It is generally perceived that members of the Committee, most of whom are tea garden employees, have minimal control on decisions taken by management.[31]

According to the information collected, Government oversight occurs through monthly reports sent by the gardens to the Block Program Manager (BPM). However, these reports are not disclosed to civil society and/or workers, denying them access to information on services available and funds disbursed.

Poor monitoring of budget allocations has also lead to a gross misappropriation of funds by tea garden managers.[32] To address this issue, the Government has withheld or threatened to withhold future funds, an action which negatively impacts the lives of workers and their families.

This results in very poor implementation of NRHM, with many gardens lacking basic equipment, free transportation, and staff. While companies must be held accountable for expenditure of public funds, workers should also be guaranteed access to essential healthcare as provided under NRHM and PLA.

Poor grievance redressal mechanisms

Pregnant women living in tea gardens and rural areas do not have access to an effective and responsive grievance redressal system.

30 Interview held by researchers from Nazdeek with tea garden workers in Tinkhurria, Dibrudarrang, Sapoi, Narayanpur and Hirajuli tea gardens in Dhekiajuli Block in December 2014.

31 Interview held by researchers from Nazdeek with tea garden workers in Tinkhurria, Dibrudarrang, Sapoi, Narayanpur and Hirajuli tea gardens in Dhekiajuli Block in December 2014.

32 Interview with Mr. Melkhas Toppo of Tinkhuria Tea estate on Feb. 5, 2015, who filed an Right To Information application on Oct. 24, 2011 inquiring withdrawal of NRHM funds from Tinkhurria Tea Estate and composition of NRHM committee.

The NRHM lacks an express grievance mechanism charging local government officials with responsibility for monitoring and oversight. Further, existing grievance hotlines are either poorly responsive or unknown to the majority of patients. By example, patients have very poor awareness about the 104 Hotline, especially in tea gardens. Hotline operators are based outside of Assam, and as a result, language barriers make it difficult for patients to communicate their grievances. Critically, the follow-up is weak, with patients not provided information over the actions (if any) taken to redress the grievance in a time-bound manner.

An effective grievance redressal mechanism can strengthen the delivery of health care and increase women's awareness over their rights and entitlements. Such a mechanism is key in reducing delays at every step of the health care chain, and closing the gap between patients and health care providers.

The End MM Now Project has demonstrated the value of implementing a community-level mechanism. A grassroots mechanism contributes to increasing awareness on maternal health rights. A survey conducted among the Project volunteers found that over 60% of those interviewed are more aware of health issues like maternal and infant mortality and prevalence of anemia. Likewise, over 70% of the volunteers interviewed gained knowledge on the facilities and services required at hospitals.

Secondly, the Project has showed that a mechanism entailing community monitoring and oversight is likely to cause immediate improvement in the delivery of services. Indeed, 60% of the volunteers interviewed perceived an improvement in the quality of treatment received at public hospitals, and in the maintenance of records by health and health and social workers (for instance earlier registration of pregnancies).

Photo: Volunteers from Dhekiajuli Block attending training on nutrition and infant health, Aug. 2014

Recommendations

The core goal of the End MM Now project has been to track availability of maternal and infant health services in Dhekiajuli and Balipara Blocks in Sonitpur District, Assam. The data collected and analyzed in the previous section serve as the basis for recommendations set forth here. The recommendations are targeted to local authorities and facilities covered by the project to improve the delivery of health services, with an aim of reducing preventable maternal and infant deaths. Recommendations reflect the 'Three Delays Model.'

Delay #1: Seeking care

A number of factors can negatively affect the decision of patients to seek care. These include: undue payment, lack of awareness, discriminatory treatment, poor hygiene and overcrowding in public hospitals.

The frequency and scale of these endemic issues has led to serious gaps between patients, especially those belonging to poorer sections of the society, and health care providers. This gap coupled with a lack of faith in the public health system, hinders the decision of a patient to seek care. As analyzed, reducing this delay is crucial in combating maternal and infant mortality. Closing the distance between patients and healthcare providers requires a long-term, multi-pronged effort, which depends on resource availability and allocation, as well as involvement with higher authorities.

However, there are key steps that if implemented would improve conditions in a limited span of time:

I. Reduce undue payment:

a) Ensure facilities are adequately supplied with equipment and medicine, eliminating the need for patients to pay out of pocket. In particular, medicines should be adequately and timely supplied to: Rakashmari PHC, Haleswar PHC, Balipara Block PHC, Dhekiajuli CHC, Tezpur Medical College (Tumuki), and Sapoi Tea Garden Hospital.

b) Prohibit staff from demanding fees for services. Strict enforcement is required in Rakashmari PHC, Tezpur Kanaklata Civil Hospital, Dhekiajuli CHC, Tezpur Medical College and Sapoi Tea Garden Hospital.

2. Maintain hygiene and reduce overcrowding:

a) Improve quality of care in lower level facilities to avoid overcrowding at Tezpur Kanaklata Civil Hospital.

b) All facilities must be supplied with drinking water, toilets and electricity, including power backup system. In particular, Dhekaijuli PHC and Tinkhurria Tea Garden Hospital must immediately be provided with electricity and water.

Delay #2: Reaching the facility

The study has identified two issues hindering women's access to facilities: availability of ambulances and inefficient referral system. In 28% of the cases there were problems in securing an ambulance. In addition, the referral system is chaotic, with patients refused entry in one health facility and sent to another with no guarantee of care. In case study 3, the patient was referred 5 times to 6 different facilities,

and eventually died on the way to Guwahati Medical College, around 20 hours after she first went into labour and sought medical assistance.

From the perspective of health providers, the current referral system results in a waste of resources, both human and material. Patients often reach facilities when their conditions are serious, decreasing the likelihood of survival and placing an extra burden on an already overworked health staff.

To avoid preventable deaths and misuse of lifesaving resources in reaching the facilities:

3. Provide better ambulance coverage:

a) Increase number of ambulances available in public hospitals of the District, particularly in Dhekiajuli CHC and PHC, Rakashmari PHC, Haleswar PHC, Dipota PHC and Panchimile PHC.

b) Consider introducing, or increase the number of, other forms of transportations, such as ambulance emergency response vehicles, or 4 wheels drive which can access remote locations more easily.

c) Ensure availability and outreach of ambulances across the two blocks, particularly reaching areas of Konamukh (Balipara), Garjuligaon (Dhekiajuli)

In tea gardens, management should:

d) Ensure all tea gardens have a functioning ambulance available 24hrs.

e) Grant permission to avail the ambulance to the medical staff of the tea garden hospital.

4. Improve efficiency of the referral system:

a) Refer patients only to facilities where they can be treated, with adequate documentation and coordination between health staff at facilities prior to patient referral.

b) Improve capacity of lower level health staff to adequately diagnose maternal health related issues so patients are appropriately referred to higher hospitals
(see Recommendation n 6 below)

c) Strengthen availability of services provided at lower level facilities, especially tea garden hospitals and PHCs (see Recommendation n. 7 below)

Delay #3: Receiving Care

This Project has identified three main issues that delay receiving care for patients who have reached facilities: lack of access to blood, lack of attendance by medical professionals, and lack of adequate services available in health facilities.

To adequately address these urgent issues, the Government should:

5. Improve availability of blood:

a) Hire a hematologist for the already existing blood bank in Dhekiajuli CHC. As seen by data collected, a functioning blood bank Dhekiajuli CHC is critical in reducing risk of preventable deaths.

b) Establish new, functioning, blood banks in Balipara BPHC and Tezpur Medical College.

c) Ensure blood units are freely available for pregnant women, for instance by increasing existing programs or implementing new schemes to encourage blood exchange/donation

6. Improve medical staff availability:

a) Ensure 24 hour availability of Doctors at facilities in line with NRHM requirements, with particular focus at Dhekiajuli CHC, Tezpur Kanaklata Civil Hospital, Balipara Block PHC, Dhekiajuli PHC and Tezpur Medical College

b) Ensure adequate and periodic training of nurses and health staff, particularly at lower level facilities

c) Ensure permanent doctors are hired in tea garden hospitals, particularly in Sapoi, Dibrudarrang, Panbari, and Dhirai tea gardens.

7. Improve the availability of services and equipment:

a) Ensure facilities are provided with services as per NRHM requirements, particularly:

- Blood availability in CHCs
- Neonatal care services, and supply of saline, in Rakashmari PHC
- Immunization and basic neonatal care in Sapoi Tea Garden hospital
- Ultrasound facility in Dhekiajuli CHC
- Additional beds in the maternity ward of Tezpur Kanaklata Civil Hospital

b) Ensure JSY payments are issued as per NRHM requirements, particularly in facilities that have been found to delay or deny payment, primarily Haleswar PHC, Sapoi Tea Garden Hospital, Balipara BPHC, Rakashmari, Panbari Tea Garden Hospital and Dhekiajuli CHC.

Further factors delaying access to healthcare

This Project focused on closing the gap between rights and their implementation, as well as between patients and healthcare providers. A qualitative analysis of the reports received identified two issues underpinning adequate access to healthcare: a poor grievance redressal mechanism and lack of transparency over NRHM funding allocation.

8. Establish an accessible and transparent grievance mechanism:

a) Establish quarterly citizen forum meetings at the Block Level between BPM and community representatives, including volunteers from the End MM Now project. Meetings should establish regular communication between health care providers and the community, enabling the sharing of specific cases reported by volunteers, and include a time-bound plan of action by the Government on issues raised.

b) Strengthen existing 104 Grievance Hotline through increased awareness and dissemination of Hotline, particularly in tea garden areas. Hotline should provide timely and regular information to the Complainant, including the contact information of public official responsible for addressing the complaint and a time-bound response on all actions taken. An appeal process should also be established.

9. Improve NRHM implementation in tea gardens

a) Resort to withdrawal of funds as a last option. Before rescinding funds, the government should ensure patients have access to another facility equally or better equipped

b) Tighten monitoring. The BPM and DPM should monitor NRHM implementations in the gardens on a more stringent basis (currently once a month), including through on site visit, periodical review of budget expenditure.

c) Ensure that NRHM Committees are truly transparent and functioning by:

- Diverse mix of workers as members of the Committee (e.g., women, men, non-union workers, etc.)
- Budget expenditure should be made public
- Committees should consult with workers regularly, including through scheduled audits

Tea garden managers should:

a) Ensure ambulance availability 24hrs
b) Ensure hospitals are open on Sundays or on worker's day off
c) Ensure 24hrs normal delivery service
d) Ensure at least one full time doctor
e) implement existing provisions of PLA

SUMMARY OF RECOMMENDATIONS TO THE GOVERNMENT (PRIORITIES HIGHLIGHTED)

Issue:	Recommendations:	Type of intervention:	Facilities concerned	Relevant Law
I. Reduce undue payment	a) Ensuring facilities are adequately supplied with equipment and medicine	Service	Rakashmari PHC, Haleswar PHC, Balipara Block PHC, Dhekiajuli CHC, Tezpur Medical College (Tumuki), and Sapoi Tea Garden Hospital.	NRHM
	b) Prohibit staff from seeking informal fees for services.	Policy	Rakashmari PHC, Tezpur District Hospital, Dhekiajuli CHC, Tezpur Medical College and Sapoi tea garden.	NRHM
2) Avoid Poor hygiene and overcrowding	a) Improve quality of care in lower level facilities	Service	All	NRHM
	b) All facilities must be supplied with drinking water, toilets and electricity.	Service	All – particularly Dhekiajuli PHC and Tinkhurria Tea Garden Hospital	NRHM
3) Ensure better ambulance coverage	a) Increase number of ambulances	Services	Dhekiajuli CHC and PHC, Rakashmari PHC, Haleswar PHC, Dipota PHC and Panchimile PHC	NRHM
	b) Consider introducing, or increase other forms of transportations	Policy	-	
	c) Ensure better outreach to rural areas	Services	Khonamuk (B), Garjuligaon (D)	NRHM
4) Improving efficiency of referral system	a) Refer patients only to facilities where they can be treated.		All	
	b) Improve coordination between hospitals	Policy	All	NRHM
	c) Strengthen availability of services at lower level facilities	Service	See Recommendation n. 7	
	d) Improve capacity of lower level health staff to adequately diagnose	Service	See Recommendation n. 6	

5) Improve availability of blood	a) Hire a hematologist	Service	Dhekiajuli CHC	NRHM Service Guarantee
	b) Establish new, functioning, blood banks	Service	Balipara BPHC and Tezpur Medical College	NRHM Service Guarantee
	c) Ensure blood units are freely available for pregnant women, for instance by increasing existing programs or implementing new schemes to encourage blood exchange/donation	Policy	All	NRHM
6) Improve medical staff availability	a) Ensure 24 hour availability of Doctors at all government health facilities,	Service	Dhekiajuli CHC, Tezpur District Hospital, Balipara Block PHC, Dhekiajuli PHC and Tezpur Medical College	NRHM Service Guarantee
	b) Ensure adequate and periodic training of nurses and health staff	Service	All, particularly PHCs and CHCs	NRHM Service Guarantee
7) Improve the availability of services and equipment in public facilities	a) Ensure facilities are provided with services as per NRHM requirements	Service	• Blood availability in CHCs • Neonatal care services, and supply of saline, in Rakashmari PHC • Immunization and basic neonatal care in Sapoi Tea Garden hospital • Ultrasound facility on Dhekiajuli CHC • Additional beds in the maternity ward of Tezpur Kanaklata Civil Hospital	NRHM Service Guarantee
	b) Ensure JSY payments are issued	Service	Haleswar PHC, as well as Sapoi Tea Garden Hospital, Balipara BPHC, Rakashmari, Panbari Tea Garden Hospital and Dhekiajuli CHC.	Janani Suraksha Yojana

8) Establish an accessible and transparent grievance mechanism	a) Establish quarterly citizen forum meetings at the Block Level between BPM and community representatives, including volunteers from the End MM Now project	Policy	All	
	b) Strengthen existing 104 Grievance Hotline through increased awareness and dissemination of Hotline, particularly in tea garden areas.	Policy	All	
9) Improve NRHM implementation in tea gardens	a) Resort to withdrawal of funds as a last option	Policy	All	MOU between State of Assam and Tea Estates
	b) Tighten monitoring by BPM and DPM	Policy	All	MOU between State of Assam and Tea Estates
	c) Ensure that NRHM Committees are truly transparent and functioning	Policy	All	MOU between State of Assam and Tea Estates

SUMMARY OF RECOMMENDATIONS RELATED TO TEA GARDENS

Yellow = State **Green = Tea garden manager**

Issue	Recommendation	Type of intervention	Tea garden
I. Ensure Implementation of NRHM within the framework of MoUs	a) Before rescinding funds, the government should endure patients have access to another facility equally or better equipped	Policy	All
	b) Stricter monitoring by BPM and DPM	Policy	All
	c) Ensure that NRHM Committees are transparent and functioning	Policy	All
2. Ensure ambulance availability	a) Ensure all tea gardens have a functioning ambulance available 24hrs.	Service	All
	b) Permission to avail the ambulance should be given to the medical staff of the tea garden hospital.		All
3. Improve medical staff availability	a) Ensure at least one full time doctor	Service	Sapoi, Dibrudarrang, Panbari, Dhirai
4. Improve availability services	a) Ensure hospitals are open on Sundays or on worker's day off	Policy	All
	b) Ensure 24hrs normal delivery	Service	All

Appendix 1 - List of codes

0. General Codes 00. Emergency Code 01. Maternal Death 02. Infant Death	4. Undue Payment: 41. Patient paid for admission and/or bed 42. Patient paid for prescribed medicines 43. Patient paid hospital staff for services 44. Patient paid for transport to/from the facility 45. Patient paid for blood transfusion
2. Conditions of Health Facility: 21. The hospital is closed during working hours 22. There is no doctor at the facility 23. No medical staff at the facility (nurses, pharmacist, etc.) 24. There are no free beds 25. Ambulance not available 26. Patient is not attended by hospital staff 27. No water/electricity/toilets at facility	5. JSY Entitlements: 51. Pregnancy was not registered 52. Pregnant woman did not receive IFA tablets or TT shots 53. Pregnant woman did not receive supplementary nutrition by Anganwadi Centre 54. Pregnant woman did no receive JSY money after delivery, or the amount received was not adequate
3. Availability of Services: 31. Pregnant woman cannot deliver 32. No blood available 33. Pregnant woman is referred to another hospital due to lack of services 34. Newborn did not receive neonatal care due to lack of services 35. Newborn did not receive immunization 36. Free medicines are not available at the facility 37. Patient is not attended 38. Patient feels she was mistreated by staff because she belongs to Adivasi community	6. Food Rations: 61. Ration shop is closed during working hours/days 62. Food rations are sold to a higher price 63. Food is rotten 64. Rations are given less than due amount 65. Ration shop does not have enough supply

Appendix 2 - List of locations

Facility	Block/Location
Dhekiajuli Primary Health Centre	Dhekiajuli Block
Dhekiajuli Community Health Centre	Dhekiajuli Block
Sapoi Tea Estate hospital	Dhekiajuli Block
Tinkharia Tea Estate hospital	Dhekiajuli Block
Dibrudarang Tea Garden hospital	Dhekiajuli Block
Panbari Tea Garden hospital	Dhekiajuli Block
Narayanpur Tea Garden hospital	Dhekiajuli Block
Dhirai Tea Garden Hospital	Dhekiajuli Block
Rakashmari New Primary Health Centre	Dhekiajuli Block
Balipara Block Primary Health Centre	Balipara Block
Haleswar Primary Health Centre	Balipara Block
Dipota Primary Health Centre	Balipara Block
Dekargaon Primary Health Centre	Balipara Block
Panchmile Primary Health Centre	Balipara Block
Sonabeel Tea Garden hospital	Balipara Block
Kanaklata Civil Hospital	Tezpur
Guwahati Medical College	Guwahati
Tumuki Medical College	Tezpur

Appendix 3 - Project Participants

The End MM Now project would not have been possible without the participation of 40 women volunteers, who reported the cases featured through SMSs to the project team.

Nazdeek, PAJHRA (Promotion, and Advancement of Justice, Harmony and Human Rights of Adivasi) and ICAAD (International Centre for Advocates Against Discrimination) are grateful for their participation. Featured below are few of these participants. Some wished to remain anonymous and have not been profiled here for this reason.

Evha Rani Marki – Volunteers Coordinator, Balipara Block

Jinita Topno – Volunteer, Balipara Block

Monika Singh – Volunteer, Dhekiajuli Block

Rina Munda – Volunteer, Balipara Block

Joshila Barla – Volunteer, Dhekiajuli Block