

Report
Reasons behind Refusal of Vaccines in Meghalaya
- An exploratory study in East Khasi Hills District, Meghalaya



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The Indian Institute of Public Health, Shillong

in collaboration with

National Health Mission- Meghalaya, and

The Directorate of Health Services (MCH&FW)

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Suggested citation:

Hazarika J, Parveen S, Lyngdoh P, Albert S. Reasons behind Refusal of Vaccines in Meghalaya - report of an exploratory study. Indian Institute of Public Health Shillong and Directorate of Health & Family Welfare, Government of Meghalaya, India. 2018

Acknowledgements

We sincerely thank Shri Pravin Bakshi IAS, Secretary, Health and Family Welfare and Mission Director, National Health Mission-Meghalaya for extending his support to this study.

We thank Dr R M Lamare, Director of Health Services (MCH & FW) cum Joint Mission Director, National Health Mission, Government of Meghalaya and Dr E A Pasweth, Joint Director (MCH & FW) for extending their support throughout the course of the study.

We would like to express our thanks and acknowledgement to Dr B Mawthoh, currently Director of Health Services (Research), Government of Meghalaya, Dr P D Chyne (Retd.), Dr Neelanjan Roy, Surveillance Medical Officer, World Health Organization, Unit-Shillong for initiating this study. They spared their time for discussions and provided unstinting support to the research team. At the time of initiation of the study Dr Mawthoh was the Director of Health Services (MCH& FW) cum Joint Mission Director, National Health Mission, Government of Meghalaya and Dr Chyne was Joint Director (MCH& FW) cum State Extended Program of Immunization Officer (SEPIO).

We thank Dr E. Dkhar, District Medical and Health Officer, East Khasi Hills, Shillong for providing a letter of support which helped in the smooth conduct of field activities.

We thank Dr N Wanswett, Medical Superintendent & Joint Director Health Services, Ganesh Das Hospital, Shillong for granting the team permission to photograph a few images related to immunization during immunization sessions at Ganesh Das Hospital¹.

We thank Ms Nandaris Marwein, Assistant Professor, Department of Social Work, Martin Luther Christian University for helping with translation of a news report that is referred to in this study.

We gratefully acknowledge the work of our field team Ms. Phibansuk C. Lyngdoh, Ms. Eugenia Kermaphi Syiem, Ms. Roza Larilang Marbaniang, Mr. Sandy Banroy Tariang for their diligent and patient work in the field.

And finally we thank Dr Nanda Kishore Kannuri, Associate Professor and medical anthropologist at the Indian Institute of Public Health, Hyderabad for critiquing this report.

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¹ Verbal consent was taken from health workers and parents before photography.

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Executive Summary

Background: Meghalaya state in northeast India has a largely tribal population; 86% belong to Scheduled Tribes, mainly to the matrilineal Khasi-Jaintia and Garo tribes. Vaccination coverage in Meghalaya has steadily increased from 33% according to the National Family Health Survey-3 (NFHS-3) to 62% according to the latest NFHS-4. But the current immunization level remains far less than optimal levels. And there are considerable rural urban differences. In spite of several programmatic initiatives by the government, child immunization continues to remain a challenge and is a major public health concern for Meghalaya. Hence a systematic effort to improve understanding on underlying reasons for low immunization rates, in particular for vaccine hesitancy among parents was imperative. To address this gap in knowledge a pilot study to explore the reasons behind refusal of vaccination in Meghalaya was conducted in selected villages of East Khasi Hills by the Indian Institute of Public Health - Shillong in collaboration with the Directorate of Health Services (MCH & FW), Government of Meghalaya.

Methods: A mix of qualitative methods such as small group or focus group discussions and in-depth interviews with parents and key informants were carried out. Interviews were useful in instances where mothers were shy to speak during group discussions. They were also used to address the low turn-out of fathers for group discussions. Observations and ‘role play’ were also employed to gain insights into behaviour and attitudes.

A list of villages with high vaccine hesitancy or ‘refusal villages’ in East Khasi Hills district was drawn up by the Department of Health & Family Welfare and a sample of seven villages from two blocks were selected in consultation with key informants in the state’s immunization team and with medical officers at the primary health centres. In addition one of the investigators was part of the 11th Common Review Mission of the MoHFW that evaluated Meghalaya’s health system; observations made during this review supplemented our findings.

The study team conducted six group discussions, 16 interviews with key informants and 23 in-depth interviews (11 with fathers and 12 with mothers) across seven vaccine hesitant or ‘refusal villages’. A total of 36 mothers and 17 fathers participated in the study. A majority of the discussions were audio recorded after obtaining prior consent from the participants. In case the participant did not give consent for audio-recording, notes were taken by the field team. The discussions and interviews were translated from Khasi to English by a team of bilingual research assistants. Data was coded and analysed using thematic content analysis approach.

Key Findings: The reasons for refusal of vaccines in this report have been broadly categorised into community perception on vaccine refusal and perceptions of health personnel (key informants) on vaccine refusal.

Fear of adverse consequences (often described as ‘side effects’ by health personnel) was one of the main reasons for refusal of immunization as reported by parents. Parents were afraid of their

children developing fever and pain after injections; “*my child gets fever*” and “*scared of the pain*” were common refrains. Development of swellings and seizures after injections were also feared and attributed to vaccines. Mothers said their “*child fell sick*” post immunization and considered such episodes of undesired consequences as troublesome for them as the additional burden of looking after sick children fell on them.

Parents often mentioned that “*my child looks healthy*” and they “*see no difference*” between an immunized and an unimmunized child. Thus, it was evident that there was considerable lack of understanding on the purpose, importance and the diseases that immunization offer protection against. There were some who hesitated for seemingly no apparent reason “*we are not interested and nobody can force anyone who does not wish to take immunization*”

Parents also reported not receiving adequate and appropriate information on immunization from health workers; “*I don’t know ...they don’t tell us much*”. Loss of wages of the mother was another reason offered for incomplete immunization or refusal of vaccines. If the child was sick on the day of immunization and missed a dose, mothers tend to discontinue immunizing the child.

Negative press/ media reports and personal experiences of actual or attributed ‘side-effects’ to immunization had a multiplier effect on other members in the community.

Similar to parents, health personnel also reported reasons like lack of awareness on the importance of immunization and fear of side effects among parents. In addition they reported lack of trust in programmes implemented by the Government, confusion with introduction of Aadhaar schemes, and religious beliefs against immunization.

Fathers in one village did offer opinions reflecting trust deficit in government schemes. However, religion as a particular reason for vaccine refusal was not reported by parents in this study sample.

There is low knowledge about the vaccination schedule and of diseases against which vaccines are provided among frontline workers in the public health system. At least one of the key informants reported that they had personally encountered frontline health workers (ASHAs and AWWs) who themselves did not believe in vaccines and refused immunization for children in their own families.

Importantly a lack of motivation was observed among some of the health workers in mobilizing families who had refused or missed immunization. Some of them had labelled these families as ‘refusal cases’ and stopped visiting these families. Interpersonal ‘soft’ skills among health workers in dealing with young mothers with the sensitivity and kindness that is required is an area for improvement.

An important factor was the gaps in delivery of the four key messages that are outlined as an important component of immunization delivery². This was largely missed or done in a rudimentary and incomplete manner by health workers. These findings were discerned through a combination of role play and direct observations of health workers.

Overall there were no major supply side issues such as vaccine stock outs reported in this small study sample. The smooth functioning of the vaccine related supply side factors was an encouraging sign. The gaps in supply side were largely related to issues in information communication and 'soft skills' of health personnel.

Recommendations: This exploratory study has largely identified demand side factors that contribute to vaccine refusal and low levels of immunization in the community. The major recommendations can be summarized as follows:

a) Focussed efforts to ensure diligent delivery of the four key immunization messages by health workers. They may have been trained in this before but clearly there is no follow through in the field. Hence refresher courses of a practical nature and supportive supervision is recommended.

b) To ensure that communication is appropriate, re-training of existing personnel is required to ensure that key messages are conveyed with sensitivity and in a fitting manner. Health personnel need to accept that clients have a right to ask questions and must be encouraged to do so. Simple tips like politely encouraging a new mother to paraphrase the four messages can be employed to ensure that she has heard and internalised the messages.

c) Rigorous monitoring of immunization session sites and regular supportive supervision of personnel can ensure activities are carried out optimally. Supervision and monitoring would be best if done in the spirit of improving quality of service rather than as a punitive measure.

d) Attention may be paid to recruiting personnel with the necessary interest and the aptitude needed for health service based on career guidance principles rather than a focus on only educational qualifications.

e) Regular refresher trainings of health workers with emphasis on 'soft skills'. The message that our people have a right to expect high quality service from the public sector is worth emphasising in every training interaction. They may also be trained to deal with questions and how to encourage the same from parents, so that miscommunication is avoided.

f) Community engagement through meetings/ health talks at a convenient time and place in consultation with the community. More effective use of VHND sessions is a good place to start.

² Four Key Messages

- What vaccine was given and what disease it prevents
- When and where to come for the next visit
- What are the minor side effects and how to deal with them
- To keep the immunization card safe and to bring it along for the next visit

Discussions can be held with influential people of the community to improve understanding about immunization programmes and the benefits of immunization.

g) Develop a quick response mechanism to ‘contain’ or prevent negative fallout from rumours, media reports (that may be based on partial and poor information) and from unexpected effects or rare side-effects encountered by members of the community. These need to be redressed in a responsible and timely manner by health personnel and/or knowledgeable others in the community if immunization uptake is to be improved.

h) Finally considering the situation of high refusal of vaccination in the State it is perhaps important to think of alternate context relevant strategies to address the situation. Keeping in mind comments such as “*we just go to the field and to do not bother about immunization at all. Well how will you force, if the mother herself does not want it. You cannot force a person who is not interested*” came from the community, alternate approaches need to be considered.

We provide an example of an innovative community engagement intervention that is currently being employed in a neighbouring state. This approach, referred to as the SALT (Simulate, Appreciate, Learn and Transfer) approach, is directed towards increasing community’s understanding and ‘ownership’ of children’s health, specifically immunization.

We acknowledge that this small study sample is not likely to be representative of the entire State of Meghalaya and that contextual factors may vary in other districts. For more representative understanding such studies may be undertaken in other districts based on the heterogeneity of the place and its people. But the observations made here could well be common for other districts. Thus attending to the findings from this study could be beneficial for the immunization programme as a whole.

List of Abbreviations

ANM	Auxiliary Nurse and Midwife
ASHA	Accredited Social Health Activist
AWW	Anganwadi Worker
BCG	Bacillus Calmette–Guérin
CRM	Common Review Mission
DHS	Directorate of Health Services
DM& HO	District Medical and Health Office
DPT	Diphtheria, Pertussis, Tetanus
EPI	Expanded Programme on Immunization
FGD	Focus Group Discussion
FIC	Full Immunization Coverage
GoM	Government of Meghalaya
IDI	In-depth Interview
IEC	Information, Education and Communication
KII	Key Informant Interview
MCH& FW	Maternal and Child Health & Family Welfare
MCP card	Mother and Child Protection card
MHIS	Megha Health Insurance Scheme
MO	Medical Officer
MoH&FW	Ministry of Health and Family Welfare
NFHS	National Family Health Survey
PHC	Primary Health Centre
SALT	Stimulate, Appreciate, Learn, Transfer
SC	Sub-centre
SMO	Surveillance Medical Officer
UIC	Universal Immunization Coverage
UIP	Universal Immunization Programme
VHND	Village Health and Nutrition Day
VPD	Vaccine Preventable Diseases
WHO	World Health Organization

Glossary notes

Vaccine hesitancy - delay in acceptance or refusal of safe vaccines despite availability of vaccination services (WHO)

‘Refusal villages’ – is a term we came across being used frequently within the Directorate of Health & Family Welfare, GoM, to refer to villages that are consistently reporting low immunization coverage. For practical purposes we have retained and used this term to indicate the same in some instances.

A. Introduction

Immunization against vaccine preventable diseases is one of the most cost-effective health interventions for saving lives and protecting children from preventable life threatening conditions. It prevents an estimated 2 to 3 million deaths every year worldwide from vaccine preventable diseases (1). However around 19.5 million infants still miss out on basic vaccines globally (1,2) . An additional 1.5 million deaths due to vaccine preventable diseases could be averted with further improvement in global immunization coverage (1,3). India introduced the Expanded Programme on Immunization (EPI) in 1978 which was renamed as Universal Immunization Programme (UIP) in 1985 to cover all districts in a phased manner (4). In spite of a long standing national programme on immunization, the full immunization coverage (FIC) among 12-23 months old children is only 62% in India(5). Full immunization coverage is defined as children receiving 1 dose of BCG (to prevent tuberculosis), 3 doses of polio (to prevent poliomyelitis), 3 doses of DPT (to prevent diphtheria, pertussis and tetanus)/ Pentavalent vaccine (DPT plus Hepatitis B and Haemophilus Influenza type B), and 1 dose of measles. Some improvement has taken place over the years with the introduction of new campaigns on immunization like Mission Indradhanush in addition to routine immunization sessions under UIP. But still India accounts for 7.4 million unimmunized children which is the largest in the world (6). Annually around half a million children die due to vaccine preventable diseases in India. Another 8.9 million children remain at risk, either due to partial immunization or no immunization at all against vaccine preventable diseases (7).

Currently UIP provides free immunization against childhood tuberculosis, poliomyelitis, diphtheria, pertussis, tetanus, haemophilus influenza type B associated pneumonia and meningitis, hepatitis B and measles in government health facilities across the country. Also rubella, rotavirus and Japanese Encephalitis have been launched in some states.

Meghalaya state is located in the northeast region of India and has a population of over 3 million, of which, approximately 86% of the population are classified as belonging to Scheduled Tribes, mainly to the matrilineal Khasi-Jaintia and Garo tribes.

In Meghalaya the FIC among 12-23 months old children has increased steadily over the years. It was around 33% according to the National Family Health Survey-3 (NFHS-3) conducted in 2005-06

and then around 49% according to the District Level Household and Facility Survey- 4 (DLHS-



Figure 1: IEC vaccine preventable diseases



Figure 2: A vaccine van

4) conducted in 2012-13 (8,9). According to the latest NFHS-4 conducted in 2015-16 the FIC among 12-23 months old children is around 62% (8). But this current level remains far less than ideal along with vast rural urban differences. According to the NFHS-4 only 58.5% 12-23 months old children are fully immunized in rural areas as compared to 81.4% in urban (8). In spite of several programmatic initiatives by the government child immunization continues to remain a challenge and therefore is a major public health concern for Meghalaya.

World Health Organization (WHO) defines vaccine hesitancy as, “delay in acceptance or refusal of safe vaccines despite availability of vaccination services” (10). A recent article in The Shillong Times on *Myths about immunization hampering children’s health in Meghalaya*, flagged strong vaccine refusal in Meghalaya (11). Elsewhere in the world a few studies have been conducted to understand the reasons why parents refuse, delay, or are hesitant to immunize their children (12–15).

Literature search in databases like PubMed and Google Scholar showed no studies on the topic from Meghalaya. Hence a systematic effort to redress this gap in knowledge is important as it can help us understand community perceptions on immunization and the underlying reasons of vaccine hesitancy among parents. This will enable the government to plan out appropriate interventions in the future.

B. Objectives

- To understand the knowledge, attitude and practices of parents / caregivers and health care personnel with respect to immunization.
- To understand the reasons underlying vaccine hesitancy in Meghalaya.

C. Methods

1. Study Design

An exploratory study using a mix of qualitative methods was done in the East Khasi Hills district to understand the knowledge, attitude and practices of parents/caregivers and health care workers in relation to immunization, in particular to explore the underlying reasons for vaccine hesitancy. The immunization section of the Department of Health & Family Welfare, Govt. of Meghalaya (GoM) maintains a list of villages where refusal of immunization is consistently reported in the state, often termed as ‘refusal villages’ by the health personnel. This study was carried out in seven selected villages under Mawryngkneng PHC and Diengpasoh PHC of Mawryngkneng block and Mawphlang PHC of Mawphlang block in East Khasi Hills, Meghalaya from Oct-Dec 2017.

2. Sampling

A full list of ‘refusal villages’ or those with high vaccine hesitancy in East Khasi Hills was drawn up by the immunization team in the government’s vaccine division. Consultative discussions with the Department of Health representatives at the state headquarters and at block level was done to identify the sampling blocks, primary health centres (PHCs) and villages. Out of the four blocks with high vaccine hesitancy in East Khasi Hills district, the Mawryngkneng block was purposefully selected for the pilot study. The PHCs that were selected were Mawryngkneng PHC and Diengpasoh PHC. During the course of the study, Mawphlang PHC of Mawphlang block was also added to the sample in consultation with the Surveillance Medical Officer (SMO) of World Health Organization (WHO) for Shillong, due to the high number of ‘refusal cases’. Also Medical Officers’ (MOs) views of the selected PHCs on villages with high immunization refusals were taken into consideration for final selection of the villages. Thus seven villages were purposively selected across Mawryngkneng PHC and Diengpasoh PHC of Mawryngkneng block and Mawphlang PHC of Mawphlang block for this study.

Table 1: List of villages selected for data collection

Block	Name of PHC	Names of village
Mawryngkneng	Mawryngkneng PHC	1. Lamlyer 2. Sohryngkham
Mawryngkneng	Diengpasoh PHC	3. Diengpasoh B 4. Mawiong
Mawphlang	Mawphlang PHC	5. Kharsaohnoh Sohtun 6. Lumsohrieh 7. Umtyrniut

3. Methods of data collection

The data were collected through various qualitative research methods including Key Informant Interviews (KIIs), Focus Group Discussions (FGDs) and In-depth Interviews (IDIs). These were supported by observations and informal conversations.

The Key Informant Interviews (KIIs) were conducted with the Medical officers (MOs), Auxiliary Nurse Midwives (ANMs) and Accredited Social Health Activists (ASHAs). A total of 16 key informant interviews (KIIs) were conducted to understand their perspective on the various reasons for refusal of vaccines in Meghalaya, the challenges they face and the activities they conduct to mobilize the community for immunization.

A total of six small group or Focus Group Discussions (FGDs) were conducted separately with groups of mothers and fathers from the vaccine hesitant families in the sampled villages. The

discussions were conducted by a moderator using a topic guide, audio recorder and field notes were taken by a note taker. They were conducted in Khasi, the local language at a time and place that was convenient to the participants.

There were informal interactions with the village headmen (Rangba Shnong) seeking his cooperation and support to mobilize parents from the vaccine hesitant families to participate in the discussions. The team prepared a notice which was distributed house-to-house of vaccine hesitant families, by ASHA or Aanganwadi Worker, inviting the parents for a discussion on behalf of the Rangba Shnong. This was done as a written notice from the headmen was considered more significant by the community for participation in any discussion. Initially in the notice it was mentioned that the discussion was on health, which resulted in less participants turning up. So the notice was changed to an invitation for a general discussion on behalf of the Rangba Shnong mentioning date, time and place. The copies of the notices used and the details of the group discussions conducted are added as Annexure 3 and Annexure 4 respectively.



Figure 3: Interaction with the Rangba Shnong of Diengpasoh village

Due to the low turn-out of fathers for the FGDs, we conducted 11 In-depth Interviews (IDIs) with fathers by visiting households of vaccine hesitant families (see Annexure 5 for details). Sometimes some of the mothers hesitated to speak during the group discussions, such mothers were interviewed (3) later to ensure their perceptions were documented. A total of 11 fathers and 12 mothers were interviewed. The details of IDIs conducted are provided in Annexure 5.

A letter of support provided by the District Medical and Health Office (DM & HO), East Khasi Hills helped in the smooth conduct of field activities and data collection (Annexure 1).

One of the investigators was a member of the 11th Common Review Mission 2017 from the MoH&FW that aimed to review the health system of Meghalaya state. She visited health facilities across East Khasi Hills. During the 11th CRM visit the team member interacted with frontline health workers to assess awareness of immunization schedule and delivery of four key messages. It was found that ANMs could not properly answer/ recall the four key messages, which suggested that it was not a practice followed during immunization sessions. To shed more light on how frontline health workers interact and communicate with mothers the team directly observed them during immunization session. Furthermore, while conducting KIIs, the team used role play to understand their interaction with mothers. For instance the researchers of the team would take the role of the mother who has come for immunizing her child and asked the health worker to demonstrate what they would do. The details of the KIIs have been listed in Annexure 2.

4. Data management and analysis

The discussions and interviews were audio recorded to the extent possible after informed consent was obtained from the study participants. Detailed field notes were taken wherever participant did not agree for audio recording. Verbal consent was obtained for participants who refused providing written consent.

The bilingual interviewers translated the audio recording from Khasi to English for analysis. The transcripts were coded and categorized and further analyzed using a thematic content analysis approach. Transcripts were compared, reviewed and discussed after the initial coding to look for common reasons for refusal of vaccines and emerging themes were identified.

D. Key findings

1. Socio-demographic profile of participants

Socio-demographic profile of the mothers

Focus Group Discussions and In-depth Interviews were held with a total of 36 mothers in seven villages of East Khasi Hills (Annexure 6). The average age of the mothers was 32 years and the age range varied from 21 years - 51 years. The average age at marriage was 20 years and the average number of children was four. The education and occupation are shown below as figures 4 and 5:

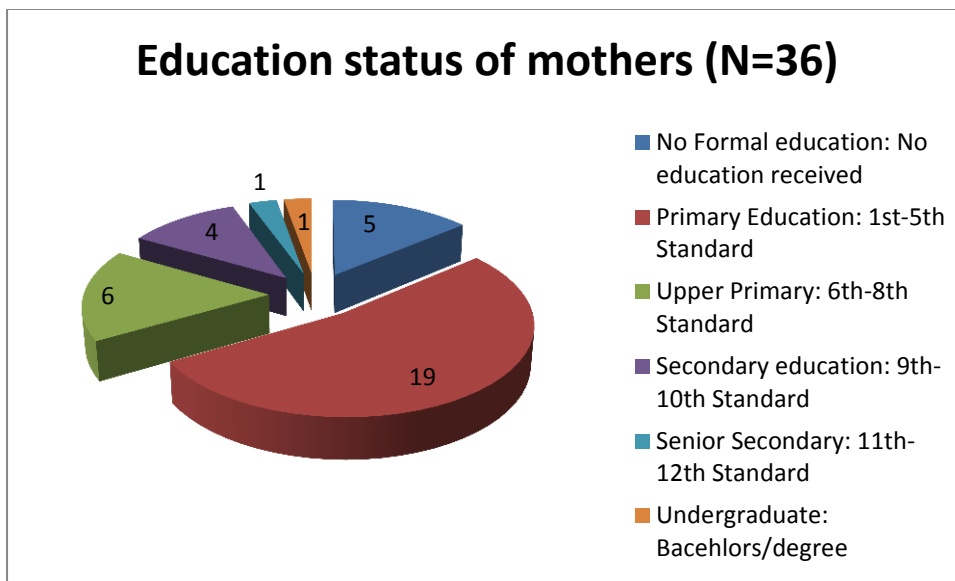


Figure 4: Education status of mothers (N=36)

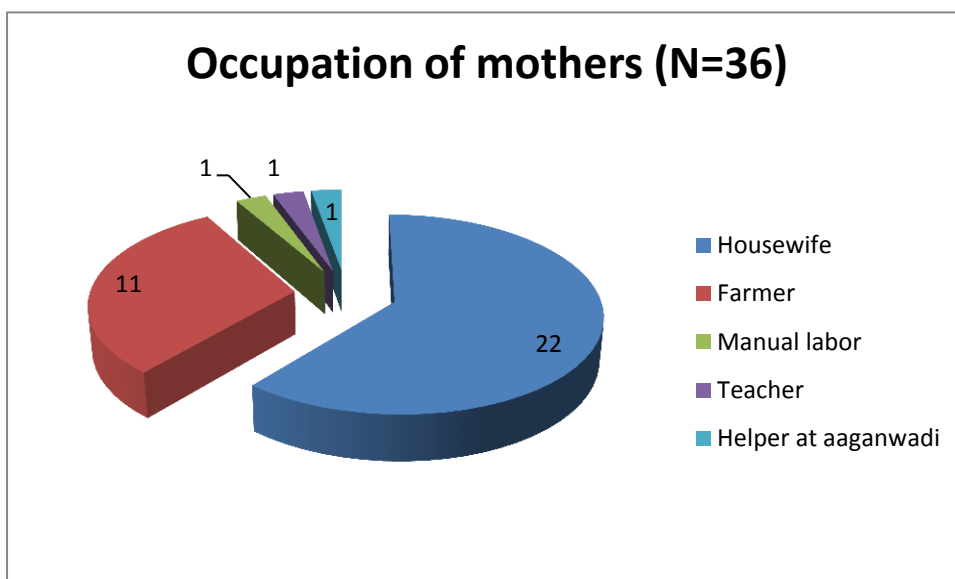


Figure 5: Occupation of mothers (N=36)

Socio-demographic profile of fathers

Focus Group Discussions and In-depth Interviews were held with a total of 17 fathers in seven villages of East Khasi Hills (Annexure 7). The average age of the fathers was 37 years and the age range varied from 20-59 years. The average age at marriage was 18 years, which is below the marriageable age for boys and the average number of children was four. Majority of the fathers worked as farmers (11 of 17) and the rest were manual labourers. In terms of education, eight fathers had primary education (1st-5th standard), two had upper primary education (6th-8th standard) and seven had no formal education.

Findings on immunization

The findings on immunization have been broadly categorised into community perception on vaccine refusal and perceptions of the key informants on vaccine refusal.

2. Community perceptions on vaccine refusal

Many mothers reported not being interested in immunizing their children. The reasons for vaccine hesitancy was varied. Some of those who refused vaccines highlighted their own choice in the matter *“Well how will you force, if the mother herself doesn’t want it. You cannot force a person who is not interested.”*

Key themes that emerged from interactions with parents (mothers and fathers) are presented in this section.

2.1 Fear of adverse consequences

The majority of the parents reported fear of adverse consequences such as fever, pain, swelling, seizures to be one of the main reasons for incomplete immunization or refusal to vaccinate their children.

2.1.1. “My child gets fever”

Majority of the parents reported that they stopped immunizing their children due to occurrence of fever post immunization resulting in incomplete immunization. They stated that they “feel sorry for the child” and “don’t feel like immunizing” as the child suffers from high fever.

“I feel pity when they have fever that is why I don’t want to give immunization.”

-Mother, Kharsahnoh Sohtun

Mild fever after certain vaccines is an expected side-effect. Ideally a mother should be forewarned about it and instructions about managing it should be given clearly until she understands it. The risks versus benefits i.e. the importance of immunization and its expected side-effects needs to be conveyed in a balanced manner. Unfortunately most of our mothers appeared not to have received these messages and instead went with the impression that immunization made their children unnecessarily sick rather than disease free.

2.1.2. *“I thought it was a mistake” - Concerns about swelling*

One of the major side-effects reported by parents was swelling of the area post immunization resulting in incomplete immunization of their children.

“When she [the child] was small I gave injection. And then, I thought it was a mistake because the child’s thigh was swollen, and the child couldn’t even stand up. And from that time on, I did not complete immunizing the child”

- Mother, Diengpasoh B

The following excerpt from a conversation with a mother illustrates their concerns and challenges faced in dealing with swellings post immunization.

“I don’t understand much about that [immunization] because I hardly immunise my child except for polio. I don’t give immunization (injek) because when I took my eldest child for immunization, he developed swelling. I took him to the sub-centre and showed the nurse [ANM]. She said to avoid contact with water. Since I don’t have much knowledge about this, I followed what she [ANM] said. But then the swelling area became bluish in colour [cyanosed], so from then I haven’t immunized my children. They have only received BCG as they were born in the hospital.” On being asked about what she did after that, she said *“I took my child to the doctor who asked me to give hot compress. I did that and the swelling came down. But I am still scared to immunize.”*

- Mother, Umtyrnuit

The above quotes besides illustrating the mother’s self-confessed lack of awareness about immunization’s benefits, also demonstrates the health systems inability to address beneficiaries concerns appropriately and in a timely manner. Possibly the above mother was given poor advice for dealing with a minor side effect by the front line health worker. Ideally such a client who dealt with a vaccine related adverse event should have been flagged as a potential for vaccine hesitancy in the future and been followed up with appropriate counselling.



2.1.3. *“Scared of the pain (pang)”*

Some mothers reported that they did not immunize their children or stopped immunization because they were scared of the pain it causes the child while getting immunized and also post-immunization. This was also reported by a few fathers that their wives refuse to immunize because it will “cause pain to the child” and “so she fears”.

Figure 6: A child being immunized

These people [ANM] they do say. But it is because I myself I’m scared. These people [ANM] would say it doesn’t pain but I feel it is painful.

-Mother, Mawiong

I can’t see them when they are in pain and it is painful to see them crying when they are injected.

-Mother, Kharsahnoh Sohtun

The research team tried to explore the reasons behind the fears, the below excerpt from an interview is a sample of both explicit and implicit reasons conveyed:

I: So in spite of the ASHA and ANM saying not to be afraid, you are still scared?

R: Yes. I'm still scared.

I: What is it that makes you scared?

R: Don't know.

I: Well. Have you received injections?

R: I have never taken myself as well [Immunization]

I: Not even once. Since birth?

R: Yes. Probably because of that, I the mother am also scared and so I'm scared for my child as well. Scared for both. It is like, how will I only give [immunise] my child it is like I am ill treating my child, as I [mother] myself I'm afraid.

I: Okay. So the child you delivered at Nazareth has received BCG after birth right, but then why didn't you complete it?

R: I didn't complete it and I did not immunise anymore [Because of the same reason]

- Mothers, Mawiong

These quotes suggest that mothers were not motivated enough to immunize their children as they lacked understanding of its purpose and importance. Mothers reported that health workers were not sensitive enough to their concerns and fears for their child. Such mothers need to be appreciated for their initial efforts at bringing their children for immunization and their concerns should ideally be listened to and dealt with in a sensitive manner.

2.1.4. "It makes my child fall sick"

Mothers often mentioned that their "child fell sick" after immunization and hence they felt it was a "mistake" to immunize as they did not "see" any benefits.

"I feel pity for the child because he gets fever after immunization so I don't want my children to fall sick"

- Mother, Diengpasoh B

This suggests that mothers lacked understanding of the purpose of immunization and the possible side-effects and so they felt immunization makes their children fall sick. It is very important that the mother understands that there might be minor side-effects and the instructions on how to manage them. So mothers can be encouraged to ask questions or doubts regarding side-effects and these should be answered accordingly. Mothers can be asked to repeat the information given to them in order to increase the chance that they have understood the warnings of side-effects and how to manage them.

2.1.5. "It was scary" - the seizures

Another side effect reported by one mother, that led to incomplete immunization of children was episode of seizure post-immunization.

"Yes, I have given [to my two older children]. But to the last child I've given only DPT1. Soon after the injection (DPT1) the child nearly died, it looks really scary. The child had

seizure. Then I wondered why it is so, so I went to tell the nurse, and then she came and gave a red mark on the card saying not to give anymore. The child cannot be immunized ever. And so it ended there.”

-Mother, Diengpasoh B

Such incidences may make parents lose trust on immunization and requires appreciation and motivation for their effort of bringing their children for immunization. Though episodes of seizure have not been reported often but such incidences tend to influence others to not go for immunization. Potentially such cases should be dealt with care and appropriate counselling.

2.2. Knowledge gaps and perceived lack of benefit

The next group of subthemes offer views on a reported lack of understanding and a perceived lack of benefit from immunization.



Figure 7: FGDs with Mothers in Diengpasoh (left) and Lamlyer villages (Right)

2.2.1. “Of what use is it?”

The parents who immunize their children perceive immunization to be beneficial for prevention of diseases. But a majority of the parents who refused immunization reported that they do not understand the benefits of immunization. They do not have sufficient information and did not understand its benefits, thus contributing to misunderstanding and fears about immunization.

“I don’t know if it is of any use, as I didn’t get proper understanding about it, so I feel scared to immunise, if the child gets pain and all.

-Mother, Umtyrnuit

Similar perceptions were reported by mothers from other villages too. Thus there was a general lack of awareness of the benefits of immunization.

2.2.2. “My child looks healthy”, “I see no difference”

Some of the parents relate physical appearance with immunization. “My child looks healthy, so why should I immunize?” was a common refrain.

“I don’t know because I don’t understand about immunization and also because all my children are healthy so I don’t feel the need to get them immunized”.

-Father, Mawiong

“He’s healthy and strong so why give immunization?”

-Mother, Lumsohriew

Clearly, there was misunderstanding about vaccine preventable diseases and how immunization was expected to work for their children. This is an aspect that needs particular attention from health workers or other knowledgeable members during the IEC campaigns.

A couple of mothers reported not immunizing their children as they felt “no difference” when they looked at an immunized and an unimmunized child.

“Well to the elder child [granddaughter] I have immunized till 5 years, who is going to be 8 years now. Then the other younger child I did not immunize at all. But looking at the children they are all the same, what else can I say.”

-Grandmother, Mawiong

This again suggests that mothers lacked understanding of the purpose of immunization even though they had immunized their children previously. The idea that vaccines only offer protection against those specific diseases for which a child is immunized was missing. The expectation appeared to be that it was a magical remedy that would protect against all childhood ailments. It is interesting that caregivers were in their own way making comparative observations in an almost experimental manner between immunized and non-immunized children within their household and their community and making decisions based on outcomes.



Figure 8: Health worker preparing for vaccination session

2.3. The negative effects – an additional chore for mothers

2.3.1. “It is troublesome and tiring” –

Mothers reported that it was difficult and troublesome for them as they had to look after their children in case of side-effects such as fever, swelling or pain post immunization.

“Injection. Mmm... That is what, the heart is not willing yet. I feel sorry for the child. The child cries, gets fever and becomes difficult. I have to carry [the child] and have to wait up and look after overnight, it’s tiring.”

-Mother, Mawiong

The above quote suggests that mothers in the midst of balancing domestic chores deprioritized immunization. Arguably taking care of a sick child experiencing adverse effects can be difficult. But information provision of such risks need to be balanced and countered with the future benefits that a vaccine can provide. Although these concepts are not easy to grasp due to their abstract nature we need to explore methods to convey these ideas in simple layman terms. Appropriate awareness raising measures need to be used in a sensitive manner to raise

consciousness about the beneficial role of vaccines and their short term relatively mild side-effects.

2.3.2. “Sometimes I feel lazy”

Some of the mothers attributed their lack of initiative to immunize due to ‘laziness’ and ‘being careless’. A couple of them acknowledged that immunization is important but still neglected immunizing their children.

“Yes, I feel bad because I could not complete the immunization for my child but I cannot help it because it’s our carelessness and laziness.”

-Mother, Sohryngkham

The tendency to postpone or forget matters that are not perceived as important or urgent is but human. The candid opinion of mothers is worth noting. It is in such instances that a reminder from health teams is particularly helpful. Especially when combined with proper information on the importance and purpose of immunization.

2.4. Gaps in information provision / IEC

Although supply side factors like vaccine stock outs were not observed in the study sample, the one area where provider or health system (supply side) related deficits were observed was in human resources related issues. In particular in the manner in which clients were treated and information was conveyed. Much can be improved in dealing with clients in a respectful manner.

2.4.1. “They do not tell us properly”

Mothers often claimed that they had no idea about what specific diseases their children were vaccinated against.

“They just said give the baby and remove the clothes. No they don’t explain [what diseases are prevented].”

-Mother, Lamlyer

Some fathers said that since none of the doctors/ health workers (ASHA/ANM) come to explain immunization to them, they do not have a proper understanding of immunization and its benefits. A few of them stated that they wanted information on immunization and said that if they understood immunization better, they would be more agreeable to immunizing their child.

“You all are the first people who have come like this and that too house to house. It’s good because when you come like this we become more aware about it [immunization]. We felt that after immunization the child will become healthy but instead child falls ill [meaning high fever]. Because nobody comes and informs us, so we get angry and stopped immunizing.”

-Father, Lamlyer

Discussions with parents also revealed that during immunization session ANMs do not deliver the four key messages. It is worth emphasizing that the delivery of four key messages is integral

to help make parents aware of vaccines and the benefits of immunization, when to immunize and for what diseases, the potential side-effects of immunization and how to deal with them.

2.4.2. Child is sick on the day of immunization

Some of the mothers reported incomplete immunization as the child was sick on the day of immunization and once the dose was missed the mother either forgot to immunize or was unwilling to take the child for immunization.

For such mothers a reminder about the importance of full immunization coverage and when next to come for immunization is worth emphasizing so that they don't miss the next session.

It was heartening to note that during the course of the study there were mothers and fathers who expressed an interest in immunizing their children in the future. It was said that if they get proper information about immunization they might consider immunizing their children in the future.

2.5. Trust deficits in public sector initiatives

This was reported in a couple of villages where it was conveyed that families did not trust the Government and therefore did not avail any services provided like immunization, health meetings, Aadhaar registration, free ration and even check-up in Government health centres. Such families preferred visiting private doctors for any health conditions.

“Where I stay there are those who don't immunize their children and they don't want any means of prevention provided by the government. And if they fall sick also they just go to the private doctors.”

- Father, Diengpasoh B

It was also reported that there was sudden decrease in the number of people who immunize their children after they heard about Aadhaar number registration initiated by the Government, and stated fear to be the reason.

Peer advocacy for vaccines

Apart from interacting with parents with vaccine hesitancy during FGDs and IDIs, a few parents who immunize their children were also interacted while conducting FGDs. They were asked about whether they have tried to motivate other parents to immunize their children. They shared that they tried motivating the families to accept vaccines but such attempts were not welcomed by the families with vaccine hesitancy. They felt that side-effects post immunization was the primary reason for refusing to immunize.

“We, used to try to motivate them and make them understand [about immunization], but we are tired.”

-Father, Diengpasoh B



Figure 9: In-depth interview with fathers in Lamlyer village

3. Perception of Key Informants (MOs, ANMs, ASHAs)

The reasons for refusal of vaccines as reported by the key informants (MOs, ANMs, ASHAs) are outlined in this section.

3.1. Lack of awareness on importance of immunization

One of the major reasons reported by the key informants for refusal of vaccines was community's lack of awareness on the benefits of immunization. Lack of information on the benefits of immunization can in turn be a reason for fear of side-effects from immunization and distrust of government programmes like universal immunization.

“Here refusal for vaccines is mostly because the people do not understand. They don't know what is immunization and the benefits of immunization.”

-Medical Officer (KII.R04)

“Can't tell exactly what might be the reasons they refuse immunization. Mostly the people are not willing to immunize. Some parents feel that immunization is unnecessary. For some it is because of their belief and faith. And some just overlook the health of their children.”

-ASHA (KII.ASHA.R03)



Figure 10: KII with ASHA worker

3.2. Influence from neighbours/ family members

It was reported that some of the families refused immunization since their neighbours also did not immunize.

“We had asked [the refusal families] the reasons for not immunizing. They said that nobody in the village gave. The mothers have also spoken among themselves that they don’t want to give. They felt that because the others didn’t give so for them also it’s not important to give.”

-Medical Officer (KII.R04)

It was also reported by key informants that some parents and grandmothers refused vaccines based on their own experience of good health despite not getting immunized themselves. Thus they believe that since they themselves were not immunized and are healthy, their children too can do without vaccines.

3.3. Birth certificate and immunization

Some of the ANMs reported that the sudden drop in immunization coverage particularly in villages under Diengpasoh PHC was the increasingly easy availability of birth certificate. They were previously given after completion of immunization schedule.

“One of the reasons is the birth certificate. Before they came and completed the immunization of their child just to get the birth certificate but they don’t understand the importance of it, because before we told them the birth certificate can be given only after they fully immunized their child. But now the birth certificate is given right from the time of birth.”

- ANM (KII. ANM. R03)

Although health workers implied that withholding a birth certificate as an incentive for immunization was appropriate, this would be a violation of a person’s health rights.

3.4. The influence of Aadhaar scheme on immunization

It was reported by some of the key informants that refusal for immunization is due to distrust in programmes implemented by the Government. They stated that after Aadhaar system that involved documentation of biometrics was implemented, it was believed to be “anti-Christ” and was a cause for refusing immunization as both are government programmes.

“Before, it [immunization] was good but after the Aadhaar system came up they all believe that it is anti-Christ, and then people stopped giving immunization.”

-ASHA (KII.ASHA.R01)

During a group discussion with fathers such opinions were shared by fathers in one village who said that implementation of AADHAAR to be a reason for decrease in the number of parents immunizing their children.

3.5. Negative press - influence of media

In Diengpasoh PHC, during discussion with the ANMs about the immunization status in the areas falling under Diengpasoh PHC, the team was shown an article published in the local Newspaper “Mawphor” dated 24th October 2017. The title of the article was “*Kaei ka Depopulation? Bad Balei?*” which meant “What is Depopulation? And why?” The article was

written by a Dr.I.H.C. Pariat from the Group, People Holistic Wing of Faith Ministry. In one of the paragraph the author stated “*Kumta u Aadhaar ka long ka jingriam batriem tam bala wallam da ka New World Order, kumjuh ruh ban pynjot ia ka pyrthei la wallam ia bunjait ki jingshyrkhei, kum ki bun jait ki inject, ki tika, ki polio. Ka jingshun eh ia ki Khristan kumta ki tika kiba long bih(virus) bad la iai pynbor ban pdiang ia u Barcode(Aadhaar) number. Lada ym pdiang yn ym lah thied ne die.*” A rough translation is as follows:

“The use of Aadhaar cards can be termed as an entrapment that has been proposed by the New World order. In order for worldwide destruction and calamity various harmful means were brought about, like injection, immunization, polio that can be deemed as anti-Christian. There exists extreme hatred for the Christians. They would be administered lethal vaccination and would be perpetually compelled to accept the bar code (Aadhaar) number. Non acceptance of Aadhaar means buying and selling can be difficult.”

- Mawphor Newspaper, 24th October 2017

Such media reports published in local newspaper were claimed to be reason why some families have refused immunization post implementation of Aadhaar.

Also, an Anganwadi Worker (AWW) during an informal discussion shared that the rate of immunization was quite good in the village. But as soon as the news of the death of a child in Sohra (a different district) post immunization was printed in one of the local newspapers, the rate of immunization at the village suddenly dropped down. According to her the community perceived the cause of death to be immunization. She added that two days after the day she heard the news, it was immunization day at her centre and she went to inform the people about it, but they refused to come. “Even the people who used to immunize, refused to come” she said.

The media is generally considered as a reliable and important medium of transferring information and its reach is extensive. Although key informants highlighted the role of the print media in influencing people against immunization, we did not hear this from parents in our sample.

3.6. Inconvenience faced by parents due to side-effects

Majority of the key informants were aware of the community perceptions about side-effects of immunization such as fever, pain, swelling etc. They reported that such side-effects post immunization caused inconvenience to parents as they require staying awake at night to look after the child. Sometimes fever lasted for 2-3 days and so the parents get fed up as they have to get medicines for the child and lose 2-3 days until the child gets well. Therefore they refuse to immunize their children thereafter.

“Another reason for refusal of vaccines is because of minor side-effects such as fever and all; because of that also some people get fed up since the fever does last for 3 days and it disturbs them.”

-Medical Officer (KII.R04)

Parents had also shared about occurrence of side-effects post immunization as one of the main reasons for refusing to immunize their children. They had also shared that dealing with side-effects was difficult for them. While there may be no easy answers, the general perception appears to be that side-effects are not as mild and transient as is often conveyed. Hence it is worth thinking through how this issue can be addressed in a manner that is realistic and helpful to parents.

3.6.1. Refusal by fathers

The key informants also reported about fathers not allowing mothers to immunize their children even if the mother wanted to immunize. This was due to adverse effects following immunization for which they might have to stay awake whole night which they perceive as negatively affecting the whole family.

“For some of the refusal households it is the fathers who refuse mainly. Because they said that after immunization the child gets fever so both the parents have to stay awake so its difficult for them. They are those who refuse just because the father/ husband does not allow.”

- ANM (KII.ANM.R06)

“Yesterday also there was one mother who wants to immunize but the husband did not allow or sometimes the grandmother does not allow. So to avoid any misunderstanding or issues in the family the mother is not willing and do not dare to immunize the child.”

-ANM (KII.ANM.R05)

Refusing to immunize suggests that fathers were not aware of the possible side-effects and how to deal with them. Moreover it was found that mostly mothers took the children for immunization and if she herself does not receive the four key messages, she is not likely to be empowered to explain to her husband. To motivate fathers health workers could encourage peer counselling by fathers of children who accept immunization.

3.7. Religious beliefs and immunization

Some of the key informants reported religious beliefs against immunization prevailing among families in some villages. Such beliefs were reported not only against immunization but also against other government programmes. An incident related to Megha Health Insurance Scheme (MHIS) introduced by the government was reported in village Kyiem, which was claimed to have also affected the immunization programme there. The people thought that they have to put “finger print” for MHIS and considered it an “evil influence”. It was claimed that it affected the immunization programme also as both are programmes of the government.

The following is an experience shared by a ‘Medical Officer (MO) related to belief,

“Except for few pockets uhhh.... those who refuse they will refuse only, because we have gone to give IEC and even I have gone myself recently, but still when they refuse they just refuse without giving any reason. They will just say that they don’t want to give. Last time we went to one house [in Rangshken village under Mawngap sub-centre] where the child had died of measles. Because of their religion they don’t want to take, the child

died because they just kept like that without taking any medicine and all, they did not even immunize also. This was due to their concern for religion and their belief.”

-Medical Officer (KII.R04)

“I can say that it is their religious belief. Because they think that they don’t need anything else, it’s just their belief which is more than enough. There are some people who don’t even take voters ID or even the ration.”

-ANM (KII.ANM.R04)

3.7.1. Beliefs of followers of “*niam Samlang*” and the Pentecostal church

It was reported about a religion followed by some people in areas under Mawphlang PHC where people do not accept any government scheme.

“I think may be from before only, because there are those who follow one religion and I don’t know what they called that religion. They don’t want any government scheme, even those who have worked in the government also they resigned.”

-Medical Officer (KII.R04)

The team made several efforts through informal discussions with frontline health workers to find out the name or which section of people belonged to that religion. However the frontline health workers also had limited information and reported that the religion is called “*niam Samlang*”. It originated from village Jongksha and was preached in other villages such as Lyngkien which is under the Mawphlang PHC. It was also reported that these people before were regular with immunization but after following the new religion they refused all the services from the government.

During such informal discussions, frontline health workers have reported that Pentecostal church has a major impact on the people in Rangskhen village. They said that people following the Pentecostal church “never take medicines and immunizations”.

However these were opinions of a few health workers under Mawphlang PHC and we did not find such opinions from the mothers and fathers who participated in the study.

3.7.2. Influence of religious leaders

The role of religious leaders in a community was reported as important by many of the key informants.

“I’ve tried, but I think the main people are the religious leaders. Because people out here go to church and they listen to the religious leader. He is like the role model. If we can involve the religious leader, talk to him, yes I think we can increase the immunization coverage.”

-Medical Officer (KII.R03)

As outlined under the previous sub heading key informants have reported that there are some churches that are not only against immunization but also they are against any kind of medications and can influence parents against immunization.

“The religious leaders, last time we had invited them to discuss, but nobody attended.”

-Medical Officer (KII.R04)

In addition, during an informal discussion with front line health workers, one of them pointed out that the people in Sohryngkham village, particularly the vaccine hesitant families, denied attending any meetings especially when it comes to health and immunization. She also added that there was a meeting held in the village in 2017 by one of the religious leader, ‘Phawa’, which was attended by many. According to her there were discussions against immunization during the meeting where many of the people got influenced.

The research team did not come across such opinions from the mothers and fathers who participated. They said their religious leaders generally did not discuss immunization.

3.8. Knowledge, motivation and aptitude of health workers

Often ASHA workers were not fully familiar with the vaccination schedule nor the diseases against which vaccines were being provided through the immunization programme in the public health system.

It was observed that some health workers lacked motivation for mobilizing refusal families because they shared that they had stopped visiting such families.

“Yes, I used to go before but now I don’t visit them anymore because they are not willing to listen, they refuse to talk, and there is no hope in talking to them.”

-ASHA (KII.ASHA.R03)

One of the key informants reported that he has encountered ASHAs and AWWs who themselves did not believe in vaccination. He shared his experience during an informal discussion on how an ASHA did not immunize her own child. Apparently during monitoring it was found that she had marked her house indicating her child has been immunized for polio. But her child had no mark on the finger and therefore was found to be unimmunized for polio vaccine.

There appears to be some health workers who have a lack of interest and aptitude for the work. In the future, attention may be paid to recruiting personnel with the necessary interest and aptitude needed for health service. Assessment based on career guidance principles rather than just a focus on educational qualification can be looked into while recruiting. To cite a culturally relevant equivalent, a study among Khasi healers revealed that those deemed to be worthy of being a healer is perceived to have *ka sap* a gift or potential for the work (16). It has resonance

with modern career guidance principles, where clients are assessed on the basis of their interest, aptitude and/or potential for a particular career.

3.9. Inadequate IEC - incomplete delivery of four key messages

Some parents mentioned that no health workers visited their homes to speak about immunization. In some circumstances parents reported that health workers address people in the community hall of the village. There was no dedicated process for mobilizing vaccine hesitant families.

Almost all key informants said that the community lacked information on the benefits of immunization. Also fear of side-effects of immunization was reported as one of the reason for refusal of vaccines. The diligent delivery of four key messages by ANMs at the time of immunization is crucial to alleviate some of these gaps. However, key informants reported that “most” ANMs miss delivering four key messages at the time of immunization.

“The common side-effects encountered are pain, fever, redness, swelling, which are quite acceptable and the community needs to be explained about them. The problem is that most of the ANMs do not give the four key messages while immunizing the children to the community, especially to the mother of the child who has brought her child for the first time.”

-Medical Officer (KII.R01)

The team also made direct observations of practices and used role-play by asking frontline health worker to demonstrate/replay their interaction with mothers. During these interactions the messages were at most partially and cursorily conveyed.

During observations of ANM in a session of Intensified Mission Indradhanush, the steps she followed can be summarized as: she calls the name of the child, starts preparing the injection, asks the mother to hold the child and injects the child. After injecting the child the ANM asked the mother to come again when the child would be 1 year 4 months old. Noteworthy by its absence was an introduction, an explanation of purpose and what to expect nor a proper polite conclusion to indicate the end of an interaction.

Thus, from observations and interactive sessions with health workers it was evident that during immunization, a majority of the ANMs do not mention anything about the vaccines they are administering, their side-effects nor the benefits of immunization. They largely attributed gaps in ‘messaging’ to paucity of time.

4. Other findings related to health

The common diseases of children in the villages were cough, cold, fever and diarrhoea. Cough, cold and fever were said to occur during winters and diarrhoea during summers. The measures taken by the parents to prevent diseases were drinking boiled water and maintaining cleanliness. The community was unaware of any other preventive measure.

Toilet facilities were said to be present in majority of the families. Use of toilet was mentioned mostly for adults in the family. In some households, pits were made for children to throw their waste. The community was aware about hand-washing and its importance but the practice was not followed by everyone, every time after using the toilet.

In terms of health seeking behaviour, self-medication, by purchasing medicines from the pharmacy at the start of the illness, was a common practice. For injury, they prefer traditional massage and in case there is no improvement then they visit the health centre. Preference for traditional methods was reported for pregnant women as they go for traditional massage or prefer local dais for delivery.

E. Challenges faced by team and measures used to overcome them

One of the challenges faced by the research team was scheduling of FGDs with parents because of the harvesting season as they were busy working in the field. Therefore the FGDs were conducted at a time which was comfortable to the parents and that led to conducting FGDs in late evenings at around 8pm and at times early mornings at around 7am.

Another challenge faced while conducting FGDs was the low turn-out of the fathers for the FGDs. Therefore we planned and conducted a few in-depth interviews with fathers by visiting households of families with reported vaccine hesitancy.

Also during the course of the study we planned and conducted a few interviews with mothers as some of them hesitated to speak up during FGD.

A field visit to Jaroit was planned for conducting FGD. However the ASHA was not cooperative and was not willing to help. She said that she was busy. She also said that “*many have come from NEIGRIHMS³ and the people might get tired to speak on the same thing*”. She also insisted the team to talk to the headman. The team did speak to the headman and the headman asked the team to work with the ASHA as it was the ASHA’s work. To avoid delay in field work the team decided to take an alternate village.

³ North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences

F. Recommendations

This exploratory study has identified primarily demand side factors that contribute to vaccine refusal and low levels of immunization. The major recommendations can be summarized as follows:

a) Focussed efforts to ensure diligent delivery of the four key immunization messages by health workers. Health workers may have been trained to do so before but clearly there is no follow through in the field.

b) To ensure that communication is appropriate re-training the current personnel to ensure that key messages are conveyed with sensitivity and in a fitting manner is required. Health personnel need to accept that clients have a right to ask questions and must be encouraged to do so. Simple tips like politely encouraging a new mother to paraphrase the four key messages can be employed to ensure that she has heard and internalised the messages.

c) Attention may be paid to recruiting personnel with the necessary interest and the aptitude needed for health service based on career guidance principles rather than just a focus on educational qualifications alone. Appropriate training and reinforcing of training through refresher courses is crucial.

d) Rigorous monitoring of immunization session sites and regular supportive supervision of personnel can ensure activities are carried out optimally. Supervision and monitoring would be best if done in the spirit of improving quality of service rather than as a punitive measure.

e) Regular refresher trainings of health workers with emphasis on ‘soft skills’. The message that our people have a right to expect high quality service from the public sector is worth emphasising in every training interaction. They may also be trained to deal with questions and how to encourage the same from parents, so that miscommunication is avoided.

f) Community engagement through meetings/ health talks at a convenient time and place in consultation with the community could be helpful. More effective use of VHND sessions is a good place to start. Discussions can be held with influential people of the community to improve understanding about immunization programmes and the benefits of immunization.

g) It is important to develop a quick response mechanism to ‘contain’ or prevent a negative fallout from rumours, media reports (that may be based on partial and poor information) and from unexpected effects or rare side-effects encountered by members of the community.

h) Finally considering the situation of high refusal of vaccination in the State it is perhaps important to think of alternate context relevant strategies to address the situation. Keeping in mind that observations such as this was not uncommon *“There is no need to remind us when we have the will. But we don’t have the will to go and nobody can force anyone who does not have*

the will to take immunization. I understand everything but I don't know why I am like this when it comes to immunization. But if I have the will from within myself we do not need anyone to remind or call us to take immunization.” (mother, Sohryngkham village)

We provide an example of an innovative community engagement intervention that is currently being employed in a neighbouring state. This approach referred to as the SALT (Simulate, Appreciate, Learn and Transfer) approach is directed towards increasing community's understanding and 'ownership' of children's health, specifically immunization.

The SALT (Stimulate, Appreciate, Learn and Transfer) is currently being evaluated in Assam for improving immunization coverage. Early assessment by the evaluation team at IIPH Shillong, suggests promising results. One positive outcome documented as a result of the SALT approach is that demand for immunization services is now shifting from being primarily provider driven to widening 'ownership' by communities as the role of vaccines are increasingly understood, desired and appreciated by communities.

Limitations: We acknowledge that this small study sample is not likely to be a representative of the entire State of Meghalaya and that contextual factors may vary in other districts. For more representative understanding such studies may be undertaken in other districts based on the heterogeneity of the place and its people. But for a start the observations made here could well be common for other districts. Thus attending to the recommendation based on this report could be beneficial for the immunization programme as a whole.

G. References

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H. Annexures

Annexure 1: Letter of support provided by the DM& HO, East Khasi Hills

GOVERNMENT OF MEGHALAYA
OFFICE OF THE DISTRICT MEDICAL & HEALTH OFFICER,
EAST KHASI HILLS, SHILLONG

No. B-1/DFWB/IEC/2017 Dated Shillong the 2017

To,

The Sr. Medical & Health Officer/ Medical & Health Officer, I/c
1. Mawryngkneng Block PMU
2. Mawryngkneng PHC.
3. Smit PHC.
4. Diengpasoh PHC.

Subject: Letter of Support for the pilot study on "Exploring Reasons behind Refusal of Vaccines in Meghalaya".

Ref: NO.DHS/MCH&FW/UIP/ST/61/2017/7424 dated Shillong, the 26th Oct 2017.

Sir/ Madam,

With reference to the above, I have the honour to inform you that that the Indian Institute of Public Health Foundation of India (IIPH Shillong/ PHFI) in collaboration with the Directorate of Health Services (MCH&FW), Government of Meghalaya is undertaking a pilot study to explore the reasons behind refusal of vaccines in Meghalaya. The study will be carried out in the Mawryngkneng Block of the East Khasi Hills District from November – December 2017. The research team during the course of the study will be involved in discussion with the community members and will also engage with the Health officials at block level and facility level.

In this regard, you are requested to take necessary action and to provide necessary support to the team members from IIPH Shillong/ PHFI to ensure the smooth progress of the study.

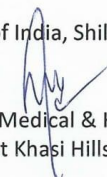
Please treat this as Top Priority.

Yours faithfully,

(Dr.(Miss). E. Dkhar)
District Medical & Health Officer,
East Khasi Hills, Shillong th
Dated Shillong the 13th - Nov 2017

Memo No. B-1/DFWB/IEC/2017 *5041-44*
Copy for information:

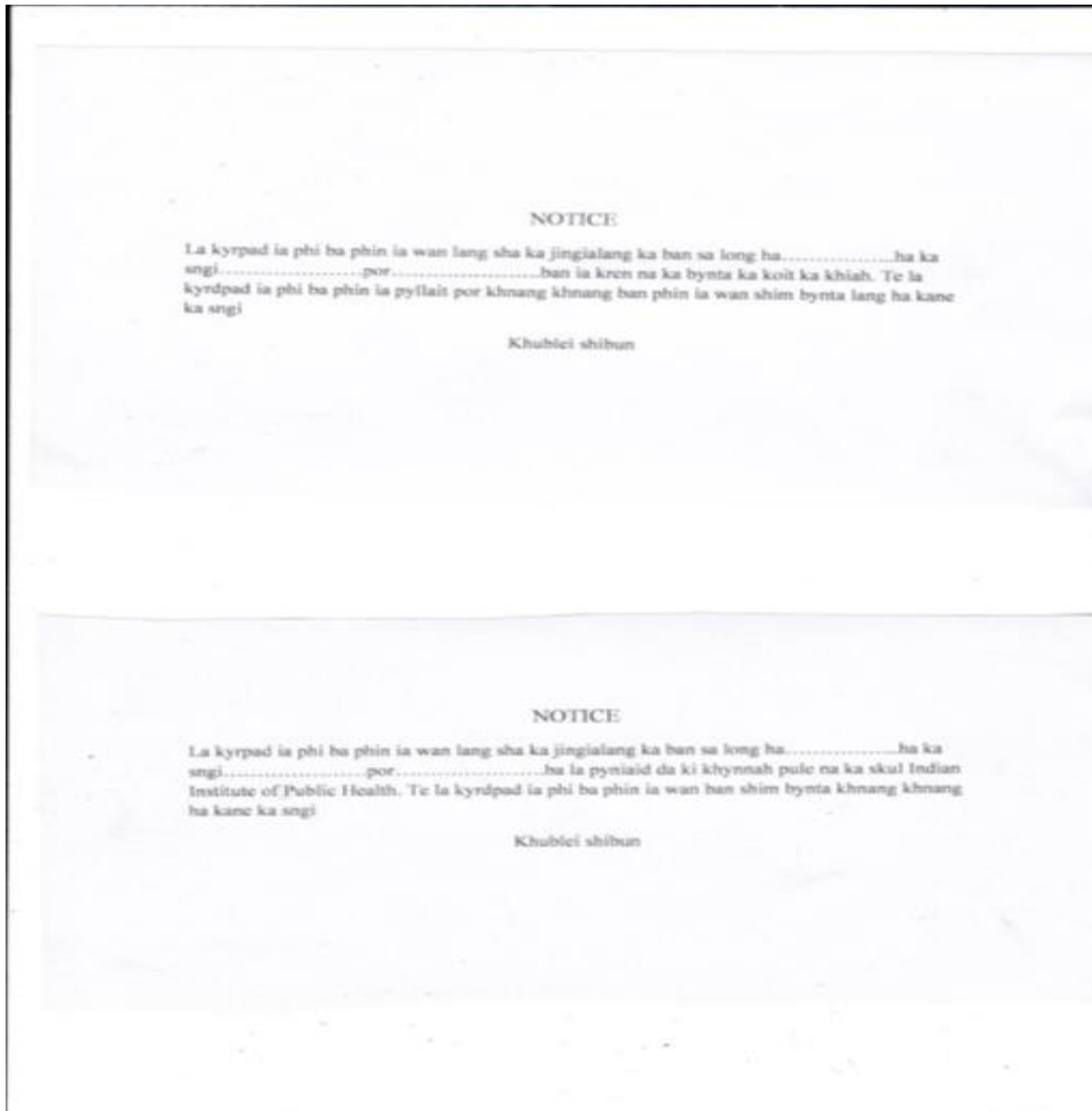
1. The Director of Health Services (MCH&FW) Cum Jt. Mission Director, NHM, Meghalaya, Shillong.
2. The Deputy Commissioner Cum Chairman, District Health Society, NHM, East Khasi Hills, Shillong.
3. The District MCH Officer, East Khasi Hills, Shillong.
4. Ms. Jahnabi Hazarika, Indian Institute of Public Health Foundation of India, Shillong.


District Medical & Health Officer,
East Khasi Hills, Shillong

Annexure 2: Details of the KIIs conducted

Sl. No.	Date	Place of work	Informant
1	19/09/2017	WHO office, Shillong	SMO- WHO
2	08/11/2017	Mawryngkneng PHC	MO
3	09/11/2017	Umphyrnai Subcentre	ANM1
4	09/11/2017	Umphyrnai Subcentre	ANM2
5	15/11/2017	Diengpasoh PHC	MO
6	15/11/2017	Diengpasoh PHC	ANM
7	15/11/2017	Diengpasoh B	ASHA
8	20/11/2017	Mawiong	ASHA
9	21/11/2017	Sohryngkham Sub centre	ANM
10	21/11/2017	Sohryngkham Sub centre	ASHA
11	29/11/2017	Mawphlang PHC	MO
12	29/11/2017	Ladmawreng Sub centre	ANM
13	08/12/2017	Kharsahnoh Sohtun	ASHA
14	08/12/2017	Lumsohriew	ASHA
15	08/12/2017	Mawngap Sub centre	ANM
16	14/12/21017	Umtyrnuit	ASHA

Annexure 3: The invitation notice distributed to potential participants



Annexure 4: Details of group discussions conducted

Sl. No.	Date	Village name	FGD conducted with	No. of Participants
1	16/11/2017	Lamlyer	Mothers	8
2	20/11/2017	Diengpasoh B	Mothers	8
3	20/11/2017	Diengpasoh B	Fathers	4
4	27/11/2017	Sohryngkham	Mothers	3
5	27/11/2017	Sohryngkham	Fathers	3
6	05/12/2017	Mawiong	Mothers	4

Annexure 5: Details of the interviews conducted

Sl no.	Date	Village	Interview with
1	08-12-2017	Kharsahnoh Sohtun	Mother
2	08-12-2017	Kharsahnoh Sohtun	Mother
3	08-12-2017	Kharsahnoh Sohtun	Mother
4	08-12-2017	Lumsohriew	Mother
5	08-12-2017	Lumsohriew	Mother
6	08-12-2017	Lumsohriew	Mother
7	14-12-2017	Umtyrnuit	Mother
8	14-12-2017	Umtyrnuit	Mother
9	14-12-2017	Umtyrnuit	Father
10	14-12-2017	Umtyrnuit	Mother
11	14-12-2017	Umtyrnuit	Mother
12	14-12-2017	Umtyrnuit	Mother
13	19-12-2017	Lamlyer	Father
14	19-12-2017	Lamlyer	Father
15	19-12-2017	Lamlyer	Father
16	19-12-2017	Lamlyer	Father
17	19-12-2017	Lamlyer	Father
18	28-12-2017	Mawiong	Father
19	28-12-2017	Mawiong	Father
20	28-12-2017	Mawiong	Father
21	28-12-2017	Mawiong	Father
22	28-12-2017	Mawiong	Father
23	28-12-2017	Mawiong	Mother

Annexure 6: Socio-Demographic details of Mothers

Sl. No.	Village	Age of respondent (years)	Education	Occupation	No. of children	Age of respondent at marriage	Age of the youngest child	Duration of stay in the village
1	Lamlyer	28	Primary Education	Housewife	3	18	9 years	Since Birth
2	Lamlyer	25	Primary Education	Housewife	6	23	24 mon	Since Birth
3	Lamlyer	29	Primary Education	Housewife	5	20	12 mon	Since Birth
4	Lamlyer	25	Primary Education	Housewife	4	19	12 mon	Since Birth
5	Lamlyer	28	Senior Secondary	Housewife	1	22	10 months	Since Birth
6	Lamlyer	23	Secondary Education	Housewife	1	19	12 months	Since Birth
7	Lamlyer	35	Primary Education	Housewife	3	20	24 months	Since Birth
8	Lamlyer	42	No formal education	Housewife	6	18	24 months	Since Birth
9	Diengpasoh B	31	Secondary Education	Helper at Anganwadi	4	20	11 months	Since Birth
10	Diengpasoh B	33	Primary Education	Farmer	3	21	8 years	Since Birth
11	Diengpasoh B	43	Primary Education	Farmer	1	20	17 years	Since Birth
12	Diengpasoh B	51	Primary Education	Farmer	7	19	12 years	Since Birth
13	Diengpasoh B	39	No formal education	Farmer	1	35	36 months	Since Birth
14	Diengpasoh B	32	Primary Education	Farmer	3	19	10 years	Since Birth
15	Diengpasoh B	46	Upper Primary	Farmer	7	20	9 years	Since Birth
16	Diengpasoh B	34	Secondary Education	Teacher	4	24	7 months	Since Birth
17	Diengpasoh B	34	Primary Education	Farmer	6	18	12 months	Since Birth
18	Sohryngkham	29	Secondary Education	Housewife	4	21	24 months	Since Birth
19	Sohryngkham	34	Primary Education	Housewife	1	21	4 years	Since Birth

20	Sohryngkham	32	Upper Primary	Housewife	7	19	6 months	Since Birth
21	Mawiong	44	No formal education	Farmer	NA	18	NA	Since Birth
22	Mawiong	33	Primary Education	Farmer	3	22	1 month	Since Birth
23	Mawiong	36	No formal education	Farmer	6	19	1 month	Since Birth
24	Mawiong	37	No formal education	Farmer	8	19	4 months	Since Birth
25	Kharsaohnoh Sohtun	31	Upper Primary	Housewife	2	20	24 months	Since Birth
26	Kharsaohnoh Sohtun	30	Upper Primary	Housewife	5	22	5 months	Since Birth
27	Kharsaohnoh Sohtun	35	Primary Education	Housewife	3	18	24 months	Since Birth
28	Lumsohriew	34	Under Graduate	Housewife	5	26	1 week	Since Birth
29	Lumsohriew	26	Primary Education	Housewife	4	18	11 months	Since Birth
30	Lumsohriew	24	Primary Education	Housewife	1	22	8 months	Since Birth
31	Umtyrnuit	25	Primary Education	Housewife	4	19	24 months	Since Birth
32	Umtyrnuit	40	Primary Education	Manual labour	3	20	24 months	Since Birth
33	Umtyrnuit	28	Upper Primary	Housewife	3	18	36 months	Since Birth
34	Umtyrnuit	21	Primary Education	Housewife	3	18	24 months	18 years
35	Umtyrnuit	28	Upper Primary	Housewife	4	18	9 months	Since Birth
36	Umtyrnuit	23	Primary Education	Housewife	3	18	24 months	12 years

Annexure 7: Socio-Demographic details of fathers

Sl. No.	Village	Age of respondent in years	Education	Occupation	Religion	No. of children	Age of the respondent at marriage	Age of the youngest child	Duration of stay in the village
1	Diengpasoh B	30	No formal education	Farmer	Christian	4	19	24 months	30 years
2	Diengpasoh B	57	Primary Education	Farmer	Christian	8	31	4 years	57 years
3	Diengpasoh B	59	No formal education	Farmer	Christian	8	33	14 years	33 years
4	Diengpasoh B	37	No formal education	Farmer	Christian	5	23	4 years	37 years
5	Sohryngkham	35	Primary Education	Mason	Christian	4	0	24 months	16 years
6	Sohryngkham	31	Primary Education	Mason	Christian	3	24	9 months	31 years
7	Lamlyer	40	Primary Education	Farmer	Christian	6	28	12 months	Since Birth
8	Lamlyer	20	Secondary Education	Manual labour	Christian	1	19	12 months	Since Birth
9	Lamlyer	40	Primary Education	Manual labour	Christian	6	22	12 months	18 years
10	Lamlyer	36	Primary Education	Farmer	Christian	3	22	24 months	Since Birth
11	Lamlyer	35	Primary Education	Manual labour	Christian	4	22	24 months	8 years
12	Mawiong	36	No formal education	Farmer	Christian	2	0	6 months	4 years
13	Mawiong	38	Primary Education	Farmer	Christian	3	0	12 months	9 years
14	Mawiong	40	No formal education	Farmer	Christian	6	24	12 months	17 years

								s	
15	Mawiong	27	Secondary Education	Manual labour	Christian	3	22	6 months	5 years
16	Mawiong	29	No formal education	Farmer	Christian	3	22	5 months	Since Birth
17	Mawiong	40	No formal education	Farmer	Christian	6	0	1.5 months	Since Birth

Annexure 8. Topic Guide for Focus Group Discussions

Instructions:

- Informed consent must be sought from each member individually prior to the start of the FGD. Moderator should reiterate at the start of the FGD that those who do not wish to participate may leave.

Instruction for note taker:

- Note the following:
 - Total number of FGD participants
 - Location of FGD
 - Timing of FGD (start and end time)
 - Disruptions during FGD, including if any member left in the middle

FGD Guide

Warm up

1. Tell me about a typical day for a young mother/ Tell us what you like about your village?

2. Can you describe about the drinking water available to you in this village?

Probe

- a. What is your main source of drinking water?
- b. How do you treat water to make it safe to drink?

3. Can you describe about availability and use of toilet facility?

Probe

- a. What type of toilet facilities is present in your households?
- b. Use of toilet facility if present- who uses and how frequently?
- c. If toilet facility is absent where do you go for defecation?
- d. How do you dispose off children's stool who do not use toilet?

4. Can you describe about your hand washing practices?

- a. When do they wash hands and what do they use for washing hands?

5. Can you describe how do you ensure cleanliness in your village?

6. Can you describe a healthy child?

- a. What makes this child healthy? probe)

7. What are the types of illnesses that children in this community generally suffer from?

8. What do parents or the family of the child do to prevent illness in their children?

[Using each paper, ask for preventative measures taken for each disease/illness. Note that these preventative measures can include the use of traditional remedies, religious acts as well as health promotion activities like hand washing, boiling water, immunization. Moderator should be open to eliciting all preventive measures as shared by the group]

9. What are the health services available for children in this community?

- a. Who delivers these health services [probe for government and private providers]
- b. How does ASHAs, ANMs, AWWs help you in accessing the health services?
- c. Which of the health problems listed earlier are treated by these health services?
- d. What are the challenges faced in using these services? Probe for:
 - i. Distance, availability of transport to access services
 - ii. Timing of service provision
 - iii. Wage loss, interruption in housework due to inconvenient timings

iv. Others

10. You may have seen children getting immunized here in this village. Can you give me your opinion on childhood immunization?
- a. Why do you think children are immunized?
 - b. What are the benefits of immunization?
 - c. What are the disadvantages of immunization?
 - What outcomes of immunization are you concerned about?
 - d. Who in the family decides about immunizing/ not immunizing the child?
 - e. Where are children immunized in this village (e.g., anganwadi, sub-centre)/ Who provides immunization services in your village?
 - f. How do you get to know of immunization sessions in your village?
 - g. Have you faced any challenges for immunizing your children? If yes, what kind of challenges have you faced?
 - h. Would you want to immunize your children? If yes, why?
If no, why?
 - Side –effects/fear of side effects
 - Repeat visits to the anganwadi/health-centre
 - Experience at anganwadi/health-centre
 - Other reasons
11. In case of a mother/father who immunises-
- a. Have you tried to motivate others to immunize who do not immunize their children, and how?

Annexure 9. Topic guide for Key Informant Interviews

Date of visit:

Name of the district:

Name of the respondent:

Designation:

Start time:

Warm up:

Sir/Madam, would you tell about your experience working in the field of health? (Probe: How long you worked and what has been your experience?)

1. What are the current immunization services available?
2. How has the commitment of the Government changed over the years and how has that impacted different supply side factors such as introduction of new vaccines, cold chain management (availability of ILRs and DFs, maintaining the temperature of the vaccines), vaccine logistics (supply and distribution of vaccines to PHCs, delivery of vaccines to session sites, reducing vaccine wastages, open vial policy), availability of health workers[**FOR ANM AND MO ONLY**]
3. What do you think of about the role of supplementary immunization activities such Mission Indradhanush in improving immunization coverage? Can it improve the health system and lead to sustainable change?
4. How has the community perception regarding immunization changed over the years?
5. What according to you are the gaps for optimal full immunization coverage (say, more than 90% FIC) in Meghalaya?
 - cold chain management (availability of ILRs and DFs, maintaining the temperature of the vaccines)
 - vaccine logistics (supply and distribution of vaccines to PHCs, delivery of vaccines to session sites, reducing vaccine wastages, open vial policy)
 - availability, commitment of health workersProbe: Which are the areas/sub-districts with low immunization in this district and why?
: What according to you can be done to overcome the gaps?
6. What is the role of the community in improving the immunization coverage?
 - Current community engagement initiativesProbe: Resistance by the communities (any other type of vaccine hesitancy)
What according to you can be done to overcome resistance?
7. As stakeholders in implementation of immunization services what challenges do you face?
8. What are the reasons that some parents miss immunizing their children?
 - Side –effects/fear of side effects
 - Beliefs
 - Lack of awareness of importance of that vaccination
 - Repeat visits to the anganwadi/sub-centre
 - Experience at anganwadi/sub-centre
 - Child is sick on the session day
 - Other reasons
9. What do you think could be the reasons for children not completing the series of vaccinations that require multiple doses– like polio and DPT/Penta?

- Side –effects/fear of side effects
- Beliefs
- Lack of awareness of importance of that vaccination
- Repeat visits to the anganwadi/sub-centre
- Experience at anganwadi/sub-centre
- Child is sick on the session day
- Other reasons

10. How often are cases of adverse event following immunization (AEFI) reported here?
11. What is done when an AEFI case is reported?
12. **To ANM and ASHA-** How do you manage your workload? Do you get enough time to perform immunization related activities?
13. Is there anything you would like to share with us?

End Time:

Annexure 10. National Immunization Schedule

Vaccine	When to give	Dose	Route	Site
For pregnant women				
TT-1	Early in pregnancy	0.5 ml	Intra-muscular	Upper arm
TT-2*	Four weeks after TT-1*	0.5 ml	Intra-muscular	Upper arm
TT-Booster*	If received TT-2 doses in a pregnancy within the last 3 years	0.5 ml	Intra-muscular	Upper arm
For infants Birth till 12 months				
BCG	At birth or before one year of change	0.05 ml till one month of age 0.1 ml above the age of one month	Intra-dermal	Left upper arm
Hepatitis B Birth dose	At birth or within 24 hours of birth	0.5 ml	Intra-muscular	Antero-lateral side of mid-thigh
OPV Zero dose	At birth or within the first 15 days of birth	2 drops	Oral	Oral
OPV 1, 2 & 3	At 6 weeks, 10 weeks and 14 weeks	2 drops	Oral	Oral
Rota Virus Vaccine (RVV) [#]		5 drops	Oral	Oral
Pentavalent 1, 2 & 3**		0.5 ml	Intra-muscular	Antero-lateral aspect of left mid-thigh
IPV***	At 14 weeks, along with other vaccines	0.5 ml	Intra-muscular	Antero-lateral aspect of right mid-thigh
IPV Fractional dose 1 and 2***	At 6 weeks and 14 weeks along with other vaccines	0.1 ml	Intra-dermal	Right upper arm
Measles-1	9 completed months- 12 months	0.5 ml	Sub- cutaneous	Right upper arm
Japanese Encephalitis- 1		0.5 ml	Sub- cutaneous	Left upper arm
Vitamin A- 1		1 ml [1 lakh (IU)]	Oral	Oral
For children and adolescents 16 months till 16 years				
DPT 1 st booster		0.5 ml	Intra- muscular	Antero-lateral aspect of mid-

				thigh
OPV booster	16-24 months	2 drops	Oral	Oral
Measles-2		0.5 ml	Sub- cutaneous	Right upper arm
Japanese Encephalitis-2****		0.5 ml	Sub- cutaneous	Left upper arm
DPT 2 nd booster	5-6 years	0.5 ml	Intra- muscular	Left upper arm
TT	10 years (one dose) and 16 years (one dose)	0.5 ml	Intra- muscular	Upper arm
Vitamin A ***** (2 nd to 9 th dose)	Along with DPT/ OPV booster and other vaccines Afterwards, one dose in every 6 months up to age of 5 years	2 ml [2 lakh (IU)]	Oral	Oral

* Give TT-2 or Booster doses before 36 weeks of pregnancy. However, give these even if more than 36 weeks have passed. Give TT to a woman in labour, if she has not previously received TT.

** Pentavalent vaccines contain a combination of DPT, Hepatitis B and HiB. Hepatitis B birth dose and booster doses of DPT will continue as earlier

*** Dosage of IPV vaccine are as per guidelines provided by the state

**** JE vaccine is given in selected and endemic districts

***** The 2nd to 9th doses of Vitamin A can be administered to children 1-5 years old during biannual rounds, in collaboration with ICDS

In selected states only



Report
Reasons behind Refusal of Vaccines in Meghalaya
- An exploratory study in East Khasi Hills District, Meghalaya
