

# **Report on Contributing Factors to the Uptake of Pediatric Cataract Surgery-A Hospital based Study in Rural Setup**

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## **Research Team**

Dr. Shamim Hayder Talukder, CEO & Founder, Eminence  
Mehedi Hasan Fuad, Associate Coordinator, Eminence  
Tania Tasnin, Senior Assistant Coordinator, Eminence

# Acronyms

<b>DECF</b>	<b>Deep Eye Care Foundation</b>
<b>FGD</b>	Focus Group Discussion
<b>KII</b>	Key Informant Interview
<b>II</b>	In-depth Interview
<b>MPhil</b>	Master in Philosophy
<b>MPH</b>	Master in Public Health
<b>MSS</b>	Master in Social Science
<b>CS</b>	Civil Surgeon
<b>FI</b>	Field Investigator
<b>FOS</b>	Friends Of Sight
<b>BRAC</b>	Bangladesh Rural Advancement Committee
<b>SSTP</b>	School Sight Training Program
<b>CEO</b>	Chief Executive Officer

# Contents

Acknowledgement.....	2
Abbreviation.....	2
Executive Summary .....	5
Chapter One-Background of the Study .....	7
1.1 Introduction.....	7
1.2 Rationale of the Study .....	7
1.3 Objective of the Study .....	8
Chapter Two-Study Methodology.....	9
2.1 Design and Approaches.....	9
2.2 Geographical Coverage .....	9
2.3 Data Collection Tools and Techniques.....	9
2.4 Study Population .....	10
2.5 Sample Size and Sampling.....	10
2.6 Study Team and Field Data Collection.....	11
2.7 Supervision, Quality Control and Data Management.....	11
2.8 Ethical Consideration.....	12
2.9 Data Analysis .....	12
2.10 Limitation of the Study.....	12
Chapter Three-Findings of the Study .....	13
3.1 Case Finding Factors.....	13
3.2 Uptake Factors of Taking Pediatric Cataract Surgery .....	14
3.3 Non Uptake Factors of Pediatric Cataract Surgery .....	16
3.4 Community Perception Regarding Service Quality of Deep Eye Care Foundation .....	19
3.5 Community Perception Regarding Service Cost and Outcome .....	19
3.6 Scope of New Cataract Identification .....	19
Chapter Four- Discussion.....	22
Chapter Five- Recommendation .....	24
Reference .....	26
Annex-1- Participants List of the Study .....	27
Annex-2-Guidelines of the Study .....	31
Annex-3-Consent Paper .....	36



# Executive Summary

**Introduction:** Blindness and cataract in children remain a major challenge in resource-poor countries like Bangladesh. Approximately 40,000 children in Bangladesh are blind and 12,000 cases due to cataract. Various studies across the globe show that one-third to half of childhood blindness is either preventable or treatable and that cataract is the leading treatable cause of blindness in children. Significant work is needed to tackle this problem in terms of research and program development.

Under these circumstances, with the support from Orbis International Bangladesh, Deep Eye Care Foundation (DECF) has been implementing the project **“Developing the capacity of Deep Eye Care Foundation to deliver quality pediatric eye care service in the northern region”** since April 2012 and the project will be finished in March 2017. A separate study was conducted to know the relevant contributing factors to uptake and non-uptake of children’s cataract surgeries performed by Deep Eye Care Foundation in those areas.

**Objectives of the Study:** The objectives of the study were to identify the socio-economic, cultural, educational and health seeking behavioral factors, community perception regarding the service quality, cost and outcome and determination of gaps and scopes to extend the service coverage for the children in northern area of Bangladesh. The study also proposed some recommendation to lift up the current project of DECF to reduce childhood blindness through pediatric cataract surgery.

**Study Methodology:** The whole study was conducted by qualitative research methodologies which includes Focus Group Discussion (FGD), Key Informant’ Interview, In-depth Interview and Case Study. For the data analysis, different qualitative data analysis techniques such as domain analysis, matrix analysis methods had been used. The subjects were administered with a guideline regarding the uptake and non uptake factors, community perception regarding the surgery, hospital’s service quality, cost and outcome, identifying the gaps and scopes for cataract identification of Deep Eye Care Foundation. The study was conducted with both groups of beneficiaries and non beneficiaries. 6 FGDs with beneficiary groups, 1 FGD with non beneficiary group, 3 case studies of beneficiaries and 11 case studies of non beneficiary people have been done in the study. In addition, 1 Consultation Meeting, 5 Key Informant Interview and 8 In-depth Interview and were done with the different stakeholders of this study.

**Study Area:** The study was conducted in three districts of northern Bangladesh: Rangpur, Gaibandha and Lalmonirhat. Among them, 4 Upazilas in Rangpur, 2 Upazilas in Gaibandha and 3 Upazilas in Lalmonorhat were covered through the study.

**Study Population:** The study was conducted with the beneficiaries, non beneficiaries and different stakeholders of the DECF’s project. In this study, Beneficiaries are those who received the surgery and Non Beneficiaries are those who did not/refused to uptake the surgery.

**Sample Size and Sampling:** The sample size was determined purposively for Focus Group Discussion, Key Informant Interview, In-depth Interview and Case Study. The data collection followed the convenient sampling technique to identify the subjects.



**Data Collection & Quality Control:** A core team consisting three team members from Eminence initially visited Deep Eye Care Foundation for a bilateral consultation meeting. After the consultation meeting, four field investigators worked for 14 days to collect the field data.

To maintain the quality of the data, the Principle investigator himself supervised the whole data collection process. Besides, he visited several fields to get a first-hand experience and to monitor the data collection procedure. To ensure the quality and validity of the data, the project coordinator talked with all the participants over phone at different stages of the study. After the translation and transcription, the data were rechecked to avoid any kind of misinterpretation.

**Result:** The study illustrated that, regular outreach camp service, school teacher's training, full or partial subsidization for the treatment of eye surgery; peer motivation and partnership with NGOs are the main factors of uptaking the pediatric cataract surgery. Moreover, there were also some contributing factors that refrain the non beneficiary groups from uptaking the surgery: misconception and social stigma of community people, lack of awareness, high direct and indirect costs of the surgery, fear of surgery and lack of skilled man power for providing medical surgery services at the center and gap of communication skill at community level social mobilization. More or less, the beneficiary groups were happy with the services of Deep Eye Care Foundation. According to the beneficiary groups, their children are now seeing properly and the treatment costs were affordable though the community people have some confusion regarding the cost of the surgery. Some people assume that, all the surgeries are free of cost though DECF only provide full free services to the ultra poor patients. Besides, Deep Eye Care Foundation doesn't have any specific method to categorize the ultra poor patients for the full free treatment. To find the new cases and ultra poor, they mainly depend on the volunteers of Friends of Sight and the health assistants of BRAC. Due to the inadequate number of field team members, Deep Eye Care Foundation is still facing problems in other coverage areas, except Rangpur to organize mass campaign and awareness.

**Recommendation:** The study is recommending to update the BCC materials of DECF to raise awareness among the mass people. This study also recommends for the expansion of service coverage area to identify new cases and more subsidization for poor patients by cross financing and increasing the price of the surgery for wealthier patients. Subsidization in indirect costs including transport, food and accommodation cost may also increase the uptaking rate. According to this study, self empowerment approach, group activities, strengthening referral linkage with other health facilities including government and non government facilities and more funding in this sector may boost up the uptaking rate of pediatric cataract surgery in Deep Eye Care Foundation.

**Conclusion:** Awareness, attitudes and financial ability of doing the pediatric cataract surgery are the major factors of uptaking and non uptaking factors of prevailing pediatric cataract surgery in the northern region of Bangladesh. Though Deep Eye Care Foundation is working hard for reducing the childhood blindness in the northern zone of Bangladesh, they can improve their quality of the services by recruiting skilled team members in the field, expansion of eye health screening camp, collaboration with other governmental and nongovernmental facilities and by raising awareness among the mass people.



# Chapter One

## Background of the Study

### 1.1 Introduction

Avoidable blindness is one of the major health problems in Bangladesh. According to The Bangladesh National Blindness and Low Vision Survey in 2000, about 7.5lac population aged 30 years and above are blind. It has been assumed that by 2020 the number of blind population will be doubled if no one takes any action immediately. Therefore, interestingly almost 80% of these blind people are the victim of cataract, which is avoidable. Prevalence of childhood blindness is 0.75/1,000 live births in this country. Available demographic data shows that there are about 67 million children living in Bangladesh. Approximately 1.5 million children have refractive errors and 51,200 are blind, of which about 20,480 are avoidable causes. Additionally, around 153,600 children have low vision problem, of which about 78,336 cases are avoidable. These children are deprived of basic eye care services, and hence are likely to negatively impact on the national economy of Bangladesh.

Some major constraints to delivery of eye care are the lack of accessible and affordable services to the majority rural population, and an inadequate number of skilled professionals. The service facilities equipped with quality eye care services are located in the district(secondary eye care) and division (tertiary or equivalent) level facilities. Under these circumstances, with the support from Orbis Bangladesh, Deep Eye Care Foundation (DECF) has been implementing the project **“Developing the capacity of Deep Eye Care Foundation to deliver quality pediatric eye care service in the northern region”** since April 2012 and the project will be finished in March 2017. This project has been addressing the problems of inadequate access to quality eye care services and uncorrected refractive error among the children of five northern districts (Rangpur, Kurigram, Gaibandha, Lalmonirhat and Joypurhat).

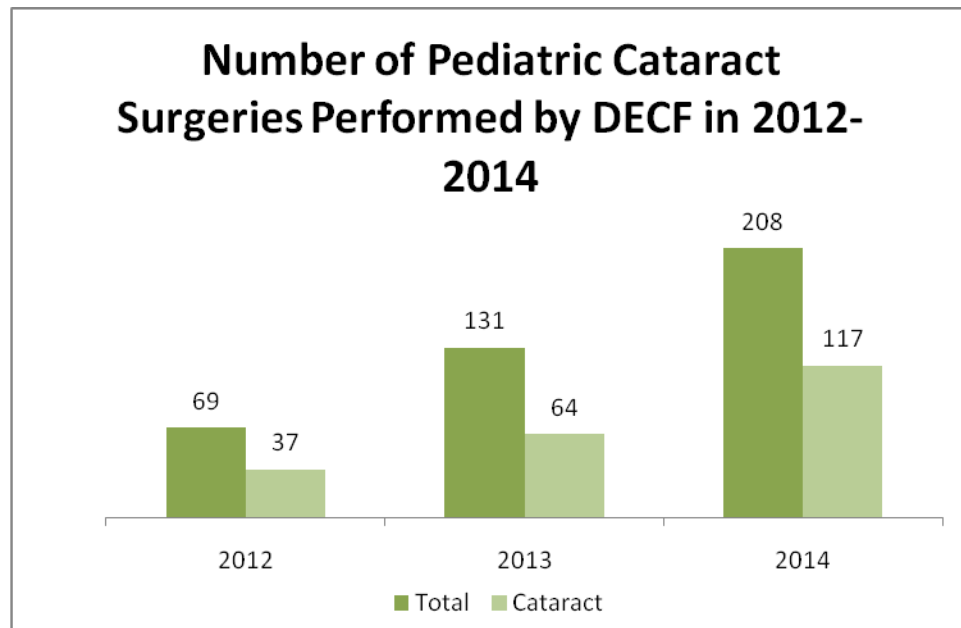
Orbis International Bangladesh initiated a study to know the relevant contributing factors to uptake and non-uptake of children’s cataract surgeries performed by Deep Eye Care Foundation by external expert and Eminence with its prior experience in qualitative research expressed its interest to conduct the study.

### 1.2 Rationale of the Study

“Childhood Blindness”, a number of diseases and conditions that occur in childhood and early adolescence, most of them, even more serious disorders, can be prevented or avoided. But when they remain untreated can result in lifetime blindness. Northern regions of Bangladesh are the poorest districts. Statistics suggests that, eye sight problem is a major challenge of Bangladesh especially to the poorest families. Children of the poor families generally deprived from regular schooling and as their parents are mostly illiterate, they fail to detect vision problem at the early stages of life. The people living in the “Char” areas are the poorest of the poor. They constantly live under threats of natural disasters. They have little access of education and health facilities. Children of these remote areas are also under major threats of unidentified ‘vision problems’. The study took part in the northern districts where there are district hospitals and other hospitals with eye care unit but mostly

underutilized. To ameliorate the situation, Deep Eye Care Foundation with the funding of Orbis Bangladesh is providing eye treatment to the children of greater Rangpur region.

Since its Inception, the eye care unit of the hospital is relentlessly working for the children with cataract or other vision problem. A brief success of their pediatric optical treatment is given below:



However, it is believed that, as the region is populous with people of poor socio-economic group and there are many hard to reach ‘char’ areas exists, the number of screened patients should get higher. Besides, there are gaps between the number of screened children and surgery performed due to various reasons. Hence, the study was particularly interested to see the situation on pediatric cataract surgery and was willing to evaluate the factors impacting the parent’s decision on up taking or non up taking surgery after their children have screened as cataract.

### 1.3 Objective of the Study

The general objective of the study was to know the contributing factors to uptake and nonuptake of Children’s cataract surgeries performed by Deep Eye Care Foundation (DECF). To attain the general objective some specific objectives were:

1. To understand the uptake and non uptake factors of pediatric cataract surgery,
2. To explore the community perception regarding the pediatric cataract surgery, hospital’s service quality, cost and outcome,
3. To know the gaps and scopes for cataract identification,
4. To identify some recommendations to boost up the ongoing project for uptaking the cataract surgery



# Chapter Two

## Study Methodology

### 2.1 Design and Approaches

The study followed qualitative methodologies to reveal the exact factors for uptake and non uptake of Children's cataract surgeries in Deep Eye Care Foundation (DECF) and to give a significantly more informed picture of community perceptions, gaps and scopes of services and other issues that relates to DECF eye care services to the given areas.

### 2.2 Geographical Coverage

The study was performed in nine Upazilas of three districts of the northern zone in this country. The study coverage area is shown below:



Photo 1: Consultation Meeting with Deep Eye Care Foundation and Research Team

Sl No	Upazilas in Rangpur	Upazilas in Gaibandha	Upazilas in Lalmonirhat
1	Rangpur Sadar	Gaibandha Sadar	LalmonirhatSadar
2	Mithapukur	Shundorganj	Teesta
3	Kaunia		Aditmari
4	Taraganj		

### 2.3 Data Collection Tools and Techniques

To identify the beneficiaries and non beneficiaries, study team sought help from the coordinator and camp organizers of DECF. In this study, beneficiaries were defined as patients who uptake the surgery and non beneficiaries were those who didn't/refused to uptake the surgery. This study undertook following qualitative tools and techniques during the field study:

**Bilateral Consultation Meeting:** A consultation meeting was held among the team members of Eminence including the CEO, Dr.Shamim Hayder Taluder, and concerned persons of Deep Eye Care Foundation including Executive Director and Program Manager. Participants of the meeting finalized the study area and the Executive Director, Program Manager and Field Coordinator of DECF gave detail idea regarding their pediatric treatment including surgery, screening, outreach camp, school sight training program, surgery cost and their monitoring procedures. The guidelines were finalized by incorporating the feedbacks from Orbis international which were then validated during the consultation meeting in DEEP foundation. Qualitative

methods such as Key Informant Interview, In-depth Interview, Focus Group Discussion and Case Study have been used in this study.

**Key Informant Interview (KII):** This method had been used to conduct interviews with the key persons of the project such as the Executive Director, Program Manager, Coordinator, and Camp Organizers of Deep Eye Care Foundation.

**In-depth Interview (II):** This method had been used to interview the local NGO authority such as Friends of Sight and BRAC, District Health Education Officer, Civil Surgeon, and Department Head of pediatric Department in Districts hospitals.

**Focus Group Discussion (FGD):** Focus Group Discussion had been performed to assess the opinion of the beneficiaries, non-beneficiaries of the project. FGDs had been conducted with the parents of the children who did uptake and who did not uptake cataract surgery from DECF. Specially trained moderators moderated the discussions. FGD guidelines were used to know the contributing factors of the study. All the data were recorded by tape recorder for transcription and translation.



Photo 2: Beneficiary Group's Focus Group Discussion

**Case Study (CS):** Case studies had been taken of the beneficiaries and non-beneficiaries to know the reasons behind taking their service, to identify the gaps of the project and how the project can be boosted up further.

## 2.4 Study Population

In this study, both beneficiaries and non beneficiaries were included as the study population. The study took representatives from the 80.3% patients who had uptaken surgery while the study also covered the non-uptake group as well. Name and contact details of all the participants can be found in Annex-1.

## 2.5 Sample Size and Sampling

Simple random sampling was used for the study as sampling design. The samples were taken as purposively for FGD, KII, II and Case Study. the study sample was:

Category of the Respondents	FGD	KII	II	Case Study	Consultation Meeting
Beneficiaries	6			3	
Non Beneficiaries	1			11	
Executive Director of DECF		1			
Program Manager of DECF		1			

<b>Coordinator</b>		1			
<b>Camp Organizer</b>		2			
<b>Concerned Person of Friends of Sight</b>			1		
<b>Health Assistants of BRAC</b>			1		
<b>Civil Surgeon</b>			2		
<b>District Health Education Officer</b>			2		
<b>Department head, Pediatric Department, District Hospital</b>			2		
<b>Project staffs in DECF</b>					1
<b>Total</b>	<b>7</b>	<b>5</b>	<b>8</b>	<b>14</b>	<b>1</b>

## 2.6 Study Team and Field Data Collection

Whole study was conducted by a small but experienced research team including the CEO of Eminence. The study team was:

<b>Name</b>	<b>Responsibilities</b>	<b>Qualification</b>
<b>Dr. Shamim Hayder Talukder</b>	Principal Investigator	MPhil
<b>Mehedi Hasan Fuad</b>	Research Associate	MPH
<b>Tania Tasnin</b>	Project Coordinator & Quality Controller	MSS

To collect the field level data, total four professional field investigators with social science background were recruited. These field investigators were trained for three days on study methods, tools and guidelines and research ethics by Eminence team. Representatives from Orbis International were also present in the training session. After the completion of the training, the field team was sent to the field for data collection.

## 2.7 Supervision, Quality Control and Data Management

The Principle investigator himself supervised the whole data collection process. He personally visited Deep Eye Care Foundation and had consultation meeting with the Executive Director, Program Manager, Coordinator and Camp Organizers of Deep Eye Care Foundation. Besides, he visited several fields to get a first-hand experience and to monitor the data collection procedure. The other team members: Mehedi Hasan Fuad and Tania Tasnin were also present with Dr. Talukder and Tania Tasnin checked the HMIS data by herself and collected all the contact details from DECF.

To ensure the validity of the tools and guidelines, the study team took feedback from Orbis and incorporated all the feedback before going to the field. The guidelines were finalized after the consultation meeting whether the tools and guidelines were valid in the present condition or not. After the translation and transcription, the data



was rechecked by Tania Tasnin, she called the Program Manager and Coordinator of DECF several times to cross check the data for avoiding any kind of contamination and misinterpretation. The study team gave highest priority for not compromising the integrity of the original data collected from the field.

## 2.8 Ethical Consideration

Orbis International and Eminence jointly developed the consent form for the study. This consent form had been used for conducting FGD, KII, II and Case Study. In the bilateral consultation meeting no consent note was read due to some technical problem. In the field level, this form was read by the field investigators to inform the participants about the purpose of the study and verbal consent was taken from each and every. In the consent note, it was mentioned that the participants can leave the conversation any time and they are not bound to answer any specific question. It was also promised that data collection team will maintain the confidentiality and in future the study will not reveal the real name and contact details of the participants anywhere.

## 2.9 Data Analysis

Several qualitative study analysis methods have been used to analyze the data including matrix analysis and domain analysis.

Matrix analysis was used for the logical reasoning process by using four-by-four square matrix. By domain analysis, the uptake and non uptake factors had been described in the context of the social situation and cultural patterns of the study area.

## 2.10 Limitation of the Study

The study team had to face some constrains while collecting the field data. Due to the political unrest in the whole country, the normal data collection procedure was hampered. Some changes were made due to the blockades and strike which were going on in the northern area of this country. The study team had to take police protection to reach Rangpur safely. The data collection team faced transportation problem from going one place to another place and it took longer hours than assumed. This delay hampered the data collection plan. The field investigators completed their data collection in 14 days instead of 10 days.

Though the field investigators were supposed to take the interview of the Civil Surgeon of Gaibandha, he refused to give any kind of interview in that political condition and he asked to take his interview a few days later. Since the CS was busy with his work and could not manage time for the interview, he suggested to take the interview of Health Education Officer which was already conducted by the field team.

The field team also faced some problems while they were seeking the list of non beneficiaries in DECF. The project team members of DECF had some kind of shakiness for providing the details of the non beneficiaries. Project Coordinator personally talked with the Program Manager of DECF to solve the problem and he instructed the field staffs for providing all kinds of possible assistance to the field team.

# Chapter Three

## Findings of the Study

32 beneficiaries and 16 non beneficiaries participated in the interview part. Among them 17% participants were female and 83% were male. Participant responded gender pie chart shows the male headed family influence and the minimum mother's independency to share their child health status, though they play key role of taking care of their children. Occupations of the participants vary from day laborer to housewife. Almost 47% (22) of the participants were day laborer, 10.64% (5) of them were farmer, 8.5% (4) were businessmen and there were also tea seller, driver, teacher, rickshaw puller, garments workers, housewives and tea seller. Their monthly income ranges from 2000-20000 taka. From the study, it has been found that most of the participants' educational qualification was not high, only two participants obtained BA degree. The participants talked about different factors regarding the uptake and non uptake of the service, costs and outcome of the pediatric cataract surgery.

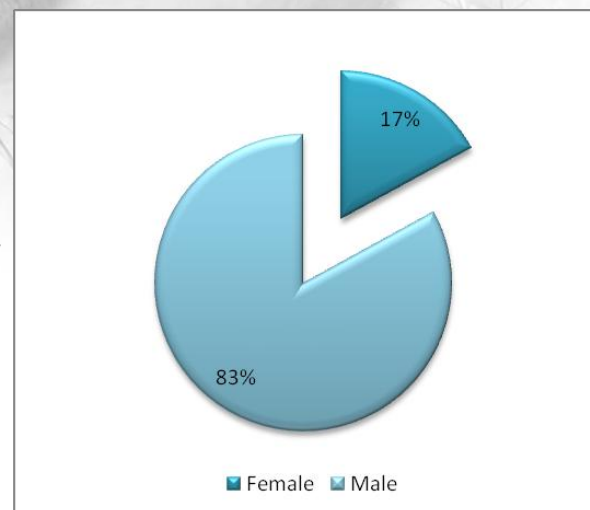


Figure 1: Male-female distribution among the interviewees

### 3.1 Case Finding Factors

Cataract remains the leading cause of childhood blindness in Bangladesh. Due to unequal distribution of health care resources, the surgical shortfall is more pronounced in the periphery areas of Bangladesh. Besides, identification of new cases is also a challenge for the local service providers as it directly affects the rates of surgery uptake. To identify new cases, they organize outreach camp and school sight training program. These types of community screening can also play role for improving awareness among the stigmatized and culturally backward people. As childhood blindness is ten times rarer than blindness in adults, finding the cases in the community is also a big challenge.

In this study, increasing the number of outreach camps, mass publicity and awareness campaigns were ranked highly by both administrators and the community people as the means of identification of new cases. Although there are total five districts are covered by the program, but except Rangpur, the study team didn't find significant activities in other districts. Apart from Rangpur district, DECF is not much recognized in other northern districts and DECF's Outreach camps in other districts have not started yet. That could be a factor for not identifying enough new cases. Although in Rangpur, DECF has referral partners like BRAC and FOS who share their community screening list with DECF. Unfortunately, DECF doesn't have such referral partners in other districts.

## 3.2 Uptake Factors of Taking Pediatric Cataract Surgery

### a. Outreach Camp Service:

*I know Deep Eye Care is providing eye care service, they are doing really great in this area. They invited me in their inauguration and training program though I haven't attend any of their outreach camp. I believe their contribution in pediatric eye care will surely reduce the rate of child blindness. Prof. Dr. M A Mostaqim, Head of Pediatric Department, Rangpur Medical College, working for last 21 years in this district.*

To improve the cataract surgery coverage in the greater Rangpur division, DECF is now working in Rangpur, Kurigram, Lalmonirhat, Gaibandha and Joypurhat. In each month at least 4 outreach camps held regularly in Rangpur division. The camps generally outreaches 5 kilometers radius around the camp. In every eye sight screening camp, organizers screen 80-100 children and refer the complicated cases to Deep Eye Care Foundation. DECF consider the camp successful when they reach the target number of patients or in case the real

number exceeds the target number of patients. The camp organizer first talk with the social gatekeepers (political and religious leaders, school teachers, social workers, health workers) of any specific area to identify the current status of eye health there. Camp organizer identify patients from the list provided by the peer organizations like 'BRAC' and 'Friends Of Sight'. During the camp, the organizers visit the patient's houses to bring them and ensure provision of services.

From the study it has been revealed that the outreach camp is one of the ways of providing services to the unidentified pediatric patients. Among the 48 participants, more than 30 said that their children were screened in these outreach camp. According to the participants, patients can get access to eye health through this camp and it doesn't require money. The participants were asked about the effectiveness of these outreach camps and they positively talked about the screening and counseling of the camps. Outreach camps are also found useful to provide screening services to the hard to reach areas. By ensuring effective coordination and harmonious working relationships with the community people to provide eye care services to their communities, outreach camps are doing excellent job for screening the pediatric cataract patients.

### b. School Teacher's Training:

DECF also works for eye care capacity building of the local communities. They currently run School Teacher's Training Program on eye health. Their strategy is to address eye health of children in those areas focusing on school eye health programs. School eye screening programs have been part of the activities of DECF since the beginning of the project. Therefore, DECF is regularly providing eye sight screening training to the school teachers so that they can screen their students' eye primarily and identify any kind of eye disease. To document the eye condition of the students, they maintain a register so that they can identify the patients later easily. DECF's project team visits a school in a week and they try to provide basic eye care services to the students if they have any kind of 'Vision Problem'. Though the project team haven't got any cataract patients in the school, but they get a clear idea about the condition of the students in that school. Literally, primary vision screening by teachers has effectively reduced the workload of ophthalmic assistants of DECF.

One of the participants said, at first he got to know about his child's vision problem while the teacher was screening the whole class and without any delay he visited DECF and he got to know that his child could not see properly due to cataract. Though he did not know that the school teachers also get training from DECF, he was grateful to the teacher who helped him to get his child's 'clear vision'.



### c. Subsidized (partial or full) eye care services:

Under the project “**Developing the capacity of Deep Eye Care Foundation to deliver quality pediatric eye care service in the northern region**” DECF is providing cataract services to the pediatric patients which is financed by Orbis International, Bangladesh Country Office. DECF provides subsidy or full surgery cost to the patients who need it most. The project team identifies the poor patients with the help of other NGOs, neighbors and relatives of the patients and keep records of those ultra poor patients. According to the records and recommendation, DECF provide subsidy for the surgery. Sometimes they even do full free surgery for the ultra poor patients.

They didn't take any amount of money for my daughters operation. I bought medicines for 1450 taka which was affordable for me.-Md. Shirajul Islam, Father of Asha Moni who uptake the service.

10 of the 32 beneficiary participants said they didn't have to pay money for the surgery since they were identified as ultra poor. Deep Eye Care Foundation carried all sorts of expenses for their surgery although the patients had to buy the medicines with their own money. By supporting the ultra poor, DECF is getting immense popularity in Rangpur district for their philanthropic activities and free surgeries (by dint of financial support from Orbis International). Poor people get interested when they come to know that they don't need to spend money for having surgery. The respondents talked about the indirect costs of the surgery such as conveyance cost, food and accommodation cost in the hospital. Some other respondents of this study said they had to pay partial costs of the surgery which ranged from 4000 to 20000 taka. This amount of money was not affordable to all the beneficiaries, one of them complained that he had to take loan from relative, one said he had to mortgage his cropland and one said he sold the spared iron sheets of his house. Both the beneficiaries and non beneficiaries recommended, if the hospital provide subsidy for these types of indirect cost along with the free surgery, more people will be interested in doing the operation of their children.

The core team also implied the observation method to know the actual condition of the costing of pediatric eye care. They talked with local people about the payment procedure. One service holder and two rickshaw pullers were asked about the payment method of Deep Eye Care. According to them, *DECF only take the admission fees and rest of the treatments are free of cost.*

### d. Peer Motivation:

Peer support connects two or more people who have the same disease and often the same frustrations, so they can relate to each other's feelings and anxieties. Since, peer support helps people cope with the necessary behavior changes and assists them in making positive lifestyle changes, this type of motivation is another key way of DECF to get the cataract patients. DECF encourages its' existing patients to spread out the importance of pediatric cataract surgery. Those who already uptake the surgery for their children influences other parents to uptake the service for their son/daughter and this kind of peer motivation also helps DECF to be recognized to the mass people.

When I meet any parents who need to uptake the surgery for children, they ask me about the cost of the surgery, which hospital would be good hospital for cataract operation, I encourage them immediately to take the service from Deep Eye Care. Mukti, mother of Bornali who took the service 1 year ago.

Those who got benefit through the project said they always encourage other parents to get the service before the condition deteriorates. The beneficiaries also informed that they suggest people to take the service in DECF

since the cost is comparatively lower than other facilities and the overall behavior of the hospital staffs are very good.

#### e. Partnership with NGO:

Partnership is one of the most important things to sustain in this competitive world. Partnership with NGOs helps to develop a strong linkage between the mass people and the health facilities. DECF also have partnership with two NGOs: BRAC, Friends of Sight (FOS). In a household, *Shasthokormi* of BRAC provides maternal and child care and screen the eyes of the children. They document all the records of the visited households and if they get any new case of pediatric cataract they inform DECF.

First we try to figure out the symptoms of cataract then we refer the patients to outreach camp and if needed we refer them to the hospital directly with a referral slip.-Miss Atifa Khatun, HA, BRAC

Additionally, volunteers from 'Friends Of Sight' also inform DECF if they find any new cases. DECF provided low cost support for patients' field kits to FOS to detect or identify eye-sight problems with local people. Volunteers of FOS organize 'vision camps' for detection of eye-sight problems in local area (usually held at a school), provide counseling services and spectacles (if needed), collect information of local people with problem in vision, refer patients to the DECF hospital with recommendation for full free or subsidized fees (if required), and provide refraction services. These two NGOs document all the history of the patients and submit it to DECF. They work like a referral network with DECF.

### 3.3 Non Uptake Factors of Pediatric Cataract Surgery

#### a. Lack of awareness among parents:

Lack of awareness is the major problem regarding eye operation of children. In most cases, parents don't notice the eye problem of their children as they don't know much about the symptoms of cataract or other eye diseases. The qualitative study reported that children often face difficulties to read and complain about headache as well, which are misinterpreted by the parents as they lack proper knowledge on the symptoms of cataract and other eye disorders. They only notice the disease when the condition deteriorate; and seek doctor's suggestion. Even when doctors suggest to operate their children's eye, many of the parents do not take the suggestion seriously as they think they have plenty of times for doing the pediatric surgery, by this time patients condition get worse.

#### b. Lack of Awareness among the traditional healers and alternative health service providers:

The study revealed that people are more likely to visit the local *kaviraj* (traditional healer) or local doctor when they first notice eye problem of their children. People also have tendency to visit the homeopathic doctors. Without knowing the proper cause of the diseases, they suggest medicines, ointments to the children and using those medicines the condition most of the time the situation gets worse. Not only in northern part of this country, almost all local service providers (quak, local healers, kaviraj) from different levels of the community have lack of awareness and knowledge regarding the eye diseases especially cataract.

As there is a huge number of people still rely on these local healers, Deep Eye Care Foundation should train and counsel the local service providers about the causes, symptoms and treatments of cataract so that they can

understand the condition of children's eye. Deep Eye Care Foundation can make a contract with these local healers and doctors so that they can refer the cataract patients when needed.

#### c. Inadequate Man Power in the Field:

Like other districts of Bangladesh, Rangpur district also have lack of man power in pediatric ophthalmology. Though, DECF is running by the skilled man power in ophthalmology, they still have inadequate man power in the field. The study found that, managing the field, bringing the patients in the outreach camp, doing counseling, making people understand about the necessity of pediatric cataract surgery needs a good number of field level workers. Due to the inadequate numbers of field workers, there might be a chance of unidentified cases of cataract in their project area.

*We have inadequate team members in the field. We need more field workers in the field and they need to be trained properly. –Swapon Tozu, Project Coordinator, DECF*

#### d. High Cost of Pediatric Cataract Surgery:

High cost of pediatric cataract surgery is one of the most important factors of not taking the service through DECF. Pediatric cataract surgery costs double/triple cost than the adult cataract surgery. Lens cost for pediatric surgery takes more than five thousand taka whereas in adult cataract surgery, the service facility can buy lens within 1000-1500 taka. Since, as most of the population of greater Rangpur is poorer than other regions of the country, they get scared after hearing the pediatric surgery cost, though DECF provide subsidy or full free surgery to the ultra poor patients.

*They said the operation will cost 30 thousand taka. How would I manage this amount money? That's why we didn't uptake the surgery for my daughter.-Md. Amirul Islam, Md. Tuhin's Uncle who didn't uptake the surgery*

*Some people think we provide free service for all, but when they hear about the cost, they lag themselves off from taking the service.-Dr. Khairul Islam, ED, DECF*

#### e. High Indirect Cost:

Apart from the direct cost of the child cataract surgery, there are also some indirect costs such as: conveyance cost, accommodation cost, food cost. Sometimes, the indirect costs also contribute for not up taking the surgery. The study illustrated that although Deep Eye Care Foundation give consent to provide full free surgery to the ultra poor, people get worried about the indirect costs of the surgery.

#### f. Misconceptions regarding Child Eye Care:

There are many misconceptions regarding the eye surgery of the children. Many people, especially elder people of the community don't take it seriously and they believe everything will be okay in future rather they use potion to mitigate the problem. The community people also think surgery in early age will create different types of health problems and they think that their children might get blind. Some people say, the doctors will pull out the eyes, some people say the eyes will be fully impaired or fully damaged. Some people say as children's eyes are not matured they can't bear the pain of a surgery. Participants from the study were talking about some social and religious norms as well. Some people think representatives from Deep Eye Care Foundation have bad eyes and it is sickening

*Surgery in eyes at childhood will create more problems in older age, he won't see anything in that age-Hazera Khatun, Mother of Firoz who didn't uptake the surgery.*



*After giving birth of my child, I found something white in her eyes, her grandmothers poured rose water in her eyes and they got more white and her eye vision is very low. –Monowara Begum, Mother of Champa Khatun, a non beneficiary.*

their children. Some people blame their fortune or think they must did anything wrong in their early life, that's why God is giving them punishment. Most of the people think cataract is the disease of adults, it can't occur in children's eye. Some of them believe eating some vegetables like banana flower in pregnancy causes cataract in their children's eyes. Especially elder women rely on local kaviraj and they think going to the hospital is not convenient for them.

To enlighten village people from all these misconceptions, Government and other stakeholders should come forward. They should take different steps to make people aware of the pediatric cataract. Different types of

BCC activities should be initiated to obviate the misconceptions and superstitions from mass people.

#### g. Social Stigma:

When a female child develop cataract in her eyes, it creates more problem and she have to face different social stigma. Parents don't want to believe that their female child have cataract in her eyes. They think it will create an issue in marriage. They think it won't be easy to get their female child married in future. Sometimes they overreact when they hear their female children have eye diseases. At the same time, illiterate people have a superstition that girls are more likely to be affected by bad eyes and their eye diseases may happen for this reason.

*Zayed's uncle died in stroke on the day when I planned to take her to the hospital. I thought someone had bad eye on her and I cancelled the plan. Now she sees almost nothing. –Imdadul Haq, father of Zayed who didn't uptake the surgery*

#### h. Weak Referral Linkage:

Still DECF has a weak referral linkage with other different types of facilities (Government, Non Government, Private hospitals and clinics). People of Rangpur know well about the activities of DECF but people from the other adjacent districts don't have knowledge about the hospital. As DECF is trying to provide eye care services in the northern zone, they need to do more publicity in other districts. Civil Surgeon of Lalmonirhat is not aware about the activities of DECF and they were never invited in any kind of program of DECF. He only knows that Deep Eye Care Foundation is providing eye care service there but they don't have detail information. For this weak referral linkage, DECF is facing difficulties in getting new cases. If they had strong linkage with other facilities, they would get more new pediatric cataract cases. DECF also need more publicity to get recognized by the mass people.

*I know Deep Eye Care is working in this district, but I don't have any idea what they actually do as they never invited me in any program. –Dr. Md. Harun-Or Rashid, Civil Surgeon, Lalmonirhat, working for last 2 year*

#### i. Fear of Surgery:

Fear of surgery appears one of the major barriers for not uptaking the surgery. However, 8 non beneficiary parents expressed fear of the hospital environment and unknown staffs while doing cataract surgery. Some of the parents also think the ophthalmic personnel will kidnap their child or steal their children's organ as they are not allowed to stay in the operation theater. Fear of surgery also ranges from damage of the eye ball, losing sight to fear of dying.

#### **j. Lack of Awareness Regarding Prevention of Eye Diseases Including Cataract:**

Though government and non government hospitals are working hard for the treatment of eye care diseases in Bangladesh, there is no program going on regarding the prevention of eye care diseases among the children. Lack of this kind of prevention program keep people unaware about the diseases and they don't know how to keep themselves away from these diseases.

### **3.4 Community Perception Regarding Service Quality of Deep Eye Care Foundation**

According to the participants of the study, patients are happy with the service quality of Deep Eye Care Foundation. They were praising about the behavior of doctors and other health workers who are currently working in the field. Apart from the uptake and non uptake group, the core team asked about the service quality about DECF in local people of Rangpur district, all of them said DECF is currently providing best eye care services in Rangpur division. There was only one exception; one non beneficiary mother stated that her child had cataract problem but she didn't uptake the service from DECF since her mother's eyes got deteriorated after doing operation in this hospital. She was wondering that her child would get blind after availing the service.

### **3.5 Community Perception Regarding Service Cost and Outcome**

All the beneficiaries except three participants of this study said the service cost was affordable and it was cheaper than other non government facilities. Though a few participants talked about medicine cost and other indirect high costs of the surgery, they were satisfied with the pricing of the surgery. The study also revealed that in the community level there is a wrong perception regarding the service cost. Though Deep Eye Care Foundation provides full free surgery to the ultra poor, people think everyone will get this privilege. Therefore, they (mostly non beneficiaries) think camp organizers lies when they convince the parents to go to the outreach camp and after that when they (parents) initiate to uptake the surgery, they demand big amount of money. This kind of communication gap should be mitigated and Deep Eye Care Foundation should be more specific about the cost of pediatric cataract surgery.

According to the secondary data, 80% of those children who were screened cataract have already taken the service by DECF. The participants were also asked about the surgery outcome, all the beneficiaries gave positive answers while non beneficiaries also said that although they know the service outcome is good, but they were not capable to take the service for some other issues (financial inability, fear, misconceptions and stigma).

### **3.6 Scope of New Cataract Identification**

Currently Deep Eye Care Foundation is organizing the outreach camps only in Rangpur regularly, whereas in other four districts they are not much active in eye sight screening camp, they also lack of skilled man power in those districts. Like Rangpur district, if DECF can accelerate the outreach camps in other districts, the chance of getting new cataract cases will increase indisputably. Building relationship with the local NGOs will also be beneficial for the facility for new case identification.

According to the participants of this study, if DECF publicize their activities by make announcements, distribute brochures about the hospital's features and facilities, mass people will be clued-up about the activities of DECF and they will get new cataract patients. Building new referral linkage with the local NGOs in other districts may also help DECF to get new cataract cases.

### Uptake-Case Study-1

*"I am really grateful to DECF for my son's clear vision. I believe DECF is the best hospital for eye care service and I want them to continue their program for the poor patients."*

Sadiqul was only 4 when I recognized he has a 'vision problem'. One day, I asked him to bring one thing from table, he was searching that thing though it was in front of him. After talking with my family I decided to take him to a kaviraj and he gave some medicine along with an ointment which he asked to massage in the eye area. I found no improvement in his eyes though we used those medicines regularly. Then we took him to a local doctor and he gave medicines again, but the situation was same, there was no improvement. The doctor asked me to take him to a good doctor. With the recommendation of the local doctor, I took Sadiqul to Rangpur Medical College. The eye specialist examined his eyes and said he has cataract which needs immediate surgery and it will cost 10000 to 15000 taka. It is really tough for a day laborer like me to arrange the big amount of money. I came back from the medical college with a broken heart and was trying to find out the alternative solution of my kid's problem. Then one of my relatives told me about Deep Eye Care Foundation who provide full free treatment of pediatric eye surgery. With a new hope I went to DECF and the doctors examined Sadiqul's eyes again and decided to do surgery on his eye. The operation cost was full free for me and they only took the medicine cost which was only 1500 taka. Now my son's eye is okay and he can see clearly. I am really grateful to DECF for my son's clear vision. I believe DECF is the best hospital for eye care service and I want them to continue their program for the poor patients.

### Uptake-Case Study-2

*"I believe each and every parent should be concerned about their child's eye and if any kind of problems occur, no one should delay."*

In 2013, I observed that Shawlin's left eye was smaller than the right eye. She could not tolerate the light and used to close her eyes in the exposure of light. I got skeptical and decided to visit a doctor. By profession I am a teacher and I have heard the praising of Deep Eye Care Foundation from different people. I took her to the hospital and Dr. Khairul examined her eye very carefully. He told me that Shawlin has congenital cataract in her eyes, I asked him if he can operate Shawlin's eye and he said it's possible. I came and discussed with my wife regarding the surgery and she also agreed to operate our child's eye. We went to Rangpur Medical College and the doctor also said that Shawlin has cataract in her eyes. We went back to Deep Eye Care Foundation and paid 13000 taka as surgery cost. There was also some cost of medicine. Dr. Khairul said, there will be some extra cost of phaco and lens transplantation and he managed the additional cost. Now my daughter's eye is okay but she uses powered spectacles, **in last six months the power has been changed for three times, most probably she is facing some problem in her eyes now. Doctors said at the age of six her spectacle's power will be adjusted.** I am really grateful to Deep Eye Care Foundation because they saved my daughter's eyes. I believe each and every parent should be concerned about their child's eye and if any kind of problems occur, no one should delay.

### Non Uptake-Case Study-1

*“Whenever representatives from Deep Eye Care Foundation come to our house, Atique gets sick. I think there is something wrong with their coming and Atique, I don’t want to see my son ill. These amulets are to save my child from all the evil works”*

After his birth, Atique didn’t want to open his eyes, four days later I opened his eyes and found something whitish and immediately went to the local doctor to know what happened to my son’s eyes. He suggested me to go to the medical college, I took Atique there but his condition remained same. Then I went to GausulAzam Hospital and after getting their treatment, my son’s eyes got improved and we came back to home. After some days, one of my relatives told me about Deep Eye Care Foundation and praised about its service. I took him to the outreach camp of DECF and after screening my son’s eyes they said he has cataract problem in his eyes and which will be fully cured if I allow them for the surgery. Deep demanded 12000 taka for the operation which was almost impossible for me to arrange. I explained them my condition and after that they asked me to give 5000 taka and rest of the costs will be provided by the hospital. But the worst part was when I arranged the money and it was stolen. Our heart was fully broken. We could not arrange the money for the second time. I hope after some day we will be able to save this amount of money for the surgery and Atique will see everything clearly.

### Non Uptake-Case Study-2

*“You told my granddaughter blind? How dare you to utter the word? She sees everything, you don’t have any right to make my granddaughter blind, keep away from her and my family, otherwise I will teach you well!”*

Shila was taken in an outreach camp of DECF. The project staffs of DECF identified she has ‘vision problem’ but her family members did not believe their words and they got arrogant. They did not take any kind of treatment and whenever the project staffs tried to convince them, they refused to take the service as they thought their child can see everything; DECF was trying to take their child in their hospital and they may pull off her eyes. When the field investigators of this study went to their home, her family members thought they want to take her to DECF and they must have evil intention.





# Chapter Four

## Discussion

Through the outreach camps DECF can reach the most unreached. It is one of the best sources of getting patients. Since, uptake is associated with the perceived quality of the services as well as trust in the project staffs, Deep Eye Care Foundation should expand their outreach camps in other districts and conduct the camps regularly by recruiting skilled staffs. In south India a study (*Robert P.F et al.* 2011) depicted that, repeat outreach eye clinics in the same vicinity and the good outcomes experienced or reported may have increased trust and hence acceptance of surgery.

According to the study, lack of awareness is one of the major causes of not up taking the surgery. By using the domain analysis, it has been found that misconceptions and superstitions, fear regarding service uptake are still prevailing in the community level mostly due to lack of education and awareness. Lack of knowledge about cataract and concerns about the quality of local services appear to be one of the principal barriers to uptake cataract surgery which has been also seen in China (*Yin Q et al.*,2008). However, *Addis Tenkir* and his team (2010) reported that, having awareness about a disease is not sufficient to lead someone to put the knowledge into an appropriate practice. Hence, there may be other barriers which hinder people from seeking cataract surgeries for their children.

Costs, both direct and indirect, are a major barrier, which hinders access and acceptance of pediatric cataract surgery. 'High cost of surgery' was the most frequently quoted obstacle in some developing countries like Nepal and Nigeria (*D Yorston*, 2005). While taking the interview, 5 participants was suggesting about the free transport facility. On the contract, in Nepal (*T Snelling et. al*,1998) even when offered free transport, under half the population accept surgery within 1 year. Since almost 50% of the total participants of the study were day laborer, they concern opportunity costs of being away from daily income earning activities while they took their children to DECF for the study the same scenario has also been seen in Nepal.

Study (*Green D.et al.* 2001) showed that, a better outcome can be found if the ultra poor patients get more subsidized by increasing the price of surgery for wealthier patients, who pay extra for better accommodation, or a shorter waiting period. This principle of 'tiered pricing' allows cataract surgery to be made available to the maximum number of patients because cost of surgery is a barrier to the study area's poor people.

The Snelling study (1998) in Nepal revealed that low socio-economic status was a barrier to the utilization of cataract surgery and our study also showed that those who were not interested to take the surgery had low socio economic status. In another study, (*Brilliant et al*, 1991) showed that cataract surgery utilization is less in illiterates. In contrast, being illiterate didn't contribute for taking the pediatric cataract surgery in this study.

Almost 50% of the study population was day laborer and according to them they were more aware about the opportunity costs of being away from daily income earning activities while they were with their children for the surgery. The same scenario has been seen in a study in Nepal (*T Snelling et al.*, 1998).

Deep Eye Care Foundation doesn't have any strong referral linkage with other government and non government facilities and it is one of the barriers of this facility to get more pediatric patients which has already mentioned as a barrier in an article (Childhood Cataract: Home to Hospital, Mohammad MA) *Community Eye Health* journal in 2004.

Due to the misconceptions and social stigma, female cataract patients in rural areas have to face more while availing the surgery. A study in south India (*Robert P.F et al.* 2011) also showed that women to be more disadvantaged than men when negotiating family support. Other study also illustrated that negotiating family support is also more difficult for women (*Geneau et al.* 2005; *Finger et al.* 2007).

Eight of the non beneficiaries mentioned that fear of surgery was one of the contributing factors of not taking the surgery, similarly in rural South Africa; the Fear of the operation was an important reason for non attendance of cataract surgery (*A.P. Rotchford et al.*, 2002).

The study revealed that, some of the non beneficiaries were skeptical about the project staffs. According to a participant, the project staffs did not want to take him while screening of his child, he was in doubt that if they (project staff) kidnap his children. A study in Maharashtra, India (*P Gogate et al.*, 2014) encouraged for the continuous development of child-friendly ambience of pediatric unit and child-friendly attitude of trained staff.



# Chapter Five

## Recommendation

The above mentioned results identified the following recommendations to improve the service as well as the coverage:

- Awareness building publication and Behavioral Change Communication (BCC) materials need to be updated focusing on cultural misconceptions regarding cataract and boost up general awareness on identifying new cases and importance of taking treatment for pediatric cataract.
- As the service coverage area's people are mostly poor and results found their concern related to the cost, even they are apprehensive about the minimum registration fees, the BCC materials should rephrase about the cost for ensuring prevention of community based negative peer activities.
- Awareness programs related to cultural misconceptions and social stigma targeting parents and their family members need to be implemented more extensively to increase the uptaking of child cataract services.
- The coverage area of DECF should be expanded by the numbers of outreach eye care camps on the basis of present low patient participation areas, upazillas and targeted districts by observing the electronic data set.
- Provision of free transport facility, accommodation cost and food cost may increase the uptake rate which require exploring funding sources or they should arrange money by increasing the service price rate for economically well off people and cross financing for poor people.
- Communication training for the staff of the hospital and field workers may improve child-friendly ambience of pediatric unit and proper information dissemination for the greater acceptance of pediatric ophthalmology services among the mass people.
- Peer education system may help the community people for uptaking the pediatric cataract surgery. All patients, parents of child beneficiaries and their family members can be involved as peer educator to motivate the non beneficiaries, stigmatized people.

- Community mobilization groups need to be formed by school teacher, elder people, political and religious leaders for raising awareness in the community regarding the good outcome and importance to prevent blindness by taking pediatric eye care services at early stage.
- Government and other private sector's health care service centers need to be involved with DECF health service system and training courses to establish the patient referral network. It is highly recommended to establish a partnership with government's recent initiative-Community Clinic for setting up a grass root level referral linkage, a community based follow up services and regularly organize a community based eye care health camp.
- The model of training for eye care refractionists and their community based service can be scale up in other institutions and government sectors. Moreover, these training courses need to be allocated more resources for increasing the number of training.
- The use of HMIS software need to be extended up to community based eye health care camp which will help to figure out the dropped out cases and continuous follow up with them. The software also needs to add several variables to establish referral linkage, patient mobile number to send SMS/MMS/automatic voice SMS for automated follow up and awareness messages. Moreover, this HMIS software needs to be promoted in other eye care facilities in Bangladesh.



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# Annex-1- Participants List

Non Beneficiaries						
Patient Name	Parent's Name	Occupation of the Parent	Educational Qualification	Monthly Income	Contact Details	Contact Number
Monowara Khatun	Hamidul Islam	Farmer	Illiterate	6000	Haragach, Kaunia, Rangpur	01785443847
Nayim Islam	Hamidul Islam	Driver		5000	Mirjapur, Mithapukur, Rangpur	01753990792
Umed Hassan	Jahangir Hossain	Businessman	Illiterate	5000	Balua, Mithapukur, Rangpur	01722978083
Shopnil Islam	AtaurRahman	Driver	Class 5	9000	Dhap, Engineer Para, Rangpur	01773857588
Chompa	Abdul Hasan	Farmer	Class 5	5000	Shontoshpur, Balua, Mithapukur, Rangpur	01740081900
Tuhin	Afser Ali	Businessman	Illiterate	4000	Mithapukur, Rangpur	01738381385
Shree Bandhan Mondol	BabuMondol	Farmer	Illiterate	3000	Borobari, rangpurSadar	01723313842
Shila Akter					Ranipukur, Mithapukur, Rangpur	01957780702
Atique Hasan	Md. Abdul Majid	Day Laborer	Illiterate	4000	Jamtola, Baunia, Rangpur	01751372402, 01731481743
Tishamoni	TumpaKhatun	House wife/Abandoned			Ershadnagar, Kaunia, Rangpur	01728822518
Md. Shumon Mia	Mohabbat Ali	Van Driver	Illiterate	4500	Keranirghat, RangpurSadar	01773469657
Md. Utshab Mia	RuzinaKhatun	Day Laborer	Class 5	5000	Jibonpur, Mithapukur, Rangpur	01941793522
Zayed	ImdadulHaq	Day	Illiterate	3000	Abirerpara, Moslembazar, Mithapukur,	01705942158

	ue	Laborer			Rangpur	
Firoz Mia	HazeraKhatun	Tea Seller	Illiterate	4000	Jibonpur, Mithapukur, Rangpur	01797870875
Shagor Adhikari	BenuVishon Adhikari	Job Holder	Class 5	4500	Krishnapur, Mithapukur, Rangpur	01710648224

Beneficiaries						
Patient Name	Parents Name	Occupation of the parent	Educational Qualification	Monthly Income	Contact Details	Contact Number
Md Wajed Miah	Md Momin	Day Laborer	Illiterate	5000	Jharbisle, Chaitrakal, pirganj, Rangpur	01792867784
Mimi Khatun	Md Mijanur Rahman	Day Laborer	Illiterate	5000	Jharbisle, Chaitrakal, pirganj, Rangpur	01792743101
Shamim Miah	Md Manik Miah	Service	Class 8	15000	Shekurpara, Moyenpur, Mithapukur, Rangpur	01734883661
Bobita Akter	Ajaha Ali	Carpenter	Illiterate	5000	Tilokpara, Changmari, Mithapukur, Rangpur	01755229686
Anika	Rohidul	Farmer	Illiterate	20000	ShahAlampur, Baluaghat, Mithapukur, Rangpur	01763119288
Shahira Shaolin	Md. Shofikul Islam	Teacher	BA	12000	Moyenpur Purbopara, Moyenpur Mithapukur, Rangpur	01739443644
Bornali	Md Bokul	Contractor	Class 8	10000	Gultipara, Rangpur City Corp., Rangpur	01765965383
Mukti	Moslem Ali	Day Laborer	Illiterate	5000	Selimpur, Gorarhat, Rangpur	01778357900
Rikta	Moslem Ali	Day Laborer	Illiterate	5000	Selimpur, Gorarhat, Rangpur	01778357900
Golam Rabbi	Md. Ajharul Islam	Carpenter	Illiterate	8000	Pirjabad, Sharkerpara, Kotoali, Rangpur	01726790817
Md. Bulbul	Asgar Ali	Day Laborer	Illiterate	5000	Keshobpur, Baniapara, Panichora, Rangpur	01786243409
Md Nabi	Md. Kamal Hossain	NGO worker	HSC	12000	Co-Bazar, Sadar, Rangpur	01718703908
Md. Raihan	Md Tajul Islam	Transport Worker	Illiterate	4000	North Dhangora, Bolomjhar, Sadar, Gaibandha	01775710337

Nayim Babu	Rayhan	Rickshaw puller		3000	Jormondi, Shundorganj, Gaibandha	01762872980 (On reuest)
Kanak Mia	Md. Babu Mia	Farmer	Illiterate	5000	Folimari, Gaibandha Sadar, Gaibandha	01966195821
Moriom	Md. Mukul	Day Laborer	Illiterate	5000	Parbaguria, Gaibandha Sadar, Gaibandha	01751327141 (On reuest, neighbor)
Ripon	Md. Nazrul	Day Laborer	Illiterate	4000	Ghagoa, Taltola, Gaibandha Sadar, Gaibandha	01764718224
Ananda	Md. Hasan Mia	Driver	Class 6	12000	Shantigram, Shundorganj, Gaibandha	01825836263
Pankaj Chandha	Sree Bideshi Babu	Day Laborer	Class 5	4000	Lalmonirhat Sadar	01750843073
Al-Amin	Amena Begum	House wife	Illiterate	4000	Lalmonirhat Sadar	01744760605
Abdur Rahman	Ashraful Islam	Day Laborer	Illiterate	4500	Lalmonirhat Sadar	01765908320
Firoza Akter	Bozlor Rahman	Businessman	Class 8	6000	Lalmonirhat Sadar	01765908320
Mahin	Abdul Kader	Businessman	SSC	5000	Teesta, Lalmonirhat	01728235580
Umar Faruq	Abdul Malek	Farmer	Illiterate	3500	Aditmari, Lalmonirhat	01768389365
Md. Saduul Islam	Md. Lutfor Rahman	Day Laborer	Class 2	6000	Noyarhat, Mondolpara, Rangpur Sadar	01774355198
Ms. Ashamoni	Md. Shirajul Islam	Day laborer	Illiterate	4000	Ajoddhapur, Najirhat, Rangpur Sadar	01797775602
Md. Rakibul Islam	Ronjini Akter	Day Laborer	Class 5	4000	Modonkhali, Pirganj, Rangpur Sadar	01755126275
Md. Mohaiminul	Mst Rubi Khatun	Day Laborer	Illiterate	2000	Parbotipur, Rangpur Sadar	01737794855
Md. Sadekul Islam	Mst. Shayra Begum	Day Loborer	Illiterate	4000	Chondonpat, Rangpur Sadar	01774355198
Mamun	Abdul Hamid	Day Laborer	Class 5	5000	Rangpur Sadar	01773075905
Alam	Mozia Begum	Garment worker	Class 5	8000	Rangpur Sadar	01767260031



Participants of KII and II		
Name	Designation	Contact Number
Dr. Md. Mojammel Hossain	Civil Surgeon, RangpurSadar, Rangpur	01712771185
Dr. A K M Mostafa Kamal	Civil Surgeon, LalmonirhatSadar, lalmonirhat	01719599394
Prof. Dr. M A Mostaqim	Head, Department of pediatrics, Rangpur Medical College	01796139669
Dr. Md. Harun-Or-Rashid	Senior Consultant, Pediatrics, AdhunikSadar Hospital, Gaibandha	01715152391
Md. Abdul Hannan	Health Education Officer, Gaibandha	01718272016 01928825107
Dr. Khairul Islam	Executive Director, Deep Eye Care Foundation	01714063389
Md. Mahmudul Islam	Program Manager, Deep Eye Care Foundation	01759655655
SwaponTozu	Project Coordinator, Deep Eye Care Foundation	01715158778
Md. Sodrul Hasan Raju	Camp Organizer, Deep Eye care Foundation	01712666064
Rashed M A Mansur	Camp Organizer, Deep Eye Care Foundation	01740837323
Ms. AtifaKhatun	Health Assistant (ShasthoShebika), BRAC	01737112121
Mst. ShirinaKhatun	Health Assistant, Friends Of Sight	01940568429

# Annex-2-Guidelines of the Study

## KII Guideline for Program Manager of DECF

1. From when did you start working in this organization? Why? How did you get involve with this pediatric cataract surgery program?
2. Can you tell us something about your daily working procedure? How many staffs does the hospital have? Do you have man power shortage?
3. How do you identify new cases? What kind of problems/challenges/barriers do you face to identify the new cases? What do you do to overcome the problems?
4. Are there any other eye care facilities in your area? Do you have any list of them? How do you differ your facility from others?
5. As you are focusing on pediatric cataract surgery, do you think the uptake ratio is good enough? If not, then why?
6. How do you measure the program success? Do you have any monitoring system? If the answer is NO, then why?
7. How do you encourage the parents to uptake the service for their children? Do you have any BCC program for this? How do you convince a parent who is not interested to up take the service for his/her child?
8. Do you think parents should be more careful about their children's eye sight? How?
9. Do you have any kind of awareness program for the pediatric eye care? What are the awareness building activities you usually do? Do you conduct outreach camp in periphery areas? How do you manage the camp?
10. What are the main misconceptions among community people while prevailing the surgery?
11. Why people don't want to uptake the service though they know their children needs the surgery? What are the main factors behind their denial?
12. What are the pros and cons of the program? What is your future plan to overcome the constrains? Please discuss.

## KII Guideline for Outdoor Coordinator & Camp Organizer

1. For how long you are working in this organization? Why are you working here? Do you have passion/interest in this type of job?
2. How do you work in this program? (Share us your job nature, techniques/way you follow to finish your job)
3. How the hospital monitors your work?
4. How do you arrange Outreach camp? What are the criteria you need to follow to select a location?
5. Did you ever face any obstacle in running the camp? What are the average number of children seek services in the camp? Do the camps refer children for surgery in Deep Eye Care Foundation?
6. How do you evaluate the performance of a camp?
7. How do you encourage the parents to uptake the service for their children? Do you have any BCC program for this? Do you have awareness program for the pediatric eye care?
8. How do you convince a parent who is not interested to up take the service for his/her child?

9. Do you think parents should be more careful about their children's eye sight? How?
10. Why people don't want to uptake the service though they know their children needs the surgery? What are the main factors behind their denial?
11. How the program can be organized more successfully? Do you have any man power shortage? Do you have any suggestion? Please discuss.

## **KII Guideline for Executive Director of DECF**

1. When did you start your organization? Why? What kind of motivation worked behind establishing this organization?
2. Tell us about the actual condition of pediatric eye care in your area.
3. From when did you started cataract surgery in your facility?
4. How the facility works? (Organogram, functioning procedure)
5. Can you tell us something about your human resources? (Technical and Administrative both) Do you have man power shortage?
6. Tell us about the different types of patients (Male, Female, Children, Elder Person) and which group is your main concern?
7. As you are focusing on pediatric cataract surgery, how do you identify the cases? What kind of problems/barriers/challenges do you face? What is your suggestion to overcome the problems?
8. Do you think the uptake rate of pediatric cataract surgery is good enough? How do you measure it? If the answer is NO, than why?
9. Do you think parents should be more careful about their children's eye sight? How?
10. Do you have awareness program for the pediatric eye care? Do you have communication materials to aware the people about pediatric eye care?
11. Do you take any step if you find any child needs cataract surgery and his/her parents don't want to do that now?
12. What is your future plan to accelerate the program? Do you think training of the hospital's staffs may boost up the program?

## **II Guideline for Civil Surgeon/Health Education Officer/Pediatric Department Head, District Hospital**

1. Name, contact details, Job experience
2. Does the Government have any specific project on Eye Care in your area? Is there any specific project on pediatric eye care? If yes, please describe.
3. What types of services do you provide for pediatric eye care?
4. Do you have any statistics of how many children have 'Vision' problem in your area? (This question will be asked to Pediatric Department Head of District Hospital and Civil Surgeon)
5. Except you, how many non government organizations work for the 'vision' problem? Do you have any list of these organizations? How many of the organizations provide cataract service to the children? Have you ever visited their Outreach camp?
6. How do you identify new cases? Is there any specific method you use to find new cases?
7. Due to what kind of misconceptions people don't want to take pediatric eye surgery for their children? What factors usually occur for not taking the services?
8. Does the government have any awareness program regarding pediatric eye care?
9. Have you heard about the activities of DECF? What kinds of services do they provide? Are you aware about their program on pediatric cataract surgery? Discuss
10. What is your opinion about their activities? Does it help you to reduce the blindness rate in your area?

11. Do you have any monitoring framework to supervise other non government facility's work?
12. Please share us your thought- How the condition can be improved regarding childhood blindness in your area.

## **II Guideline for Health Assistant of Local NGO**

1. For how long you are working in your organization? Do you work in the field? In which locality do you work?
2. What are your responsibilities?
3. What are the main concerns of your NGO? Do you work for the pediatric eye care? Do you have any specific program for pediatric eye care?
4. What do you do when you find a child with 'vision' problem?
5. Do you have any idea about the actual condition of the children with 'vision' problem in your area?
6. Do you know about DECF? What do they do? What type of service they usually provide?
7. Do you recommend your patients (who have 'vision' problem) to take service from DECF?
8. How do you refer patients to DECF and why? How do you encourage the parents to uptake the service for their children? How do you convince a parent who is not interested to up take the service for his/her child?
9. What is your opinion on not taking the cataract service of the parents (especially from DECF) who already know their children need treatment?
10. What are the common misconceptions which can be found in your community for not taking the cataract surgery?
11. How the percentage rate of service uptake can be increased? What do you think?
12. How do you keep records of the patients who have 'Vision' problem?

## **II Guideline for Friends of Sight (FOS)**

1. Name, Contact details
2. For how long you are working in this organization? How do you work here? (Voluntary basis/pay basis) Share us your job nature, techniques/way you follow to finish your job. How do you work in the community? Can you show us the method you follow?
3. How do you locate and specify/identify your patients? Please discuss. After identifying a child with vision problem how do you approach to their parents.
4. How do you collect information of those who have 'Vision' problem?
5. How do you arrange 'Vision Camp' in a specific locality? Please discuss.
6. Tell us some success stories of eye care services in your area.
7. What kind of barriers/challenges do you face while you identify a patient? Please tell us about the condition of children with cataract problem in your area.
8. How do you refer patients to DECF? How do you encourage the parents to uptake the service for their children? How do you convince a parent who is not interested to up take the service for his/her child?
9. How do you select the patients who need full/partial free treatment? Do you have specific way to find out the patients who are poor but need treatment?
10. Do you have awareness program for the pediatric eye care services? Briefly discuss.
11. What are the main misconceptions among the community people while taking the surgery?
12. Why people don't want to uptake the service though they know their children needs the surgery? What are the main factors behind their denial?



13. Is there any monitoring procedure to monitor your work?
14. Please share your thought-how DECF can improve their quality of services regarding pediatric cataract surgery.

### FGD Guideline for Uptake Group

1. Socio-economic status (Age/sex of the children, Parents' educational qualification/monthly income)
2. When and how did you realize your child has vision problem?
3. Where did you go for your child's vision problem? Did you visit other places for his/her eye disease?
4. How did you know about Deep Eye Care Foundation?/Who gave you the hospital information?
5. Why did you uptake the surgery? Reasons behind taking the surgery from DECF/ Who inspired you for up taking the surgery.
6. How much did it cost for up taking the service? Was that costly/fairly good/affordable? Please explain.
7. Was there any post operative complications? If yes, please discuss. What is the present condition of your children's eye?
8. What was your perception before taking the service?/ What are the common perceptions prevailing in the community about pediatric cataract surgery?
9. What types of constraints did you face while you took decision for up taking the surgery? What were the difficulties you had to overcome?
10. Do you know what sorts of services are provided by Deep Eye Care Foundation? Do you know about their treatment cost? Is it expensive/affordable?
11. When you meet other child's parents who came to take the service, what are the main concerns can be found in your conversation regarding up taking the service?
12. What do you think, why people don't want to take the service from DECF?
13. How the service can be improved? What can be done to find new cases? How can they provide treatment to those who are not willing to take the service?

### FGD Guideline for Not Uptake Group

1. Socio Economic Status (Age/sex of children, educational qualification/monthly income of parents)
2. When and How did you realize your child has vision problem?/ Do you know your child has vision problem?
3. Did you go anywhere for the treatment of your child?
4. How did you know about Deep Eye Care Foundation?/Who gave you the hospital information?
5. When did you come to Deep Eye Care Foundation for the first time?/Why did not you come to Deep Eye Care Foundation though you knew about the facilities (if it was not first contact)?
6. Have you heard anything about the cataract surgery service of Deep Eye Care Foundation? Did anybody from the facility suggest you to take the surgery? Who?
7. Have you ever visited Deep's outreach camp? Did anybody (Volunteers of Friends of Sight) take you there?
8. Do you know what sorts of services are provided by Deep Eye Care Foundation? Did you (your child) take any kind of treatment from the facility? (Medicine/Tips/Counseling/Advice)
9. Do you know/What do you know about their treatment cost? How about their behavior? Were/weren't you satisfied with their services.
10. What was your perception when you heard your child needs to take the service?/ What are the common perceptions prevailing in the community about pediatric cataract surgery?
11. Why did not you uptake the surgery? Reasons behind not taking the surgery.

12. What type of constraints did you face? (Illiteracy/Distance/Cost/Female child/Superstitions/others)
13. What do you think, why people don't want to take the service specially pediatric cataract surgery?
14. When you meet other child's parents who came to take the service, what are the main concerns can be found in your conversation regarding up taking the service? Don't they inspire you to take the surgery?
15. What kinds of efforts should be taken to attract the parents who did not take the services for their children?

# Annex-3-Consent Paper



It starts with vision.

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বিষয় : গবেষণায় তথ্য সংগ্রহের কাজে সহায়তা প্রসঙ্গে।

জনাব,

আপনার অবগতির জন্য জানানো যাচ্ছে যে, অরবিস ইন্টারন্যাশনাল, বাংলাদেশ কান্ট্রি অফিস ন্যাশনাল আই কেয়ারের অধীনে বাংলাদেশ সরকারের সাথে সারা দেশব্যাপী যৌথভাবে জাতীয় অন্ধত্ব নিবারণ প্রকল্প বাস্তবায়ন করছে। এরই ধারাবাহিকতায় অরবিস ইন্টারন্যাশনাল দ্বীপ আই কেয়ার ফাউন্ডেশন, রংপুরের সাথে যৌথভাবে একটি প্রকল্প বাস্তবায়ন করছে। এই প্রকল্পের অন্যতম উদ্দেশ্য হলো শিশুদের চোখের ছানি অপারেশনের মাধ্যমে তাদের দৃষ্টিশক্তি ফিরিয়ে দেয়া। যার ফলে বৃহত্তর রংপুর অঞ্চলের সকল শিশুকে নিরাময়যোগ্য ছানিজনিভ চোখের সমস্যা থেকে মুক্ত রাখা যাবে বলে আশা করা হচ্ছে। বর্তমানে অরবিস বাংলাদেশ একটি গুণগত গবেষণা কাজ পরিচালনা করছে যার মাধ্যমে প্রকল্পটিতে সুবিধাভোগী এবং যারা সেবা গ্রহণ করেননি তাদের মতামত গ্রহণ করা হবে, সমাজে শিশুদের ছানি অপারেশন সম্পর্কে প্রচলিত ধ্যান-ধারণা সম্পর্কে ধারণা নেওয়া হবে, প্রকল্পটির ঘাটতি এবং কিভাবে প্রকল্পটির মান আরো উন্নত করা যায় সেই সকল বিষয়ে মতামত নেয়া হবে। এই গবেষণার মাঠ পর্যায়ের তথ্য সংগ্রহ, তথ্য বিশ্লেষণ এবং প্রতিবেদন তৈরিতে Eminence নামক একটি গবেষণা প্রতিষ্ঠান অরবিস ইন্টারন্যাশনালকে কারিগরি সহায়তা প্রদান করবে।

বর্তমানে Eminence এর একটি দল বৃহত্তর রংপুর অঞ্চলের বিভিন্ন গ্রাম/হাসপাতাল/সদর হাসপাতাল/বেসরকারি হাসপাতাল/এনজিও হতে তথ্য সংগ্রহ করছে। মাঠ পর্যায়ের তথ্য সংগ্রহের কাজে তাদের সার্বিক সহযোগিতা প্রদানের জন্য বিশেষভাবে অনুরোধ জানানো হলো।

ডা. মুনির আহমেদ  
কান্ট্রি ডিরেক্টর  
অরবিস বাংলাদেশ।

Bangladesh Country Office  
Rangs Barnali, Apartment F2  
Plot 1, Road 137, Gulshan 1  
Dhaka 1212, Bangladesh

www.orbis.org  
T. +88.02.9858033, 9858050  
F. +88.02.8820284  
E. info@bd.orbis.org