



# Childhood cancer in Bangladesh: a qualitative evaluation

Taufique Joarder<sup>1^</sup>, Samiun Nazrin Bente Kamal Tune<sup>2^</sup>, Shahaduz Zaman<sup>3^</sup>

<sup>1</sup>SingHealth Duke-NUS Global Health Institute, Singapore, Singapore; <sup>2</sup>Abt Global, Dhaka, Bangladesh; <sup>3</sup>Brighton and Sussex Medical School, University of Sussex, Sussex, UK

*Contributions:* (I) Conception and design: T Joarder, S Zaman; (II) Administrative support: T Joarder, S Zaman; (III) Provision of study materials or patients: T Joarder, S Zaman; (IV) Collection and assembly of data: T Joarder, S Zaman; (V) Data analysis and interpretation: All authors; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

*Correspondence to:* Samiun Nazrin Bente Kamal Tune, MPH. Abt Global, 13<sup>th</sup> Floor, Concord Bilkis Tower, 40/6, Madani Avenue, Gulshan 2, Dhaka 1212, Bangladesh. Email: samiun.tune@gmail.com.

**Background:** Childhood cancer persists as a prominent public health concern in low- and middle-income countries (LMICs), with only a 20% survival rate. In Bangladesh, 67% of healthcare expenses are out of pocket. Since 2012, World Child Cancer-UK (WCC-UK) has collaborated with Bangabandhu Sheikh Mujib Medical University (BSMMU) to address this issue. This evaluation aimed to assess the project's purpose and impact, delivering insights to donors regarding their contributions, best practices, lessons learned, potential challenges encountered, and recommendations for future project development or refinement.

**Methods:** This study employed a qualitative method to evaluate the WCC-UK project objectives from May to June 2017. It involved seven document reviews and nine key informant interviews (KIIs) with project leadership, collaborating partners at the Hub and Satellites, management staff, and Twinning Partners. Besides, two in-depth interviews (IDIs) were carried out with certain beneficiaries, particularly parents of children with cancer. Thematic data analysis was performed to emanate the findings.

**Results:** Despite facing challenges such as an unclear management structure, ambiguous patient eligibility criteria, personnel issues, and communication gaps, the project made strides in several areas. BSMMU provided essential space and leadership, while Satellite Centers supported the project with continuing medical education (CME) and data entry. The project offered subsidies to poor patients and improved cancer awareness among healthcare providers and service seekers. Despite some parents receiving health and nutrition education during their hospital stays, developing a long-lasting system to educate them about long-term cancer care for their children was found to be formidable. The analysis also highlighted staffing shortages, a hierarchical gap between physicians and nurses, and a predominantly male leadership structure.

**Conclusions:** While the project has made progress toward its goals, there are critical areas that require attention to fully realize its objectives. Specifically, it is recommended that the project clarify its management structure, establish clear patient eligibility criteria, address staffing and communication issues, and work towards a more inclusive leadership. These improvements are essential for the project's long-term success and sustainability.

**Keywords:** Childhood cancer; palliative care (PC); Bangladesh

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<sup>^</sup> ORCID: Taufique Joarder, 0000-0002-3299-2628; Samiun Nazrin Bente Kamal Tune, 0000-0003-0308-2817; Shahaduz Zaman, 0000-0003-1340-1869.

## Introduction

Childhood cancers are the ninth most common cause of childhood illnesses (1), and 200,000 children are newly diagnosed with cancer worldwide each year (2). Among them, 80% belong to low- and middle-income countries (LMICs), where resources and drugs (or pharmaceuticals) are scarce for the treatment of cancer or providing pain relief. The survival rate of children is also significantly skewed towards the high-income countries (HICs), where 80% of children with cancer survive, as opposed to only 20% in LMICs (2). Despite resource constraints, some initiatives may still be effective in improving the survival and quality of life of child cancer patients in LMICs. For example, generic drugs and relatively simple treatment

procedures can be used within the existing healthcare systems (3).

Bangladesh is an LMIC with a per capita income of \$2,688.3 (in current international \$, World Bank data 2022) (4). Only 27.9% of the public expenditure is spent on health, and the per capita expenditure on healthcare is only \$31. Bangladesh has one of the highest out-of-pocket payment rates, which is 67%; and 90% of this is spent on medicines; 74% of the people are at risk of catastrophic expenditure for surgical care, and 79% are at risk of impoverishment due to surgical expenditure (4).

There is no population-based child cancer database in Bangladesh, so it is difficult to provide accurate statistical data. However, it is estimated that there are between 4,200–8,000 new childhood cancer cases per year [based on International Agency for Research on Cancer/World Health Organization (IARC/WHO) standardized incidence rates of 80–150 cases per million children aged 15 years and under] (4).

The largest centre for treating children with cancer in Bangladesh is the government-funded, but self-governed institute called Bangabandhu Sheikh Mujib Medical University (BSMMU) in Dhaka. It diagnosed 350 children between September 2012 and August 2013 and strives to collaborate with other government-funded hospitals (5). However, the number of new cases has increased over the years. An estimated 9,000 to 12,000 children are diagnosed with cancer annually in Bangladesh, yet only one-third of them receive proper diagnoses (6). These hospitals each see a relatively small number of cases each year and do not have trained staff or the resources to treat these cases. It is estimated that at most 1,000 children with cancer (12–24% of all suspected cases) can receive some supportive care and even less curative care. The average survival rate for a child diagnosed at BSMMU is 48% for 1-year event-free survival. Survival rates at district hospitals are probably no more than 20% (anecdotal evidence). Moreover, due to delayed diagnosis and the presence of advanced disease upon initial assessment, more than 20% of children were categorized as incurable at the time of diagnosis, and an additional 10% faced mortality during the early stages of treatment (5). The WHO has introduced a public health strategy to ensure that palliative care (PC) knowledge is accessible to all children facing life-threatening or life-limiting conditions (7). Unfortunately, Bangladesh has a limited number of PC services, most of which are customized to specifically address the needs of adult cancer patients (8).

### Highlight box

#### Key findings

- The World Child Cancer (WCC)-funded twinning partnership effort provided favourable results such as the provision of pharmaceuticals at cheaper prices and a strengthening of data plans, treatment protocols, procedures, and capacity. It did, however, encounter initial administrative challenges and differing opinions from the community.
- Due to poor planning pertaining to the budget and constraints on human resources, sustainability issues persisted.

#### What is known and what is new?

- The WCC-UK-funded initiative targeted enhancement in child cancer care in Bangladesh, facing managerial challenges and sustainability issues.
- Progress was made in capacity building, medication access, and data integration, highlighting the importance of increased community involvement, and addressing gender imbalances in healthcare leadership for sustained effectiveness.

#### What is the implication, and what should change now?

- The implication suggests that although improvements have been achieved in child cancer care, there's a pressing need to refine approaches for lasting impact.
- Therefore, changes should prioritize strengthening community involvement, rectifying gender imbalances in healthcare leadership, improving sustainability measures, and refining managerial frameworks to ensure enduring success in child cancer care endeavors.
- Future actions should handle shortcomings in project management, community engagement, and human resource allocation. Initiatives should focus on producing a sustainable framework, learning from past ventures, and managing cultural aspects influencing care practices in Bangladesh. Besides, long-term financial support should be ensured.

**Table 1** Evaluation methods, sample size and study tools

Method	Tools	Sample	Number
Document review	Thematic guideline	Project documents	7
KII	KII guideline	Project leadership	2
		Collaborating person at the hub	1
		Collaborating persons at the satellites	2
		Management staff	2
		Twinning partner	2
IDI	IDI guideline	Beneficiaries	2

KII, key informant interviews; IDI, in-depth interviews.

To improve the situation, World Child Cancer-UK (WCC-UK) has been working in Bangladesh since January 2012 at the BSMMU in Dhaka. WCC-UK has facilitated an international twinning partnership between the BSMMU and two hospitals in Canada and the UK, respectively—British Columbia Children’s Hospital (BCCH) and University College London Hospital (UCLH). The project ran for 5 years (9). The project worked to improve the outcomes for children with cancer by increasing the collection of statistical data, providing training for doctors and nurses, and assisting with the provision of medicines. Capacity building was a key component, with training for healthcare professionals and the establishment of electronic databases for patient management. The project also involved awareness campaigns, the development of shared care protocols, and the creation of support groups to foster community engagement and sustainability. WCC-UK provided strategic oversight, and fundraising, and facilitated international partnerships, while the satellite centers worked to improve local diagnosis, treatment, and care for children with cancer (10,11). An overview of the project, including detailed activities, is provided in [Appendix 1](#). This study aimed to qualitatively evaluate the management, partnership, beneficiary impact, and sustainability potential of the WCC-UK project implemented in BSMMU, Bangladesh.

## Methods

### Study design

This evaluation employed qualitative methods in 2017 in Dhaka, Bangladesh. It included document reviews, key informant interviews (KIIs), and in-depth interviews (IDIs).

*Table 1* provides an overview of the evaluation methods employed in the study. *Figure 1* summarizes the intervention, the details of which are available in [Appendix 1](#).

Further details of these methods are described below.

### Document review

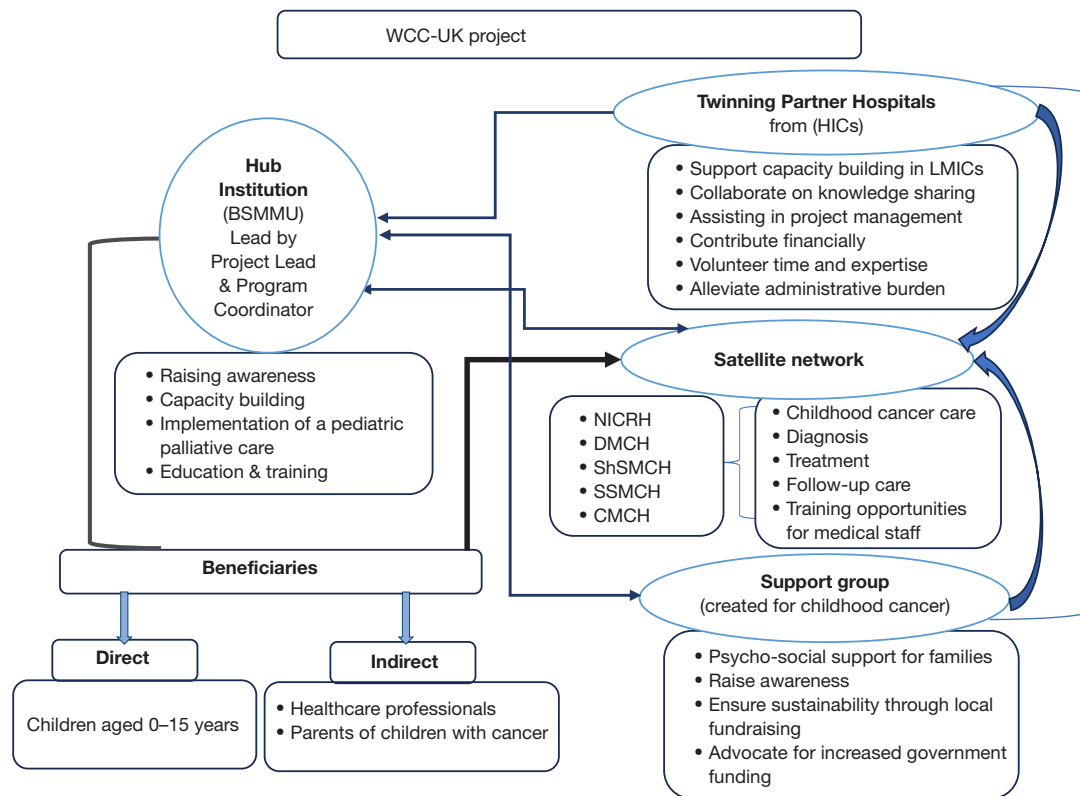
Documents related to the project were collected and reviewed to gain a better understanding of the project. The review also informed the KII and IDI guidelines, i.e., which areas for the project to probe further. Documents were identified by consulting with the project personnel. These included the project proposal, mid-year reviews, annual reviews, guidelines developed through the project, and other relevant documents prepared during the project period.

### KIIs

KIIs were conducted with the project’s leadership, management personnel, and other relevant stakeholders.

The list of interviewees includes:

- (I) Project Lead;
- (II) Programme Coordinator;
- (III) Chair of the Department of Paediatric Oncology, BSMMU;
- (IV) Drug Subsidy Administrator;
- (V) Charge Nurse;
- (VI) Coordinator of the Satellite at the National Institute of Cancer Research and Hospital (NICRH), Dhaka, Bangladesh;
- (VII) Coordinator of the Satellite the Sylhet Osmani Medical College Hospital (SOMCH), Sylhet, Bangladesh;



**Figure 1** WCC-UK project overview. WCC, World Child Cancer; BSMMU, Bangabandhu Sheikh Mujib Medical University; HICs, high-income countries; LMICs, low- and middle-income countries; NICRH, National Institute of Cancer Research and Hospital; DMCH, Dhaka Medical College Hospital; ShSMCH, Shaheed Suhrawardy Medical College and Hospital; SSMCH, Sir Salimullah Medical College and Mitford Hospital; CMCH, Chittagong Medical College Hospital.

- (VIII) A nurse, with experience in visiting Bangladesh, from a twinning partner at the UCLH, London, UK;
- (IX) A doctor, with experience in visiting Bangladesh, from a twinning partner at the UCLH, London, UK.

### IDIs

IDIs were conducted with some project beneficiaries. Since the project is already over, no patients were staying in the hospital facilities involved in the project at the time of the evaluation. Therefore, finding beneficiaries was difficult. However, coordinating with the former project leadership and management (Project Lead and Project Coordinator), we managed to interview two beneficiaries:

- (I) Caregiver of a child patient suffering from leukaemia;
- (II) Attendee of health education session organized by the project.

### Sampling, tool development, and data collection technique

The data collection, as well as the interviews conducted for the study, took place during the second and third weeks of May 2017. All the study participants were selected through purposive sampling. Key informants were identified through the review of the project documents and were the most knowledgeable people and most closely involved in the project implementation. Project beneficiaries were identified by the project implementers to have firsthand experience of receiving the benefits from the project. Separate data collection tools were developed for KIIs and IDIs, through consultation between the first (T.J.) and the senior author (S.Z.). The tool encompasses project management, with a particular focus on partnership management. It addresses the impact on final beneficiaries and their caregivers, as well as potential sustainability. Detailed information about the tool is provided in [Appendix 2](#). The first author (T.J.)

conducted interviews with participants at their preferred times and locations. Most interviews were conducted in Bengali, the mother tongue of the respondents from Bangladesh. However, the twinning partners, who were from the UK and Canada, were interviewed in English, also in their mother tongue. Verbal and written consent were obtained from all participants before the interviews, and they were informed about the project objectives. Only the consenting participants were interviewed in the study. The interviews lasted 30 to 45 minutes and were all audio recorded. Handwritten notes were also taken to avoid the possibility of data loss.

### **Data analysis**

Verbatim transcripts were prepared for each interview and then anonymized by removing their identifying information. The transcripts underwent a thorough review by the researchers, with a minimum of three readings to ensure a comprehensive understanding of their contents. The subsequent data analysis was conducted meticulously, characterized by precision, consistency, and exhaustiveness. This process involved recording, systematizing, and transparently detailing the analytical technique, providing readers with adequate information to determine its credibility. Thematic data analysis was conducted manually by color-coding the transcripts (12). The initial codes were formulated based on existing literature as a priori codes, while inductive codes emerged during the process of becoming familiar with the data. Subsequently, these evolving codes were applied to specific text segments. The first (T.J.), second (S.N.B.K.T.), and senior author (S.Z.) coded the transcripts separately to ensure inter-coder reliability. After coding segments of transcripts, they discussed reconciling the discrepancies among themselves. The following themes were used for data analysis:

- (I) Management aspects;
- (II) Partnership aspects;
- (III) Impact on beneficiaries;
- (IV) Sustainability potentials.

While our analysis process involved reviewing transcripts and grouping similar contents under each theme, we applied codes to segments of the data to identify patterns and themes. Simultaneously, we grouped similar sub-themes under main inductive themes to further organize the data. This allowed us to develop a reliable storyline that expressed the essence of our findings. Eventually, the analysis was conducted with transparency and maintained its credibility.

The senior author (S.Z.) played a crucial role in maintaining the four key components of data trustworthiness: credibility, transferability, dependability, and conformability. He ensured the trustworthiness components through random checks of the transcript, ensuring quality by comparing transcripts with recordings of KIIs and IDIs. In case any discrepancies were found, they were revised by the data collection team and transcriber. Furthermore, he conducted double checks to maintain data trustworthiness. Data triangulation involving document review, KIIs, and IDIs was conducted to validate findings, further enhancing the study's qualitative data reliability. The thematic analysis of the document review was also conducted by the first author (T.J.) and the senior author (S.Z.).

### **Ethics approval**

The evaluation was approved by the Ethical Review Committee of the James P Grant School of Public Health, BRAC University (Protocol # 2017-008). When the study was conducted in 2017, the first author was an Assistant Professor of BRAC James P Grant School of Public Health, BRAC University. He conducted the study as a Consultant and was eligible to get the research review by his institution. All ethical principles were strictly adhered to. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Informed consent was obtained from all individual participants.

## **Results**

### **Management aspects**

#### **Management and decision-making structures**

The Programme Coordinator effectively maintained a structured management protocol. She created a monthly work plan, which was approved by the Project Lead and subsequently implemented. All activities were diligently recorded in an event log. The coordinator stated, “*I came sometime in the middle of the project period. Some of the management aspects of the project were not quite orderly at the time I joined. I tried to maintain a defined protocol and responded to WCC-UK's demands in this regard*”—project leadership.

Despite these efforts, the project lacked a specific management structure in several areas. For instance, there was no formal memorandum of understanding (MoU) between the Hub (BSMMU) and the Satellite Centres, nor a formal term of reference (ToR) or job description

for the Coordinators of the Satellite Centres. This lack of formal structure made it difficult to hold stakeholders, such as Satellite Center Coordinators, accountable for project requirements. The line of authority was not explicitly defined, leading to confusion among project personnel about their roles and responsibilities.

The Twinning Partners also lacked clear guidelines, leading to uncertainty about whom to report back regarding their assignments. The Twinning Partner representatives, who were volunteering their time to WCC, were formally accountable to WCC-UK, despite working practically with the Project Lead and the Head of the Department of Paediatric Oncology Department.

The project did maintain a record of drug distribution, but it lacked a formal definition of eligible recipients for free drugs. Information about the availability of free medicine for poor patients was not properly disseminated, and patients typically learned about this facility through word of mouth. The Drug Subsidy Administrator never gave the whole course of medicine to any patient at a time to prevent the possibility of patients selling the drugs outside. The drugs were given to the nurse, who then administered them to the patient. However, since there was no formal screening mechanism to identify the poor, drugs were dispensed to all patients. The Drug Subsidy Administrator was instructed to clarify to the patients that the drugs were intended for the poor, and economically solvent patients were requested to purchase their medicine from the open market.

### **Integrated management and analysis protocols**

The project utilized a database known as the Paediatric Oncology Database (POnD) to record patient data at both the Hub and Satellite Centres. This database was installed at BSMMU by St. Jude Children's Research Hospital, based in Memphis, USA. Satellite Centre Coordinators were responsible for recording patient information in POnD and sharing it themselves, as there was no separate operator for this task. A Coordinator at a Satellite Centre commented,

*"We are clinically trained, but very bad with the technology. POnD is an easy software, however, we often found it difficult to comply with the requests of WCC for data, given our high patient load and lack of a dedicated person to operate it."*—collaborating partner at a Satellite Centre.

The data collected proved to be invaluable for both clinical and management decision-making. Notably, the system helped reduce the treatment abandonment rate from 34% to 18% by enabling easier patient tracking and

communication. The data also facilitated the detection and subsequent addressing of high infection-related mortality.

The project also contributed to the development of a common protocol for managing child cancer patients, an initiative that was later adopted by several other institutions. This success was largely due to the network of physicians developed through the project's capacity-building activities. A nursing curriculum or guideline, now widely shared, was also developed primarily through WCC-UK funding.

Strict record keeping was maintained for drug distribution. The Drug Subsidy Administrator would estimate the monthly requirement and forward it to the Accounts Manager, who would then place a requisition with the Programme Coordinator. Once approved by the Project Lead, the Programme Coordinator would purchase the required amount from a local drug company. For drug disbursement, the duty physician would send a slip with the patient's name, diagnosis, and medicine name to the Drug Subsidy Administrator, who would then distribute the drug to the patient and record it in the medicine logbook.

### **Developing and nurturing local or community support**

As part of their community mobilization efforts, the program implementation team organized various activities such as rallies and seminars on WCC Day. However, the majority of clinician respondents expressed skepticism about the potential and benefits of community engagement. This skepticism is often attributed to the lack of community orientation and a reductionist approach to health conditions common among Bangladeshi physicians. The Project Lead questioned, *"I am not sure what you are referring to by community support. Child cancer is a rare disease, and there is hardly anything that can be done in the community setting."*—project leadership.

Contrary to this viewpoint, the Twinning Partners emphasized the importance of family or community involvement in a child's treatment. They cited the example of the Tata Memorial Hospital in Kolkata, where treatment is primarily home-based rather than hospital-based. They suggested that if the project is renewed, it should focus on enhancing the capacity of caregivers in addition to physicians and nurses.

### **Movement for funding for drugs or PC**

Numerous private organizations have stepped forward to support child cancer patients. For instance, the Akij Foundation, a prominent Bangladeshi business conglomerate, began donating Taka 200,000 worth

of medicine per month to underprivileged patients. Additionally, some staff members have also contributed by donating medicine and other essential items for these patients. The Project Lead stated, “*Currently Ramadan (the Muslim month of fasting) is approaching. Many doctors are giving their zakat (a certain percentage of income donated by Muslims) money in this fund to give medicine to the poor child cancer patients.*”—project leadership.

Contributions have also come from expatriate physicians living abroad. Furthermore, wealthy relatives of patients who have been cured from the department often donate to this fund. The Ashic Foundation has established a home for poor patients and their attendants who travel from outside Dhaka and require accommodation. Similarly, the Paediatric Hemato-Oncology Society has created a home on the outskirts of Dhaka, on a piece of land donated by a philanthropist. They have also purchased an ambulance to transport patients.

### Main challenges in project management

One of the main challenges faced in the early stages of the project was maintaining the accounts. This issue was later addressed by the recruitment of a Programme Coordinator by WCC-UK. However, the Project Lead expressed a preference for someone with additional training in medicine, reflecting a hierarchy among Bangladeshi clinicians, especially physicians, over non-clinicians. The project reportedly required a manager with some understanding of cancer morbidity, which was difficult to communicate with someone lacking a clinical background.

Another management shortfall, as highlighted by the Head of the Department of Paediatric Oncology at BSMMU, was a gap in internal communication. The Project Lead did not keep him updated about medicine distribution, leading him to suggest that the project leadership should engage the department more in various decision-making processes. He stated,

*“There is often an information gap between me and the Project Lead, which is not at all desirable. I am never informed how many drugs are received and how it is being distributed. I try my best to cooperate. But if this cooperation is extended from everyone, then this gap could have been well mended.”*—collaborating partner at the Hub.

In terms of drug distribution, the main challenges, according to the Drug Subsidy Administrator, were that many patients requested drugs after office hours and had difficulty locating him due to the lack of a specific room

or office. His mobile number was printed on a paper and pasted in different places within the Paediatric Oncology Department, and patients often had to call him to set an appointment and obtain free drugs.

For nurses, the challenge was their lack of knowledge in pediatric oncology care. They requested a morning educational session, similar to that of the physicians, either separately for the nurses or in conjunction with the physicians. A nurse said,

*“We did not have any knowledge on paediatric oncology prior to coming here (Paediatric Oncology Department). So, if we could either stay with the physicians in the morning with education sessions; or at least have a separate session among ourselves (Nurses), that would improve our skills.”*—nurse at the Hub.

### Partnership aspects

#### Fulfillment of obligation by different partners

The main partner of the project was the Hub, specifically the Paediatric Oncology Department of BSMMU. They provided space, permitted activities, volunteered their time and effort, and the Project Lead offered overall leadership. Both the Project Lead and the Head of the Department acknowledged the importance of such a project and expressed their support for it.

The Satellite Centre partners also demonstrated a keen interest in collaboration. They recognized the importance of this partnership and organized many continuing medical education (CME) sessions with physicians from various departments. One Coordinator stated, “*Since pediatric oncology is a multi-disciplinary field, we invited all relevant departments to our CMEs. For example, we involved radiology, surgical oncology, etc.*”—collaborating partner at a Satellite Centre. They primarily involved physicians but occasionally invited nurses as well. They organized these programs every two to four months. Most of their activities were geared towards service providers, less so towards patients. However, they did organize WCC Day, an art competition for children, and a sports event.

The Twinning Partners visited Bangladesh and primarily contributed to capacity building. They visited the Wards, held sessions with nurses and physicians, and shared their experiences from their home institutions. They introduced a monthly award, ‘Nurse of the Month’, which was highly appreciated by the local nurses. The Project Lead said,

*“Doctors and nurses came and stayed for weeks in a difficult place like Bangladesh. They were nice and very helpful. We*

*did not pay them anything. They took leave from their home institution and came here to contribute voluntarily.*—project leadership.

There were no reported or observed partnerships with community-based organizations or non-governmental organizations (NGOs).

### Reflections from the Twinning Partners

According to a nurse from the Twinning Partner, their training in Bangladesh encompassed a variety of topics including the foundation of oncology care, hygiene, infection control, and family education and support. They also conducted observations in the ward and engaged in spontaneous teaching while observing the nurses at work.

The Twinning Partners also participated in a medical symposium and nurses' work, which involved a combination of classroom teaching and hands-on training. The primary goal of their visit was to enhance the knowledge and skills of the doctors and nurses.

They introduced scenario-based training, which involved both doctors and nurses. This type of learning was found to be beneficial. However, according to the respondents from the Twinning Partners, it was uncommon for doctors and nurses in Bangladesh to study together. One of the Twinning Partners recalled,

*“I remember during my first visit in 2012, a female registrar doctor oversaw translating for me. She said, ‘Gosh, these nurses are smart; I had no idea. I had no idea about their capacities to retain information, to ask challenging and thoughtful questions.’ And she was amazed.”*—Twinning Partner.

### Challenges in partnership and recommendations from them

From the Hub's perspective, the project was highly beneficial, particularly due to the partnership with the Twinning Partners. The nurse at the Hub stated,

*“I am very much thankful to WCC-UK for the project, especially for bringing in the experts from the Twinning Partner hospitals. I learned a lot from them.”*—nurse at the Hub.

The Nurse suggested that visits from the Hub to the Satellites would also be beneficial for cross-learning. The Head of the Department suggested using electronic media to foster more frequent meetings and activities with partners.

From the Satellite Centres' perspective, the partnership could be more effective if free medicine for poor patients was provided. They also faced challenges due to a lack of a dedicated person to carry out many activities requested

by the Project Lead. They requested a person to enter and analyze data using POND, as the Data Manager's role was limited only to the Hub. They recommended more exchanges between the Satellite Centres and the Hub.

The Twinning Partners reported the main challenges around hierarchy and gender. They pointed out that nurses were not empowered, which compromised their ability to serve patients more innovatively and effectively. This was attributed to the hierarchical structure. In terms of gender, all senior management positions were held by males. Language was another challenge, as Bangladeshi nurses often struggled to follow instructions given in English. This issue was resolved by arranging English language classes for the nurses. The Twinning Partners were curious about how much of the learning from overseas training was disseminated back in Bangladesh, especially in the context of a hierarchical system where proactive dissemination by nurses might be restricted.

### Impact on beneficiaries

#### Social, psychological, and economic impact on patients or caregivers

The drug subsidy provided by WCC-UK was the last hope for many impoverished patients. As seen by the respondent service providers, many people turned into beggars or rickshaw pullers just to bear the cost of the medicine for their children. The father of a patient suffering from lymphoma stated,

*“I had spent all my money to treat my daughter. After many days of treatment, when I was almost broke, I came across the Drug Subsidy Administrator. The Administrator reportedly said some medicine had been donated as zakat for the poor patients. Zakat or not, I had no other way to continue the treatment without free medicine (Vincristine).”*—father of a patient.

He expressed that he would have benefited more had he known about this subsidy earlier.

Similarly, the mother of another patient suffering from leukemia shared,

*“When I first came here, I did not know anybody; I had to buy all the medicines myself. I saw a neighboring patient taking a piece of paper from the doctor and bringing in medicine for free. I asked her what this paper was about. She said, don't you know, they give Vincristine for free from here.”*—mother of a patient.

She also said that most of the patients did not know about this. She said, *“We are often afraid of the big doctors. We can't reach them to talk about our misery. They help if we do, but we don't know how to reach them in the first place.”*—a patient's



mother. She also suggested that providing free antibiotics, in addition to cancer drugs, would be even more beneficial to patients as most cancer patients developed infections.

To provide social and psychological support, WCC-UK established a playroom for children. However, it was not properly maintained and lacked an assigned person to accompany the children. Since the phasing out of the project, another organization, Ashic Foundation, has been maintaining the room.

One of the Satellite Centres, NICRH, organized an art competition for child cancer victims to keep them engaged and happy. The visit by Twinning Partners reportedly enhanced their prestige and built trust and acceptability among patients. One Coordinator said,

*“Activities of WCC-UK, especially the twinning partners, helped develop confidence among our patients. When they saw people from abroad coming, they developed trust in our activities. It enhanced the prestige of our institutions.”*—collaborating partner at a Satellite Centre.

The Twinning Partners also acknowledged the benefits of the project, noting improvements in care organization between their visits.

### **Impact in terms of awareness, nutrition, and hygiene**

Nurses organized health education sessions, which they learned from the Twinning Partners, with patients in the presence of physicians. Patients were instructed on how to cook nutritious diets for their children, wash hands, keep clean, etc. The father of a patient informed that he learned about the condition of his child better from the sessions. He said,

*“Attending patient education sessions, I learned about metastasis, prognosis and the signs and symptoms. This was useful as I understood when to contact the physician immediately.”*—father of a patient.

He also learned about the importance of cleanliness, hygiene practices, hand washing, and a nutritious diet from these sessions. He said the sessions were clear and easy to understand, but he expressed concerns about the quality of care, responsiveness, and competency of the nurses.

The Twinning Partner Nurse reported that there was more cancer awareness observed during her last visit compared to her earlier visits. According to her, data also suggested there was less attrition on treatment, indicating a greater understanding among patients about the treatment.

### **Impact on the capacity of the service providers**

Two nurses from the project went to Pakistan for 18 days

of training on pediatric oncology nursing, with another training visit to Thailand scheduled shortly after, all thanks to the WCC-UK project. The nurses reported a significant improvement in their knowledge and practice due to the WCC-UK project activities. One nurse at the Hub expressed gratitude for the training received from the Twinning Partners stating,

*“The training was very helpful. I would like to thank them, particularly for the special type of bandage that they taught us. Even now, when there is any extravasation, I find this bandage quite helpful; and feel grateful to the trainers.”*—nurse at the Hub.

The project also contributed to the capacity development of Satellite Centre personnel, as their staff received training at the Hub (BSMMU). A collaborating partner at a Satellite Centre noted,

*“Many doctors said that even they did not know that cancer patients can get cured. Now you will not find this type of comment from doctors. This means they became aware, and WCC-UK should be acknowledged for a large part of it.”*—collaborating partner at a Satellite Centre.

In one of the Satellites, WCC-UK sponsored a staff member to go to Chittagong and train their staff on how to do data entry and analysis in POnD. The Coordinators suggested that this database should not be limited to BSMMU or Satellite Centres, but should be introduced throughout the country.

According to a Twinning Partner Nurse, there was a hunger for training among Bangladeshi nurses to learn about oncology care. However, they showed less interest in teaching the patients how to care for their children. Despite this, there was reportedly much better understanding and practice around infection control and hygiene practice among the caregivers. The nurse also noted that many doctors and nurses were coming from Satellites, so the knowledge and skills were being disseminated in many parts of the country. Many Bangladeshi nurses were found to be compassionate about providing care to child cancer patients.

### **Sustainability potential**

#### **Potential activities to be carried on by local partners**

The project team extended their activities beyond the designated Satellite Centres, reaching additional locations such as Mymensingh and Comilla Medical Colleges. The team's efforts in building awareness about child cancer were successful in convincing policymakers to establish pediatric oncology departments in several other medical colleges.

The Project Lead reflected on this expansion, stating,

*“There are patients in other places too, and they also need treatment. So, can we limit ourselves just to these five Satellite Centres, under the WCC-UK project?”*—project leadership.

The knowledge and training in pediatric oncology received by the nurses and physicians are sustainable and continue to be applied to patient care even after the project's completion. The sustainability of knowledge and training in pediatric oncology is achieved through community engagement, policy advocacy, resource mobilization, institutionalization of services, and shared protocols. Many nurses expressed appreciation for the capacity development sessions, such as the morning sessions, and suggested their continuation beyond the project period. The Programme Coordinator emphasized the sustainability of these activities, stating,

*“Sirs need to be convinced that activities are not finished with the finishing of the project. They can still do many things. I believe they will do it, as they are dedicated.”*—project leadership.

The drug subsidy continues after the project's completion, thanks to donations from different organizations. The Project Lead is maintaining the salary of the Drug Subsidy Administrator from other sources. The Satellite Centre Coordinators have also expressed their commitment to continuing the CME sessions. The shared protocol developed during the project has the potential to be utilized for a long time. Lastly, the POnD can continue to guide decisions through the data it stores.

### Challenges to sustainability

Despite encouraging notions of sustainability, respondents identified several challenges. A significant challenge identified by many was the constraint of human resources. Twinning Partners emphasized the need for staffing the playroom, which they considered crucial for distracting child cancer patients from their pain. A nurse from a Twinning Partner hospital stated,

*“I found the small children lying listless all day in the bed. I felt pity for them. There is a playroom in the ward, but unfortunately, there is no one to attend the children there.”*—Twinning Partner. They also recommended increasing the number of nurses to allow them time to play with the kids and provide better care.

Another sustainability challenge identified by the Twinning Partners was the arrangement of wards according to consultants' preferences, rather than the needs of patients. Some beds were located far away from the nursing station to facilitate consultants' ease of access,

compromising patient care due to the distance from the nurses' reach. This situation threatens the project's success as well as sustainability.

Satellite Centre Coordinators identified a lack of funding as an obstacle to organizing CME sessions. These issues could potentially be addressed with additional attention and resource mobilization.

The evaluator noted that there were no clear plans for financial sustainability, as understood from interviews with the project leadership. Although medicines for poor patients were being provided by a private organization, there was no clear and structured plan for further fundraising. It was uncertain how long and in what form this philanthropic flow of medicine would continue. Most Bangladeshi respondents preferred to rely on the traditional method of maintaining a poor fund or medicine bank donated by physicians. Generating larger sustainable donations was not seen as a priority. The evaluator felt that it was important to have a clear plan for fundraising.

### Discussion

Over the course of 3 years, this WCC-UK-funded twinning partnership project displayed a partial impact across various dimensions. It contributed to the enhancement of capacity in child cancer care, promoted the establishment of integrated data systems, and facilitated the development of shared care protocols, in addition to providing free or subsidized medications for child cancer care. However, the project encountered initial managerial challenges, and its community engagement initiatives elicited mixed reactions. While it achieved some positive outcomes, the project still struggled with sustainability challenges due to constraints in human resources and a lack of clearly defined financial plans.

#### *Awareness and capacity building in child cancer care*

One of the important objectives of the project was to raise awareness about child cancer among different stakeholders. We found this objective addressed as both service providers and service seekers were found to have a better awareness of this condition. This change in the level of awareness was noticed and reported by the Twinning Partners, who visited the project both towards the beginning and end of the project. Training and capacity building for healthcare professionals need to be integrated into the functions of a pediatric care unit, along with the provision of follow-up

and PC for child cancer patients (13). Capacity building was another objective, which was also aptly addressed by the project. The nurses attended overseas training on pediatric oncology, physicians in both the Hub and the Satellites attended CMEs, and all staff reportedly benefitted from the experiences and expertise shared by the Twinning Partners—all denoting improved capacity. The Twinning Partners also acknowledged a positive change in this regard.

### *Integrated data and shared care protocol*

A shortage of high-quality data on pediatric PC exists globally (14). Thus, improving the collection of statistical data was another purpose of this project. We found that data, crucial for clinical management and long-term decision-making, were generated through the project, with the contributions from both the Hub and the Satellites. POnD, a software installed by Saint Jude Children's Research Hospital, was being used by the project for data collection. Some important decisions were also made, informed by the statistical analyses of the data.

The Project Lead took the initiative to develop a shared care protocol, which was another goal of the project. As we found, a shared protocol and an elaborate nursing care guideline were developed, largely through the project money. These have not only been used by the Hub and the Satellites but also by several other institutions beyond the scope of this project. That shared care protocol was developed between the hub hospital and the satellite centers to ensure that children receive as much treatment as close to their homes as possible. In a roadmap developed in India, it was suggested that incorporating PC into pediatric oncology using a shared care model approach could help create a national collaborative policy to reduce disparities in childhood cancer care access (15). Such an approach could also be effective for Bangladesh as well.

### *Medications in child cancer care*

Ensuring access to affordable essential medications for pediatric cancer treatment is crucial for maintaining continuous care and preventing loss of follow-up (16). The project did not limit itself to distributing anti-cancer drugs to poor patients; rather, it embarked on convincing other private organizations to contribute to this venture. A renowned Bangladeshi corporate organization, Akij Foundation, has come forward to donate medicines; another organization, Ashic Foundation, developed a home for the

attendants of poor patients. Even physicians were found donating to the medicine bank. However, a clear plan for larger donations or fundraising was not evident.

### *Community engagement*

It is expected that all stakeholders, including governing authorities, policymakers, health service providers, civil society organizations, and communities, should collaborate to support WHO's global goal of achieving a 60% childhood cancer survival rate by 2030 (17). One important objective of the project was to develop and nurture local support groups and the local NGOs. This objective, however, was partially fulfilled. Although some parents were given health education and nutrition messages during their stay in the hospital, a more sustainable approach to educating them in long-term cancer care for their children was not found. Community-based or family-oriented cancer care has been suggested by Twinning Partners, who gave examples of such efforts by Tata Memorial Hospital in Kolkata. Some local activities in favor of cancer care and support were found, e.g., medicine donation by the Akij Foundation, building homes by the Ashic Foundation, and contributions by the Paediatric Oncology Society and individual physicians.

It is evident that this project fared well in addressing most of its objectives. However, the weakness of the project mainly lies in its management structure and initial planning in this regard. As a result, it was not possible to hold the stakeholders responsible, had they failed to comply with any project requirement. Another weakness was its failure to engage the community or involve the families in patient care. Some of the weaknesses in the program may be easily addressed, based on the project learning, through careful designing of similar programs in the future. However, some weaknesses are more inherent to the Bangladeshi culture and the historical development of care practices in the country (18). Openness to the shortfalls and attention to them in future endeavors would serve child cancer patients better in the future.

### *Human resource issues*

The shortage of nurses compromised their care. There was no separate data operator or dedicated person to carry out different activities expected from the Satellites. Demand for an appropriately trained manager was also pronounced. An earlier study also revealed shortages in human resources and a lack of adequate infrastructure for childhood cancer

care in several LMICs, including Pakistan, Jordan, Iraq, and Lebanon (19). Moreover, the hierarchical distance between physicians and nurses, and a male-dominated leadership were reported in this study. These might limit the leadership role of nurses, e.g., in organizing morning sessions, disseminating the learning from overseas training, etc.

### *Limitations of the study*

Since the project had ended before the evaluation of this study, it was not possible to reach a vast number of parents of children who received cancer treatment through the project. This impediment resulted in an insufficient beneficiary perspective. Likewise, due to time constraints, the study could not reach out to the key informants from recently added institutions to the WCC-UK project, such as Mymensingh Medical College and Comilla Medical College and Hospitals. Moreover, the data were collected in 2017, after over 3 years of the project had been completed, leaving about 2 years remaining. It would have given more depth to the scenario to collect data immediately after the completion of the entire project.

### *Recommendations*

#### **Improving patient identification and community engagement**

The research suggests that structured and easy criteria and methodology for identifying poor patients should be developed and strictly implemented. The project should shift its focus towards community engagement, and home/family-based child cancer care. Caregivers should be trained, along with clinical service providers. Better information sharing on the project activities and planned benefits for the poor needs to be devised. For example, all patients should learn about the project benefits right upon admission. The ways of garnering the benefits should be clearly delineated. The benefits should be provided in a way that is convenient for the patients.

#### **Reinforcing human resources and achieving financial stability**

Challenges to sustainability need to be further explored and solutions to them should be sought. For example, some sustainability challenges were human resource constraints, absence of staff and proper maintenance of the playroom, organization of wards according to consultants' preference (ignoring patients' welfare), lack of funding in Satellite

Centres to organize CMEs, etc. Also, there were no clear plans for financial sustainability. Solutions to these issues need to be implemented one by one.

#### **Addressing gender dynamics in healthcare leadership**

Some issues are more culturally ingrained, which demand long-term strategy building to be addressed. Issues around hierarchy and male domination fall under this category. In Bangladesh, most of the higher professional leadership positions are occupied by males (20). Nurses are not expected to take leadership in clinical or management decision-making (18,21,22). There is also a sense of hierarchy among the clinicians (especially physicians) over the non-clinicians (23,24). Lack of community orientation and reductionist approach to health conditions is also common among physicians. Trans-professional education (i.e., providing education to different professional groups, such as physicians and nurses, in the same classroom or close collaboration) should be encouraged both in general health professional education and in hospital-based training (25). Female leadership should be encouraged in higher positions in the department.

### **Conclusions**

The 3-year-long child cancer project accomplished its objectives of raising awareness regarding child cancer, capacity building, and improving data collection and shared care protocols. It also secured some support from private organizations for medication donations. However, the project had drawbacks in its management structure and community engagement. While some weaknesses can be addressed through improved program design, others are deeply rooted in cultural and historical factors. Acknowledging and addressing these shortcomings in forthcoming endeavors will be crucial to enhancing child cancer care in Bangladesh.

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*Ethical Statement:* The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. While the study was conducted in 2017, The first author was an Assistant Professor of BRAC James P Grant School of Public Health, BRAC University. He conducted the study as a Consultant and was eligible to get the research review by the BRAC James P Grant School of Public Health, BRAC University (Protocol # 2017-008). All ethical principles were strictly adhered to. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Verbal and written consent were obtained from all participants before the interviews, and they were informed about the project objectives.

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## Appendix 1

### World Child Cancer-UK (WCC-UK) project overview

A Professor from Bangabandhu Sheikh Mujib Medical University (BSMMU) served as the Project Lead, and he strove to build on the successes of the development of paediatric cancer care at BSMMU and extending the project to a nationwide satellite network. Satellite network was developed in the following institutions-

1. National Institute of Cancer Research and Hospital (NICRH), Dhaka
2. Dhaka Medical College Hospital (DMCH), Dhaka
3. Sir Salimullah Medical College and Mitford Hospital (SSMCMH), Dhaka
4. Sylhet M.A.G. Osmani Medical College Hospital (SOMCH), Sylhet
5. Chittagong Medical College Hospital (CMCH), Chittagong

### Project beneficiaries and benefits they receive

#### *A. Direct beneficiaries (boys and girls aged 0-15 years)*

1. Reduce child mortality and combat non-communicable diseases by increasing survival rates for childhood cancer
2. Increase access to curative treatment and palliative care for children with cancer, by providing them with the chance of a cure or effective pain relief for incurable cancer.

#### *B. Indirect beneficiaries*

##### **a. Healthcare professionals**

1. Development of knowledge, skills, and expertise amongst healthcare workers, including doctors, nurses, pharmacists, database managers and other support staff.
2. Empowerment of healthcare professionals to develop locally appropriate and sustainable solutions to the problems of childhood cancer in their country.

##### **b. Parents of children with cancer**

1. Improved awareness about childhood cancer, its potential curability, and the importance of completing the full course of treatment.
2. Financial support for the cost of drugs (where these are funded by the family), preventing many families from tipping over into poverty.
3. Psycho-social support for families provided through the support groups and social workers / nurses.
4. Empowerment of families to take an active role in the treatment and care of their children and support to become a strong advocate for the rights of children with cancer in their country.

##### **c. Hospitals**

1. Building capacity in the skills, knowledge and expertise of healthcare professionals working at the hospital in relation to the treatment of childhood cancer.
2. Positive impact on other departments of the hospital as a result of training provided through the childhood cancer project. For example, training in infection control and management is often disseminated through staff to other departments, having a positive knock-on effect, and an improvement in hospital facilities improve conditions for all professionals and patients.

## **Project description**

### *Activities by the Hub institution and the Project Lead*

The Project Lead in Bangladesh worked full-time on the project. However, during the second year of implementation of the project, WCC-UK introduced, with the agreement of the funder, the Department for International Development (DfID), a different management structure. WCC-UK hired a Programme Coordinator in charge of the project management, and the Project Lead (Also the Head of the Paediatric Oncology Department at BSMMU at the time of data collection) remained in charge of providing technical advice and leadership for the implementation of all the aspects of the project.

Over three years, the project was expected to establish a five-centre satellite network in Bangladesh (with BSMMU as the hub hospital in Dhaka). The focus had to be on providing curative treatment for curable and effective palliative care for those children with cancer that were too advanced or difficult to treat. The purpose of the satellite network was to extend access to diagnosis, treatment, and care to a larger population of children across a greater geographical area, thereby helping to reduce poverty and inequality.

WCC-UK managed the project through the local Project Lead, which was assigned the following activities.

### **Raising Awareness**

Raised awareness in the areas surrounding each satellite center through a public education awareness campaign to increase the accuracy of diagnosis and encourage earlier diagnosis. The local Project Lead directed the design, development, and implementation of the awareness campaign and worked closely with support groups, local non-governmental organizations (NGOs), and the Ministry of Health and Family Welfare (MoHFW).

### **Capacity building**

Built capacity in local hospitals by training staff in diagnosis, treatment, and care of children with cancer. The project funded new Nurse Educator and Database Manager posts.

Improved the collection of statistical data by establishing new electronic databases – specialist childhood cancer registries for recording patients' details, treatment plans and outcomes.

Developed shared care protocols between the hub hospital and the satellite centres to ensure that children receive as much treatment as close to their homes as possible.

### **Implementation of a Paediatric Palliative Care Service**

Improved the funding for drugs for curative and palliative treatment to improve access to treatment. This element of the project was expected to have helped prevent families from tipping into poverty by supplementing the cost of drugs, ensuring that children could remain on treatment and reducing the financial burden on families.

### **Education and Training**

Developed and nurtured local support groups / local NGOs to improve psycho-social support for children with cancer with the aim of reducing abandonment, providing training for fundraising to increase local donations, and supporting the public education campaign through public talks and the distribution of posters. These groups are critical to reducing the poverty associated with childhood cancer. Groups were expected to raise funding locally to supplement food and transport costs whilst the children received hospital treatment. Their support could prevent families from tipping into poverty.

### *Activities by the twinning partner hospitals*

Twinning partner hospitals in high income countries (HIC's) provided mentoring, advice, and guidance for medics. Whilst support groups from HIC's were to assist with mentoring and training for new groups at the satellite centres.



### *Activities by WCC-UK*

The role of WCC-UK was to facilitate the project and provide strategic oversight to ensure no duplication of efforts with other NGOs. Its responsibilities were to

- Secure funding for the project and manage relationships with funders through the charity's experienced professional fundraising team.
- Facilitate the twinning partner relationships between the hub hospitals and the hospitals in HIC's.
- Provide project management through the Operations Team in London. A member of staff will work on the project 2 days a week.
- Provide an independent review at the mid-term and end of the project by a member of the Project Committee not associated with the project.
- Monitor and evaluate the effectiveness of the project and the impact of funding.
- Disseminate information about the impact of the project amongst key stakeholders.
- Recruit support group twinning groups from HIC's.
- Provide fundraising and advocacy training for support groups / NGOs in Bangladesh.

### *Activities of the Satellite Centres*

Satellite centres were in district hospitals in strategic locations with high population densities and/or good communication links. The Project Lead was expected to identify several suitable hospitals for the satellite centres. The role of the satellite centres was to support the principles of the project and work with the hub hospital to achieve improved survival rates for children with cancer in each country. Specifically, the roles of the satellite centres were to:

- Provide improved diagnosis and access to treatment for children in its catchment area.
- Provide improved treatment and care for children in its catchment area, working within the shared care protocols developed with the hub satellite centre. This means that surgery and chemotherapy induction took place at the hub hospital, but follow-up treatment and day-care treatment were carried out at the satellite centre. The satellite centre would also manage ongoing problems such as infections and symptoms and/or pain relief management.
- Allocate a senior paediatrician as its lead childhood cancer representative for the project.
- Identify suitable community/family members for the creation of a new support group in its catchment area.
- Ensure that doctors and nurses are provided with study/training leave to attend training workshops at the hub hospitals or to undertake training internships.
- This is to note that the only resources made available to improve the satellites were those to organise training in the context of the twinning visits.

### *Activities of the Childhood Cancer Support Groups*

The creation of new groups was considered important to the success of the project. Groups were supposed to be run by volunteers providing their time pro bono. The project envisaged that each group had between 5 and 20 members. The role of each group would be:

- Reduced abandonment of treatment by improving psycho-social support for families.
- Raised awareness by giving talks and distributing awareness campaign posters in consultation with the local Project Lead.
- Developed long-term sustainability by fundraising from the local community for drug costs and food and transport costs.
- Advocated for increased government funding for childhood cancer treatment.

## Appendix 2 Development of Childhood Cancer Satellite Treatment Networks in Bangladesh KII and IDI Tool

### General objective of evaluation

At the end of this three-year long project this evaluation is being commissioned to understand, from the perspectives of the stakeholders the donors worked with, the extent to which this investment has helped the final beneficiaries (or not) to access to improved childhood cancer services during this period. The donors are interested to better understand the contribution they have made and evidence of good practice, as well as what lessons they can take away from this programme.

We are interested to hear from you about the following issues:

#### *A. Project management – with a special focus on the partnership [For KII]*

##### **a. Management aspect:**

1. What kind of management and decision-making structures were put in place to support the project implementation and how helpful/supportive were these structures?
2. What was done on the following aspects of management:  
-Record keeping, reporting, shared protocol development, statistical data collection?
3. Has there been any achievements in terms of developing and nurturing local support groups / local NGOs?
4. Has there been any improvement in terms of the funding for drugs for curative and palliative treatment?
5. What were the main challenges of managing the project? What steps were taken to address those challenges?

##### **b. Partnership aspect**

6. To what extent the different partners have fulfilled their obligations in this project?
7. How has each partner contributed to the achievement of the project's objectives?
8. Have there been any challenges working with any of the partners?
9. What was done to address those challenges?
10. What lessons are to be learned from this project about successful partnership work?
11. What were the main challenges of implanting the project, what went well?

#### *B. Impact on final beneficiaries (and their carers) [For KII and IDI]*

12. What social psychological and economic impact has been created in beneficiaries or carer's life?
13. Has there been any impact in terms of raise of child cancer awareness in the areas surrounding each satellite center through a public education awareness campaign?
14. Has there been any impact of the training on child cancer on the capacity of the staff in local hospitals?

#### *C. Sustainability [For KII]*

15. Has the participation of the community and ownership been ensured?
16. Will the project's activities will be carried on by local partners/beneficiaries after the funding comes to an end.
17. What are the main challenges of sustainability of the project?
18. Are there plans for the sustainability of the project?

Thank you very much for your valuable time. Now you can ask if you have any questions or give us any suggestions.