

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.