IMPACT ASSESSMENT

PAEDIATRIC SURGERIES & TREATMENTS

APRIL - 2023



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Social Audit Network India (SAN India) was appointed by HDFC Limited (HDFC) to conduct an impact evaluation study of Paediatric Surgeries and Treatments project (project) supported by HDFC Limited through its philanthropic entity, H T Parekh Foundation (HTPF).

The team at Social Audit Network, India is grateful to the representatives at HTPF and the implementing partner hospitals for their support and co-operation with this assessment.

Abbreviations

CONGENITAL HEART DEFECT	CHD	Congenital Heart Defect				
Corporate SOCIAL Responsibility	CSR	Corporate Social Responsibility				
GENESIS FOUNDATION SAVE LITTLE HEARTS	GF	Genesis Foundation				
AISHWARYA TRUST	ΑT	Aishwarya Trust				
Narayana Hrudayalaya Hospitals Caring with Compassion	NH	Narayana Hrudayalaya				
THE MORIAL CHARLES THE PROPERTY OF THE PROPERT	ТМС	Tata Memorial Centre				
ICMS INDIAN COUNCIL OF MEDICAL RESEARCH INFORMATICS AND RESEARCH	NCDIR	National Centre for Disease Informatics and Research				

Executive Summary

In the context of Healthcare, HDFC CSR's mission is to "Ensure provision of quality healthcare to children and women that are vulnerable and/or economically marginalized." 1485 children were supported through a total grant of Rs 19.05 crores given to four implementation partners during the period August 2019 to March 2022. Paediatric cardiac surgeries were performed through three organisations, Genesis Foundation, Aishwarya Trust, Narayana Hrudayalaya, and paediatric cancer treatments were provided through Tata Memorial Centre and Narayana Hrudayalaya.

The study was conducted based on an analysis of data provided by the four partners and calls made to a random sample of beneficiaries to obtain their views on different aspects of their experience during the project.

The study results showed that the project has achieved its identified objectives.

- 1485 children were supported by enabling them to obtain required care for life-threatening diseases in the areas of CHD, cancer and heart transplants
- Holistic care has been provided, from counselling and discussions from the time the patient caregivers contacted the partner to support for surgery and follow-ups and training on how to look after the child at home
- Families were from the **lower socio-economic strata**. 17% of the parents have a monthly income of less than Rs.5,000 and 75% have a monthly income between Rs.5,000 to Rs.15,000/-
- The project brought about parity in treatment between genders. Where partners were requested to focus on the girl child, this has been done with 48% and 54% girls respectively, among the children helped. Overall, 39% of the patients were girls.
- Various kinds of financial support (beyond medical care) were provided to beneficiaries such as accommodation, concessional transport and medicines.

As the beneficiary survey demonstrated, **nearly 90% of the treated children have resumed normal life** and currently enjoy improved health. The project has resulted in increased well-being for the children as well as the caregivers, who mentioned that the financial support provided gave a sense of comfort and relief.

The project has created a positive social impact on the beneficiaries and their families as it has achieved the 5 A's of Access to Health Care: Acceptability, Availability, Accessibility, Affordability and Accommodation. The holistic support that the partners were able to provide improved survival rates and quality of life of children with Congenital Heart Disease and Cancer.

1. Background

HDFC Ltd's CSR initiatives are undertaken through direct partnerships with non-profit organizations and through its primary implementing agency, the H T Parekh Foundation. The CSR projects undertaken by HDFC Ltd are located across the country in areas of Healthcare, Education, Persons with Disabilities and Environment.

In the context of Healthcare, HDFC CSR's stated aims are to "*Ensure provision of quality healthcare to children and women that are vulnerable and/or economically marginalized*." The focus areas are Cancer Care, Nutrition, Paediatric Surgeries and Eye Care.

With regards to Cancer, the Foundation aims to improve services for cancer patients and their families through early detection, prevention, treatment, and care programmes. For Paediatric Cardiac ailments, the objective is to reach to a larger number of children where families are unable to fund themselves.

HDFC has appointed Social Audit Network India (SAN India) for an independent impact evaluation of the Paediatric Surgeries and Treatments project supported through the following four implementation partners:

<u>Genesis Foundation</u> - Genesis Foundation (GF) was founded in 2001 by eminent lawyers Prema & Jyoti Sagar of JSA Associates. Genesis facilitates medical treatment and care for critically ill, underprivileged children suffering from Congenital Heart Defect (CHD). Genesis has so far supported the medical treatment of over 2300+ critically ill children and works through a network of government, charitable and private hospitals across all major metros in India.

<u>Aishwarya Trust</u> - Established in 2008 by Chitra Viswanathan and K Nagarajan, Aishwarya Trust (AT) provides a comprehensive programme on screening, diagnosis, treatment, surgery and review of under-privileged children suffering from congenital heart defects. Aishwarya Trust has done screening across government hospitals in Tamil Nadu and Karnataka and has supported over 5,000 Congenital Heart Defect Surgeries, 120 Heart transplants and approximately 1.8 lakh screenings.

<u>Narayana Hrudayalaya Charitable Trust</u> - Established in 2004 by Dr Devi Prasad Shetty, Narayana Hrudayalaya (NH) was created with an objective to make available quality & affordable healthcare without any discrimination based on socio-economic background of the patient. The organisation has been providing support towards reducing the impact of catastrophic expenses incurred by patients from poor socio-economic status, thereby leading them into a perpetual cycle of debt and poor life quality.

<u>Tata Memorial Centre</u>: The Tata Memorial Hospital and Cancer Research Institute merged in 1966 to form the Tata Memorial Centre (TMC). Under the aegis of TMC, there are eight dedicated cancer hospitals which operate in Mumbai, Navi-Mumbai, Guwahati, Varanasi, Vishakhapatnam, Sangrur and Muzaffarpur. The eight hospitals provide cancer treatment to approximately 1,20,000 new patients and 7,50,000 follow-up patients every year, just under 10% of India's cancer burden. About 60% of these patients are treated either completely free or at highly subsidized costs. ImPaCCT Foundation is the division of paediatric oncology and co-ordinates and manages the treatment funding for Paediatric care at TMC.

2. Scope and methodology

2.1 Scope

The scope of the assignment was to assess performance of the project for the grant support made during FY 2019-20 to 2021-2022 for the following categories of paediatric surgeries:

Type of surgery	Amount (Rs. crore)	Partners
Congenital heart defect surgeries and heart transplants	9.31	Genesis Foundation, Aishwarya Trust, Narayana Hrudayalaya
Cancer treatment & surgeries	9.74	Tata Memorial Centre, Narayana Hrudayalaya
Total	19.05	

2.2 Methodology

The SAN India team comprising of social auditors, Ms. Karuna Luthar and Ms. Latha Suresh along with a team of 5 tele callers conducted the assessment. Qualitative and quantitative techniques were used for the study. The qualitative assessment included virtual interactions and semi-structured interviews with the project teams of the four organizations.

The assessment was conducted in three phases:

- i. Review of processes at each partner through on-line interviews with key informants
- ii. Analysis of patient data submitted by the partners to HDFC CSR
- **iii.** Obtaining the views of patient caregivers through phone calls to assess their satisfaction and the impact of the project. Their feedback was sought through a structured questionnaire.

The project has been assessed under the specific indicator framework REESS which evaluates Relevance, Effectiveness, Efficiency, Sustainability and Social Impact.

Indicator	Description
Relevance	The extent to which the objectives of the intervention are consistent with the beneficiary requirement, organization and donor policies and country's need.
Effectiveness	The extent to which the objectives were achieved or expected to be completed and their relative importance.
Efficiency	The extent to which the intervention delivers, or is likely to deliver, results in an economical and timely way.
Sustainability	The extent to which the partner can continue to deliver the services after major development assistance has been completed.
Social Impact	The extent to which the intervention has generated or is expected to generate significant positive or negative, intended or unintended, higher-level effects.

Figure 1: REESS Indicator

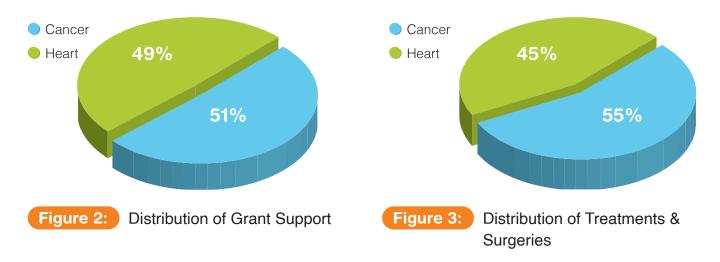
2.3 Sample

Due to privacy requirements, contact information of around 700 cancer treatment patients was not available. A sample size of about 20% (150 patients) was randomly selected from the remaining patients. Of these, caregivers of 117 patients shared their feedback.

3. Report on Performance

3.1 Support for Surgeries and Treatments

1485 children were supported through a total grant of Rs 19.05 crores given to four implementation partners during the period August 2019 to March 2022



3.2 Process flow

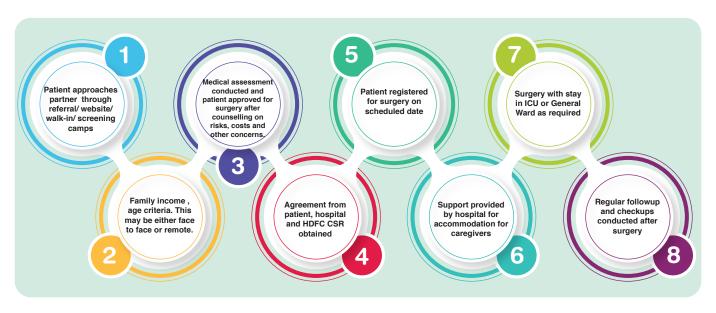


Figure 4: Overall process flow for all partners

Observations



- Each of the partners has in place well defined processes for patient identification, coordination, follow up and counselling. In some cases, gender bias, family pressure and stigma of the disease are reasons for caregivers to oppose the operation even after getting financial support.
- In addition to the surgery costs, financial support includes accommodation, concessional transport and medicines post-surgery.
- Some partners conduct periodic calls to assess the health of the child even after the medical follow-up period is over. This practice is recommended to be followed consistently for all patients.

3.3 Gender and region-wise classification

Analysis of the gender and region wise breakdown of patients is shown below.

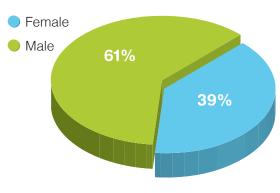


Figure 5: Surgeries by Gender

Observations



- The Project has served 39% female children. This is commendable as there appears to be a gender bias towards boys in obtaining treatment, as mentioned by the partners.
- A focus on the girl child was specifically requested for two partner grants. This has been adhered to, with over 50% of the beneficiaries as female for these two partners.
- Intervention by the partners was across all regions. The highest proportion of surgeries was in the Eastern states, followed by Southern, North-East (NE) and Northern areas.

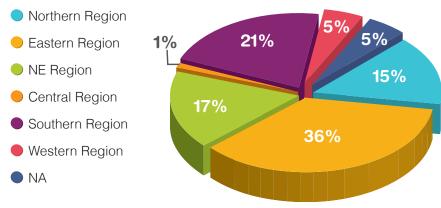


Figure 6: Surgeries by Region

4. Survey Findings

Key results from the survey are presented below.

4.1 Income and occupation profile

The project met the objective of supporting those most in need of financial assistance, as shown by the income and occupation profile of the beneficiaries. **92% of the caregivers mentioned they were earning less than Rs 15,000 a month**. The respondents were mainly in daily-wage or low-income generating jobs.

Family Income per month (Rs.)	< 3,000	3,000- 5,000	5,001- 10,000	10,001- 15,000	15,000- 25,000	25,000- 50,000	50,000 - 1 lakh	1 - 3 lakhs	Total Nos
Respondents	1%	16%	51%	24%	5%	1%	1%	1%	117

Figure 7: Beneficiary wise distribution of family income

	Farming	Office worker	Driver	Constr- uction	Labour	Hotel worker	Shop assistant	Tailor	Misc.	Total Nos
Respondents	13%	15%	12%	4%	27%	3%	5%	3%	18%	117

Figure 8: Beneficiary wise distribution of occupation

In the survey, nearly all respondents said they were asked for proof of income. In this context, all respondents had provided an Aadhar card, however separate income-related documents had been provided only in a few cases. For the future, the grant provider may like to consider specifying the document proofs that beneficiaries can provide while availing of the financial support.

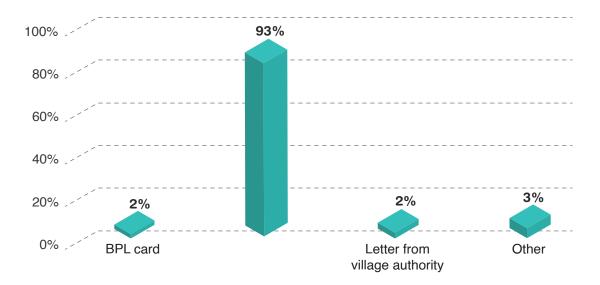
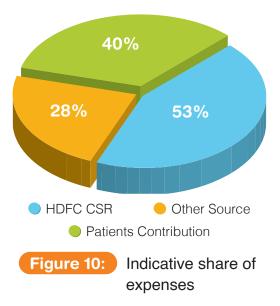


Figure 9: Documentation provided

4.2 Costs sharing

As an indicative exercise, data was obtained from one partner to understand the cost contribution pattern. The patients had undergone a mix of heart and cancer treatments.

Outofthe average cost of surgery (after removing the amount the hospital had waived) a **considerable proportion was supported through HDFC CSR alleviating a significant financial burden on the families**.



4.3 Accessibility

A positive feature of the project has been that most beneficiaries were able to obtain support within a short period of 1-2 months.

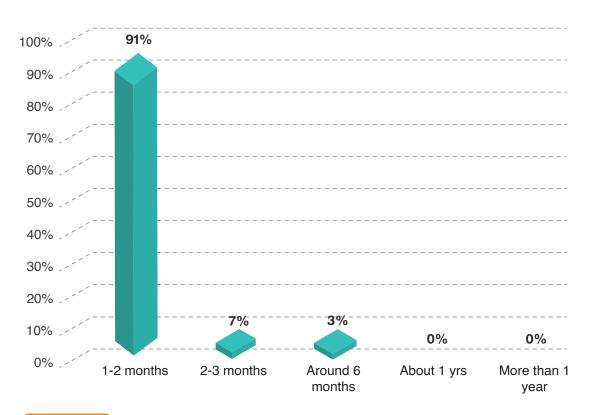


Figure 11: Period of time that caregivers waited for treatment

4.4 Reasons for choosing the partner

All the respondents mentioned that there were either private or government hospitals close by their house (between 10-20 kms on an average); however, they chose to come to the hospital. **95% of the respondents came to the hospital because of the quality of care, good staff or its reputation**. 1% mentioned that the reason for their choice was that it was free.

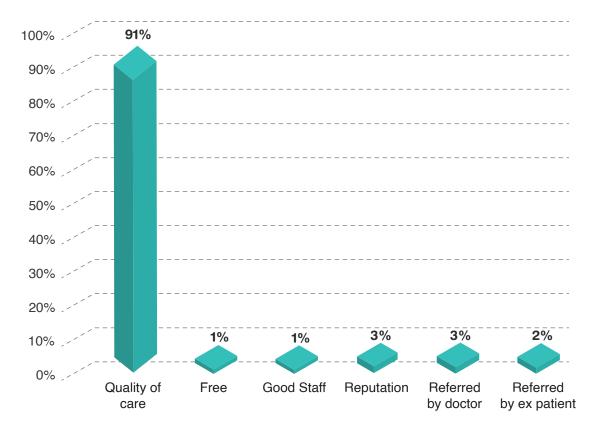


Figure 12: Reasons for choosing the implementation partner

4.5 Satisfaction

The chart below shows how the respondents rated various aspects of the services on a scale of 1 to 5, with 5 being the maximum. The satisfaction levels were at the **highest levels for all the aspects considered.** All the respondents confirmed that they had received explanations about the issue, counselling sessions about treatment, advice after the treatment and calls from the hospital staff to remind or follow-up

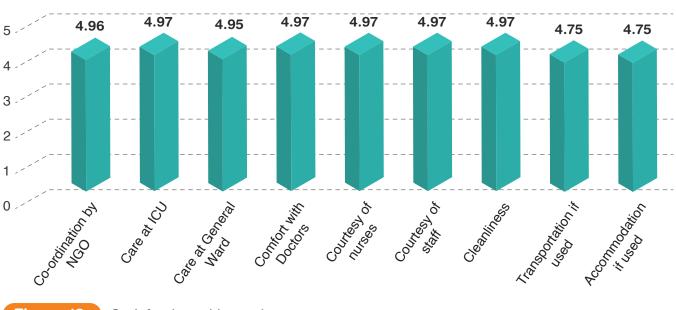
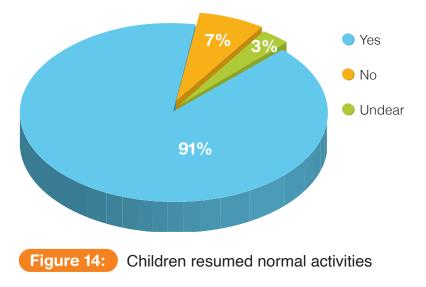


Figure 13: Satisfaction with services

4.6 Benefits to the children

The programme has had extensive benefits for the patients supported, indicated by the fact that over 90% of the caregivers confirmed that their children had resumed normal activities. The patients who answered "no" were waiting for the next visit to the hospital.



5. Measurable impact and effects of intervention

5.1 Relevance

Considering a birth prevalence of congenital heart disease as 9/1000, the estimated number of children born with congenital heart disease in India is more than 200,000 per year. ¹ Currently advanced cardiac care is unavailable to many of these children, due to financial constraints, geographic distribution of cardiac care facilities within the country and lack of awareness.

A report by the National Centre for Disease Informatics and Research (NCDIR) under the Indian Council of Medical Research, in collaboration with the World Health Organisation-India, notes that childhood cancers, in the 0-14 year age group, account for 4% of all reported cancers in India. The main barriers in the treatment of childhood cancers were treatment abandonment, treatment refusal, financial barriers and gender barriers in seeking care, care-seeking from traditional healers, lack of palliative care facilities, sub-optimal treatment at peripheral health centres, poor accessibility, shortage of health workforce and cancer treatment facilities and lack of referral pathways.²

Providing Paediatric health care

The activities and outcomes show that the project is consistent with the ultimate goals of the donor, hospitals and beneficiary families. In addition, the project supports the goals of the Government which has set up specific programmes aimed at children, particularly those who are poor and neglected.

¹ Congenital Heart Disease in India: A Status Report by Anita Saxena from the Department of Cardiology, All India Institute of Medical Sciences, 2018

² A Situational Analysis of Childhood Cancer Care Services in India 2022, by the National Centre for Disease Informatics and Research (NCDIR) under the Indian Council of Medical Research, in collaboration with the World Health Organisation-India

By providing financial support to world-class hospitals for paediatric care, directly and through NGOs, the project has ensured provision of quality healthcare to children that are vulnerable and/or economically marginalized.

Providing healthcare access to the needy

The project has been relevant as it has served patients from low-income and marginalized families while providing care in the best private hospitals. It is relevant as children from the target population of lower income group face a higher risk of mortality, co-morbidities and poor quality of life

Accessibility

The hospitals and NGOs are located to serve patients from the states where they are based as well as provide support to people in other regions. Camps and website add to the ease with which caregivers can approach these centres.

5.2 Effectiveness

Treatment to required beneficiaries

The program aims to ensure that quality medical treatment has been provided at a subsidised or zero cost to a minimum number of beneficiaries from certain areas. The target numbers have been exceeded in the project, in terms of female children and overall numbers.

Required level of care

As indicated in the survey, patients are happy with the level and quality of care being provided by the hospitals.

Improved well-being

Children with life threatening diseases like cancer and CHD cannot pursue normal activities, which impacts their overall development and sense of well-being. The surgeries have helped combat these severe diseases, bringing a semblance of normality to the children. Most caregivers in the survey confirmed that their children had resumed normal activities.

Affected families also benefit from the support. Parents and caregivers of children who have recovered with the help of the project can seek employment as well as pursue a normal social and family life. Siblings also gain from an improved atmosphere in the home as well as the availability of more funds for the family.

5.3 Efficiency

Affordable treatment

Patients from low-income groups were able to obtain high-quality care due to the financial support.

Quality health facilities

As mentioned in earlier sections, the processes followed by partners are accessible and patient focused. Key areas of additional support such as counselling and accommodation are addressed. The survey respondents confirmed that the hospitals provide excellent care in a welcoming environment.

Staff-Patient interaction

Patient happiness, a measure of a program's performance, is influenced by staff behaviour. The interviewed patients had high satisfaction with the services provided by hospitals as well as the physicians, nurses, and other hospital personnel with whom they engaged.

5.4 Sustainability

Continuity of Services

The hospitals and NGO partners have a robust network of donors and funders who support the cause. While a small fee is taken from patients in some cases, this is more to ensure they intend to follow through with the treatment. Each partner in the project maintains a long-term relationship with its contributors, and confirm they are able to meet their operating expenses with no difficulty if so required.

Alignment with UN SDG

The program supports the UN's 17 Sustainable Development Goals through its different activities.





5.5 Social Impact

A healthcare service's social impact is assessed on the 5 A's of Access to Care: Acceptability, Availability, Accessibility, Affordability and Accommodation. The project performance meets all criteria, indicating that it has a positive social impact:

- Acceptability patients have a high opinion of the hospitals and medical care as indicated in the survey.
- Availability The hospital partners have the necessary infrastructure, facilities, technology, personnel, and capacity to meet the needs of its patients. The number of patients supported by the partners exceeded those mandated.
- Accessibility Patients can reach the hospitals and NGOs through direct access, camps and website. As mentioned in the survey, most respondents felt there were no delays in treatment.
- Affordability- The grant ensures that necessary medical care is accessible to those in need of assistance. Additionally, caregivers are helped in other ways such as free lodging and subsidised transport to minimise their expenses.
- Accommodation A team of counsellors/volunteers at each partner interacts with the patients to explain various aspects of care and facilitate local accommodation.

6. Recommendations

This project has made a significant contribution with supporting underprivileged children through Paediatric surgeries and treatments over the last three years.

Certain areas may be considered for future support:

- Description and nutritional intervention for pregnant mothers can be supported to reduce the incidence and seriousness of CHD and other paediatric heart diseases.
- Creating awareness: A programme of spreading knowledge about these diseases in parents, health providers and the community will help to reduce abandonment of care and therefore mortality.
- Geographic distribution: To ensure that the benefit has reached the most needy amongst the lower socio-economic strata, partners could be asked to specifically report on the health benefits to children from the remote/ rural areas.



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