

# IMPACT ASSESSMENT OF KOTAK MAHINDRA BANK'S CSR HEALTHCARE PROJECT IMPLEMENTED BY KARO TRUST

(DECEMBER 2022)

**REPORT BY**



# Acknowledgment

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# Abbreviations

**Table 1 : List of abbreviations**

Abbreviation	Full Form
ALG	Anti-Lymphocyte Globulin
ATG	Anti-Thymocyte Globulin
BMT	Bone Marrow Transplant
COVID-19	Coronavirus disease
CSR	Corporate Social Responsibility
DAC	Development Assistance Committee
FGD	Focus Group Discussion
FY	Financial Year
GLOBOCAN	Global Cancer Observatory
INR	Indian Rupee
KII	Key Informant Interview
KMBL	Kotak Mahindra Bank Limited
NHM	National Health Mission
NHS	National Health Service
OECD	Organization for Economic Cooperation and Development
SDG	Sustainable Development Goals
SOP	Standard Operating Procedure
TYA	Teenage Young Adult
UN	United Nations
VOD	Veno-occlusive Disease

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# Executive Summary

KMBL's healthcare project focuses on providing financial support for the treatment of patients suffering from Ewing's Sarcoma, Aplastic anemia, and diseases that require a bone marrow transplant (BMT). The project is implemented by KARO Trust. The aim of the project is that no patient aborts treatment due to a lack of funds. 144 patients who were in need of funds to start/continue treatment, were supported by KMBL under this project in FY 2020-21.

KMBL has commissioned Sattva Consulting to conduct an impact assessment study of its healthcare project for FY 2020-21. The study focuses on assessing the following:

- **Relevance** of the project to the needs of the beneficiaries and its **coherence** with national and regional priorities
- The **effectiveness** of the project in achieving the desired outcomes and creating an impact in line with the strategies defined by KMBL
- The **impact** created by the project among beneficiaries
- **Sustainability** of the project in the long run

The insights in this study are mapped based on the aforesaid points.

Sattva Consulting followed a mixed-method approach to conduct the impact assessment study, which included both qualitative and quantitative methods of research. Surveys were conducted for 105 patients and their families as a part of the quantitative data collection. For qualitative data collection, case studies, FGDs, and key informant interviews were conducted with patients and their families. Other stakeholders such as doctors, medical social workers, and individuals from the project implementation team were also interviewed for the study. In total, 7 qualitative interviews were conducted. The study was conducted over a period of 4 months, between August 2022 - November 2022.

## Key Insights from the Impact Assessment Study

**The financial support provided by KMBL ensured that patients could start, and/or continue their treatment**

- When asked about alternate sources of funding available to families, **80% (50/63)** shared options such as selling land, taking loans, etc. Arranging funds from such alternate sources could have taken more time, leading to a potential delay in the patient receiving treatment. The remaining **20% (13/63)** of the families did not have any alternative plan for arranging funds for treatment.
- Any delay in the treatment of cancer can prove to be detrimental to the patient's life. This clearly indicates that the financial need for treatment required immediate attention, and in most cases, patients and their families would not have been able to address this need independently on time.

### **Effective implementation of the project helped patients with completing and/or continuing treatment and led to a 100% satisfaction level among patients and their families**

- **105** patients and families were surveyed, of which **60% (63/105)** patients were alive. A shorter survey was conducted with caregivers of **40% (42/105)** of deceased patients, due to the sensitivity of their situation.
- As of October 2022, **48% (30/63)** of alive patients had completed treatment and **49% (31/63)** were undergoing treatment. The remaining **3% (2/63)** patients had stopped treatment.
- **87% (55/63)** of caregivers shared that they would continue treatment till their child is better or till the doctor advises them to do so, highlighting their awareness about the importance of completion of treatment.
- **100% (63/63)** of patients and their families were satisfied with the support provided by KARO Trust.
- Overall, **96% (101/105)** of patients and their families would recommend KARO Trust to other patients who require financial support for treatment, potentially expanding KARO Trust's reach. The remaining **4% (4/105)** of respondents belonged to the families of deceased patients.

### **Factors such as the nutrition intake of patients, availability of affordable accommodation, etc. have an impact on the treatment and recovery of the patient**

- Taking proper nutrition plays a crucial role in the recovery process. **46% (29/63)** of patients have a prescribed nutrition plan from the doctor. The remaining **54% (34/63)** of patients are asked to follow a regular diet at home or have a different treatment approach.
- **90% (26/29)** of patients are able to follow the prescribed nutritional plan by themselves or with their family's support. In some cases, the food is provided by the hospital.
- When enquired about challenges faced during treatment, **46% (29/63)** respondents shared that they are unable to afford accommodation in the treatment city. **67% (42/63)** of patients' base locations and treatment cities were different.
- Other major challenges highlighted by respondents were the lack of a source of income and their inability to afford travel costs and food expenses.

### **There were possible disruptions in the treatment of patients suffering from any of the diseases during the COVID-19 pandemic due to travel restrictions**

- Although, COVID-19 drastically impacted the healthcare system during 2020-21, the project ensured treatment for patients during that time.
- There might have been some disruption in the treatment timelines of patients due to travel restrictions. **14% (9/63)** of patients shared that they missed at least one appointment or treatment session due to travel restrictions.
- It is likely that COVID-19 had an impact on the outcomes of patients supported in the project during the financial year 2020-21.

KMBL's healthcare project implemented by KARO Trust has considerably impacted the lives of patients and their families. The financial support provided to the patients has enabled them to continue or complete treatment and likely improved their quality of life. The aim of the project has been achieved, as envisioned by KMBL.



# Chapter 1: Overview

The chapter gives an overview on cancer (Ewing's Sarcoma) and life-threatening diseases (Aplastic Anemia and diseases that require a bone marrow transplant) in the global and national context. It also provides details about KMBL's healthcare project and details its coherence with international and national goals.

## About the disease

### Cancer - Ewing's Sarcoma

Cancer is a disease in which abnormal or damaged cells grow uncontrollably in some parts of the body and spread to other parts of the body. These cells may form tumors (lumps of tissue) which can be cancerous or non-cancerous (benign). Cancer can start almost anywhere in the human body. Cancerous tumors spread into, or invade nearby tissues and can travel to distant places in the body to form new tumors (a process called metastasis).<sup>1</sup>

Ewing's Sarcoma is a rare type of cancerous tumor that affects bones or the tissue around bones. It most often forms in the bones of the legs, arms, feet, hands, chest, pelvis, spine, or skull.<sup>2</sup> Ewing's Sarcoma can rapidly spread to other parts of the body. The earlier it is diagnosed, the greater the chance of treatment being successful.<sup>3</sup>

The disease predominantly affects children and teenage groups, but is also found in adults. It is found to be more common in males than females. Ewing's Sarcoma is difficult to diagnose since it is a rare disease and its symptoms are often similar to other conditions.<sup>4</sup> Treatment often involves a combination of radiotherapy (radiation is used to kill cancer cells), chemotherapy (medicine is used to kill cancer cells), or surgery to remove cancer.<sup>5</sup> Targeted therapy and Immunotherapy are a few new kinds of treatment being tested in clinical trials.<sup>6</sup>

Ewing's Sarcoma is the second most common bone tumor in children and adolescents with its incidence being 15% of the primary bone tumors.<sup>7</sup> The overall 5-year survival rate for people with Ewing's Sarcoma tumor is 61%.<sup>8</sup>

### Aplastic Anemia and other diseases that require a Bone Marrow Transplant (BMT)

Aplastic Anemia is a type of bone marrow failure. In Aplastic Anemia, the bone marrow's stem cells do not make enough new blood cells. Most often, all three types of blood cells (red blood cells, white blood cells, and platelets) are affected. Severe Aplastic Anemia requires urgent

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<sup>1</sup>National Cancer Institute, "What is cancer?", Accessed November, 2022, <https://www.cancer.gov/about-cancer/understanding/what-is-cancer>

<sup>2</sup>National Cancer Institute, "Ewing Sarcoma Treatment", Accessed November, 2022, <https://www.cancer.gov/types/bone/patient/ewing-treatment-pdq>

<sup>3</sup>NHS, "Ewing Sarcoma", Accessed November, 2022, <https://www.nhs.uk/conditions/ewing-sarcoma/>

<sup>4</sup>NHS, "Ewing Sarcoma", Accessed November, 2022, <https://www.nhs.uk/conditions/ewing-sarcoma/>

<sup>5</sup>NHS, "Ewing Sarcoma", Accessed November, 2022, <https://www.nhs.uk/conditions/ewing-sarcoma/>

<sup>6</sup>National Cancer Institute, "Ewing Sarcoma Treatment", Accessed November, 2022, <https://www.cancer.gov/types/bone/patient/ewing-treatment-pdq>

<sup>7</sup>Nancy V Jeniffer, Arpitha Panduranga and BP Karunakara, "Atypical Presentation of Primary Ewing's Sarcoma", Published June 2017, [https://www.ijmpo.org/assets/articles/2018/pdf/ijmpo.ijmpo\\_71\\_17.pdf](https://www.ijmpo.org/assets/articles/2018/pdf/ijmpo.ijmpo_71_17.pdf)

<sup>8</sup>Cancer.Net, "Ewing sarcoma - childhood and adolescence - statistics", Accessed November, 2022, <https://www.cancer.net/cancer-types/ewing-sarcoma-childhood-and-adolescence/statistics>

medical treatment and is linked to a high risk of severe infections. If untreated, a person with this disorder can die of infection or bleeding.<sup>9</sup>

A rare and serious condition, aplastic anemia can develop at any age. Treatment approaches depend on the severity of the patient's condition and age and primarily include medications, blood transfusions, or a stem cell transplant, also known as a bone marrow transplant.<sup>10</sup>

A bone marrow transplant is the preferred treatment for severe Aplastic Anemia since it can cure the patient for life. In the transplant procedure, the patient's unhealthy or missing bone marrow is replaced with healthy cells from a donor, such as a family member or a matched unrelated donor.<sup>11</sup>

A few other diseases for which a bone marrow transplant is preferred are types of sickle cell anemia (an inherited blood disorder that causes misshapen red blood cells), thalassemia (an inherited blood disorder where the body makes an abnormal form of hemoglobin), and few types of cancers such as leukemia, lymphoma, and multiple myeloma.<sup>12</sup>

Aplastic Anemia is a life-threatening condition with very high death rates (about 70% within 1 year) if untreated. The overall five-year survival rate is about 80% for patients under age 20.<sup>13</sup> India has the largest number of children with Thalassemia major<sup>14</sup> in the world – about 1 to 1.5 lakhs.

### **Challenges faced by patients in receiving treatment**

“An uncomplicated bone marrow transplant in a 12 kg child may cost Rs. 9-10 Lakhs while serious complications (infections, VOD or graft versus host disease) after transplant can increase the cost to as much as Rs. 25 Lakhs or more, mainly because of costs related to prolonged hospitalization, additional immunosuppressive drugs (ATG/ALG), antibiotics, transfusions, and parenteral nutrition.”<sup>15</sup>

Having a low household income presents a diverse set of problems for families, with affordable healthcare being one of the most prevalent. Since the diseases (Ewing's Sarcoma, Aplastic anemia, and diseases that require a bone marrow transplant) have long-term treatment approaches, families that do not have sustainable funds available, are unable to opt for such treatment options. Even if they try to fund the treatment, it leads to a huge financial pushback for the families. Lack of awareness, lack of proper facilities especially in rural areas, and shortage of trained healthcare professionals are some of the other predominant challenges in tackling the diseases.<sup>16</sup>

Additionally, teenage young adults (TYA) are a neglected demographic in terms of financial

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<sup>9</sup>St. Jude Children's Research Hospital, "Aplastic Anemia" Accessed November 2022, <https://www.stjude.org/disease/aplastic-anemia.html>

<sup>10</sup>Mayo Clinic, "Aplastic Anemia", Accessed November 2022,

<https://www.mayoclinic.org/diseases-conditions/aplastic-anemia/symptoms-causes/svc-20355015>

<sup>11</sup>St. Jude Children's Research Hospital, "Aplastic Anemia" Accessed November 2022, <https://www.stjude.org/disease/aplastic-anemia.html>

<sup>12</sup>Healthline, "Bone Marrow Transplant", last modified July 2022, <https://www.healthline.com/health/bone-marrow-transplant>

<sup>13</sup>St. Jude Children's Research Hospital, "Aplastic Anemia" Accessed November 2022, <https://www.stjude.org/disease/aplastic-anemia.html>

<sup>14</sup> a disease that requires bone marrow transplant as treatment

<sup>15</sup>National Health Mission, "Prevention and Control of Hemoglobinopathies in India", Published 2016,

[https://nhm.gov.in/images/pdf/in-focus/NHM\\_Guidelines\\_on\\_Hemoglobinopathies\\_in\\_India.pdf](https://nhm.gov.in/images/pdf/in-focus/NHM_Guidelines_on_Hemoglobinopathies_in_India.pdf)

<sup>16</sup>Kasthuri Arvind, "Challenges to Healthcare in India - The Five A's" Published 2018, doi: [10.4103/ijcm.IJCM\\_194\\_18](https://doi.org/10.4103/ijcm.IJCM_194_18)

support opportunities available for treatment. “Within the oncology community, young persons’ cancer is an unrecognized issue. The GLOBOCAN 2018 reports that of the annual burden of over a million cancers in India, 54,538 persons in the age group (15–29) were diagnosed with 30,286 (55%) deaths. Survival in adolescent and young adult cancers are improving in Western countries, while survival data from India in this age group is lacking.”<sup>17</sup> This could potentially be due to a lack of initiatives and support opportunities for the TYA demographic.

The above-mentioned challenges highlight a strong need for intervention in these areas.

## About KMBL - KARO Trust project

Kotak Mahindra Bank Limited (KMBL) is a leading Indian banking and financial services company headquartered in Mumbai. In a journey spanning nearly three decades, the company has grown both in scale and in stature.

KMBL’s Corporate Social Responsibility (CSR) vision is to improve the quality of life of the communities through positive impact on economic, social, and environmental parameters and in alignment with India’s social development objectives and UN’s SDGs. KMBL has been impacting communities across the country through its interventions in the areas of healthcare, education and livelihood, environment and sustainable development, sports, and relief and rehabilitation.

### About the project

As part of its healthcare initiatives, KMBL identified the need to financially support treatment for patients suffering from Ewing’s Sarcoma, Aplastic anemia, and diseases that require a bone marrow transplant. This initiative was implemented by KARO Trust.

The project focuses on providing financial support to low-income background patients for treatment of Ewing’s Sarcoma, Aplastic Anemia, and other diseases that require a bone marrow transplant. The project is primarily implemented in hospitals of Maharashtra (Mumbai), Uttar Pradesh, and a few other states of India including Ahmedabad and Karnataka.

144 unique patients were supported in FY 2020-21.

### About KARO Trust

This healthcare project under KMBL’s CSR initiative is implemented by KARO Trust, a public charitable trust founded in 2015, with a focus to provide holistic healthcare support to patients in need throughout their medical journey. Patients suffering from cancer and other life-threatening conditions who require organ transplants or bone marrow transplants are primarily supported by the trust. KARO Trust’s aim is to ensure that no patient should abort treatment due to lack of funds, and this is in alignment with KMBLs vision for this project. While financial aid is a key

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<sup>17</sup>Indian Society of Medical and Paediatric Oncology, “Teenage and Young Adult Cancer: A Low-Hanging Fruit or the Final Frontier?”, Published June 2021, doi: [10.4103/jimpo.jimpo\\_119\\_19](https://doi.org/10.4103/jimpo.jimpo_119_19)

focus area for KARO Trust, efforts are made to provide accommodation, emotional support, and any other support that would enable the patient and their family to complete the treatment.

### **About the intervention**

The project focuses on providing financial support to patients suffering from Ewing's Sarcoma, Aplastic anemia, and diseases that require a bone marrow transplant.

To identify patients suffering from any of the above issues and facing financial challenges, KARO Trust is associated with close to 90 hospitals in India. When a patient reaches the hospital, a check-up is conducted by the doctor to reach a diagnosis. The doctor then evaluates if the case is curative<sup>18</sup> and recommends the appropriate course of treatment to the patient. An estimated amount of funding required for such a course of treatment is calculated and conveyed to the family. At this point, the MSW (Medical Social Work) department analyzes the financial status of the patient's family through a socioeconomic assessment and review of documents such as an income certificate, to confirm the family's eligibility to receive financial support. The social worker then raises a fund request for the patient's treatment with KARO Trust. Under this project, only curative cases are sent by the hospital to KARO Trust for funding support.

The diseases covered in the project have large costs of treatment. To arrange for the entire fund requirement for a patient's treatment, the MSW department of the hospital pools funds from various organisations.

A control sheet is maintained by KARO Trust to record patient data. The control sheet consists of patient details, their treatment status, updates on their visits to the hospital for treatment and follow-ups, and any other details that may be important to the case. Additionally, case files containing in-depth patient details are maintained in a hard copy format. To ensure financial transparency, a separate bank account is opened by KARO Trust to manage funds provided by KMBL. Monthly, quarterly, and annual reports are shared with KMBL highlighting the progress updates on the intervention.

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<sup>18</sup>Curative cases are administered with the goal of achieving a complete remission and preventing the recurrence of the disease.

## Coherence with international and national goals

The project is aligned with UN Sustainable Development Goal 3 and the central government initiative – National Health Mission.



### **SDG 3 – Good Health and Wellbeing<sup>19</sup>**

“Ensure healthy lives and promote well-being for all at all ages”

The project contributes to Target 3.4 (Reduce mortality from non-communicable diseases through prevention and treatment) and Target 3.8 (Access to quality essential health-care services).



### **National Health Mission (NHM)<sup>20</sup>**

Under the NHM, the project contributes to the National Programme for i) Prevention and Control of Cancer and ii) Prevention and Control of Hemoglobinopathies<sup>21</sup>.

<sup>19</sup>United Nations, “Goal 3 - Ensure healthy lives and promote well-being for all at all ages”, Accessed November 2022, <https://sdgs.un.org/goals/goal3>

<sup>20</sup>National Health Mission, Accessed November 2022, <https://nhm.gov.in>

<sup>21</sup>Hemoglobinopathies are inherited disorders of red blood cells. They include thalassemias and abnormal variant hemoglobins. Bone Marrow Transplant (BMT) is the best known curative therapy for such diseases.

## Chapter 2: Sattva's Approach and Methodology

This section highlights the objectives of the study, the study design, the sampling approach, and the limitations of the study.

### Objectives of Study

KMPL commissioned Sattva to conduct an impact assessment study to evaluate the healthcare project for the financial year 2020-21. The objective of the study is to understand the following:

- **Relevance** of the project to the needs of the beneficiaries and its **coherence** with national and regional priorities
- The **effectiveness** of the project in achieving the desired outcomes and creating an impact in line with the strategies defined by KMPL
- The **impact** created by the project among beneficiaries
- **Sustainability** of the project in the long run



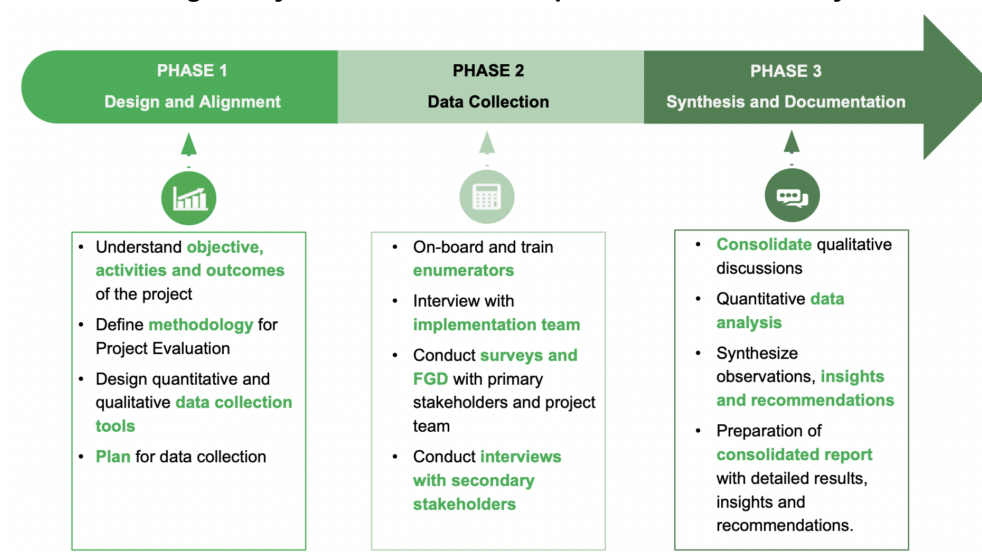
### Study Design

#### Impact Assessment Approach & Execution Timeline

Sattva Consulting undertook a descriptive cross-sectional study with a mixed-methods approach, consisting of quantitative and qualitative data collection methods. This helped gather meaningful impact-related insights from a 360-degree perspective across the stakeholders involved and was fundamental to providing relevant recommendations.

The impact assessment study was divided into 3 distinct phases: (i) Design and Alignment, (ii) Data collection, and (iii) Synthesis and Documentation. The study was conducted between August 2022 and November 2022. The key milestones for each phase of the study are described below.

Fig 1: Key milestones of the impact assessment study



## Impact Assessment Framework

The study deployed the OECD DAC framework (The Organization for Economic Cooperation and Development's (OECD) Development Assistance Committee (DAC)) for the purpose of the assessment. The six pillars of the DAC framework have been explained below (See Fig. 2)<sup>22</sup>.

**Fig 2: Research Methodology Framework**

### RELEVANCE

Assessing to what extent the program objectives and design respond to the target group's global, country, and partner/institution needs, policies, and priorities, and continue to do so if the circumstances change.

### COHERENCE

Assessing the alignment of the program, or what it is likely to deliver with the needs of the community. Also checking its alignment with the priorities of the region, at a state, national or international level.

### EFFICIENCY

Assessing the extent to which the intervention delivers, or is likely to deliver, results in an economic, efficient, and timely way

### EFFECTIVENESS

Assessing the supporting systems and processes influencing the achievement or non-achievement of program objectives, through concurrent measurement of program outputs.

### IMPACT

Assessing the extent to which the program has generated significant positive or negative, intended or unintended impact, in terms of social, economic, environmental and other development indicators

### SUSTAINABILITY

Assessing to what extent the impact of the program is likely to continue after funding support has been withdrawn by determining operational, financial and institutional sustainability

ASSESSMENT  
FRAMEWORK

## Sampling

### Stakeholder Mapping

For the purpose of the study, 3 key stakeholders were identified.



**Patients and their families (caregivers):** Patients and their family members were the direct beneficiaries of the intervention and were key stakeholders of the study. Both quantitative (surveys) and qualitative (case studies) data were collected from them.



**Doctor and Medical Social Workers:** Doctors and Medical Social Workers are in close contact with the patients and their families during the entire course of treatment and have certain medical expertise on the diseases and treatment approaches. Sattva team conducted KIIs/FGDs with Medical Social Workers and Doctors to understand their views and insights on the study.



**Implementation Agency:** The project was implemented with the support of KARO Trust. Insights from the implementation agency are captured in this study.

22 OECD, "Evaluation Criteria", Accessed November 2022, <https://www.oecd.org/dac/evaluation/daccriteriaforevaluatingdevelopmentassistance.htm>



Additionally, interviews were conducted with the KMBL CSR team head and Project Team to understand the long-term vision, goals, and objectives of the project.

### Sampling Approach

For this study, Sattva Consulting collected qualitative and quantitative data from patients and their families<sup>23</sup>.

Sattva Consulting adopted a stratified random sampling approach to ensure adequate representation of the patients in the impact study. The patients were divided into two categories, alive patients and deceased patients. The patients were then randomly selected from both categories proportionately using the nth selection process.

The sample size for the study was 105 patients and families. Surveys with 20 patients and their families were conducted in person in Mumbai. The remaining 85 surveys were conducted virtually through phone calls.

Of the 105 patients, 63 were alive patients and 42 patients had passed away. Considering the sensitivity of the situation, a shorter survey was conducted with the family members of patients who had passed away. The survey attempted to understand the support provided by KARO Trust to those patients.

**Table 4: List of stakeholders interviewed to gather qualitative data**

Stakeholder	KII		FGD		Case Story	
	Planned	Actual	Planned	Actual	Planned	Actual
Patients and Caregivers					2	2
Medical Social Workers/Doctors	2	2	0	1		
Project Implementation Team - KARO Trust	1	1				
KMBL CSR Team	1	1				

<sup>23</sup>Considering a considerable sample of the study belonged to young age groups, family members were present during interviews to provide their inputs on the impact of the project.



## Data Sources



### Primary Sources of Data:

Primary data was collected in two ways; quantitative (Surveys) and qualitative (FGD, KIIs, and Case Stories).



### Secondary Sources of Data:

Literature review was done of project documents shared by the Wockhardt Foundation team. Information was also gathered from existing studies on similar initiatives by organisations such as the NHS, UK, and the Government of India.

## Limitations of the Study

This section explains the limitations of the study in detail.

- **Sensitivity of the situation** - The study sample included families where the patient had passed away from the disease. Considering the sensitivity of the situation, a shorter survey was conducted with the family members of those patients who had passed away. The survey attempted to understand the support provided by KARO Trust to those patients. There might be some bias in their answers due to feelings of grief in such a situation.
- **Low proportion of in-person interviews** - The study was able to achieve a lower proportion of in-person interviews due to the unavailability of patients and their families on the day of data collection and logistical constraints such as being located outside of Mumbai. To mitigate this, virtual interviews were conducted with the remaining patients and their families. To maintain the quality of data, data enumerators were given training on the background of the project and data collection tools. There was regular quality assurance conducted through data monitoring and audio audits.

## Chapter 3: Findings of the Impact Assessment Study

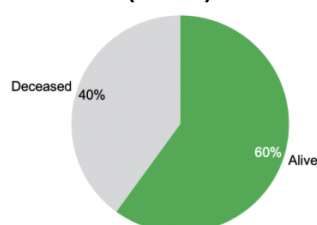
This chapter describes the key insights emerging from the impact assessment study.

### Demographic profile of sampled patients

This section details the demographic details of the 105 patients and their families who were surveyed for the study.

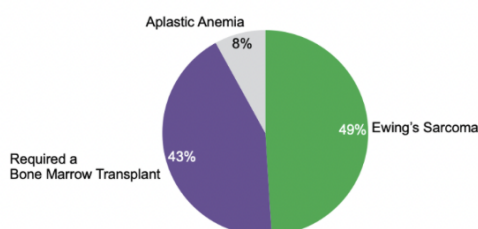
**60% (63/105)** of the patients were alive whereas **40% (42/105)** of the patients were deceased as of October 2022.

**Fig 3 : Current status of patients (n=105)**



Of all the 105 patients covered in the study, **49% (31/63)** were suffering from Ewing's Sarcoma, **43% (27/63)** were suffering from a disease that requires a bone marrow transplant and **8% (5/63)** had Aplastic Anemia.

**Fig 4 : Type of disease patients were suffering from (n=105)**

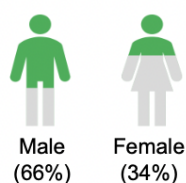


Overall, around **66% (69/105)** of sampled patients in the study were male and **34% (36/105)** were female. A similar gender distribution trend of 63% male and 37% female patients is seen across the patients that were supported under the project during the financial year 2020-21. Ewing's Sarcoma is found to be more common in males than females.<sup>24</sup> This could be a potential reason for a skewed gender distribution ratio.

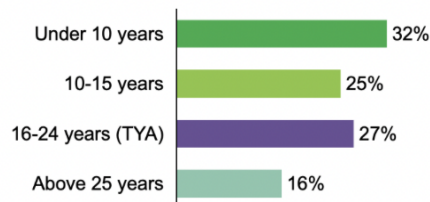
The age of the sampled patients ranges between 2-49 years.

<sup>24</sup>NHS, "Ewing Sarcoma", Accessed November, 2022, <https://www.nhs.uk/conditions/ewing-sarcoma/>

**Fig 5 : Gender distribution of patients (n=105)**

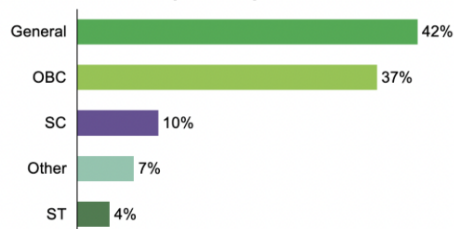


**Fig 6 : Age categorisation of alive patients (n=63)**



The patients and their families typically belonged to the general (42% - 44/105) and OBC (37% - 39/105) social categories. The remaining 21% (22/105) of patients and their families belonged to SC/ST or 'other' social categories. The families had an average annual income of INR 1,33,029. This clearly indicates that they would not have been able to manage the costs of treatment.

**Fig 7 : Social category of patients (n=105)**



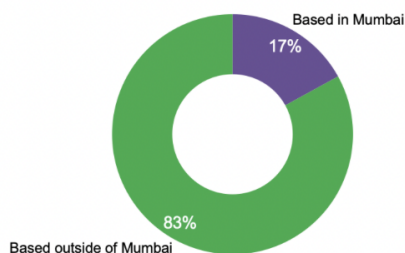
**Fig 8 : Average annual household income of patients (n=102)**



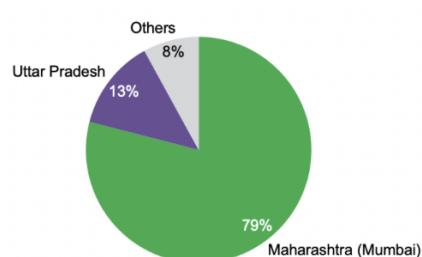
3 respondents did not share their household income

83% (52/63) of sampled patients and their families were based outside of Mumbai, whereas 17% (11/63) were based in Mumbai. 79% (50/63) patients were treated in Maharashtra (Mumbai), 13% (8/63) were treated in Uttar Pradesh, and the remaining 8% (5/63) patients were treated in Gujarat, Madhya Pradesh, and Karnataka.

**Fig 9 : Base location of alive patients (n=63)**



**Fig 10 : Location where alive patients were treated (n=63)**



## The patients in the study required financial support to start or continue their treatment, indicating a need for this project

Referring to the challenges faced by families in receiving treatment in Chapter 1, it was found that the financial need was adhered to in the project. The patients supported under this project may not have been able to begin or continue treatment, without the intervention.

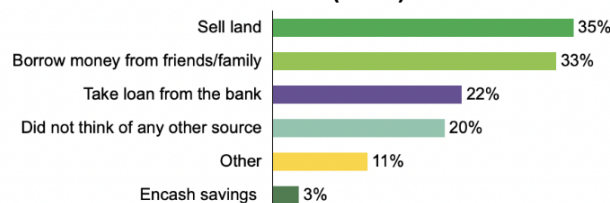
As shared during qualitative interviews, arranging funds for treatment on time was a major challenge for 2/2 patients' families. The Medical Social Worker from CTC Borivali hospital shared that a majority (95%) of patients belong to low-income backgrounds and cannot afford treatment.

*"The doctors gave us (caregiver) an idea about the cost of treatment. We were not in the mental state to arrange money. We asked our relatives for help, but they did not support us. Doctors were a big support during this time."*

- Caregiver, Thalassemia Patient

It can be inferred that all families would have been distressed without KARO Trust's financial support. When asked about alternate sources of funding available to families, 80% (50/63) shared options such as selling land, taking loans, etc. Arranging funds from such alternate sources could have taken more time, leading to a potential delay in the patient receiving treatment. The remaining 20% (13/63) of the families did not have any alternative plan for arranging funds for treatment.

**Fig 11 : Alternate source of financial support if KARO Trust services were not available (n=63)**



*"Without KARO Trust's support, I would have arranged money anyhow but it would have been very troubling."*

- Patient, Ewing's Sarcoma

*"At a point, we felt that treatment would not happen if we were not able to arrange the money."*

- Caregiver, Thalassemia Patient

Any delay in treatment of cancer can prove to be detrimental for the patient's life. In a study conducted to assess the impact of delay in cancer treatment, a four week delay in treatment was found to be associated with an increase in mortality across all common forms of cancer treatment.<sup>25</sup>

<sup>25</sup>Hanna TP, King WD, Thibodeau S, Jalink M, Paulin GA, Harvey-Jones E, O'Sullivan DE, Booth CM, Sullivan R and Aggarwal A, "Mortality due to cancer treatment delay: systematic review and meta-analysis", Published November 2020, doi: [10.1136/bmj.m4087](https://doi.org/10.1136/bmj.m4087)

During qualitative interviews, the doctor from CTC Borivali confirmed that any delays in the start of treatment can adversely impact the outcome of the patient, as there is a risk of loss of life.

This clearly indicates that the financial need for treatment required immediate attention, and in most cases, patients and their families would not have been able to address this need independently on time.

### **Effect of continued treatment on patient outcomes**

In qualitative interviews, 2/2 doctors highlighted that continued treatment has a positive impact on outcomes.

*“The protocols are devised with a lot of research. They should be followed as is without diverging from it. On-off treatment will allow cancer regrowth or repopulation. The next cycle may not be that effective. Continued treatment and completion of treatment is of paramount importance.”*

- Medical Oncologist, Tata Memorial Hospital

Hence, timely start/continuity of treatment is extremely crucial for the outcome of the patient. The project ensures the same through the provision of financial support to patients on time.

## **Effective processes have helped ensure zero waiting period for emergency cases**

### **Time duration to receive treatment**

51% (32/63) of patients shared that they received treatment within a week of the hospital reaching out to KARO Trust for financial support. 27% (17/63) of patients received treatment within 2-3 weeks. The remaining 22% (14/63) patients received treatment after more than a month of the hospital reaching out to KARO Trust.

KARO Trust shared that they disburse funds to the hospitals within a week of receiving a request so that the patient's treatment can begin/continue.<sup>26</sup> The ideal time of treatment is dependent on factors such as the type and stage of the disease, and the treatment approach. Therefore, a later treatment does not necessarily indicate a 'delay' in treatment.

2/2 Medical Social Workers shared that they are able to reach out to KARO Trust for expediting the process in cases of emergencies. This ensures that there is no waiting period for patients in case of emergencies.

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<sup>26</sup>Potential reasons shared by KARO Trust for the gap of time in patients receiving treatment were prioritization of patients in need of immediate treatment by the hospital due to COVID-19, bandwidth issues, or delay from the patient's end in reaching the treatment city during lockdowns.

## Awareness among patients about KARO Trust and donors

During the study, it was found that the patient and their families were not **formally informed** in the initial stage, about their funding organisation(s), in this case, KARO Trust. Creating a space where this information is shared with the patient, would help the patient and their family feel connected with their supporters.

*“The patients are informed that someone is giving them money for support, but they might not know about KARO Trust. Those who are staying with us for longer or are in touch with KARO Trust might eventually get to know about them. We need to find a way to inform them in the right space.”*

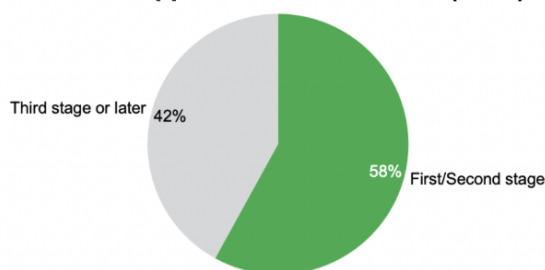
- Medical Social Worker, Tata Memorial Hospital

## Effective implementation of the project helped patients with completing and/or continuing treatment and led to a 100% satisfaction level among patients and their families

### Current status of patients' treatment

Out of 105 patients and families surveyed, **41% (43/105)** were aware of the stage of the disease when they received support from KARO Trust. **58% (25/43)** of the patients were in the first or second stage of the disease and **42% (18/43)** patients received support in the third stage or later.

**Fig 12 : Stage of disease when patients received support from KARO Trust (n=43)**



27

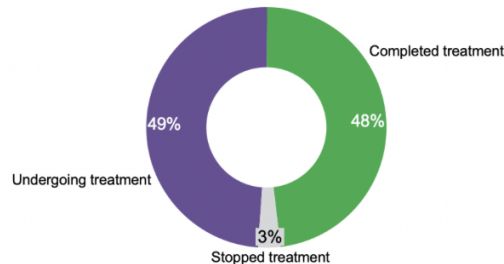
As of October 2022, **48% (30/63)** alive patients had completed treatment and **49% (31/63)** were undergoing treatment.

The patients who have 'completed' treatment may have completed surgery or transplant and

<sup>27</sup>Stage I: The cancer is localized to a small area and hasn't spread to lymph nodes or other tissues. Stage II: The cancer has grown, but it hasn't spread. Stage III: The cancer has grown larger and has possibly spread to lymph nodes or other tissues. Stage IV: The cancer has spread to other organs or areas of your body. This stage is also referred to as **metastatic** or advanced cancer. Cleveland Clinic, "Cancer", Accessed November 2022, <https://my.clevelandclinic.org/health/diseases/12194-cancer>

would likely be in the follow-up stage with their doctors as of October 2022. During qualitative interviews, the doctor shared that due to the nature of the disease, relapse may occur for up to 10 years in case of malignancies and up to 2 years in benign cases. Hence, the patient cannot be declared safe until then. Considering only less than 2 years of duration has passed since the intervention, it cannot be ascertained that the patients have recovered from the disease.

**Fig 13 : Current treatment status of patients (n=63)**



**3% (2/63)** of patients have stopped treatment as of October 2022. One patient stopped treatment since they were mentally exhausted and did not want to continue treatment. Another patient passed away between the time of follow-up by KARO Trust and the day of the survey conducted for the study.

For **100% (63/63)** of patients, treatment lasted/has been continuing for more than 1 year. This is in alignment with information shared by doctors during interviews, who highlighted that treatment for Ewing's Sarcoma lasts for more than a year, and for BMT cases, it lasts for 1-2 years on average.

### **Families' perception regarding treatment**

**87% (55/63)** of caregivers shared that they would continue treatment till their child is better or till the doctor advises them to do so, highlighting their awareness regarding the importance of completion of treatment.

*"Once the patients come in, they believe in treatment more. The patients know that this is an important aspect of treatment and hence are determined to complete treatment."*

- Doctor, CTC Borivali



## Frequency of follow-up calls conducted for check-ins with patients and families

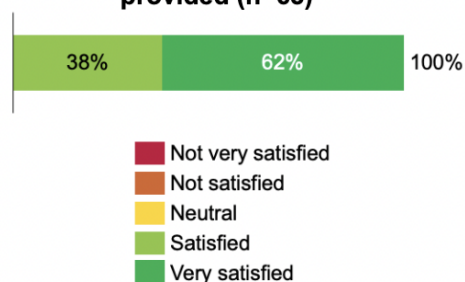
Though **all (105/105)** families receive follow-up calls from KARO Trust, **54% (34/63)** patients and their families shared that KARO Trust followed up with them at least once a month. For the remaining **46% (29/63)**, the follow-ups happen at no fixed duration. KARO Trust shared that the follow-ups are personalised as per the condition of the patient. The follow-ups are stopped six months after a patient's treatment is complete and the remission is going well, or if the patient is deceased. During qualitative interviews, **2/2** patients and their families shared that the follow-up calls from KARO Trust provided them a space to share any concerns.

"People who have had cancer during childhood or adolescence need follow-up care and enhanced medical surveillance for the rest of their lives because of the risk of complications related to the disease or its treatment that can last for, or arise, many years after they complete treatment for their cancer."<sup>28</sup> Though patients attend follow-ups with their doctors, the follow-ups conducted by KARO Trust may help the patients be more regular with their treatment and help solve any challenges that may lead them to drop treatment.

## Satisfaction levels of patients and families

**100% (63/63)** of patients and their families were satisfied with the support provided by KARO Trust.

**Fig 14 : Rating on KARO Trust's support provided (n=63)**



When probed further **90% (95/105)** of patients and their families chose 'reduction in financial stress' as a reason for their satisfaction.

*"The best thing about KARO Trust is the timely help and that I was able to have my surgery timely. My mind is relieved because of KARO Trust's help."*

- Patient, Ewing's Sarcoma

Overall, **96% (101/105)** patients, and their families would recommend KARO Trust to other patients who require financial support for treatment, potentially expanding KARO Trust's reach. The remaining **4% (4/105)** of respondents belonged to the families of deceased patients.

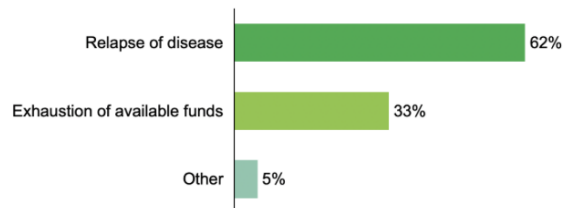
<sup>28</sup>National Cancer Institute, "Cancer in Children and Adolescents", last modified November 2021, <https://www.cancer.gov/types/childhood-cancers/child-adolescent-cancers-fact-sheet#35>



## Additional financial support provided to patients

Of the patients who are alive, **71% (45/63)** reached out to KARO Trust for financial support after the first instance (through hospital social workers) for reasons such as relapse of diseases and exhaustion of funds.

**Fig 15 : Reasons for reaching out to KARO Trust for support again (n=45)**



The instances of repeated financial support are highest (**about 80% (4/5)**) amongst patients suffering from Aplastic Anemia, followed by patients suffering from Ewing's Sarcoma (**74% (23/31)**), and patients undergoing a Bone Marrow Transplant (**67% (18/27)**).

Based on reports shared by KARO Trust, of the 144 patients supported under this project, **15% (22/144)** received additional financial support<sup>29</sup> for treatment (for reasons such as continued treatment or relapse) in the consecutive year (2021-22).

## Factors such as the nutrition intake of patients, availability of affordable accommodation, etc. have an impact on the treatment and recovery of the patient

### Fulfillment of nutrition requirements prescribed to patients

Taking proper nutrition plays a crucial role in the recovery process. **46% (29/63)** patients have a nutrition plan prescribed by the doctor, and **54% (34/63)** patients are asked to follow a regular diet at home or have a different treatment approach.

Of the patients who have a nutrition plan, **90% (26/29)** are able to follow them by themselves or with their family's support. In some cases, the food is provided by the hospital.

During interviews, **2/2 doctors** shared that in most cases, home-cooked food is sufficient to meet their nutritional requirements during and post-treatment.

*"After BMT, she [the patient] had a fixed diet, and was able to manage with home-cooked food. She was advised to avoid fruits and eat only cooked food. We were able to manage it."*

- Caregiver, Thalassemia Patient

<sup>29</sup> The financial support in 2021-22 could have been provided by KARO Trust using funds from KMBL, or from any other donor.

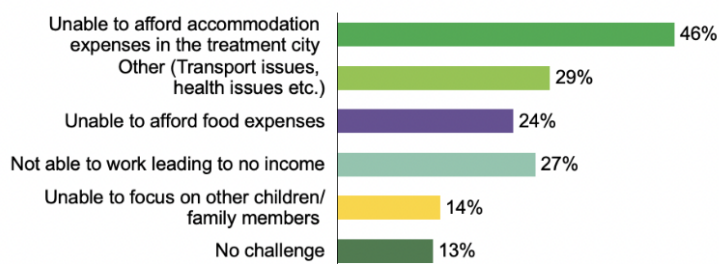
## Challenges faced by families in receiving treatment

When enquired about challenges faced during treatment, **46% (29/63)** respondents shared that they are unable to afford accommodation in the treatment city. **67% (42/63)** of patients' base locations and treatment cities were different. This indicates that they relocated or frequently traveled to the treatment city to receive treatment. This also points to an additional cost that they might have to incur. The remaining **33% (21/63)** patients received treatment in their base city.

As shared by the doctor at CTC Borivali, patients requiring bone marrow transplants need to stay in the city for 3-6 months for constant follow-up post surgery. During this time, the patients are most immune to infections which could have an adverse impact on the outcome of treatment. A safe and hygienic accommodation becomes crucial for the patients in the project.

Other major challenges highlighted by respondents were the lack of a source of income and their inability to afford travel costs and food expenses.

**Fig 16 : Other challenges faced by patients and families during treatment (n=63)**



Additionally, **2/2** doctors highlighted that cases of abandonment of treatment majorly happen due to challenges such as logistics or social reasons. These are some areas that can be focused on during future interventions.

*"We had trouble finding accommodation. We had to live on the road."*

- Patient, Ewing's Sarcoma

*"If we can get help in finding work that is suited for us, we can earn a daily income and support ourselves. It will help me become independent."*

- Patient, Ewing's Sarcoma

Another concern shared by a caregiver was the inability to finance higher education for their child. Since the family's funds are exhausted in financing part of the treatment of the child, they do not have sufficient funds for other future expenses such as higher education. Work and education provide patients with a sense of identity and income needed for follow-up care or for treatment in cases of relapse. The ability to return to or maintain occupational and educational pursuits after a cancer diagnosis has been demonstrated to improve the quality of life of patients with cancer, reducing social isolation and increasing self-esteem.<sup>30</sup>

<sup>30</sup>Parsons HM, Harlan LC, Lynch CF, Hamilton AS, Wu XC, Kato I, Schwartz SM, Smith AW, Keel G and Keegan TH, "Impact of cancer on work and education among adolescent and young adult cancer survivors" Published July 2012, doi: [10.1200/JCO.2011.39.6333](https://doi.org/10.1200/JCO.2011.39.6333)

*“We are focusing on treatment, but once the treatment is complete, the patients face fertility challenges, education, and other challenges. It would be great if we could do something for these aspects also.”*

*-Medical Oncologist, Tata Memorial Hospital*

As per records shared by KARO Trust, **8% (11/144)** of patients supported during the financial year 2020-21, received additional support such as financial support for lab tests, accommodation support, tablets for education purpose, or financial support for travel during the pandemic. This support was financed using other donor funds available with KARO Trust. Such support helped ensure the continued treatment of these patients.

## **There were possible disruptions in the treatment of patients suffering from any of the diseases during the COVID-19 pandemic due to travel restrictions**

Although, COVID-19 drastically impacted the healthcare system during the financial year 2020-21, the project ensured treatment for patients during that time.

During the pandemic, the shortage of medical staff due to the admission of a large number of COVID-19 patients reduced the interaction frequency between patients and oncologists.<sup>31</sup> Additionally, COVID-19 lockdowns restricted movement which added to the delay in interaction and hence, the next steps of treatments.

**14% (9/63)** of patients shared that they missed at least one appointment or treatment session due to reasons such as travel issues caused by COVID-19 restrictions. The doctors emphasized that missing or delaying appointments or treatment sessions for non-justifiable reasons like logistical issues should be strongly avoided. Delays or missing appointments can have a negative effect on the patient's outcome.

As highlighted previously in this chapter, a delay of even a few weeks can have adverse effects on the patients' outcomes. COVID-19 drastically impacted the healthcare system during the financial year 2020-21. Hence, it is likely that it had an impact on the outcomes of patients supported in the project.

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<sup>31</sup>Li Y, Wang X and Wang W, “The Impact of COVID-19 on Cancer” Published September 2021, <https://doi.org/10.2147/IDR.S324569>

## Case Stories

### Case Study 1:

Priya<sup>32</sup> (age 9) is from Akola (Maharashtra), around 600 km away from Mumbai. Her father shared that, three months after her birth, she was diagnosed with Thalassemia. Her family was in shock and was trying to adjust to the situation. Medicines were not available in Akola and had to be arranged from other cities. A bone marrow transplant was recommended for her as a course of treatment. Fortunately, Priya's brother was found to be a match for her. The transplant would cost INR 20-25 lakhs approximately. The family could only arrange about 10% of the money. They were unable to find any other source of funding. They felt that the treatment may not happen due to their financial constraints. Doctors helped them reach out to multiple donor organisations to arrange for funds for the transplant. One such organisation was KARO Trust, which supported them by contributing INR 50,000 for the transplant.

Her treatment is ongoing and she has regular follow-ups with her doctor. They have never missed a treatment session or appointment.

Priya is currently in class 4. Her hobbies are playing and dancing. The family believes that education is a crucial part of life and they look forward to providing her with a good higher education.

### Case Study 2:

Prakash<sup>33</sup> (age 32) is from Uttar Pradesh and was treated in Mumbai (Maharashtra) for Ewing's Sarcoma in his leg. Initially, he went to a few hospitals in Uttar Pradesh but the treatment did not give him relief. He was then referred to Tata Memorial Hospital in Mumbai. The doctor at Tata Memorial Hospital recommended surgery as the best course of treatment. Since the surgery was expensive, Prakash had trouble arranging for funds for it independently within the stipulated time. Medical Social Workers workers at the hospital recommended his case to KARO Trust. He received timely financial support for his surgery from KARO Trust in October 2020. The surgery was successful and he is currently in the follow-up stage with his doctor. He says that his mind is relieved as he feels supported by KARO Trust. He receives regular check-in calls from them. He is currently looking for employment opportunities to earn a stable income and support himself.

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<sup>32</sup>Name changed to maintain confidentiality.

<sup>33</sup>Name changed to maintain confidentiality.

## Conclusion

The healthcare project by Kotak Mahindra Bank Limited, implemented by KARO Trust has had a considerable impact on the patients and their families. The financial support provided to the patients has enabled them to continue or complete treatment. It has helped the families reduce their financial stress, and also supported them to be emotionally stronger to deal with their situation. The project has helped the now deceased patients have a better quality of life during their last days. The aim of the project has been achieved, as envisioned by KMBL. There are effective systems in place for the implementation of the project. Hospitals have a good working relationship with KARO Trust and are smoothly able to recommend patients for support.

The number of people affected with such diseases in a country of more than 140 crore population is high. It has also been established that the treatment in such cases can be long and expensive. There is an opportunity for corporates such as KMBL, to contribute towards such causes consistently, through its CSR initiatives, and support organisations such as KARO Trust.

# Annexures

## Annexure 1 : Glossary for 'n's used in insights

Annexure Table 1 : Table of 'n's used in insights

'n' used in insights	Explanation
144	144 patients were financially supported for treatment in the year 2020-21.
105	105 patients were surveyed for the study.
63	63 alive patients and their families were surveyed for the study.
42	Families of 42 deceased patients were surveyed for the study. Considering the sensitivity of the situation, a shorter survey was conducted with the family members of patients who had passed away, to understand about the support provided by KARO Trust to those patients.
43	43/105 patients and families were aware about the stage of their disease when they received support from KARO Trust.
45	45/63 alive patients reached out to KARO Trust for additional support.
29	29/63 alive patients have been prescribed a nutrition plan by their doctor.

## Annexure 2 : Data Collection Tools

**Annexure Table 2 : Survey for alive patients and their families**

Sr No.	Type	Questions	Options/Probes
1	Text	Name of caregiver	
2	Single Choice	Relationship with patient	Self
			Father
			Mother
			Aunt
			Uncle
			Sister
			Brother
			Other
3	Text	If others, please specify	
4	Text	Name of patient	
5	Single Choice	Gender of patient	Male
			Female
			Other
6	Number	Age of patient	
7	Single Choice	Social Category	General
			OBC
			ST
			SC
			Other
8	Text	If others, please specify	
9	Text	City from where patient and caregiver is based	
10	Number	What is your approximate annual household income?	
11	Single Choice	Type of disease/treatment that child is undergoing/has suffered from	Ewing's Sarcoma
			Aplastic Anemia
			Bone Marrow Transplant
			Other
12	Text	If others, please specify	
13	Single Choice	Is your child currently undergoing treatment?	Yes
			No, we have stopped treatment

			Treatment is completed
14	Text	Hospital where treatment is taking/took place	
15	Text	City in which treatment is taking/took place	
16	Single Choice	How long has the treatment been going on for your child?/How long did treatment go on for your child?	Less than 6 months
			6 months - 1 year
			1-2 years
			2-3 years
			More than 3 years
17	Single Choice	Has your child missed any appointments or treatment sessions during the course of their treatment?	Yes
			No
18	Text	If yes, when and why could your child not attend an appointment or treatment session?	
19	Single Choice	How did you get to know about KARO Trust?	Friends/family
			Online sources
			Treatment Hospital Staff (Doctors/Nurses/Social Worker)
			Previous Hospital Staff
			Other
20	Text	If others, please specify	
21	Single Choice	How was the process for reaching out to KARO Trust for support?	Easy
			Neither easy nor difficult
			Difficult
22	Multiple Choice	What challenges did you face in the process of reaching out to KARO Trust for support?	I did not face any challenge
			There were too many forms to fill
			The process took a long time to complete
			I had to arrange a lot of documents in less time
			I had a lot of doubts which were not answered



			Treatment started after a lot of time after applying
			Other
23	Text	If others, please specify	
24	Single Choice	How long after reaching out to KARO Trust did treatment start for your child?	Less than a week
			2 weeks - 3 weeks
			1 month
			2 months
			3 months
			More than 3 months
25	Multiple Choice	What would have been your alternate source of support if KARO Trust services were not available?	Mortgage house
			Sell land
			Encash savings
			Take a loan from the bank
			Borrow money from friends/family
			Did not think of any alternate source
			Other
26	Text	If others, please specify	
27	Single Choice	Has the doctor prescribed any particular nutrition requirements for your child?	Yes
			No
28	Single Choice	Are you able to follow it?	Yes
			No
29	Text	If yes, how do you manage to follow it?	
30	Text	If not, what challenge do you face in following it?	
31	Multiple Choice	What challenges did you face since your child's treatment started? (Apart from finances for the treatment)	Unable to afford food expenses
			Unable to afford accommodation expenses in the treatment city
			Unable to focus on other children/family members
			Not able to work leading to no income

			No challenge
			Other
32	Text	If others, please specify	
33	Single Choice	What is your approach for your child's treatment?	I will continue treatment till my child is better
			I will continue treatment till we have external support for money
			I am thinking of dropping treatment
			Other
34	Text	If others, please specify	
35	Single Choice	How frequently a follow up was done by the KARO Trust to understand your needs and check on you and your child?	Once in a week
			Once in two weeks
			Once a month
			No fixed duration
			No follow up was done
36	Text	What was discussed during the follow ups, and were they helpful to you?	
37	Multiple Choice	How did you feel supported by KARO Trust?	It helped me with my financial worries
			It helped me continue treatment for my child
			It has helped me increase my household savings
			It helped us by providing ration and hygiene kits
			It helped me with accommodation support
			It did not help me
			Other
38	Text	If others, please specify	

39	Single Choice	Overall, on a scale of 1-5 how satisfied are you with the support you received from KARO Trust?	(1 - Extremely dissatisfied 2 - Dissatisfied 3 - Neutral 4 - Satisfied 5 - Very satisfied)
40	Single Choice	Did you reach out to KARO Trust for support again after the first time?	Yes No
41	Single Choice	If yes, what was the reason behind reaching out again to KARO Trust?	Relapse of disease Exhaustion of available funds Other
42	Text	If others, please specify	
43	Text	What can be improved in support you received from KARO Trust, according to you?	
44	Single Choice	Would you recommend anyone to reach out to KARO Trust for support, if they require?	Yes No
45	Text	Additional Comments	

**Annexure Table 3 : Survey for families of deceased patients**

Sr No.	Type	Questions	Options/Probes
1	Text	Name of caregiver	
2	Single Choice	Relationship with patient	Father Mother Aunt Uncle Sister Brother Other
3	Text	If others, please specify	
4	Text	Name of patient	
5	Single Choice	Social Category	General OBC ST SC Other
6	Text	If others, please specify	

7	Number	What is your approximate annual household income?	
8	Single Choice	How did you get to know about KARO Trust?	Friends/family
			Online sources
			Treatment Hospital Staff (Doctors/Nurses/Social Worker)
			Previous Hospital Staff
			Other
9	Text	If others, please specify	
10	Single Choice	How was the process of reaching out to KARO Trust for support?	Easy
			Neither easy nor difficult
			Difficult
11	Multiple Choice	What challenges did you face in the process of reaching out to KARO Trust for support?	I did not face any challenge
			There were too many forms to fill
			The process took a long time to complete
			I had to arrange a lot of documents in less time
			I had a lot of doubts which were not answered
			Treatment started after a lot of time after applying
			Other
12	Text	If others, please specify	
13	Multiple Choice	In what ways did KARO Trust's support help you?	It helped me with my financial worries
			It helped me support my child during his/her last days
			It helped us by providing ration and hygiene kits
			It helped me with

			accommodation support
			It did not help me
			Other
14	Text	If others, please specify	
15	Single Choice	Would you recommend anyone to reach out to KARO Trust for support, if they require?	Yes
			No
16	Text	Additional Comments	

**Annexure Table 4 : Questionnaire for alive patients and their families**

Sr No.	Questions
1	Introduction
2	Could you give a little background about yourself? (what do you do, since when have you been in the city/town, base location)
3	When did your child get their initial diagnosis? What did you do after the diagnosis?
4	When did treatment for your child begin? Which hospital and city did the treatment take place in?
5	What kind of challenges were you as a family facing in receiving treatment for your child, prior to KARO Trust's intervention?
6	How did you come to know about KARO Trust?
7	What was the process for reaching out to KARO Trust for support? How much time did it take to get in touch with them?
8	Did you face any challenges in the process of reaching out to KARO Trust for support? How long after reaching out to KARO Trust, did the treatment begin for your child?
9	Do you know how KARO Trust raised funds for your child's treatment?
10	What meals do you provide to your child on a day to day basis?
11	Has the doctor prescribed any particular nutrition requirements for your child? Are you able to follow it? if yes how if not why
12	Has your child missed any appointments or treatment sessions? If yes, when and why could you not attend an appointment or treatment session?
13	How frequently a follow up was taken by the KARO Trust to understand your needs and check on you/your child? What was discussed during the follow up conversation? How was it helpful?
14	Did the support from KARO Trust have any impact on your decision to complete treatment for your child? How?
15	How do you feel receiving support from KARO Trust helped you/your child?
16	What kind of support other than treatment was provided by KARO Trust? How was it helpful?
17	[If base city and treatment city are different] What challenges have you faced since relocating for your child's treatment?

18	Did/do you feel a need for any additional support during your child's treatment? If yes, what kind of support would have been helpful to you?
19	Do you have any feedback for the support you received from KARO Trust? Could you elaborate?
20	Would you like to share anything else about your experience with KARO Trust?

**Annexure Table 5 : Questionnaire for families of deceased patients**

Sr No.	Questions
1	Introduction
2	Could you give a little background about yourself? (what do you do, since when have you been in the city/town, base location)
3	How did you come to know about KARO Trust?
4	What was the process for reaching out to KARO Trust for support? Did you face any challenges in the process of reaching out to KARO Trust for support?
5	Would you like to share anything else about your experience with KARO Trust?

**Annexure Table 6 : Questionnaire for Doctors/Medical Social Workers**

Sr No.	Questions
1	How do you and KARO Trust work together to help a patient?
2	What challenges do patients and their parents face when they visit the hospital?
3	How do you support patients and their families during treatment at the hospital?
4	Social worker - What is the process followed for recommending patients to KARO Trust? Doctor - Are you involved in the process of recommending patients to KARO Trust? How does the process work?
5	Under what time duration does the hospital receive funds from KARO Trust for a patient?
6	What are the other sources of funding opportunities available to patients?
7	How long does treatment usually last for the following conditions? Ewing's Sarcoma Aplastic Anemia Bone Marrow Transplant
8	What are the prescribed nutrition requirements for the patients of Ewing's Sarcoma, Aplastic Anemia, Bone Marrow Transplant? Are your patients able to maintain the nutritional requirements?
9	Are your patients regularly able to attend their appointments and treatment sessions? What are some reasons for delays as per your observations?
10	How critical is their absence from one appointment or session?
11	Do you think KARO Trust has helped improve access to treatment for patients? How?

12	Have you seen a change in beneficiaries' perception towards the importance of completion of treatment due to KARO Trust's intervention?
13	What happens if there is a delay in the start of treatment?
14	What is the impact of continued treatment on the life span of the patients?
15	How does the outcome of treatment differ as per various stages of the diseases?
16	Overall, how do you think KARO Trust has been helpful to the patients?
17	Do you follow up with patients/their families during treatment and after they leave the hospital? How?
18	How many cases of abandoned treatment do you usually see in a year for these conditions (Ewing's Sarcoma, Aplastic Anemia, Bone Marrow Transplant)? As per your observations, why do families abandon treatment after diagnosis/mid treatment? Are there any reasons other than monetary issues?
19	Additional Comments

**Annexure Table 7 : Interview for KARO Trust**

Sr No.	Questions
1	What is the intent of the project? How do you think the collaboration with KMBL led to achieving it?
2	How were the three specific conditions picked for the intervention? (Ewing's Sarcoma, Aplastic Anemia, Bone Marrow Transplant)
3	What is the broad criteria of selection of beneficiaries for funding? Is there a SoP on the criteria? When recommendations are received from the hospital for patients to support, is there a discussion on the same?
4	Could you briefly share with us, the processes and any SoP documents available for Referring of beneficiaries for funding Transfer of funds to hospital
5	What parameters were considered while designing the structure of the implementation team? (qualifications, procedure, RnRs, experience)?
6	What were the systems in place to track the progress of the project?
7	How do you track the budget utilisation? Is a break-down of specific expenses incurred for each patient and their family available?
8	What are the processes in place to ensure financial transparency to KMBL?
9	Is the project aligned to national and international health goals? How?
10	Did COVID-19 have any impact on the project? Were any changes made to the project to accommodate the effects of the pandemic?
11	How does the KARO Trust follow up with patients and their families? (Process, frequency)
12	What are the prescribed nutrition requirements for the patients of Ewing's Sarcoma, Aplastic Anemia, Bone Marrow Transplant? Considering the patient's family backgrounds, how easy or difficult is it for the family to provide meals to the patients?

13	What is included in ration kits that are distributed to the patient families? How much does a ration kit cost?
14	Are the patients regularly able to attend their appointments and treatment sessions? What are some reasons for delays as per your observations?
15	At what critical stage do the patients usually come to KARO Trust? What is the impact of continued treatment on the life span of the patients?
16	How many repeat patients have approached KARO Trust for funding? Are there any records on this?
17	Have any beneficiaries of the project stopped treatment? If yes, how many and why?
18	Have there been any additions to the project to prevent beneficiaries from abandoning treatment?
19	Have there been any revisions to planning and processes based on learnings from the previous years of the project?
20	How is sustainability of the project ensured from the project team's end? Do you have alternate sources of funding other than KMBL?
21	Are there any plans for collaborations for funding/research/ideation or partnerships with external organizations working for Ewing's Sarcoma cancer and Aplastic Anemia and Bone Marrow Transplant to utilize the synergies?
22	Were there any efforts towards reflecting KMBL's visibility under the project? If yes, what were they?



## Annexure 3 : Ethical considerations of the study

The assessment followed the ethical protocols in all aspects and at all stages of the engagement based on the discussion with team:

- **Informed consent and voluntary participation:** All respondents and participants have been given appropriate and accessible information about the purpose, methods and intended uses of the evaluation, what their participation in the project entails, and what risks and benefits, if any, are involved. The assessment has been undertaken only after consent - free from coercion or undue pressure - is received from the respondents. They have been made aware of their right to refuse participation whenever and for whatever reason they wish, without fear of penalisation or victimisation. Participants have also been made aware of where and for how long their data will be stored and how the data will be treated. Consent has been taken with regard to recording and usage of all information acquired - written, verbal, photographic. It has been kept in mind that the primary research is conducted in a place where the participants feel comfortable and safe in sharing their responses. At no point has any information been sought, either through explicit pressure or false promises, from the respondents.
- **Anonymity and confidentiality:** The identity of participants has been protected at all times through anonymity or confidentiality, unless the participants explicitly agree to, or request the publication of their personal information.
- **Sensitivity :** Proper consent was taken from participants for the study. The data enumerators were given proper training on the data collection tools, with special focus on the sensitivity aspect of the project. It was ensured at all times that the participants were comfortable during the data collection.

## Annexure 4 : Data policy

Sattva Consulting has in place internal security protocols to protect the privacy of all data collected from respondents, especially any personally identifiable information (PII). Some of the relevant protocols for this project are:

- **Data Storage and Access:** Any devices used for data collection are password-protected to prevent unauthorized access. Survey software with encryption features, such as Collect, have been used so that encryption occurs during data collection and transmission to a central server. Data with PII is shared only using encrypted files, unless being shared directly from Sattva's cloud storage. Access to data on Sattva's cloud storage has been further limited to project team members who require access.
- **Data Retention:** Data with PII is only retained for pre-decided periods based on project requirements. Any data stored on data collection devices is removed after data collection for the project is complete, to minimize risk. Where possible, data stored on stolen/ lost devices is remotely deleted.
- **Training:** Personnel are provided adequate training on maintaining privacy of data collected, including procedures for handling devices to maintain data security.
- **Removal of PII:** All PII is removed from the raw dataset and separated into an "Identifiers Dataset" and "Analysis Dataset". A common ID is generated to allow re-joining PII data if required. Access to "Identifiers Dataset" is limited to select personnel as required. Limited and necessary PII is re-shared with enumerators/field supervisors to allow for quality checking and back-checking of data as per project requirements.