



AN IMPACT ASSESSMENT REPORT OF PROJECT SBI CANCER CURE

Implemented by Indian Cancer Society



ACKNOWLEDGEMENTS

I would like to express my deepest gratitude to SBI Foundation for their donation. 260 underprivileged cancer patients were treated and many of them are currently leading productive lives. Special thanks to Mr. Rajaram Chavan, Deputy Manager, SBI Foundation for his valuable guidance and support throughout the project.

I also take this opportunity to acknowledge the efforts taken by CCF empanelled hospital teams for guiding and assisting the patients during their treatment and co-ordinating with the CCF team for the study within the stipulated time frame.

Furthermore, I would like to appreciate the crucial role of the Due Diligence Team and the Governing Advisory Committee but for whom the Cancer Cure Fund project would not have been a success.

A special acknowledgment to Social Lens who has helped ICS CCF design the impact study. Last but not the least, the CCF team who made certain that all the processes and procedures were followed diligently as per the proposal agreed with SBI Foundation.

Best Regards,

Usha Thorat

ICS CCF Trustee In Charge and GAC Chairperson

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1. Introduction

A cancer diagnosis is sudden and devastating. Apart from the toll it takes on the patient's health, it causes an emotional strain on them and their families. This anxiety and uncertainty is further exacerbated if the patient does not have the financial means to access treatment. This report aims to demonstrate the impact delivered by the joint efforts of the Indian Cancer Society (ICS) and the SBI Foundation in their mission of reducing the cancer burden of those who are socio-economically vulnerable. ICS is unique in its approach in that they are able to provide large sums of money with a quick turnaround time. For cancer patients, this means not having to look at multiple sources to fund their treatment, and having the chance to get access to the best possible treatment immediately. Doctors are able to treat patients with the most effective medication, techniques and with the right rigour which leads to faster and more successful rates of recovery.

1.1 STATE BANK OF INDIA (SBI) FOUNDATION

The idea of 'service beyond banking' lies at the centre of the SBI Foundation's (SBIF) activities. It has always been believed that Corporate Social Responsibility (CSR) is an ethos and is committed to making a difference and creating a positive impact on society. The vision of the Foundation is aimed at improving the socio-economic well-being of society and creating an inclusive development paradigm that serves all Indians.

With this in mind, SBIF has a wide range of Focus Areas which include:

- (i) Healthcare and Sanitation
- (ii) Education
- (iii) Livelihood and Skill Development
- (iv) Women Empowerment and Care for Senior Citizens
- (v) Sustainability and Environment

- (vi) Rural Development
- (vii) Conservation of National Heritage, Arts and Culture
- (viii) Promotion of Sports

The SBI Foundation aims 'to make resources available to the most vulnerable sections of the society directly and through strategic partnerships/collaborations with impact making entities in the social and development sector.' (1)

1.2 THE INDIAN CANCER SOCIETY (ICS)

Established by Dr DJ Jussawalla and Mr Naval Tata in 1951, Indian Cancer Society is India's first non-profit organisation dedicated to cancer. With the vision to be 'a beacon of hope' against the disease, ICS today has offices in Bengaluru, Kolkata, Lucknow, Mumbai, Nagpur, New Delhi, and Patna. Through its pan-India presence, the organisation has been able to support the treatment and rehabilitation of people diagnosed with cancer across the country.

INDIAN CANCER SOCIETY'S MISSION



Reference: Data obtained from Indian Cancer Society's Website

INITIATIVES INTRODUCED BY ICS

Cancer Screening	Dr Arun Kurkure Initiation and Treatment Fund	the Cancer Registry (1963) and Indian Journal of Cancer (1963)	Survivorship Programme: • Ugam - Support Group of Childhood Cancer Survivors (2009) • After Completion of Treatment (ACT) Dr DJ Jussawalla Education Program
Cancer Cure Fund (2011)	the Cancer Awareness Program	Indian Cancer Society Rehabilitation Centre (1963)	

Reference: Data obtained from Indian Cancer Society's Website

As the organisation relies on public support for its initiatives, it works with individuals and corporations to raise money for the Cancer Cure Fund and enable treatment for those diagnosed with the disease. This report will focus on the partnership between ICS and the State Bank of India Foundation for the Cancer Cure Fund as it highlights the role of collaboration in Indian Cancer Society's initiatives.

1.3 BACKGROUND

Cancer has evolved to become a major cause of death globally, with incidence and mortality rates on the rise over the last few decades (2). In 2020, the World Health Organisation (WHO) reported that cancer was a leading cause of death globally and was responsible for nearly 10 million deaths that year (3). The situation in India is no exception. India's cancer burden has increased 2.6 times between 1990 and 2016 and the rate of deaths from the disease has doubled (4).

In August 2020, the Indian Council of Medical Research (ICMR) and the National Centre for Disease Informatics and Research (NCDIR) published the Report of the National Cancer Registry Programme (2012-2016) and found that the cancer burden is estimated to increase to 1.57 million by 2025 from 1.39 million in 2020 (5).

MOST COMMON CANCERS IN INDIA



Lung, Mouth, Stomach, Oesophagus



Breast, Cervix Uteri



Leukaemias, Lymphomas

Reference: Report of National Cancer Registry Programme, 2020

 $⁽²⁾ Weiderpass\ E,\ Stewart\ BW,\ editors\ (2020).\ World\ Cancer\ Report:\ Cancer\ Research\ for\ Cancer\ Prevention.\ Lyon, France:\ International\ Agency\ for\ Research\ on\ Cancer.\ Available\ from:\ <math display="block">\underline{http://publications.iarc.fr/586.}\ Licence:\ CC\ BY-NC-ND\ 3.0\ IGO.$

⁽³⁾ World Health Organisation. (2021). Cancer. Available from: https://www.who.int/news-room/fact-sheets/detail/cancer_

⁽⁴⁾ Bhargava, B and Mathur, P. Reducing India's cancer burden. (September 2020). The Hindu. Available from: https://www.thehindu.com/opinion/op-ed/reducing-indias-cancer-burden/article32594589.ece

India is a lower-middle income country and findings from the World Cancer Report 2020 suggest that socioeconomic background has an impact on whether an individual/population is at the risk of exposure to cancer (6). Further, the report found that in India, exposure to cervical and oral cancer is higher among those with a lower socioeconomic status, while breast and colorectal cancer is more prevalent among those with a higher socioeconomic status. The former, especially oral cancer is linked to tobacco use, while the latter is attributed to a sedentary lifestyle, obesity, and a lack of physical activity (7).

In 2016, it was also found that approximately 70% of deaths from cancer occurred in low and middle-income countries (8), highlighting a visible inequality in cancer awareness, prevention, diagnoses, and care. The World Health Organisation has recommended a few steps for reducing the cancer burden through early detection and management of the disease (9):

- Awareness and accessing care
- Clinical evaluation and diagnoses
- Timely access to treatment

Early diagnoses or detection must be followed by screening and treatment. These three components must go hand in hand, to cure patients, or at least improve their quality of life (10).

The findings of a report by the Parliamentary Committee on Science and Technology, Environment, Forests, and Climate Change in 2019 highlight how far reaching the implications of a cancer diagnosis can be. The report presents a submission made by the Tata Memorial Centre, which states that "two-thirds of the cancer care is actually provided in the private sector with the result that almost every year, six crores of India's population goes below the poverty line because of the catastrophic healthcare related expenditure on cancer"(11).

The statistics from the National Sample Survey, 75th round, state that average medical expenditure for cancer treatment per hospitalisation case during stay at the hospital can range from around Rs. 20,000 to around Rs. 1 lakh in rural and urban India(12). According to the estimates of the Indian Cancer Society, the complete cancer treatment in India, depending on type, extent, and duration, could cost anywhere between INR 1 to 10 lakh(13). This is a cause of concern for two reasons - India's cancer burden is set to rise and India's per capita income was less than around INR 1,50,000 in 2019(14).

⁽⁶⁾Rengaswamy Sankaranarayanan, Kunnambath Ramdas in Wild CP, Weiderpass E, Stewart BW, editors (2020). World Cancer Report: Cancer Research for Cancer Prevention. Lyon, France: International Agency for Research on Cancer. Available from: http://publications.iarc.fr/586. Licence: CC BY-NC-ND 3.0 IGO. (7)Ibid..

⁽⁸⁾ American Cancer Society. (n.d.). The Global Cancer Burden. Available from: $\frac{\text{https://www.cancer.org/health-care-professionals/our-global-health-work/global-cancer-burden.html}{\text{https://www.cancer.org/health-care-professionals/our-global-health-work/global-cancer-burden.html}}$

 $⁽⁹⁾ World\ Health\ Organisation.\ (2021)\ Cancer.\ Available\ from: \underline{https://www.who.int/news-room/fact-sheets/detail/cancer}$

⁽¹⁰⁾ World Health Organisation. (2021) Cancer. Available from: https://www.who.int/news-room/fact-sheets/detail/cancer

⁽¹¹⁾ Parliamentary Committee on Science and Technology, Environment, Forests, and Climate Change. (November 2019). An Expanded Role for the Department of Atomic Energy in Cancer Treatment in India through an Enlarged Network of the Tata Memorial Centre. Available from:

https://rajyasabha.nic.in/rsnew/Committee site/Committee File/ReportFile/19/126/325 2020 2 12.pdf

 $^{(12) \} Ministry \ of \ Statistics \ \& \ Programme \ Implementation. \ (2020). \ NSS \ Report \ No. \ 586 \ Health \ in \ India. \ Available \ from: \\ \underline{http://mospi.nic.in/sites/default/files/publication_reports/NSS\%20Report\%20no.\%20586\%20Health\%20in\%20India.pdf}$

 $[\]left(13\right)$ Obtained from Project Proposal Form - Indian Cancer Society.

⁽¹⁴⁾ World Bank. (2019). GDP per capita (current US\$) - India. Available from:

 $https://data.worldbank.org/indicator/NY.GDP.PCAP.CD?locations=IN; \ Figure\ converted\ at\ the\ rate\ of\ \$1=INR\ 72\ on\ 10\ March\ 2021$

AVERAGE MEDICAL EXPENDITURE FOR TREATMENT PER HOSPITALISATION CASE DURING STAY AT HOSPITAL OVER LAST 365 DAYS

Area	Approximate Expenditure (INR)
Rural	57,000
Urban	68,000

Reference: NSS Report No. 586 Health in India, 2020

The gravity of the situation becomes clearer when one considers the public expenditure on cancer in India, which is estimated to be below US \$10 (approximately INR 720) per person (15). Reports also suggest that 'out of pocket payments account for more than three quarters of cancer expenditure in India' (16), which is in line with what Tata Memorial Centre submitted to the Parliamentary Committee in 2019. It is important to also note that approximately, only 14% of the rural population and 19% of the urban population had health expenditure coverage in 2018 (17). The significant financial burden a cancer diagnosis inflicts on cancer patients in India has ramifications on the welfare of the entire family, which may also continue for several generations (18).

The Government of India is committed to the 2030 Agenda for Sustainable Development. In the Agenda, Goal 3 (Good Health and Well-Being) highlights the need to 'ensure healthy lives and promote well-being for all at all ages' and Target 3.4 within that Goal includes reducing by one-third premature mortality from non-communicable diseases including cardiovascular disease, cancer, chronic respiratory disease and diabetes (19). With the present circumstances, attaining this goal could be a challenge.

This is where, in a country like India, organisations such as ICS potentially play an important role. Through their interventions, they not only aid in reducing the cancer burden in this country, but contribute towards a larger goal such as the Agenda for 2030.

⁽¹⁵⁾Pramesh, CS, Badwe, RA, Borthakur, BB, Chandra, M, Raj, EH, Kannan, T, et al. (2014). Delivery of affordable and equitable cancer care in India. The Lancet. Available from: https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(14)70117-2/fulltext;; Figure converted at the rate of \$1 = INR 72 on 10 March 2021 (16)Ibid..

⁽¹⁷⁾Ministry of Statistics & Programme Implementation. (2020). NSS Report 586 Health in India. Available from: http://mospi.nic.in/sites/default/files/publication_reports/NSS%20Report%20no.%20586%20Health%20in%20India.pdf (18) Pramesh, CS, Badwe, RA, Borthakur, BB, Chandra, M, Raj, EH, Kannan, T, et al.(2014). Delivery of affordable and equitable cancer care in India. The Lancet. Available from: https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(14)70117-2/fulltext

⁽¹⁹⁾ Department of Economic and Social Affairs. Goal 3. Available from: https://sdgs.un.org/goals/goal3

1.4 OVERVIEW OF PROJECT SBI CANCER CURE

1.4.1 INTRODUCTION

In 2016, ICS approached the SBI Foundation to support the treatment and rehabilitation of 100-120 cancer patients whose families earn less than INR 2 lakes per year through its Cancer Cure Fund. SBI Foundation was able to support ICS as one of its focus areas is Health and Sanitation and it is committed to Goal 3 of the 2030 Agenda for Sustainable Development - Good Health and Well Being.

1.4.2 OBJECTIVES OF SBI-CANCER CURE (20)

- To provide financial assistance for the treatment of needy and low-income patients diagnosed with any curable cancer.
- To offer emotional support and medical aid to cancer patient[s].
- To reintegrate cancer survivors back into society.

1.4.3 FINANCIAL OUTLAY AND GEOGRAPHICAL REACH



The collaboration was able to cover treatment for patients from Andaman and Nicobar Islands, Dadra and Nagar Haveli, Daman and Diu, Goa, Haryana, Jammu and Kashmir, Jharkhand, North East India, Punjab, and Rajasthan at an estimated cost of INR 3 crore (21).

Each patient was entitled to receive upto INR 4 lakes for the treatment (22). This was in line with ICS' commitment to collaboration and showcase how access to quality care can be within the reach of all.

The collaboration then centered around the idea that a lack of funds should not hinder access to quality care, with SBI Foundation noting that the Cancer Cure Fund provides much-needed support, and hope to those who need it most (23). Keeping in mind the nature of the collaboration, it was observed that the disbursement of INR 3 crore may go beyond 1 year (24). Between 2016-17 and 2020-21, the SBI Foundation through ICS has supported the treatment of 260 patients. Lastly, through this collaboration with ICS, SBI Foundation has potentially been able to contribute toward the achievement of Sustainable Development Goal 3 - Good Health and Well Being.

⁽²⁰⁾ Obtained from Project Approval Document received from Indian Cancer Society.

⁽²¹⁾ Obtained from Project Proposal Form - Indian Cancer Society.

⁽²²⁾ Ibid.

⁽²³⁾ Obtained from Project Approval Document received from Indian Cancer Society.

⁽²⁴⁾ Ibid.

1.4.4 INDIAN CANCER SOCIETY CANCER CURE FUND (ICS CCF)

The Cancer Cure Fund was established in 2011 with HDFC AMC Ltd. It is one of ICS' flagship initiatives. The objective of this Fund is "to provide financial assistance to low income patients diagnosed with curable cancer" (25). Further, the rationale behind this Fund is to highlight how swift assistance against the disease can ensure timely treatment, and a return to regular life (26). With CCF, the Indian Cancer Society aims at ensuring that patients receive holistic care against cancer, through its treatment protocol represented in Graphic Y.

COMPONENTS OF THE TREATMENT PROTOCOL

Chemotherapy Radiation Surgery Supportive care Prosthesis

Reference: Data obtained from Indian Cancer Society's Website

Between 2011-12 and 2020-21, ICS through the Cancer Cure Fund, has supported approximately 10,000 patients and disbursed more than INR 153 crores (27). Over the years, collaboration with other corporate partners, foundations, and individuals has increased. Further, ICS CCF has signed an agreement with Navya Technologies to provide a standardized clinical information service based on Machine Learning and Artificial Intelligence to conduct the initial screening of applications from the empanelled hospitals. This will enable the Fund to scale up the number of applications it can handle each month. Given the increasing load of patients applying for funding, it has implemented advanced technology to modernize and streamline its operational methodology.

1.4.5 IMPLEMENTATION MODEL

Indian Cancer Society-Cancer Cure Fund has put in place a transparent and robust due diligence process. This is in place not only to provide financial assistance to the patients but also a detailed criterion is laid down for empanelling hospitals under the project.

The partnership's implementation involved patients being referred by hospitals empanelled with Indian Cancer Society as per its eligibility criteria that was shared with them. ICS has 16 empanelled hospitals across the country and they play a role in the approval process.

List of Documents to be submitted along with ICS CCF forms while applying for treatment funds:

- 1. Hospital Registration Page
- 2. Cost certificate from hospital with complete break-up.
- 3. Address Proof: Ration card, Aadhaar card, driving license or any other acceptable proof of residence
- 4. Identity proof: Aadhar card, driving license, voter's ID
- 5. Income certificate, Salary slip, BPL card or original affidavit
- 6. One photograph of the patient
- 7. Treatment test and scan reports as applicable

Treatment Fund Sanction limits:

Minimum sanction limit per patient Rs. 50,000 Maximum Sanction limit per patient Rs. 4 lakhs for SBI Foundation supported patients

 $[\]left(25\right)$ Obtained from Project Proposal Form - Indian Cancer Society

⁽²⁶⁾ Ibid

 $^{(27) \ \} Indian \ \ Cancer \ \ Society. \ (n.d.). \ \ \textit{Cancer Cure.} \ \ Available \ from: \\ \underline{https://www.indiancancersociety.org/what-do-we-do/cancercure.aspx}$

Overall Evaluation Sanction & Disbursement Process

- 1) Each empanelled hospital appoints a coordinator to implement the requirements of the Cancer Cure Fund. The coordinator holds discussions with the treating doctor and eligible patients' case files are sent for consideration for funding. The eligibility criteria:
 - Family income should not exceed Rs 2 lakh per annum for SBI Foundation supported patients
 - The patient should be treated at an ICS empanelled hospital only
 - Patients should be registered under general category
 - Projected survival rate 50% for adult patients and 70% for pediatric patients
 - Only for Indian citizens
- 2) Once the patients are deemed eligible as per approved patient selection guidelines and the internal checks of the empanelled hospitals, the patients are referred to ICS by the empanelled hospitals and a filled application form is sent to ICS CCF.
- 3) The applications are evaluated medically and commercially by the ICS CCF Due Diligence Team appointed by ICS CCF. This comprises leading oncologists across reputed public & private cancer hospitals. The screening is conducted once a week.
- 4) Due diligence is carried out for the financial status, and to examine the medical status and the cost of treatment for the particular patient's diagnosis.
- 5) The Due Diligence Team then recommends the specific proposals to the Governing Advisory Council with comments against each application for approval and subsequent disbursement of sanctioned funds for the patient's treatment. The funds are finally sanctioned by the ICS-CCF Governing Advisory Council (GAC) comprising of leading finance, corporate and medical professionals at meetings held twice a month.

- 6) The disbursement of the approved grant is through a direct transfer to the bank account at the hospital and later transferred to the hospital account of the patient.
- 7) Disbursements are processed in installments based on the decision of the GAC. Each subsequent disbursement is only given after verification of the utilization of the earlier disbursal.
- 8) The amount sanctioned from the Fund is to be used only for payment of bills raised by the hospital for that patient's cancer treatment. No cash reimbursement is permitted from the grant given by the Fund.
- 9) ICS CCF has the right to cancel the cases where no disbursement has been made within 3 months of sanctioning.
- 10) ICS CCF has the right to review and take necessary steps to cancel cases where unutilised sanctions prevail for more than 6 months.

Further, once the treatment is completed, ICS CCF follows up with the patient and understands the progress they have made. They also receive medical follow up remarks from the hospital. If there is any money that remains unutilised post the treatment/follow-up, or in case of the demise of a patient, the hospital refunds it to ICS.

1.4.6 PROGRAM CARDINALS

Making Cancer Care Accessible in India: Indian Cancer Society (ICS) and State Bank of India (SBI) Foundation

Access to cancer care is a challenge that India is undoubtedly grappling with. With its network of individual and institutional donors, the Indian Cancer Society Cancer Cure Fund (ICS CCF) is seeking to bridge this gap to access, and one of its partners in this has been the SBI Foundation.

THE GOALS OF THE PARTNERSHIP

- To give productive life to underprivileged cancer patients once again in their life
- To support economic, social, and mental condition of the patients and their families

Reference: Project Approval Document received from Indian Cancer Society

1.4.7 PATHWAYS OF CHANGE

Through the reports shared and interviews conducted, the pathways of change for Indian Cancer Society, which form part of their theory of change, have been identified as:

- The Fund is able to process substantial sums of money with relative speed
- The processing of applications and their approval ensures that patients receive adequate treatment at the appropriate time
- The funds released are appropriately and clearly earmarked for various aspects of treatment

From the patients' and their family's point of view, it is important to note that the longer one waits, the worse and more aggressive the cancer can get. In such a situation, treatment could become very expensive and the cancer may become incurable. Further, if one looks at the patient profile of those assisted by ICS, one can gauge that most of the patients and their families live on limited means. So the longer they are away from their jobs, the more money they are losing every day which affects their ability to provide for themselves and their families.

From a doctor's point of view, ICS' interventions highlight how the treatment is carried out with the interests of the patients and their families in mind. The availability of adequate funds at the right time ensures that doctors are able to comply with the treatment schedule and quality of care.

They do not have to use generic medications or cut corners in terms of care provided. They are also able to follow the required treatment protocol without any halts or alterations.

This ensures that care is continuous and consistent. ICS' assistance through the Fund enables hospitals to maintain a high curative rate of patients. They are also able to approach the treatment with a curative intent, as it is often better when they are aggressive with the medications.

Lastly, when access to quality and adequate care is available, the dropout rate (28) is much lower. An example of an instance from Cachar Cancer Hospital and Research Centre indicates the dropout rate in 2011 post-investigation before diagnosis was 60% and 50% before the treatment. Post ICS' intervention, the average abandonment rate has now dropped to approximately 30%. Therefore, assistance such as this enables patients and their families to maintain faith in the system and the doctors. They believe that the support will come.

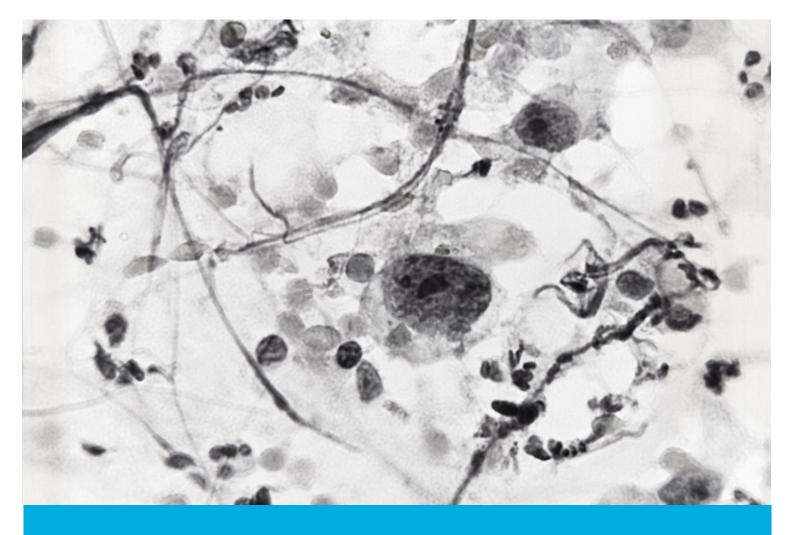
(28) Dropout Rate - dropout rate refers to the attrition from adhering to prescribed treatment protocols. Kayal, S, Dubashi, B and Cyriac, SL. (2018). High Dropout & Early Deaths on Chemotherapy in Real World Sounds Alarm Bells: Audit from Department of Medical Oncology of a Tertiary Care Cancer Centre in South India. Asia Pacific Journal of Cancer. Available from: http://waocp.com/journal/index.php/apjcc/article/view/29



Objective of the Study

This report aims to assess the impact of the funds provided by the State Bank of India (SBI) Foundation to the Indian Cancer Society (ICS) as part of their Cancer Cure Fund project. These funds are directed towards the treatment of cancer patients that hail from low-income earning families and are diagnosed with a cancer with a medium to high chances of successful recovery.

This report documents the efforts taken by ICS and SBI Foundation, and attempts to understand how the lives of the beneficiaries were impacted as a result of this collaboration. It describes the context of cancer in India, the mission and purpose of ICS, the Cancer Cure Fund and their partnership with SBI Foundation. Finally, the impact is defined in numbers and through exploring the stories of the stakeholders that are part of the ICS ecosystem.



3. Methodology of the Study

The study aimed to highlight how the collaboration between Indian Cancer Society and SBI Foundation impacted the lives of the beneficiaries along the following parameters:

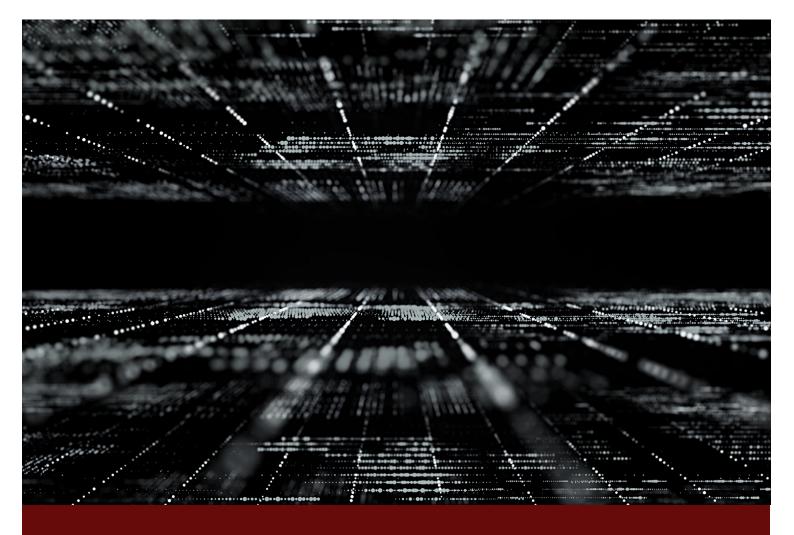
- Access to funds
- Access to and quality of treatment
- Reintegration into society

A mixed-methods approach was adopted for the evaluation of the program's impact that integrated both quantitative and qualitative data. Data was collected through both primary and secondary sources.

Secondary Research: This included understanding the prevalence of cancer in India, and challenges to overcoming the cancer burden in the country. This was primarily gleaned from the World Health Organisation's publications, reports by the National Centre for Disease Informatics and Research, Parliamentary Committee Reports, and published articles from The Lancet, and the World Cancer Report.

Primary Research: To better understand and evaluate the impact of the program, this included identifying and conducting one-on-one interviews with various stakeholders. The interactions took place via phone calls, where patients and their families were requested to share their experiences of living with cancer, overcoming their diagnosis, with an emphasis on the role of the assistance from the CCF.

The qualitative approach to measuring impact is seen in trying to gauge what each of the stakeholders, particularly the patients and their families went through during their respective journeys - from diagnosis to the end of treatment. Through the interviews it was also important to hear the stories of the participants; this helped contextualise the importance of ICS' program and allowed us to visualise how far many of the patients had come.



Sample Size of Data

Though this collaboration between ICS and SBI Foundation covered 260 beneficiaries across 12 empanelled hospitals. This report's sample (29) was selected using random sampling to include 10% of beneficiaries:

- 27 beneficiaries
- 1 coordinator
- 2 doctors
- 2 program staff



Tools of Data Collection

Four different questionnaires were prepared, for each group of stakeholders. All the interviews were conducted remotely. The questionnaires were vetted by ICS and a representative from the organisation was present during the interview calls, given the potentially sensitive nature of what beneficiaries and their families were to share.

5.1. INTERVIEWS OF BENEFICIARIES

The interviews with patients and their families aimed to assess their experience with their cancer diagnosis - from investigation to post-treatment care. The interviews had three major focus areas, the wellbeing of the patients, the extent of the financial burden they would have had to undertake if they hadn't received funds, and their treatment process. A majority of the questions delved into the significance of the monetary support that ICS was able to provide, and how lives were impacted by the assistance.

5.2 INTERVIEWS WITH KEY INFORMANTS (DOCTORS, FAMILY MEMBERS, HOSPITAL STAFF)

We interviewed the program staff to get an overview of how ICS functions, what it aims to achieve and how it works as a bridge between patients, their families, and the hospitals. We were able to understand the application and approval process and the administrative responsibilities of the ICS team through the perspective of the program staff. Doctors and hospital coordinators associated with ICS were also asked about their views on such assistance and how they see it impact the work that they do.

5.3 CASE STUDIES

ICS, a harbinger of hope for hospitals - Dr. Ravi Kannan's experience with ICS

Padma Shri Dr. Ravi Kannan is the Director of the Cachar Cancer Hospital and Research Centre at Silchar in the Barak Valley of Assam. He has been associated with the Indian Cancer Society for a decade and spoke highly of the work the organisation has done over the years and the impact their support has had. He recollected a time before organizations like ICS could sponsor treatments for patients, when dropout rates were high and patients didn't trust hospitals to treat them. He feels that the funds have been able to add value through multiple avenues; not only does it serve a material and financial purpose, it also helps keep up the morale of the patients and their families and builds psychological security

He states that the combination of the speed with which funds are approved and that ICS is able to give a sufficient amount of money to complete the treatment of a patient is a rare occurrence. This gives hospitals and doctors the flexibility and confidence to treat the patients with a "curative approach", without cutting corners and putting the patient's quality of life at the forefront.

This flexibility and completeness of support reflects in a story about a young boy who had cancer in his bones. The initial treatment plan for which money was sanctioned, was to remove the cancerous portion of the bone and place a prosthetic in his leg. Through ICS' support they were able to use the funds to amputate his leg and provide him with an artificial limb instead. The boy is now able to run around, play football, and has been able to get his life back.

According to him, the biggest reward as a doctor is that he can focus on lives first and funds second.

He is able to provide his patients with the best and most appropriate treatment without being concerned about administrative red tape, insufficient funds, or a long lead time. The difference is clearly visible in the quality of life in the community in which he works and that is the gift that ICS has given him.

From Cancer Patient to Cancer Survivor and Advocate - Ajanta's Story

Ajanta was a young housewife when she was diagnosed with breast cancer. She, like other young married women, took a lot of pride in her house and her child and dreamt of a better life for her family. Being diagnosed with cancer at the young age of thirty was unfathomable to her and shook the foundations of her family's lives.

She wasn't aware of the symptoms of breast cancer, but she started to experience some pain in her right breast. Her aunt who worked in a hospital's canteen suggested that she go for a check up. She was really afraid when she was told it was cancer because she knew that her family did not have enough money to support the treatment. Her husband, a daily wage earner, paints houses for a living. His income is barely enough to cover household expenses. She thought she would have to abandon the treatment protocol or would have to beg for money. She felt that she had no direction and was brought to tears due to the enormity of the problem at hand. This is when she was introduced to ICS. She applied for a grant from ICS which was given to her without any delays and her treatment was able to start immediately. She paid a negligible amount towards her treatment since ICS was able to cover more than fifty percent of her treatment expenses. She has made a full recovery since then, and even though there was some psychological trauma that lingered post the treatment, she has also been able to work through that.

She is now able to look after her son and her house and looks forward to spending time with her family. She has also become an advocate for cancer checkups, she speaks within her community about the importance of regular checkups and care. She also helps ease the hesitation that people have regarding the cost of checkups and treatment. She encourages people not to hide their symptoms because they fear the cost of the treatment as she knows that there are people in this world that will help. Her outlook towards life is positive, she believes that the money and help she received has been a miracle. She knows that if they were able to overcome such a daunting hurdle, better things are meant to happen in their lives.

Solace at last - Lala's story

Mr. Lala has a case that is unfortunately all too common with individuals from low-income communities. Although he was diagnosed with a Non-Hodgkin's Lymphoma in 2017, he began treatment only in 2020 because he couldn't access sufficient funds for his treatment or further investigation. Even though he was told that there would be monetary support, he was overwhelmed by the cost of the treatment and the money he would lose out by not earning. He is a rickshaw driver, so every day spent getting treated are days where he is not earning money to support his family.

He eventually got back in touch with ICS through a different hospital because his pain had worsened. His wife was also able to bring in money as she was working as a domestic helper. Through the support of ICS and other such organisations he was able to begin chemotherapy and start his road to recovery. He has now recovered and while his job is still hard to accomplish, he gets stronger every day.

He feels that he would not have been able to survive without the support of ICS. He feels privileged that he has been given the gift of life as many members of his community have died of liver cancer. He is now looking forward to getting fully back to work and getting his daughter married.

<u>Taku's Story - The challenges of a Cancer Diagnosis</u>

A cancer diagnosis overturns the lives of individuals and their families in more ways than one. This often goes beyond treatment, where the financial and physical ramifications are the most visible. Added to this is that families often have to travel long distances for a shot at survival. This is what Taku did after his diagnosis in 2017 - he travelled from Arunachal Pradesh to Tamil Nadu for treatment. Further, at the end of his chemotherapy, his body became so weak that he had to leave his job and rest for 6 months. This is a difficult decision that is representative of an unfortunate reality that many cancer survivors face as they are unable to work as they did before. Today, he is able to run his own shop.

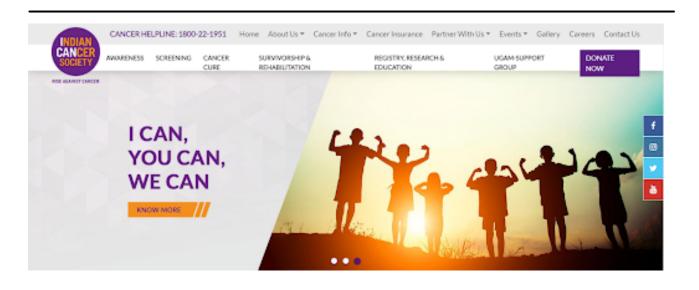
Despite these challenges, Taku said that his diagnosis made him realise the value of life and his family, because of how they supported him through his ordeal. He wants to take care of them and help other people as well, as a lot of people helped him too. This feeling of paying it forward can be traced to the assistance he received from Christian Medical College, Vellore and ICS, as a result of which he was able to afford his treatment. Taku's journey is representative of his spirit - that in the face of these challenges, he wanted to overcome them, and move forward with the purpose to help others.

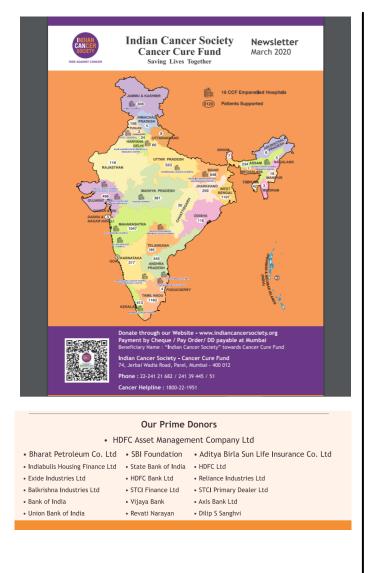
<u>Anu's Story – A Journey from Despair to</u> <u>Hope</u>

When Anu was diagnosed with cancer, she was acutely aware of the difficulties that lay ahead. Seeing her aunt suffer from cancer, there were two facts that she knew - that cancer treatment is expensive and adequate and appropriate treatment is essential. She had to move from Kathua in Jammu and Kashmir to Gujarat because doctors there were not able to ascertain the cause of her symptoms. It was only in Gujarat (where her husband works as a driver) that she was finally diagnosed and treated. She had to leave their children in her mother's care to get treated, a difficult task for any mother. For Anu, the treatment protocol included chemotherapy and injections which took a toll on her. While she and her husband could afford the former, they knew they would be lost without assistance to afford the latter. She was even prepared to stop treatment as the burden was overwhelming, though she knew that this could result in her children losing their mother.

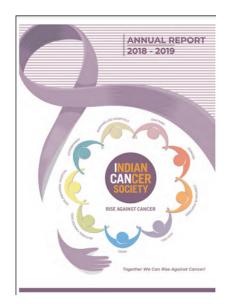
At this juncture, she was introduced to ICS, where after her application was approved, she was able to afford the 17 injections that she needed post chemotherapy. She is now able to do all that she was doing earlier, and attributes her health to the monetary support she was able to receive and the hospital where she got treated. She mentioned that she has seen families being hesitant to treat someone who is ill, but her husband was ready to do whatever it took to ensure her recovery. Her mother and husband also suggested they borrow money and repay it later. Further, she said that she did not know of organisations like ICS, but post her treatment she recognised their importance for the common person. She added that 'an ill person is anyway worried, and if one does not have the means to get treated, one gets more tense.' After seeing the feeling of being alive diminish within her, Anu today is determined to live and has found a new lease of life.

5.4 BRANDING AND VISIBILITY













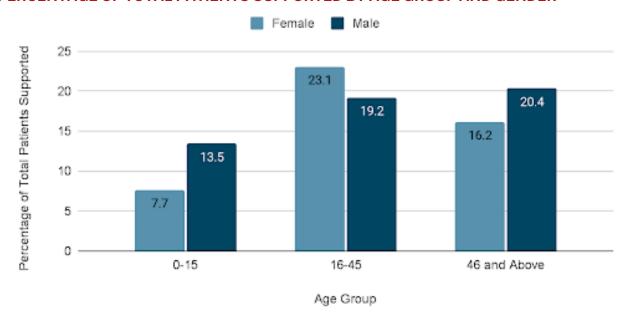


Quantitative and Qualitative Outcomes

6.1 QUANTITATIVE OUTCOMES

Over the last five financial years, this program, executed in collaboration with the SBI Foundation, has been able to impact the lives of a total of 260 cancer patients. The gender composition of the beneficiaries is almost balanced with around 53% male patients and around 47% female patients. Out of all the patients supported by ICS, the majority (around 42%) belong to the age group of 16 - 45 years, followed by around 37% in the age group 46 years and above, and around 21% in the age group 0 - 15 years.

PERCENTAGE OF TOTAL PATIENTS SUPPORTED BY AGE GROUP AND GENDER



Reference: Indian Cancer Society's SBI Beneficiaries List

Since the inception of this joint collaboration around five years ago, the total funds disbursed by the program have exceeded INR 3 crores. The average funds disbursed per patient are around INR 1.15 lakhs. Majority of the patients supported by ICS suffer from diseases such as Breast Cancer, Acute Lymphoblastic Leukemia, Non-Hodgkin's Lymphoma, Chronic Myeloid Leukemia, and B Cell Acute Lymphoblastic Leukemia. This is in line with the high prevalence of breast cancer, lymphomas, and leukemias in India.

Total Amount Disbursed	Average Amount Disbursed	Most Amount Disbursed
INR	INR	INR
3,00,75,452	1,15,675	4,00,000

Reference: Indian Cancer Society's SBI Beneficiaries List

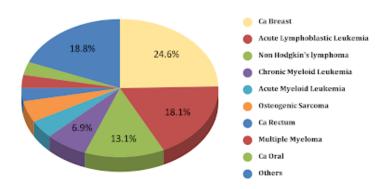
Further, the average turnaround time between applying for assistance and the sanctioning of funds for the 260 patients was <u>9 days</u>. In some cases, patients received sanctioned funds within <u>1</u> day. However, there was a delay of over <u>30 days for 6 patients</u>, with the longest delay being <u>65 days</u>. On enquiry it was found that the delays occurred when mandatory documents were not received. The process followed by ICS has always attempted to ensure that no patient's treatment is delayed.

MOST COMMON TYPES OF DIAGNOSIS AMONG SBI-ICS BENEFICIARIES

Diagnosis	Number of Beneficiaries
Ca Breast	64
Acute Lymphoblastic Leukemia	47
Non Hodgkin's lymphoma	34
Chronic Myeloid Leukemia	18
Acute Myeloid Leukemia	11
Osteogenic Sarcoma	13

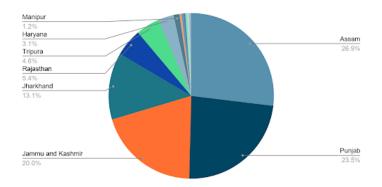
Reference: Indian Cancer Society's SBI Beneficiaries List

TYPE OF CANCER DIAGNOSIS AMONG SBI-ICS BENEFICIARIES



Reference: Indian Cancer Society's SBI Beneficiaries List

PERCENTAGE OF TOTAL PATIENTS SUPPORTED BY GEOGRAPHY



Reference: Indian Cancer Society's SBI Beneficiaries List

The collaboration between SBI Foundation and ICS was aimed at supporting patients from Andaman and Nicobar Islands, Dadra and Nagar Haveli, Daman and Diu, Goa, Haryana, Jammu and Kashmir, Jharkhand, North East India, Punjab, and Rajasthan. Most of the patients supported by the program were based in Assam. The program was able to assist patients from all these places except Dadra and Nagar Haveli, Daman and Diu, and Meghalaya. Twelve hospitals empanelled with ICS were a part of the collaboration with the SBI Foundation. The maximum number of patients supported by this program have been from the states of Assam, Jammu and Kashmir and Punjab. Consequently, the empanelled hospitals (Cachar, Sher I Kashmir, and Patel) in these states have treated the most patients as well.

6.2 QUALITATIVE OUTCOMES

Monetary Support

A cancer diagnosis upends the lives of not just patients but also those who surround them. Added to the stress of being in or seeing a loved one in pain or discomfort are the very real financial implications of such a diagnosis. While some are able to grapple with it, a vast majority are not. Many live paycheck to paycheck or are day labourers with little to no savings to take on unexpected expenses. Some even have to make the choice between their children's education or cancer treatment. When patients and their families were asked to describe how they felt the first time they found out they would receive monetary support, relief and gratefulness were the two emotions at the forefront.

They saw this support from ICS as an act of kindness, which they were often unable to express in words. They attributed their lives or their loved ones' lives to timely assistance. One patient's brother highlighted how the Fund, 'helped [them] when [they] were absolutely helpless.' This feeling is representative of the emotional implications of a cancer diagnosis as well. It captures a journey from worry and frustration to relief and hope, showing what patients and their families go through in search of another chance at life.



"How would you have paid for your treatment if you hadn't received support from ICS?"

- Stopped treatment midway
- Asked for less expensive medicines
- Sold property/land
- Sold their house
- Raised money
- Taken loans
- Taken loans from friends
- Sought help from relatives
- Seen no way out

As part of the interviews, when patients and their families were asked about alternate means they would have considered to fund their treatment, a majority of their responses were either to abandon the treatment or take on some form of debt.

Reference: Interviews with beneficiaries and their families

Beneficiaries' experience with ICS

Among the patients and the families that Social Lens interacted with, a sense of relief and gratitude was palpable in their voices. This was directed at everyone (Hospital Staff, Doctors, Coordinators, and ICS) involved in making one part of a difficult moment in their lives, a bit easier. What emerged from these conversations was that no one had to wait for long to access these funds. The timelines varied, with one respondent saying he had to wait for 2-3 months, while there was another who said 2-3 days. A few said that their applications were approved within 10-15 days. However, no one's treatment was affected, in terms of quality and time. Their experiences also highlight how people come to each other's aid - whether it is the doctors informing patients that help will come their way, or coordinators and social workers assisting overwhelmed patients in accessing the funding they need. In some cases, it was patients telling other patients of the assistance that they can receive.

The beneficiaries felt a sense of safety, with one even saying that his son's treatment was 'more than what [they] expected'. Another patient, as a point of comparison shared that, 'with assistance from the other fund, [she] was able to get medicines free of cost, but with ICS' assistance, [she] did not have to make any out of pocket expenses for other things such as fees for check-ups either'. This highlighted that though there are other organisations that provide funds for certain aspects of the treatment, a large percentage is funded by ICS. Lastly, one patient's brother shared that he truly understood the meaning of 'medicine is a service, not a profession' through the way his brother was taken care of - by everyone associated with the hospital and through timely financial assistance.

Post Treatment Journey

Through the interactions with the beneficiaries and their families, one could gauge that they all have become more aware of their health and well-being. The patients themselves have been taking precautions and placing their health at the forefront. Some have stopped consuming food that is not cooked at home. One parent mentioned that he even goes on to advise other children and their families to stay away from junk food. While some have been able to resume working or living as they were before, others have not been able to. This varies depending on the extent of the diagnosis and time passed since the treatment. Many patients are not able to do work that is demanding or physically taxing, however many have been able to find new avenues of income and sustenance. Some patients worked/are working through their treatment because they have families to look after.

The interactions also highlighted that all the beneficiaries recognised the need and importance of follow-ups. Most have been able to go regularly, on-time and are able to afford it. However, some have struggled. One parent said that he has taken loans for his son's follow-ups and has had to miss work to ensure that his son receives the care that is required. The COVID-19 pandemic has also caused some disruptions, with patients waiting for trains to resume as flight tickets are expensive. During the pandemic, some patients have been able to speak to their doctors either virtually or over the phone. Indian Cancer Society regularly enquires about the status of the beneficiaries' followups from the hospitals and tries to ensure that they are able to go. They also encourage the coordinators to persuade the patients to come for their follow-ups so as to ensure that no one is left behind

Lastly, in looking to the future, there are some beneficiaries who seek to give back. One has become an advocate to ensure that those around her are not hesitant to visit the doctor or seek treatment, when needed. At least three parents said that their children want to become doctors. One parent relayed what his son says - 'I will treat people just like I was treated.' Gratitude, awareness, and the will to get better - were all seen in the patients' post treatment journeys.



"What are you hopeful for?"

- Health
- Life will change
- Getting back to work
- See children grow up
- See children settled
- See children get married
- Continued support

As part of the interviews, when patients and their families were asked about what they are looking forward to, a majority of their responses were good health and seeing their children prosper.

Reference: Interviews with beneficiaries and their families

Coordinators and Doctors Experience with ICS

Coordinators - A coordinator in an empanelled hospital communicates and works with Indian Cancer Society's Cancer Cure Fund. Social Lens was able to speak to one hospital appointed coordinator. He has been working with ICS since 2011 (when the Fund started) and sees ICS as a trusted partner in ensuring that adequate and quality care is provided to beneficiaries. The coordinator emphasised on how closely doctors work with ICS, because some of them even fill their patients' forms despite being pressed for time. More than anything, this coordinator also spoke of the organic relationship between his hospital and ICS, where they can call each other anytime and expect a response. Therefore, what was highlighted through this conversation is the need for a strong working relationship, where the two organisations trust each other, especially when there are people waiting to get treated, get better, and have another chance at life.

<u>Doctors</u> - Doctors play an important role in the stories of each of their patients. It is therefore important to understand how they view the impact of timely assistance on patients and their families. Social Lens interacted with two doctors working in hospitals empanelled with Indian Cancer Society to shed light on the value of such assistance.

One doctor from Jammu and Kashmir has been associated with ICS for nearly a decade. In terms of administrative effectiveness, he said that ICS has a smooth system which ensures that patients do not have any out of pocket expenses. He sees the real impact of what ICS does in terms of how patients and their families do not have to worry about their finances and can focus on treatment, especially if the prognosis is good. Lastly, he believes that the timely access to funds ensures immediate treatment, quick administration of medicines, and a reduction in drop-out rates.

The second doctor highlighted how ICS is able to process relatively large amounts of money within a short period of time, something their counterparts are unable to do. With ICS, he sees a level of trust that allows hospitals to start treatment because they know that the payments will arrive, even when there is a delay. He also emphasised how such support results in doctors not having to cut any corners and confidently proceed with the required treatment protocol. Lastly, he noted that assistance from ICS is not just a form of financial or material security, it is also psychological, and that is equally important in maintaining the morale of beneficiaries and their families.

Program Staff Experience

Social Lens had interactions with two of the program staff associated with the Cancer Cure Fund to better understand its workings. They spoke of their roles within the program, and highlighted the procedure from when an application is received to when it is approved, and what happens once the treatment has ended. It is important to note from the program manager's experiences that the beneficiary is at the centre of their activities. Even if there is a delay in fund disbursal, treatment continues. Further, funds are released based on the treatment shared by the hospital. So the program staff ensure that each need, as defined by the hospital, is adequately met. They also play a role in ensuring that beneficiaries attend their followup sessions regularly. The CCF also conducts survivorship studies to gauge how each of their beneficiaries is doing five years after they have been cured. Lastly, the program managers shared how the impact they see among their beneficiaries is very real, and when they visit ICS' Office, one needs to only look at their expressions to understand what this assistance means to them.

Overview of Reintegration

Recovery post cancer treatments can be a long, difficult and tedious process.

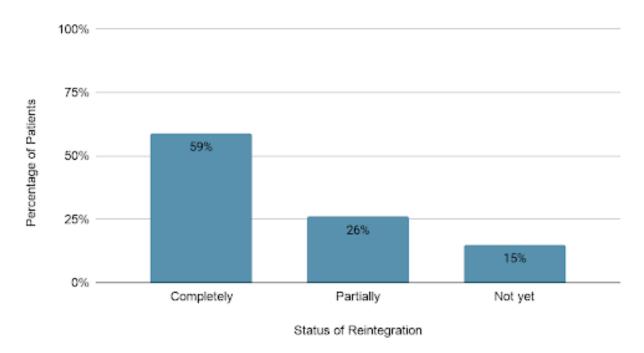
Reintegration, therefore, is dependent on several factors - energy levels, pain management, body functioning, additional adages (colostomy bag, etc.) and the nature of activity. To assess the status of reintegration we asked patients to what extent they were able to get back to their primary responsibilities.

Approximately 59% have been able to return to normalcy to quite a large extent, with their cancer diagnosis not causing major hindrance in their life. These individuals have been labelled as "completely" in the graph. Examples of reintegration vary across lifestages and lifestyles of the patients. Several of these are adults who have been able to go back to their means of employment, income generation and to independently provide for their families. Those adults who were homemakers have also been able to conduct their day to day tasks smoothly. Finally, the children were able to go back to school and continue their education. All these patients have also been able to enjoy their preferred leisure activities - such as spending time with their families, play, and other hobbies.

Around 26% of the patients were able to partially return to their pre-cancer life. Some of them were back to their earlier jobs but had reduced their original responsibilities to avoid the associated stress and exertion. And some of them had just finished or were at the tail end of their treatment and had recently started the process of reintegration and made some progress.

For around 15% of the patients, the treatment was still in process or had only recently completed at the time of the interviews and they had not begun the process of reintegration yet.

STATUS OF REINTEGRATION OF PATIENTS



Reference: Interviews with Beneficiaries

No. and Patient Initials	Status of Treatment	Status of Reintegration
1 (AD)	Complete	Completely
2 (RC)	Complete	Completely
3 (SR)	Complete	Partially
4 (LN)	Complete	Partially
5 (TR)	Complete	Completely
6 (MSR)	Ongoing	Not yet
7 (IR)	Complete	Completely
8 (K)	Complete	Partially
9 (RD)	Ongoing	Not yet
10 (JK)	Complete	Completely
11 (MG)	Complete	Completely
12 (KM)	Complete	Partially
13 (Minor)	Complete	Completely
14 (JC)	Complete	Completely
15 (GA)	Complete	Completely
16 (PK)	Complete	Completely
17 (SK)	Ongoing	Partially
18 (AL)	Ongoing	Not yet
19 (NC)	Complete	Not yet
20 (JD)	Complete	Partially
21 (M)	Complete	Completely
22 (AGS)	Complete	Completely
23 (JB)	Ongoing	Partially
24 (BD)	Ongoing	Completely
25 (SRD)	Complete	Completely
26 (V)	Ongoing	Completely
27 (N)	Treatment through Medication	Completely



7. FINDINGS

ICS works to serve the most vulnerable members of our society. The individuals they help face monetary burdens on a daily basis and do not have the cushion to absorb additional financial shocks. Knowing that there are funds available, has allowed doctors to provide the most superior quality of care to patients quickly. Doctors and patients both acknowledge the ease with which funds can be obtained, the thoroughness of the vetting process and the trust that is placed when the money is disbursed. The funds have given many individuals hope, when they had none, and eased financial burdens that they may have had to experience.

The findings of this impact study primarily highlight the role that timely financial assistance played in the lives of the beneficiaries and their families. With the funding of the treatment partly or wholly taken care of, they were able to look forward to a second chance at life and this came through in the interviews that Social Lens conducted with 27 of them. The guick turnaround time between a beneficiary applying for assistance and receiving it ensured that no one's treatment was affected. Apart from gaining their health back, they also received mental and emotional solace as a result of the money they received. This has allowed most of them to return to some level of normalcy and regain the ability to live their pre-cancer life. Lastly, the collaboration between ICS and SBI Foundation impacted the lives of 260 beneficiaries from different parts of India, staying true to their commitment of assisting those who are underserved and perhaps needed assistance the most.

While other programs at ICS are able to support the investigation and diagnostics phases of the treatment process as well as elements of post treatment care, looking ahead, this program could also consider integrating these components along with provision of awareness to patients around managing their health and nutrition in the future.

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LIST OF ABBREVIATIONS

BPL - Below Poverty Line

ICS CCF - Indian Cancer Society Cancer Cure Fund

COVID-19 - Coronavirus Disease (2019)

GAC - Governing Advisory Council

HDFC AMC Ltd - HDFC Asset Management Company Limited

ICS - Indian Cancer Society

SBI - State Bank of India

SBIF - State Bank of India Foundation

WHO - World Health Organisation

ETHICAL CONSIDERATIONS

- All the data and testimonials have been collected after obtaining consent and permission from participants.
- The participants could withdraw at any point in the study.
- Confidentiality of data is maintained by the researchers.
- All References are provided wherever required.
- Unlawful means/ plagiarism are not reported to present data.

11.

ABOUT SOCIAL LENS

Social Lens was founded in 2016 out of Mumbai as a for-purpose organisation that brings professionals working in close collaboration with philanthropy and grant making institutions to drive transformation for SPOs in India. Social Lens services INR 200+ crores of philanthropy capital working with change makers and grant giving bodies with solutions that touch over a million end participants. With 10 years of experience, we have the expertise to strengthen the Impact Ecosystem, by making value driven changes. It addresses the critical challenges in organisation development or program building. We collaborate and design sustainable solutions to achieve better outcomes for end beneficiaries that encompass education, livelihood, women's empowerment, water, micro-finance, and healthcare initiatives.

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ASSESSMENT TOOLS

INDICATIVE QUESTIONS FOR DATA COLLECTION FROM DOCTORS AND PATIENTS

Doctors

- 1. How long have you been associated with ICS?
- 2. Administratively how has the process been? (In terms of receiving money, processing patients, time taken, documentation process etc.)
- 3. What have your learnings been through this experience?
- 4. How is the application and approval process with ICS? How does this compare to that of other funders?
- 5. How do you think an inflow of funds impacts the quality and quantity of care that cancer patients receive?
- 6. How does a lack of funds impact the same?
- 7. Can you share instances where a patient received the required support, and an instance where a patient did not? What happened in both cases in terms of access to care?
- 8. What are your views on India's cancer burden and the level of cancer care in the country?

Beneficiaries

- 1. Please tell us a bit about yourself (Student/Working/Occupation/City, etc).
- 2. Tell us a bit about your family and how they supported you through your treatment?
- 3. How did you hear about ICS?
- 4. Tell us about your process with getting funds from ICS?
- 5. How long did it take for your application to be approved?
- 6. Did you face any delays in your treatment at any point?
- 7. How was this money received able to help you?
- 8. How was your experience with the treatment that you received?
- 9. Were you able to speak to the coordinators if you needed any help and were they able to help you?
- 10. Are you able to get back to studying/working in a similar way before your diagnosis?
- 11. Did you travel away from your home for treatment?
- 12. Did you have health insurance such as Mediclaim?

^{*}Please note this is not the complete list of questions