Cancer Care Disparities in Punjab and a Policy Framework for Bridging the Divide

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Cancer is a major public health challenge at the global level, with severe repercussions in developing nations like India. Socio-economic disparities in cancer care are a critical concern, as people from poorer socio-economic backgrounds frequently face hardship in obtaining prompt and right treatment. This study aims to examine the extent and nature of disparities in cancer care and to propose a suitable policy framework to address this chronic disease in India. The present study is based on both secondary and primary data, with a specific focus on the reports released by National Cancer Registry Program (NCRP), Global Cancer Observatory (GLOBOCAN), and Ernst & Young - Federation of Indian Chambers of Commerce and Industry (EY-FICCI). A total of 202 cancer patients were also interviewed and results are analyzed.

1. Introduction

Cancer is classified as a Non-Communicable Disease (NCD) and is characterized by the unregulated growth of cells inside any organ system. The incidence of cancer is on the rise, and the report published by WHO in 2020 predicted that the number of new cases of the disease will reach 29.4 million by 2040, which is a significant increase from the 18.1 million cases recorded in 2018. According to the Global Cancer Observatory data, cancer incidence cases are anticipated to cross 24.1 million by 2030 (Ferlay et al., 2024). Furthermore, as per the research of the American Cancer Society, it is projected that there will be 28.4 million cases of cancer worldwide in 2040, which is a 47 per cent increase from 2020. There exists an inequality in the incidence and prevalence of cancer cases globally. The increase is greater in countries that are transitioning from one stage to another (from 64 per cent to 95 per cent) compared to those that have already transitioned (from 32 per cent to 56 per cent) (Sung et al., 2021). Furthermore, malignancies associated with lifestyle factors are more prevalent in countries with high to very high-income levels. In contrast, cancers related to infections are more commonly observed in low-income countries.

In India, as per the report of NCRP, 2020, for all cancer-affected anatomical sites, the estimated number of cancer cases (incidence number) in 2022 was 14,61,427. But as per the report of Ernst & Young LPP (EY) and Federation of Indian Chambers of Commerce & Industry (FICCI), published in 2022, the projected incidence rate for cancer in the year 2022 ranges from 19 to 20 lakhs. It had been conservatively estimated that the actual incidence could range between 1.5 to 3 times higher than the reported figures, resulting in a projected

range of 29 lakhs to 60 lakhs during the year 2022. The report anticipated that the actual incidence of cancer in India might exceed the reported incidence cases in NCRP, primarily due to the low population coverage of cancer registries and substantial underdiagnosis of the disease. According to projections of GLOBOCAN, 2020, the cancer incidence in India for the year 2022 was estimated to be around 14.24 lakhs. Although the reports of GLOBOCAN and EY-FICCI were also based on NCRP data, however, all three of these reports provided their own figures. The incidence and prevalence rates of all three reports were distinct, revealing a disparity among them.

India is a diverse country, and socio-economic gap exists among states. States such as Punjab, Goa, Kerala, and Tamil Nadu belong to the high ETL group (levels of Epidemiological transition) and also exhibit elevated Human Development Index (HDI) levels. The epidemiological transition, characterised by a shift in disease burden from communicable to non-communicable diseases, occurred earlier in these states compared to those with low economic transition levels and low human development indices, such as Uttar Pradesh, Bihar, Chhattisgarh, and Jharkhand. Cancers associated with lifestyle factors were more prevalent in states characterised by prosperity and elevated HDI levels. However, cancers associated with infections are more frequently observed in low HDI states.

Cancer is a medical condition that can happen to anyone irrespective of their economic status, caste, creed, or other socio-demographic factors. In India, the cost of cancer treatment in private hospitals is multiplicatively greater than that of government hospitals. Consequently, it frequently reduces households to destitution. According to a study conducted by Rajpal et al. (2018), 40 per cent of the financing is provided by families via borrowing, asset sales, contributions from friends and family, and so forth. Singh and Kumar (2013) found that the mean expense for cancer treatment per individual is 2.75 lakh rupees, with an average duration of 1.9 years for the ailment. As an illness, it has the capacity to hamper an individual's physical, physiological, psychological, and socio-economic development.

The present study aims to investigate the inequalities present in cancer care, from case registration at cancer registries to the initiation of treatment, as well as socio-economic factors and the end of treatment.

2. Research Methodology

The present study has used survey method. Primary data has been collected with the help of structured research schedule. Though, the study is based on both primary and secondary sources of data. The study has obtained secondary data from a range of reputable sources, including the various reports of the World Health Organisation (WHO), Global Cancer Observatory (GLOBOCAN), Cancer Atlas, Ernst & Young – Federation of Indian Chambers of Commerce & Industry (EY-FICCI) and National Cancer Registry Program (NCRP).

The primary data collected from all the districts of Punjab and Chandigarh, India. A total of 202 cancer patients were interviewed and the purposive sampling technique was used to select the patients for the study. In the first stage, it was planned to gather data by visiting hospitals, but during the pilot survey, it was found that we will have to visit individuals who had undergone all necessary treatment after a cancer diagnosis. We attempted to get information about cancer patients from different hospitals who had previously been admitted to their facilities, but they refused, citing patient privacy and a confidentiality agreement between the hospital and the patients.

Ultimately, we contacted World Cancer Care Organization, which is very popular in the state of Punjab, to collect the list of cancer patients who had already completed their treatment. On the basis of list provided by the World Cancer Care Organisation, a phone call was made to that number to inquire if the family was from the state of Punjab. If a respondent was from another state, they were not included in our sample. Only respondents from Punjab were asked for the appointments either in person or over the phone. The respective villages, towns and cities were visited. Contacts were also established with the village leaders and other prominent people, and they were inquired about other cancer patients in their area. Hence, we succeeded in identifying 202 patients from different parts of Punjab. All of the 202 families were interviewed, out of which 70 percent of the interviews were held in person, whereas 30 percent of them were telephonic interviews. The results were analyzed using SPSS version 19.

3. Results & Discussion

Disparities in cancer care starts from the registration of cancer cases, as not all individuals in the population are covered, resulting in incomplete reporting of cancer cases in India. There are several challenges associated with cancer registration in India, notably the absence of mandated reporting for cancer patients, which complicates data collection efforts (Satishkumar et al., 2023). With the aim of accurately documenting cases of cancer, the National Cancer Registry Programme (NCRP) was initiated in India by the Indian Council of Medical Research (ICMR) in December 1981. The programme included two types of cancer registries, namely Population-Based Cancer Registries (PBCRs) and Hospital-Based Cancer Registries (HBCRs). PBCRs record all newly diagnosed cancer cases occurring in a clearly defined population within a specific geographic area, while HBCRs gather information on cancer patients receiving care at a particular hospital, focusing on clinical treatment and outcomes.

Although, the number of registries had increased, and other population-based registries had been established in recent years. Unfortunately, disparities in access to population by NCRP persist even after more than 43 years since its inception. Many populous states lack cancer registries, and the majority of registries in India were located in urban regions, making it challenging to analyse rural cancer burden trends across the country (Dhillon et al., 2018). In

North India, for instance, there is no PBCR covering the population of Himachal Pradesh and Uttarakhand. Moreover, the Patiala district PBCR in Punjab covers just 3325 sq km, in contrast to large area of the state of Punjab, which spans 50,362 sq km. Furthermore, Bihar and Kolkata were the only two PBCRs in the eastern region of India and the region covered by the Kolkata PBCR was also quite small. As per the findings of the Cancer Samiksha study conducted by ICMR, Population-Based Cancer Registries (PBCRs) were estimated to cover only around 10 per cent of the total population in India (Cancer Samiksha, 2019).

The EY-FICCI report also indicates substantial gaps in access to healthcare infrastructure, resulting delays in the diagnosis of many cancer cases. Moreover, owing to significant underdiagnosis, medical professionals were unable to identify or appropriately diagnose a medical condition in the majority of cancer cases. Therefore, it can be concluded that the entire population is not covered, early diagnosis of cancer cases is not universal, and not all cancer cases were diagnosed accurately. This illustrates the disparities in registration, accurate diagnosis, and early diagnosis.

3.1 Socio-Economic Characteristics of Patients

Disparities in socio-economic aspects among cancer patients were identified and are presented in Table 1. Higher levels of education are often found to have positive correlation with improved patient experience, enhanced economic outcomes, and more effective utilisation of social resources (APA, 2007). The present study revealed a very low level of educational attainment, with only 17.82 per cent of patients possessing a bachelor's degree or higher. A total of 7.92 per cent of patients were illiterate, while 6.93 per cent reported that they did not go for formal schooling but can read and write. Only 13.86 per cent of patients had completed elementary school, whereas 27.72 per cent had studied between 6^{th} and 10^{th} class of schooling. Further, 22.77 per cent of the patients had completed the senior secondary school. This suggests that the sampled patients had a low level of education, which may have impacted on their interactions with healthcare practitioners.

The results of the economic analysis of patients' profiles are presented in Table 1. It indicates a notable discrepancy in the financial status of patient households. The findings of the study reveal that the calculation of the annual total household income resulted in a mean income of 4,78,080 rupees, while the median income was determined to be 2,38,680 rupees.

The study further analysed the patterns of expenditures of households, and respondents were asked to provide an estimate of their spending on health and medications, as well as overall expenditure (Table 1). The mean expenditure per annum was estimated to be 3,51,756 rupees, whereas the median expenditure was found to be 2,20,080 rupees. The analysis of data revealed that the disparity between the mean and median expenditure was relatively less in comparison to the mean and median income of households.

Table 1 also shows the total expenses of individuals affected with cancer, encompassing the costs accrued during the pre-diagnosis phase, during treatment, and post-treatment expenditures, as well as expenses incurred for transportation, sustenance, lodging, and vehicle parking during hospitalization. The study found that the overall mean cost associated with cancer disease is Rs. 711039, while the median expenditure is Rs. 350000.

Table 1: Socio-Economic Characteristics of Patients

S. No	**Characteristics of Patients**	**Category**	**Frequency**	**Percentage Share**	
1	Educational Qualification	Illiterate	16	7.92	
		No formal education but can read and write	14	6.93	
		Up to primary (Class 5)	28	13.86	
		Above primary, Up to Secondary (6-10)	56	27.72	
		Senior Secondary School (12)	46	22.77	
		Graduate	24	11.88	
		Post Graduate & Above	12	5.94	
		Others	6	2.97	
	Characteristics	**Total Family Income**	**Frequency**	**Percentage Share**	
2	Income	Less than 10,000	23	11.39	
		10,000-20,000	82	40.59	
		20,000-30,000	19	9.41	
		30,000-40,000	14	6.93	
		Above 40,000	64	31.68	
				Mean (Monthly)	**Median (Monthly)**
		Total Income from all the sources	202	39840	19890

		Total Income (Annual)	**202**	**4,78,080**	**2,38,680**
3	Expenditure	Expenditure on Health and Medicine	202	6661	3402
		Total Expenditure of Household	202	29313	18340
		Total Expenditure (Annual)	**202**	**3,51,756**	**2,20,080**
	Characteristics	**Categories**	**Frequency**	**Percentage Share**	
4	Overall Expenses incurred (in Rs.)	0-200000	62	30.69	
		200000-400000	52	25.74	
		400000-600000	23	11.39	
		600000-800000	19	9.41	
		Above 8 lakhs	46	22.77	
		Median	**350000**		
		Mean	**711039**		

*Source***:** Author's Calculation from Primary Data

3.2 Inequalities during the Patient Journey

Disparities are experienced by patients throughout their journey, from initial diagnosis to the completion of treatment. It encompasses aspects such as the time taken for diagnosis, the distance travelled, and the adoption of health insurance, among others. There is a significant association between routine checkups and improved short-term survival in cancer cases (Song et al., 2021). In India, there persists a mindset among individuals to seek medical attention only in response to a perceived health issue. The analysis of data in Table 2 revealed that a mere 7.43 per cent of the cancer cases are detected through routine patient examinations. The vast majority of cases (91.58 per cent) are diagnosed subsequent to patients seeking medical assistance due to a decline in their health. Furthermore, it was found that 50 per cent of the patients experienced treatment delays of more than 30 days, primarily due to households lacking immediate funds, indecision in starting treatment, or taking too long to choose a hospital.

Regarding the travel patterns of patients, the one-sided median distance travelled has been calculated to be 80 kilometres. This indicates that half of the households travelled less than 80 kilometres to reach the hospital of their choice,

while the other half covered a distance greater than 80 kilometres. The mean distance travelled by an individual diagnosed with cancer is calculated to be 126 kilometers.

The present study also examined whether the patients utilised any form of healthcare coverage and results are presented in Table 2. The study revealed that a minority of patients, specifically 27.23 per cent, utilised the health insurance option, while the majority of patients, comprising 72.77 per cent, did not possess any form of insurance. It is noteworthy that a mere 5.45 per cent of patients have procured health insurance through the payment of premiums. The findings indicate that the rate of private health insurance adoption in Punjab is very low. A significant proportion of patients lack any form of health insurance, leading to a frequent occurrence of poverty within households. Furthermore, the study revealed that a significant segment of the patients, precisely 18.18 per cent, reported that their insurance coverage was not accepted by the healthcare provider. The majority of these patients held Ayushman Bharat Card, which certain private hospitals refused to acknowledge during the COVID-19 pandemic. Additionally, 27.27 per cent of patients reported that their insurance partially covered hospital expenses, leaving the remaining costs to be paid out-of-pocket.

The majority of patients had inadequate levels of education and were unaware of the correct symptoms or treatment procedures. The patient from Ropar who received treatment at Post Graduate Institute of Medical Education & Research (PGIMER), Chandigarh reported to the researcher that "*Mere dhid vich pani bhar janda si".* However, upon reviewing his reports, the researcher discovered that he had been diagnosed with Pleural Effusion, which is an excessive accumulation of fluid between the pleural membranes surrounding the lungs.

Table 2: Gaps along the patient journey

S. No	Characteristics	Source	Frequency	Percentage Share
1	Identification	After deterioration of health & seek medical help	185	91.58
		During regular check-up	15	7.43
		Others	2	0.99
	Characteristics	**Category**	**Frequency**	**Percentage Share**
2	Do you have any health insurance	Yes	55	27.23
		No	147	72.77
3	If Yes, Type of Insurance	Ayushman Bharat Card	29	52.73

		ECHS	4	7.27
		ESIC	8	14.55
		Govt. Employee	10	18.18
		Brought by paying premium	3	5.45
		Others	1	1.82
4	Whether Insurance accepted at the hospital	Yes	30	54.55
		No	10	18.18
		Partial	15	27.27
5	Distance of hospital (in KM) one sided	0-50	85	42.08
		50-100	33	16.34
		100-150	28	13.86
		150-200	17	8.42
		More than 200	39	19.31
		Median	**80**	
		Mean	**126**	

*Source***:** Author's Calculation from Primary Data

3.3 Patient Satisfaction

The study also examined the patient's expectations regarding the quality of health care prior to his or her hospitalisation following a cancer diagnosis, as well as the patient's actual service ratings during his or her general hospitalisation and the COVID period. Results have been calculated using paired sample t-test which is shown in Table 3. Pair 1 constituted the mean comparison between expectations prior to availing the services and overall realisation. Pair 2 consisted of a comparison of mean values of expectations before visiting the hospital and actual service delivery (realisation) during the COVID pandemic period. Difference between expectations and realisations for both the pairs was recorded. The study found a significant difference between expectations and realisations as the p-value for both cases was found to be less than 0.05.

Table 3: Paired Sample Test Results

		Paired Differences					T	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% CI				
					Lower	Upper			
H_{01}	Expectation – Realisation	1.436	1.378	.097	1.244	1.627	14.807	201	.000
H_{02}	Expectation – Realisation during Covid period	2.267	1.345	.095	2.081	2.454	23.961	201	.000

*Source***:** Calculated value through SPSS

The key differences in mean value between overall realisation and expectations (R-E) and the difference in mean between realisation specifically during the COVID period and expectations of the patients (C-E) for both types of patients i.e. public and private are shown in Table 4. The study found a wide gap between expectations and realisation. Patients were asked to rate the expectations regarding the treatment on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Similarly, respondents were asked about their actual rating of health care delivery (Realisation) and were also asked to rate the service delivery during the COVID period. However, 24 patients who died before the start of COVID pandemic were not included in the statement measuring the realisation of service during the COVID period. Hence, valid responses to this statement were 178.

The study observed a huge gap in expectations of patients and actual realisation about the healthcare service delivery (mean difference = -1.43). This gap widens when the mean difference was noted for expectations and realisation during the COVID period (-2.02). The gap analysis was also carried out separately for public and private hospitals as well which is shown in Table 4.

Table 4: Gap in Expectations and Realisations of the patients by hospital type (a) R-E (b) C-E

Hospital Type	Expectation (E)			Realisation (R)			Gap in Mean (R-E)	Experience during COVID (C)			Gap in Mean (C-E)
	N	Mean	SD	N	Mean	SD		n	Mean	SD	
Public	84	3.85	.789	84	2.41	1.003	-1.44	72	1.75	.931	-2.08
Private	118	3.95	.765	118	2.51	1.235	-1.44	106	2.02	.976	-1.93
Total	202	3.90	.779	202	2.47	1.110	-1.43	178	1.88	.948	-2.02

Source: Calculated value through SPSS

Policy Recommendations to Deal with Cancer in Punjab

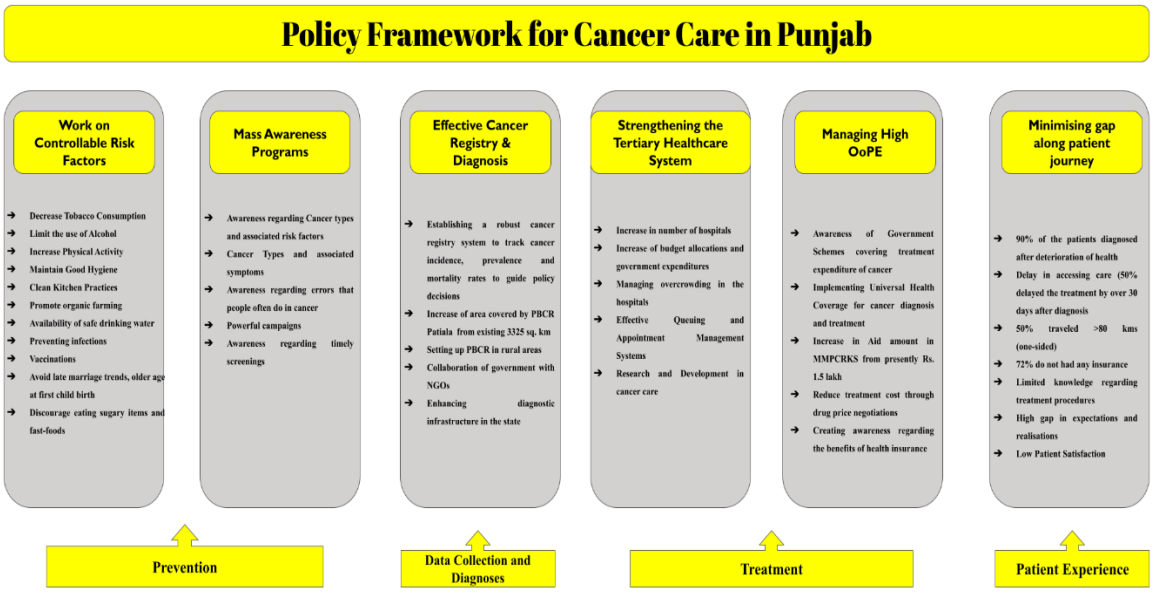
In the light of above discussion, the study proposed a suitable policy framework to deal with cancer in India, particularly, the state of Punjab. Figure 1 shows the policy recommendations which were based upon comprehensive analysis including the inequalities which were found during the research. The research findings pointed out the necessity of implementing diverse policy interventions in different Indian states, based on the economic conditions of the state and nature of the disease burden prevalent in each region. It could also be done by understanding the distribution of diseases and risk factors within clusters of states that share similar levels of development and epidemiological transition.

Punjab's policy framework outlines a multi-faceted approach to tackling the state's cancer burden, addressing prevention, diagnosis, treatment, and patient experience. A cornerstone is combating controllable risk factors. This includes reducing tobacco and alcohol consumption, promoting physical activity, ensuring safe drinking water, preventing infections through vaccination and hygiene, and encouraging dietary changes. Complementing this are mass awareness campaigns focused on educating the public about cancer types, symptoms, common misconceptions, and the critical importance of timely screening to enable early diagnosis. Furthermore, the framework prioritizes establishing a robust cancer registry system to accurately track incidence, prevalence, and mortality. Simultaneously, enhancing diagnostic infrastructure across the state is essential to reduce delays in confirming cancer.

To manage the demand for tertiary care, the framework calls for increasing the number of specialist care hospitals and boosting budget allocations. Addressing systemic challenges like hospital overcrowding through effective appointment management systems is crucial. Recognizing the financial devastation cancer causes, the policy emphasizes financial protection. This involves raising awareness of existing government schemes, implementing Universal Health Coverage for cancer care, increasing aid under government linked programs, negotiating lower drug prices, and promoting health insurance uptake to mitigate expenses.

The framework clearly identifies critical gaps: 90 per cent of patients diagnosed at advanced stage, 50 per cent experience significant treatment delays (>30 days post-diagnosis), 75 per cent lack insurance, and limited knowledge leads to low satisfaction. Addressing these requires streamlining pathways from symptom recognition through diagnosis, treatment initiation, and supportive care, ensuring affordability and clear communication to bridge the gap between patient expectations and experiences.

This integrated framework aims to move Punjab towards a more effective, equitable, and patient-centred cancer control system, focusing on saving lives through prevention, early detection, accessible treatment, and reduced financial hardship.



Source: Researcher's own framework

Conclusion

Cancer is an illness that incurs the most expense among all non-communicable diseases. The financial burden frequently complicates the patient's household in securing the necessary cash. The study revealed a significant disparity in income distribution, with the mean roughly double the median as a result of high-income households' impact. The significant discrepancy in income and expenditure levels among the Indian population imposes a financial hardship on middle-income households and those with meagre financial resources. The study's conclusions aligned with those of the EY-FICCI (2022) report titled 'Call for Action: Making quality cancer care more accessible and affordable in India.' The findings necessitate the need for the implementation of robust healthcare policies that can provide appropriate financial aid to individuals afflicted with cancer. Potential strategies to mitigate the financial strain of cancer in Punjab could involve increasing the fund allocation to cancer patients through the Mukh Mantri Punjab Cancer Raahat Kosh Scheme beyond the current limit of 1.5 lakhs, allocating additional public resources to mitigate the impact of cancer, or instituting a comprehensive healthcare insurance policy for the cancer victims in Punjab. The implementation of such measures may serve as a preventive strategy to mitigate financial distress among households in the event of a cancer to save the precious lives.

Additionally, it is found that hospitals occasionally refuse to accept patients' insurance policies. The bulk of these patients possessed an Ayushman Bharat

Card, which several private hospitals declined to recognise during the COVID-19 outbreak. Governments should be cognisant of these immoral actions that have occurred as well. A majority of the patients (over 90 per cent) were initially diagnosed on the basis of their symptoms, while over 64 per cent were diagnosed at an advanced stage of the disease. The patients' one-sided median distance travelled of 80 kilometres indicates a dearth of high-quality care services in their local area. Therefore, it has been found that the initial diagnosis is the primary issue that must be addressed, along with delays in treatment by patients and a scarcity of quality hospitals in the surrounding area. The majority of patients are also found to have inadequate levels of education and were unaware of the correct symptoms or treatment procedures. There is a need that individuals must be educated on the importance of insurance adoption, the various types of cancer, their symptoms, and the necessity of timely treatment.

Additionally, gaps between patient's expectations and realizations of cancer treatment have been found, and these disparities grew during the COVID-19 pandemic. Therefore, in order to improve satisfaction of cancer patients, it is important to address these gaps. Potential strategies to address these issues may include establishing additional tertiary care hospitals, managing overcrowding, delivering personalised patient care, introducing advanced diagnostic and treatment technologies, enhancing research and development in healthcare, implementing effective queuing and appointment management systems, increasing government funding, implementing universal health coverage, negotiating drug prices to reduce treatment costs, promoting awareness of clean kitchen practices, launching impactful cancer awareness campaigns, and organising timely screening camps and awareness initiatives, among others

Lastly, not the entire population is encompassed by the PBCR and HBCR programs of NCRP. It is essential to add more PBCRs, especially in rural regions. In India, these registrations cover barely 10 per cent of the population, whereas the coverage in the UK and USA is 90 per cent. Moreover, there is significant underdiagnosis in our nation, making it imperative to upgrade the current diagnostic apparatus and enhance investment in the tertiary healthcare sector.

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