

**Community Participation in Cancer
Screening and Diagnosis Outreach
Activities towards Bridging Cancer
Disparities: “An Asset-Based
Community Development Model”
Partnering with Communities in India**

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Cancer Health Disparities

- Communities in low-income countries are characterized by limited access to cancer prevention and early detection services, even for the commonest types of cancer. Limited resources for cancer control are one of the contributors to cancer health disparities.
- Cancer control programs are not usually the top priorities of the top-level policymakers and international funders compared to infectious diseases in low-income countries.
- Cancer health disparity, also termed cancer health inequities refers to differences in access to cancer care, including information, early detection, treatment modalities, and cancer-related outcomes such as incidence, prevalence, mortality, and other adverse cancer-related health conditions among specific groups.

Cancer early detection and treatment cost

- The individual patient-level clinical cost per patient including diagnostic test, staging, treatment based on the FIGO stage I-IV cancer, chemotherapy and outpatient care increases with the stage of cancer disease.
- On average, costs at stage II, III, and IV were found to be 32%, 95%, and 109% higher than treatment costs at stage I.

Country	USA	Uganda	Europe
Cervical Cancer	\$ 6.12	1050 Shillings	8 Euros
Breast Cancer	\$ 27.96	1820 Shillings	30 Euros
Colorectal Cancer	\$ 30.55	1580 Shillings	25 Euros
Prostate Cancer	\$ 28.20	1360 Shillings	22 Euros
Others (Lung, Oral & Skin)	\$28.80	2400 Shillings	35 Euros

The concept of mobile cancer prevention and early detection clinic in India

Since 1967, India has one comprehensive cancer treatment centre, the TMC, located in the Central region of Mumbai and have many centers all over country.

The integration of cancer information, screening and referral of suspected cancer cases in primary health-care facilities was initiated in 2014 through training of primary health-care workers. This is envisaged to contribute to increasing population cancer awareness to promote prevention and early detection.

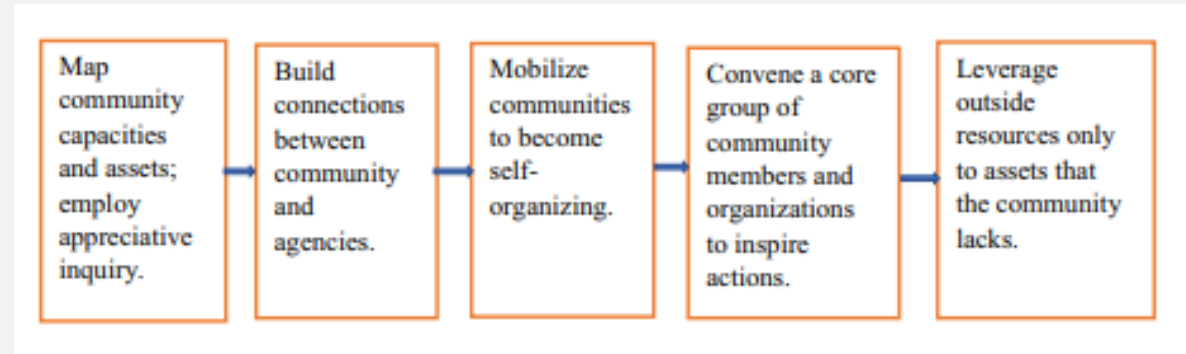
In 2009 the concept of community cancer program came to reality when TMC received a donation of a 35-foot mobile mammography unit van from Johnson & Johnson program. The purpose of this mammography-van was for community breast cancer education and screening services.

The Concept of Mobile Cancer Prevention and Early Detection Clinic in India

In 2015, with additional staff, the TMC-Community cancer unit, established daily cancer information and early detection services at TMC and routine community cancer outreaches. In 2018, received another mammography-van donated by Madhusudan Agrawal, the Samta Foundation and Tata Group. The new mobile van is equipped with a mammography unit for breast cancer screening and space for cervical cancer screening.

The Community Program also called the Comprehensive Community Cancer Program (CCCP) is a community health section of the TMC that takes lead in the primary prevention of cancer and early detection. The goal of CCCP is to reduce cancer risk by increasing access to and utilization of cancer prevention services. This is done through mass media cancer awareness, outreach and hospital-based health education on cancer risk factors, prevention, early detection measures, and screening for the leading cancers; cervical, breast, and prostate cancer.

Rationale for asset-based community development (ABCD) model



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- The “needs-based” or problem-based approach to community health development is well-intentioned by the central and local governments, nongovernmental organizations (NGOs), donors, and other actors but reflects a one-sided deficiency view of the community profile and offers short-term benefits.
 - This creates a situation that render the provision of community health services like cancer prevention and early detection efforts costly to implement and denies access to services, especially for the rural, hard-to-reach, and hard-to-live populations.

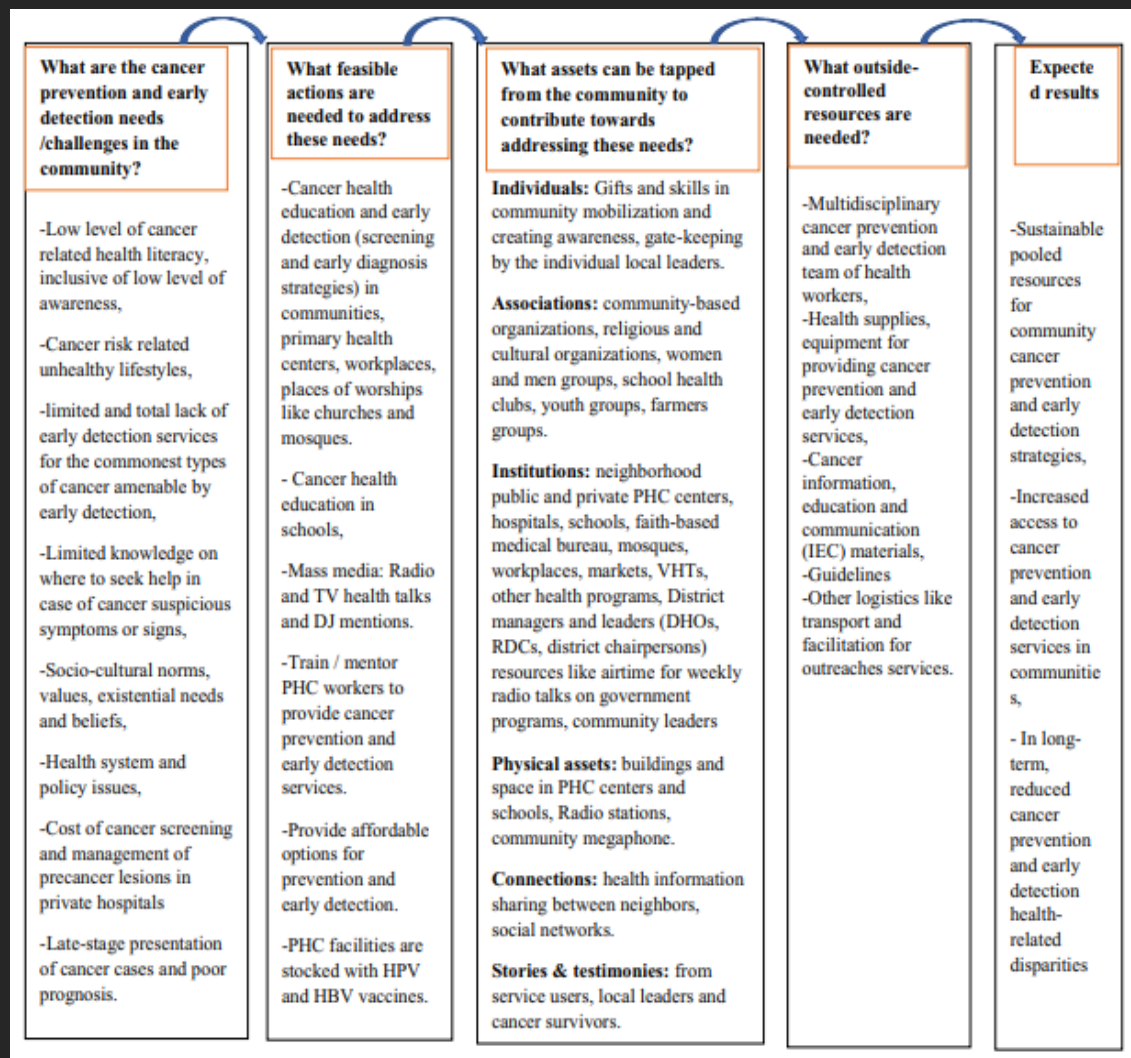


Figure 2: Conceptualization of ABCD model in community cancer program based on the current settings in India. Including Rural level Subunits, Community health workers (ASHA, ANM), PHC (primary healthcare center), CHC (community health centers), and DHOs (district health officers).

- However, the ABCD model is an assets-based model of community engagement and development including programming of health services that recognize the community's capacities and resources to leverage the externally-coordinated services. This could be applied to community health services such as cancer control efforts, in particular cancer prevention and early detection.
- The ABCD model aims to identify and mobilize resources in the communities; the local governments, community-based organizations, voluntary associations, businesses, and individuals.

Impact of COVID pandemic on community participation for Oncology Care Pathwa

The coronavirus disease 2019 (COVID-19) pandemic led to prioritizing emergency care dedicated to infection management. Other conditions, such as cancer management, may have been affected during the sanitary lockdown. Consequences of this “Distraction Effect” are suspected, but the immediate impact of this pandemic is still unknown.

Research Gaps (In doing this, the following were some of the questions reflected on)

What are the cancer prevention and early detection needs in the communities? (sources of data: previous studies and surveys);

What feasible actions are needed to address those cancer prevention and early detection related needs in the communities? (sources of data: recommendations from previous studies, surveys, knowledge of the health system and policy, evidence of what works in related settings and recommendations from international health bodies like WHO);

What assets can be tapped from the communities to leverage cancer prevention and early detection? (sources of data: previous studies, surveys, knowledge of the health system, policy and sociocultural norms and values);

What outside-controlled resources are needed to provide access to cancer prevention and early detection services in the community? (Sources of data: health system, policies, guidelines, and recommendations)

Research Objective

- We explored the feasibility and benefit of conducting outreaches in partnership with local communities using the “asset-based community development (ABCD)” model.
- In this report, despite limited funding for primary prevention and early detection of cancer in India, we share how working with local communities as partners to leverage resources for increasing access to primary prevention and early detection of cancer in India is feasible.
- We aimed to examine the contribution of working with community organizations to increase access to cancer prevention and early detection services over 3 years period. We also sought to provide insight into the accrued benefit/monetary value of community assets and feasibility of conducting outreaches in community health centers, places of worships, schools, and workplaces in partnership with local communities.
- The study evaluated changes in oncological care pathways during the COVID-19 crisis.



Materials & Methodology

- **Study Design:** Integrative exploratory cohort model-based study (ABCD);
- **Study Type:** Analytical Study (Comparative study)
- **Research Data:** Secondary data research for TMC community participation and HMIS data for oncological activity from THM Mumbai and TMC Kolkata.
- **Research Location/Time:** TMH Mumbai and TMC Kolkata; Data collected from July 2016 to December 2019 and Oncological activity status from Jan 2020 to July 2020.
- **Data Source:** We analyzed the quarterly CCCP reported output data without individual identifiers from July 2016 to December 2019 to compare the hospital-based and outreach cancer awareness and screening services outputs as a short-term assessment of the contribution of ABCD model-based outreach.
- **Outreach Partnership Model:** As an ongoing community program, in outreaches, community partners mobilized the community, arranged for venues and other logistics including mass media (TVs and radio) airtime using their resources.

COVID Pandemic Model

Monthly oncological activity indicators were extracted using electronic files and nation-wide procedure codes for TMC from January 1, 2019, to June 30, 2020, in area of high COVID19 incidence, in a tertiary care center (TMH Kolkata), and in a general hospital (in the first national outbreak epicenter TMH Mumbai). The daily number of infected and deceased inpatients with COVID-19 and the monthly number of different steps of oncological care pathways (screening, diagnosis, multidisciplinary tumor board meeting [MTBM], diagnosis announcement procedure [DAP] and treatment) were collected. We calculated monthly activity differences between 2019 and 2020, focusing on the 6-month COVID-19 pandemic period, to identify changes and to compare DAP and MTBM between both areas. Statistical analyses were performed using R (R Development Core Team, version 1.2.5019) and Excel Macros(Microsoft, version 2018).

Results & Interpretation

From 2016 to 2019, the community outreach model worked with 107 local partners either once or more than once to conduct 151 outreaches to extend cancer awareness and screening services in rural hard to reach and live populations.

Ninety-two (95%) of cancer awareness radio and TV talk-shows conducted were sponsored by local partners. Out of the total people screened; 22,795 (63.0%) cervical, 22,014 (64.4%) breast, and 4,904 (38.7%) prostate screening clients benefited from the outreach model.

Table: Community partnership, outreaches activities, and cancer healthcare education activities during 2016-2019 in India

Years	No of Community partnership	No of Outreach activity	Community sponsored activities	Govt Sponsored activities	Total Health Educated	Health in	Educated outreach	Health at	Educated ICI
			TV/radio/talk	TV/radio/talk		Male	Female	Male	Female
2018/19	42	61	22	1	143436	30289	87563	5461	20123
2017/18	34	53	44	2	64488	16847	34737	3387	9517
2016/17	31	37	26	2	50838	6846	25286	3106	15600
Total	107	151	92	5	258762	53982	147568	11954	45240

The screen-positive rates were higher in hospital-based screening except for Prostate screening; cervical, 8.8%, breast, 8.4%, prostate, 7.1% than in outreaches; cervical, 3.2%, breast, 2.2%, and prostate, 8.2%.

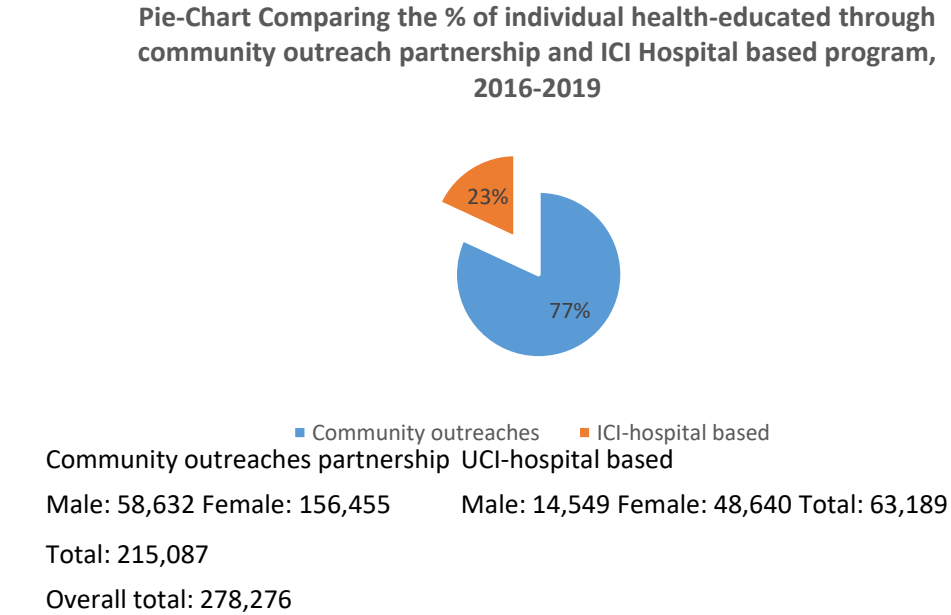


Figure: Pie-Chart Comparing the % of individual health-educated through community outreach partnership and ICI Hospital based program, 2016-2019

Of the total number of people health educated in group sessions and one-on-one on primary prevention of cancer, early detection and cancer management, 201 568 (77.9%) were reached through the outreach model

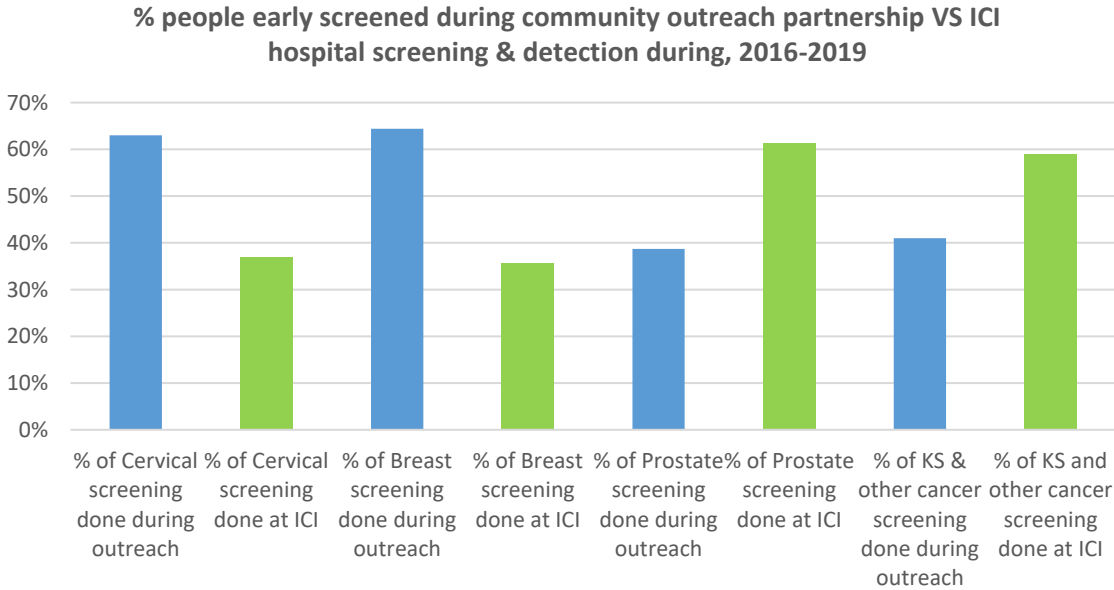


Figure: % people early screened during community outreach partnership VS ICI hospital screening & detection during, 2016-2019

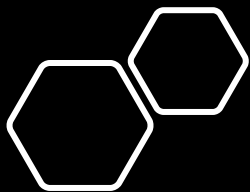
- The unit cost incurred in Cancer screening was thousands folds less than the unit cost of managing in any stage of cancer disease. The cost of managing cancer increases with the stage of cancer progression.
- Regarding Cervical cancer; the average unit cost for managing localized Cervical cancer cases was 2941 times (18,000/6.12) higher than the average unit cost of cervical screening. The average unit cost for managing advanced cervical cancer (Regional or distant) was 6005 times (36,751.07/6.12) higher than the average unit cost of screening.
- The average unit cost for managing advanced Cervical cancer (Regional or distant) was 1314 times (36,751.07/27.96) higher than the average unit cost of pre-cancer treatment of Cervical lesions using cryotherapy.

		Outreach with	Community	Support	ICI-Hospital	Based	Screening
Year	Total screened in both outreach & ICI	Screened (% of total screened)	Positive (%)	Suspicious for cancer (%)	Screened (% of total screened)	Positive (%)	Suspicious for cancer (%)
2018/19	16 666	11 432 (67%)	457 (3.9%)	387 (3.4%)	5234 (33%)	271 (5.2%)	988 (18.9%)
2017/18	14 173	9059 (64%)	161 (1.7%)	179 (2.0%)	5114 (36%)	615 (12.0%)	1128 (22.0%)
2016/17	5490	2304 (42%)	115 (4.9%)	188 (8.2%)	3186 (58%)	309 (9.7%)	516 (16.2%)
Total	36 329	22 795 (63%)	733 (3.2%)	754 (3.3%)	13 534 (37%)	1195 (8.8%)	2632 (19.4%)
Breast screening							
Years	No. screened outreach with community participation			ICI hospital-based centers			
2018/19	16 186	11 067 (68.4%)	231 (2.1%)	221 (1.9%)	5119 (31.6%)	418 (8.2%)	317 (6.2%)
2017/18	11 774	8933 (75.9%)	164 (1.8)	216 (2.4%)	2841 (24.1%)	313 (11.0%)	179 (6.3%)
2016/17	6233	2014 (32.3%)	91 (4.5%)	134 (6.6%)	4219 (67.7)	296 (7.0%)	194 (4.6%)
Total	34 193	22 014 (64.4%)	486 (2.2%)	571 (2.6%)	12 179 (35.6%)	1027 (8.4%)	690 (5.7%)
Prostate screening & detection							
Years	No screened outreach with community participation			ICI-Hospital based screening centers			
2018-19	8901	3143 (35.7%)	215 (6.85)	97 (3.1%)	5658 (64.3%)	186 (3.3%)	274 (4.8%)
2017-18	1692	856 (50.6%)	107 (12.5%)	95 (11.1)	836 (49.4%)	249 (29.7%)	216 (25.8%)
2016/17	2172	905 (41.6%)	82 (9.1%)	141 (15.5)	1267 (58.4%)	114 (8.9%)	191 (15.1%)
Total	12 665	4904 (38.7%)	404 (8.2%)	333 (6.8%)	7761 (61.3%)	549 (7.1)	681 (8.8%)

Table: Outreaches activities and ICI hospital based early screening Comparison based on cancer suspicious lesion and Screened positive during 2016-2019 in India

Early Screening Comparison based on Cancer

- In Breast cancer; the average unit cost for managing localized Breast cancer cases was 708 times $(29,724/42)$ higher than the average unit cost of screening. The average unit cost for managing advanced Breast cancer (Regional or distant) was 1479 times $(62,108/42)$ higher than the average unit cost of breast screening.
 - The average unit cost for managing advanced Breast cancer was 21 times $(62,108/3000)$ higher than the average unit cost of pre-cancer treatment of Breast cancer lesions using Lumpectomy.
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- In prostate cancer; the average unit cost for managing localized Prostate cancer cases was 212 times $(6,369/30)$ higher than the average unit cost of screening. The average unit cost for managing advanced Prostate cancer (Regional or distant) is 600 times $(18,000/30)$ higher than the average unit cost of screening.
 - The average unit cost for managing advanced Prostate cancer (Regional or distant) was 4.2 times $(18,000/4286)$ higher than the average unit cost of pre-cancer treatment of Prostate lesions using surgical intervention.



Kaposi Sarcoma and other types
of cancer suspicious lesions
based on clinical assessment,
2016-19, India

Year	No Screened	Outreach with	Partnership communities	ICI hospital Screening	Based
		Medical Examination	Suspicious for prognosis	Medical Examination	Suspicious for prognosis
2018/19	1619	725 (44.8%)	101 (13.9%)	894 (55.2%)	172 (19.2%)
2017/18	1185	523 (44.1%)	66 (59.0%)	662 (55.9%)	136 (20.5%)
2016/17	1269	415 (32.7%)	45 (10.8%)	856 (67.3%)	72 (8.4%)
Total	4073	1663 (41.0%)	212 (12.7%)	2412 (59.0%)	380 (15.8%)

The screen-positive rates were higher in hospital-based screening except for Prostate screening; cervical, 8.8%, breast, 8.4%, prostate, 7.1% than in outreaches; cervical, 3.2%, breast, 2.2%, and prostate, 8.2%

Cancer type	No. Screened	Average pricing of screening	total pricing incurred	precancers/ screen positives (d)	pricing of treating precancer US\$ (e)	in treating precancers US\$ (f)	Total price of screening US\$	Suspicious cancer lesions (i)
screened (a)		US\$ (b)	US\$ (c)					
Cervical	36,329	6.12a	22,23,334	1928	27.96a	53,907	22,77,241	3386
Breast	34,193	42a	14,36,106	1513	3000a	45,39,000	59,75,106	1261
Prostate	12,665	30a	379,950	953	4286	40,84,558	44,64,508	1014
Total	83,187		40,39,390	4394		86,77,465	1,27,16,855	5661

a The average unit cost for Cancer screening were based on; cervical screening, Quentin et al, Cervical pre-cancer treatment, Quentin et al, breast screening, Gross et al while Prostate screening was based on average market cost.

The unit cost incurred in Cancer screening was thousands folds less than the unit cost of managing in any stage of cancer disease. The cost of managing cancer increases with the stage of cancer progression.

Comparing the unit costs for screening, pre-cancer treatment, managing localized, and advanced cancer

Est.Min. No. that would be detected with cancer(j) d + i	Early stage cancer = 20% of j	Late stage cancer = 80% of j	Est.Unit cost for localized cancer mgt	The would be cost incurred in managing localized cancer US\$	Est. Unit cost for managing advanced cancer (Regional or distant) US\$ (k)	The would be cost incurred in managing regional & distant cancer US\$ (l)	The would-be total cost of managing cancer disease
5314	1063	4251	18 000 ^b	19 134 000	36 751.07 ^b	156 228 799	175 362 799
2774	555	2219	29 724 ^b	16 496 820	62 108 ^b	137 817 652	154 314 472
1967	393	1574	6369 ^b	2 503 017	18 000 ^b	28 332 000	30 835 017
10 055	2011	8044		38 133 837		322 378 451	360 512 288

b The average unit cost for managing early stage and late stage cancer were based on; Cervical, Ostensson et al, Breast, Sun et al and Prostate cancer; localized prostate cancer, Fourcade et al; regional prostate cancer, De Oliveira et al.

- Compared with the same trimester in 2019, oncological activity decreased dramatically on all essential oncological care pathway steps during the COVID-19 pandemic. The trends and comparisons of monthly activity volume are depicted.
- Colon and breast cancer screening test fell by 46% to 60%, respectively. All activities linked to sampling, histopathological (–38%), and biomolecular analyses (–39%) were drastically reduced. A decrease in medical announcement consultations (–24%) and oncogeriatric evaluations (–56%) was also observed; fewer medical patient files (–31%; including those of new patients; –39%) were reviewed in MTBM. Regarding treatment, systemic chemotherapy (–6%) and radiotherapy (–12%) experienced a lighter decline, whereas oncological surgical procedures were heavily impacted (–20%) over a 4-month period.
- Although the COVID-19 outbreak occurred earlier and with more intensity in Mumbai (TMH), it had a comparable impact in both areas regarding MTBM and DAP.

Oncology Care Pathway	Monthly Activity Indicators (%)	TMH						TMC					
		Jan	Feb	Mar	Apr	May	Jun	Jan	Feb	Mar	Apr	May	Jun
Screening	Mammograms	2%	3%	-8%	-58%	-70%	-60%	5%	11%	8%	-14%	-28%	-35%
	Overall FIT Performed	8%	12%	-10%	-30%	-66%	-34%	10%	8%	2%	-8%	-21%	-26%
	Positive FIT	-1%	3%	-5%	-11%	-7%	-9%						
Histopathologic Analyses	Biopsies	14%	10%	4%	-27%	-32%	-24%	12%	18%	4%	-20%	-26%	-35%
	Surgical specimens	-8%	-14%	-11%	-35%	-30%	-28%	16%	12%	5%	-22%	-31%	-48%
	Extemporaneous	42%	25%	20%	-23%	-62%	-38%						
	Cytology	-2%	19%	-29%	-70%	-28%	-25%	3%	7%	7%	-5%	-12%	-17%
	Samples (Overall)	0%	6%	-4%	-31%	-46%	-28%	4%	10%	2%	-12%	-21%	-29%
Biomolecular Analyses	Germline Analysis	22%	16%	-20%	10%	-39%	-15%						
	Colorectal Cancer	18%	13%	-12%	-25%	-32%	-17%	20%	8%	5%	-10%	-16%	-21%
	Somatic Analysis	8%	6%	-5%	-20%	-34%	-15%						
	Others							28%	23%	15%	2%	-10%	-18%
	Biomolecular Analysis	28%	-12%	-18%	-30%	-38%	-19%	15%	13%	8%	3%	-16%	-21%
Assessment and Diagnosis	PET/CT Performed	20%	13%	7%	-5%	-18%	-16%	48%	38%	23%	-2%	-16%	-24%
	Oncogeriatric Evaluation	32%	26%	12%	-3%	-15%	-12%	12%	26%	22%	2%	-12%	-20%
	Medical Diagnosis	28%	21%	6%	-8%	-20%	-21%	21%	18%	13%	3%	-2%	-10%
	Assigned personalized care	16%	17%	8%	-3%	-11%	-23%	34%	27%	12%	0%	-5%	-6%
	Post diagnosis consultation	23%	18%	-3%	-16%	-25%	-28%	18%	14%	20%	-2%	-8%	-14%
Multidisciplinary Tumor Board	First time reviewed patient referred from review center	52%	33%	-1%	-18%	-22%	-16%	20%	12%	15%	1%	-6%	-9%
	First time reviewed patient referred from external center	36%	27%	-2%	-22%	-30%	-26%	15%	11%	18%	-3%	-2%	-4%
	First time reviewed patient	28%	21%	-4%	-10%	-21%	-22%	12%	16%	6%	-4%	-10%	-12%
	Reviewed patient files	33%	27%	-3%	-12%	-24%	-22%	8%	13%	12%	-2%	-3%	-8%
Cytotoxic Chemotherapy	Implanted venous devices	25%	16%	-10%	-18%	-26%	-25%	18%	14%	22%	10%	-22%	-30%
	Occupation rates	18%	10%	-14%	-20%	-27%	-30%						
	Daycare admission for chemo	22%	14%	-10%	-25%	-32%	-26%	54%	32%	28%	-2%	-11%	-24%
	Regular oncology outpatients	16%	5%	-2%	-12%	-20%	-26%	6%	11%	3%	-4%	-9%	-11%
	Prepared Chemotherapy bags	-2%	-7%	-18%	-24%	-30%	-21%	2%	3%	7%	-2%	-8%	-11%
	Hepatic chemoembolization	-3%	-7%	-18%	-32%	-45%	-33%						
Surgery	Carcinological Surgery	30%	18%	11%	-8%	-10%	-14%	18%	22%	26%	-10%	-18%	-21%
Radiotherapy	CT simulation session	25%	10%	-8%	-20%	-27%	-22%	12%	10%	21%	-6%	-12%	-20%
	Courses of radiotherapy	15%	18%	6%	-7%	-20%	-12%						
	Regular radiotherapy patients	22%	10%	12%	-2%	10%	18%						

Conclusion

- Working in collaboration with communities and community based organizations through assets-based community development model is feasible.
- This helps in cost-sharing, leverage for scarce resources and it is an ecological approach to bridging cancer health disparities.
- In low- and middle-income countries with limited number of cancer hospitals and early detection centers, increasing population cancer awareness to promote prevention and early detection should leverage from community-based assets through an organized outreach model as an intermediate solution.
- Deliberate efforts are required to outreach communities in low-income settings with affordable cancer preventive and early detection services.
- However, an equitable and cost-effective comprehensive national cancer control program is a prerequisite.
- Outbreak occurred earlier and with more intensity in MUMBAI but had a comparable impact in both areas regarding MTMBs and DAPs. The current study is still in progress and with a longer follow-up to analyze post-lockdown situation.

Recommendations

The study suggests there is a reduction in all Community outreach activities and health education session during COVID pandemic which results in decline in number of early screening & detection and other oncological care pathway activities in India and other developing countries, which can eventually result to rise in cancer burden.

The cancer burden can foster out of pocket expenditure of individuals if not screened in early stages of cancer.

Thus, the study gives an idea to policy makers and government authorities to organize such education and outreach activities to reduce the burden and spreading awareness about early screening and detection of cancer.

Moreover, the high risk or prevalence population should be screened with yearly universal screening program.

An abstract composition of various geometric shapes. In the top left, a green triangle points towards the right. To its right is a solid blue circle. Below the green triangle is a blue ring. In the center is a large orange semi-circle. To the right of the semi-circle is a vertical yellow dashed line. In the bottom left is a large solid orange circle. To its right are four short, curved yellow dashed lines. In the bottom right is a green square.