AUGMENTING COMPREHENSIVE CANCER CARE PLAN FOR TELANGANA STATE, INDIA

Abridged Report 2021

Report Prepared by

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CONTENTS

LIST OF TABLES
LIST OF FIGURES
SPOTLIGHT8
EXECUTIVE SUMMARY
1.0 EPIDEMIOLOGY OF CANCER15
1.1 Global scenario
1.2 Situation in India15
1.3 Status in Telangana15
1.4. Situation in Hyderabad district15
2.0 DETERMINANTS OF CANCER15
2.1 Modifiable risk factors15
2.2 Non-Modifiable risk factors
3.0 NATIONAL CANCER CONTROL PLAN
3.1 National Cancer Control Programme16
3.2 National Strategies targeting Non-Communicable Diseases
3.3 Cancer control activities under the National Health Assurance Scheme
3.4 Activities under NPCDCS and NCCP16
3.5 National Cancer registry program17
4.0 CANCER CONTROL PLAN IN TELANGANA17
4.1 Measures being implemented for primary prevention17
4.2 Early detection of common cancers17
4.3 Facilities providing diagnosis and treatment
 4.3 Facilities providing diagnosis and treatment
 4.3 Facilities providing diagnosis and treatment
 4.3 Facilities providing diagnosis and treatment
4.3 Facilities providing diagnosis and treatment 18 4.4 Services under the palliative care component 18 4.5 State government plans for the fiscal year 2020-21 18 4.6 Best practices implemented in Telangana 18 5.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES 19
4.3 Facilities providing diagnosis and treatment 18 4.4 Services under the palliative care component 18 4.5 State government plans for the fiscal year 2020-21 18 4.6 Best practices implemented in Telangana 18 5.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES 19 5.1 Rationale for undertaking the project 19
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim19
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim195.3 Specific Objectives20
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim195.3 Specific Objectives206.0 METHODOLOGY20
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim195.3 Specific Objectives206.0 METHODOLOGY206.1 Review of existing published literature20
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim195.3 Specific Objectives206.0 METHODOLOGY206.1 Review of existing published literature206.2 Interviews with stakeholders20
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim195.3 Specific Objectives206.0 METHODOLOGY206.1 Review of existing published literature206.2 Interviews with stakeholders206.3 Projections21
4.3 Facilities providing diagnosis and treatment 18 4.4 Services under the palliative care component 18 4.5 State government plans for the fiscal year 2020-21 18 4.6 Best practices implemented in Telangana 18 5.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES 19 5.1 Rationale for undertaking the project 19 5.2 Aim 19 5.3 Specific Objectives 20 6.0 METHODOLOGY 20 6.1 Review of existing published literature 20 6.2 Interviews with stakeholders 20 6.3 Projections 21 6.4 Modified Delphi –Round 1 21
4.3 Facilities providing diagnosis and treatment184.4 Services under the palliative care component184.5 State government plans for the fiscal year 2020-21184.6 Best practices implemented in Telangana185.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES195.1 Rationale for undertaking the project195.2 Aim195.3 Specific Objectives206.0 METHODOLOGY206.1 Review of existing published literature206.2 Interviews with stakeholders206.3 Projections216.4 Modified Delphi – Round 1216.5 Modified Delphi – Round 221

7.0 EVIDENCE SYNTHESIS	22
7.1 Review of Existing Publications	22
7.2 Projected Magnitude of Different Cancers in Telangana over the next 10 years	22
7.3 Workload for common cancers	24
7.4 Barriers in accessing cancer care services	26
7.5 Application of Information Technology to promote cancer care services	34
7.5.1 Mobile-based applications	34
7.5.2 Audio-visual aids	34
7.5.3 IT-enabled screening, imaging and clinical care	35
7.6 Results of the Delphi process	35
7.6 Patient Journey Funnel	39
8.0 FUTURE DIRECTIONS FOR STRENGTHENING COMPREHENSIVE CANCER CARE IN TELANO	ANA
•••••••••••••••••••••••••••••••••••••••	39
9.0 IMPACT OF COVID-19 ON CANCER CARE PATHWAYS	43
REFERENCES	44

LIST OF TABLES

. 17
. 19
. 22
. 23
. 23
. 23
. 24
. 24
. 24
. 25
. 25
. 25
. 25
. 26
. 26
. 32
. 34
. 36

LIST OF FIGURES

Figure 1. Methods used for evidence synthesis	
Figure 2. Reasons enumerated by providers for delayed presentation	
Figure 3. Causes for non-compliance to recommended therapy or referral advice	
Figure 4. System level barriers perceived by healthcare providers	
Figure 5. Recommendations with the highest/maximum expected impact	
Figure 6. Patient Journey Funnel for all cancers - Showcasing leakages across major points	
Figure 7. General Comprehensive Cancer Care Framework	

ABBREVIATIONS

AIIMS – All India Institute of Medical Sciences **ASHA** – Accredited Social Health Activist **ANM** – Auxiliary Nurse Midwife AI – Artificial Intelligence AYUSH – Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homoeopathy **APC** - Annual Percentage Change **AERB** – Atomic Energy Regulatory Board **AB-PMJAY** – Ayushman Bharat Pradhan Mantri Jan Arogya Yojana **ASCO** – American Society of Clinical Oncology **BCC** – Behaviour Change Communication **CPHCP** - Comprehensive Primary Health Care Programme **CHC** – Community Health Centers **CPHC** – Comprehensive Primary Health Care **COTPA** – Cigarettes and Other Tobacco Products Act COVID-19 – Corona Virus Disease 2019 **CHW** – Community Health Worker **CHE** – Catastrophic Health Expenditure **CGHS** – Central Government Health Schemes **CBE** – Clinical Breast Examination **DALYs** – Disability Adjusted Life Years **DM** - Diabetes Mellitus **DH** - District Hospital ESIC - The Employees' State Insurance Corporation EHRs - Electronic Health Records **EMR** – Electronic Medical Record **ESMO** - European Society for Medical Oncology **GOI** – Government of India HPV - Human Papilloma Virus

HWCs – Health and Wellness Centers **HIT** - Health Information Technology **HCFs** – Health Care Facilities **HCPs** – Health Care Providers **HR** – Human Resources **HBCR** – Hospital Based Cancer Registry **ICMR** – Indian Council of Medical Research IARC - International Agency for Research on Cancer **IEC** – Information Education Communication **IQR** - Interquartile Ranges **IIPHs** - Indian Institutes of Public Health **IIPH-H** – Indian Institute of Public Health Hyderabad **LMICs** – Low- and Middle-Income Countries **LINACs** – Linear Accelerators MCH – Maternal and Child Health **MOs**- Medical Officers **MOHMW** – Ministry of Health and Family Welfare MNJ - Mehdi Nawaj Jung **MNJIO-RCC** - Mehdi Nawaj Jung Oncology **Regional Cancer Center MOOCs** – Massive Open Online Courses NDHM - National Digital Health Mission **NDPS** - Narcotic Drugs and Psychotropic Substances **NGO** – Non-Governmental Organization **NSS** – National Sample Survey **NABH** – National Accreditation Board for Hospitals and Healthcare Providers **NABL** – National Accreditation Board for Testing and Calibration Laboratories

NTCP - National Tobacco Control Programme **PBCRs** - Population-Based Cancer Registries **NHM** – National Health Mission **PHC** – Primary Health Centers **NIMS** – National Institute of Medical Sciences **POCSS** - Pattern of Cancer and Survival Studies **PBCR** – Population Based Cancer Registry **NPPC** - The National Program for Palliative PIP - Programme Implementation Plan Care **NICPR** – National Institute of Cancer Prevention **PLHIV** – People with Human Immunodeficiency and Research Virus NHSRC - National Health System Resource **PACS** - Picture Archive Communication Systems Centre **RT** – Radiotherapy **NFHS-5** – National Family Health Survey RMNCH+A - Reproductive, Maternal, New born, **NCCP** - National Cancer Control Programme Child and Adolescent Health **NCDs** – Non-communicable Diseases **RNTCP** - Revised National Tuberculosis Control **NPCDCS** – The National Programme for Programme Prevention and Control of Cancers, Diabetes, SCs – Sub-canters Cardiovascular diseases and Stroke **SN** – Staff Nurse **NCG** – National Cancer Grid **TS** – Telangana State NCCN – National Comprehensive Cancer VIA - Visual Inspection with Acetic acid Network WHO – World Health Organization

PHFI – Public Health Foundation of India

SPOTLIGHT

- Telangana Government has been a leader in cancer care in India. Telangana Cancer Care Program is a proactive, comprehensive initiative encompassing infrastructure development, human resource skilling and ensuring financial protection to those below the poverty line.
- Diagnostic services and palliative care have been strengthened in the past three years.
- District coordination committees, mammography units, colposcopy units and tobacco cessation programs have been set up.
- Due to the changing demography, the magnitude of cancer will continue to increase and initiatives will need scaling up.
- Patient-centric barriers to cancer care including rural residence, lack of awareness, stigma and out-ofpocket expenses need to be addressed.
- The patient journey can be improved further by better coordination of care at the provider level, including across sectors.
- Infrastructure and skills at the district and sub-district level need to be supplemented further.
- Satellite centres at district level for tertiary level cancer institutions can provide better connectivity and smooth transitioning of patients from the rural areas.
- Community-based and facility supported systematic screening programs at the district and CHC levels will facilitate early detection resulting in better prognosis.
- Ensuring privacy for examination of breast and cervical cancers at health facilities and by mobile clinics will improve early detection.
- Skills for clinical breast examination by women, facilitated by ANMs should be strengthened.
- Skilling of the health workforce at the district and sub-district level using digital platforms using Massive Online Open Course (MOOCS) models can be used effectively both for induction training and continuous professional development by reaching a large number with uniform training modules. A cell to facilitate this can be set up in the office of the Commissioner of Health or Institute of Health & Family Welfare.
- Palliative care services should be easily accessible to the rural population by training the existing health work force.
- COVID has created a new pathway for remote consultation and follow up. Tele-consultation and counselling services should be strengthened for the future. A cell to support the same can be set up at MNJ and NIMS hospital.
- A system for digitising medical records should be established. This should also ensure portability and confidentiality of data within and between sectors.
- Emerging digital technologies for cancer should be effectively harnessed to support early diagnosis, management and follow-up. A number of new technologies are emerging and these should be used after validation.
- Public private partnerships should be facilitated for better access and quality of services. Mapping of available infrastructure should be done so that the gaps in service delivery can be addressed synergistically.
- Need for mandating tumour boards at all treatment facilities. If needed, tumour boards can be set up by a consortium of cancer delivery institutions if load is low or requisite facilities are not available. Members can be co-opted from different sectors Government and Private sector if required.
- All channels of communication should be used for cancer awareness in a mission mode. Supporting peer ambassadors to be role models for communication and counselling is an effective strategy to encourage uptake of screening, diagnostic and therapeutic services.

- Immunization against Human Papilloma Virus (sub-types) needs to be prioritized. This will reduce cervical cancer case load further over the next 10 years.
- Standardized screening and treatment guidelines need to be formulated and adherence to the protocols should be monitored.
- Expanding the population-based cancer registry in Hyderabad district to include the entire state by networking and linking cancer care centres is important for timely evidence for planning.
- District NCD cells and cancer units should be established as district nodal cancer centres.
- A cancer care advisory group to strengthen and provide technical support to the Cancer Cell in the Government should be constituted. Such an advisory group should be all encompassing and invite oncology and public health and program experts from the government as well as the private sector, industry, civil society and patient support groups. This should be chaired by the Commissioner of Health and Co-Chaired by a leading non-government sector senior oncologist of repute.

EXECUTIVE SUMMARY

Magnitude

- Cancers are an important public health problem globally and in India. In 2020, it was reported that there
 were an estimated 19.3 million new (incident) cancer cases and 10 million cancer associated deaths
 worldwide. Over the next 20 years, it is projected that there will be a 60% increase in magnitude of
 cancers globally. The trajectory of increase will be steepest in low- and middle-income countries,
 including India.
- The second leading cause of premature death in the productive age group in India is cancer. Five cancers (breast, lung, oral cavity, stomach and colorectal cancers) were responsible for nearly half of all new cancer cases in India in 2018.
- Compared to the high-income countries, survival from cancers is poorer in India.
- Telangana State has a high burden of cancer as reported by the Global burden of disease study for India.
- The age-standardized incidence rate was estimated to be 88.7 per 100,000 population, in 2016.
- Among specific cancers in Telangana, age-standardized stomach cancer incidence rate was the highest compared to all other cancers when both sexes were combined.
- Stomach cancer is the leading cause of cancer-related mortality among both sexes in Telangana.
- Lung cancer among men and cancers of breast and cervix among women are also responsible for cancerrelated deaths in the state.
- The population-based cancer registry at Hyderabad data showed that of all cancer types prevalent among women in Hyderabad district, 35.5% are breast cancers, 8.7% are cervical cancers and 6.9% are ovarian cancers and that the highest incidence of breast cancer among all population-based registries in India is reported from Hyderabad.
- Among men, the Hyderabad cancer registry reported that mouth, lung and tongue cancers are the commonest cancers in this region.
- Among the prevalent risk factors, tobacco consumption among males is 22.3% against 5.6% among women in Telangana. Since tobacco consumption is attributable to many cancers, this high rate of consumption is worrisome.

Current Status of Comprehensive Cancer Care in India

- The NPCDCS programme supports awareness on common cancers and screening at community level. This (population-based screening under comprehensive primary healthcare) was started in 2018 and is gradually being rolled-out as a regular activity.
- Capacity building, skilling and infrastructure strengthening are the other areas supported under the programme.
- The National Cancer Registry project through continuous data collection at the Population and Hospital level provides the evidence for action in India.

Current Status of Comprehensive Cancer Care in Telangana

- Available data from Telangana is not truly representative of the cancer status as there is only one population-based and one hospital-based registry in the State, both being located at Hyderabad.
- Reported screening rates for cancer among both males and females are < 5% for different cancers.
- Despite being the being the youngest State in the country, Telangana has committed strong support to comprehensive cancer care.
- Technology has been used to developed applications that can tag NCD outputs of ASHAs using a community-based assessment checklist.
- The State *Aarogyasri* project caters to the needs of cancer patients, especially those from low socioeconomic strata.
- Diagnostic, cancer care and palliation services are being strengthened at the district level.
- Mobile vans also support the palliative care component.
- The State has committed funds for mammography units and video colposcopy units, district hubs for cancer care and school awareness programs for reducing the risk of tobacco consumption.

• The State has also established district level coordination committees.

Aims and Objectives

- The aim of the project is to identify modalities to augment the Telangana State Cancer Control Plan to implement a sustainable comprehensive cancer care model for Telangana, which could also be replicated in other regions/ states of the country.
- The primary objectives of this work were identification of measures that can add value to the existing robust government cancer care continuum and to see how different sectors of the health system can work together to co-create tangible shared interventions.

Methodology

- A multi-method approach using both quantitative and qualitative research methods was used for evidence synthesis. This included review of existing published literature, stakeholder interviews (both patients and providers), Delphi consultations with experts and modelling to project future trends.
- For estimating the cancer-specific burden in Telangana, five-year prevalence of cancer in India as reported by Global Cancer Observatory, 2020 was considered. Due to the absence of data on cancer-prevalence in Telangana in 2021, the available proportions for India were applied and prevalence for Telangana was estimated.
- Crude incidence rates of all cancers as estimated by the Global Burden of Disease study group for states of India in 1990 and 2016 were used to project annual incidence from 2021 to 2030 in Telangana. Crude incidence rates for specific cancers were also projected in a similar manner.
- Workload estimations were also computed using assumptions supported by expert opinion. Workload was estimated based on the site and stage of cancer.
- Expert opinion was sought using a modified Delphi method using a virtual platform as in-person meetings were not possible due to COVID.
- An expert panel comprising oncologists, palliative care experts and behavioural scientists with expertise in the management of common cancers (breast, cervical, oral and lung) was constituted for this purpose.
- For an equitable representation, specialists with expertise in surgical, medical, gynaecological and radiation oncology, psychiatry and palliative care were identified.
- Experts ranked each of the recommendations based on five criteria importance (due to magnitude and community concern), relevance, feasibility, affordability and expected impact.
- This helped in identifying the top 25 recommendations which could provide additional support to the Telangana State Cancer Control Plan.
- The project was approved by the Institutional Ethics Committee of the Indian Institute of Public Health Hyderabad.

Evidence Synthesis

<u>Magnitude</u>

- It was estimated that the magnitude of cancer survivors would increase from 92,379 in 2021 to 208,002 by 2030 which is a 125% increase in absolute numbers.
- Increasing life expectancy leading to a larger proportion of people living to older ages is a driver of the increased magnitude.
- A 37% increase is anticipated in the crude incidence of breast cancer between 2016 and 2036 in Telangana.
- A 28% decrease is projected in the crude incidence of cancer of the cervix between 2016 and 2036.
- It was estimated that for early-stage breast cancers, the workload will increase by nearly 33% between 2021 and 2036.
- Similarly, a 17% decrease in workload is anticipated between 2021 and 2036 for cervical cancer.
- The study also attempted to estimate requirement for chemotherapy, radiotherapy and surgical oncology in the State.

Patient related barriers to cancer care

- Lack of awareness, financial constraints, place of usual residence were the three commonest drivers of delayed presentation in cancers.
- All healthcare providers at the tertiary level perceived financial constraints as a barrier for early presentation. However, this perception was limited to 28.6% of providers at the primary level of the public health system.
- Providers at the tertiary and secondary levels contended that indirect costs in terms of loss of wages and productive work hours is a constraint for patients from families below the poverty line.
- Health care providers interviewed stated that financial cover for cancers should also include indirect costs like transportation, accommodation, loss of wages etc.
- Inadequate knowledge on risk factors and screening measures such as procedure for self-examination; negligence of early symptoms and preference of local non-formal qualified practitioners to allopathic practitioners were the common patient-related barriers perceived as important by primary healthcare providers. The side effects of allopathic treatment like fall of hair etc. also affect compliance with treatment.
- Awareness levels on cancers were significantly higher among those with higher educational attainment. This also affected the delay in presentation for treatment after diagnosis of a cancer. The widespread belief that cancers are incurable also lead to defaulting on treatment.
- Stakeholders at the community level emphasized that stigma was the prime reason responsible for the late presentation of cancer patients at health centres as villagers have a taboo and apprehension that revealing their diagnosis may lead to them being 'labelled' by the community which results in them facing hardships due to societal norms.
- Healthcare providers also opined that an awareness campaign would pay rich dividends and that such endeavours should educate women on how to conduct procedures like breast self-examination and on preventing tobacco and alcohol consumption.

Provider-related barriers impacting cancer care

- Lack of coordination between hospitals and specialty oncologists was also highlighted as a provider related barrier to cancer management by healthcare providers.
- Lack of skills among primary care providers for effective screening, counselling and referrals were also perceived as barriers. Periodic training of ANMs was suggested as a modality to improve skills.
- It was also felt that the lack of dedicated personnel for cancer care at primary level is also a barrier.
- Complex reporting formats were also highlighted as a barrier.
- The absence of a systematic screening program was perceived as a barrier by 60% of the respondents.
- Lack of appropriate infrastructure, especially at the district and sub-district level was also flagged as a barrier.
- The need for a decentralized district cancer plan was suggested as an important input to dismantle barriers.
- Establishing satellite cancer care centres attached to tertiary centres was felt to be an important step to improve follow-up at local levels. This should include palliative care services and medicines.
- Clinical breast examination (CBE) performed by community-health workers is comparable to that by physicians, indicating the plausibility of task-sharing.
- Appointing counselors within hospitals to explain the prognosis to the caregivers of patients under treatment and ensure psychological preparedness in advance was also thought as an initiative that could improve follow-up and reduce the barriers.
- Palliative care services need to be augmented further and making them easily accessible to the patients was also mentioned as important.
- It was felt that emerging digital technologies for cancer should be effectively harnessed to support early diagnosis, management and follow-up. A number of new technologies are emerging and these should be used after validation. During the COVID pandemic, the benefit of teleconsultations was observed and work should be done to use these channels for the future also.
- The need for developing Electronic Medical Record Systems for portability and access of records was felt as desirable for the future.

Human Resource Requirement

• Based on recommended norms, Telangana would require 150 radiotherapists, 60 each of oncopathologists, surgical oncologists, medical oncologists, palliative care specialists and clinical pharmacists by 2024. By the same year, there is a need for 361 radiation therapy assistants and 120 medical physicists.

Recommendations of cancer care providers

- An expert panel was constituted and using a virtual Delphi technique, the top 25 recommendations were compiled. The recommendations were finalized based on a robust ranking system developed for the study.
- The top recommendations included provision of pain and medication dairies, ensuring privacy for breast/ cervical screening, provision of palliative medications including opiates at district level, promoting breast self-examination, incentivizing ASHAs for cancer detection and referral, regular reorientation of ANMs on cancer detection, developing guidelines and Standard Operating Procedures, sensitizing oncologists on available financial packages for cancer management, increasing awareness on cancers using all channels of communication, operationalizing EMRs, mandating tumor boards at all treatment facilities, implement uniform guidelines for cancer management, engage private and NGO sectors, increase penetration of health insurance packages among those not covered by State insurance and universal HPV vaccination.
- Experts were also asked to rate the expected impact of the recommended interventions. Translational research, clinical and epidemiological research was felt to have the highest expected impact. Amongst activities for comprehensive cancer care, Universal HPV vaccination, convergence of health insurance schemes, designated skilled palliative care personnel, regular monitoring of empanelled hospitals, implementation of uniform treatment guidelines, operationalizing a networked cancer registry both at hospital and population level and investing in a portable EMR were ranked very high in terms of expected impact.

Patient Journey

- Patient journey funnels were developed to appreciate at what levels of care leakages occur. Attention to these leakages will improve care and survival by improving follow up.
- Assuming 5% of the population is screened for cancers in 2021, it was estimated that 8396 would screen positive for cancer of the cervix, beast, oral cavity and lung. Numbers are low as the existing technology to screen for these cancers is mostly manual examination. Among 1805 who would be diagnosed with cancer in 2021 from these four conditions, it was estimated that 1380 would complete initial treatment. Plugging the major leakages in the patient journey from screening to follow up will improve prognosis and survival.

Actions for the Future to strengthen the Telangana Cancer Control Plan

- While the state has made commendable efforts towards improving the health profile of its citizens, there is scope for improvement in the delivery of comprehensive cancer care services in Telangana.
- Using digital and print media for mass communication on cancer (its risk factors and available services) is indispensable to reduce the increasing rates of incidence in Telangana.
- Immunization against Human Papilloma Virus (sub-types) needs to be prioritized. This will reduce cervical cancer case load further over the next 10 years.
- Supporting peer ambassadors to be role models for communication and counselling is an effective strategy to encourage uptake of screening, diagnostic and therapeutic services.
- Public private partnerships should be facilitated for effective comprehensive cancer care services.
- Both patient and system related barriers should be addressed.
- Standardized care pathways should be developed to ensure confirmatory diagnosis and staging which remains a huge challenge, principally for those residing in remote areas.
- A well distributed cancer care network is essential.
- Patient navigation services including EMR based across the cancer care continuum should be supported.
- Establishing appropriate referral linkages is important.

- Contextualizing the global, evidence-based therapeutic guidelines to benefit the needs of Telangana population is imperative. Monitoring providers' compliance to the same is important.
- Standardized screening and treatment guidelines need to be formulated following available National Comprehensive Cancer Network (NCCN), European Society for Medical Oncology (ESMO), American Society of Clinical Oncology (ASCO), and National Cancer Grid (NCG) based on resources available.
- Portable Oncology-specific electronic medical records should be facilitated.
- Expanding the population-based cancer registry in Hyderabad district to include the entire state by networking and linking cancer care centres is important for timely evidence for planning.
- District NCD cells and cancer units should be established as district nodal cancer centres.
- The pandemic has highlighted the potential and need for optimizing tele-health and remote consultations for comprehensive cancer care.
- A cancer care advisory group to strengthen and provide technical support to the Cancer Cell in the Health, Medical and Family Welfare Department, Government of Telangana should be constituted. Such an advisory group should be all encompassing and invite oncology and public health and program experts from the government as well as the private sector, industry (pharmaceutical, life sciences, IT, medical device manufacturers), civil society and patient support groups. This should be chaired by the Commissioner of Health and Family Welfare, Government of Telangana and Co-Chaired by a leading nongovernment sector senior oncologist of repute.

1.0 EPIDEMIOLOGY OF CANCER

1.1 Global scenario

Cancer, was responsible for 9.8 million deaths globally in 2018.⁽¹⁾ In 2020, there were an estimated 19.3 million incident (new) cancer cases and 10 million cancer deaths, world-wide.⁽²⁾ The global burden is predicted to increase by more than 60% from an estimated 18.1 million incident cases in 2018 to 29.4 million, by 2040.⁽³⁾

1.2 Situation in India

Cancer is the second leading cause of premature death (at ages 30-69 years) in India. One in ten Indians have a life-time risk of developing cancer and one in fifteen Indians have a probability of dying due to cancer. In 2018, breast, lung, oral cavity, stomach and colorectal cancers accounted for 49% of all the incident (new) cancer cases in India.⁽¹⁾ 8.3% of all deaths in India in 2016 were cancer-related.

Compared to the high-income nations in North America and Europe, survival from cancer is lower in India.

1.3 Status in Telangana

According to the global burden of disease study, Telangana had a crude cancer incidence rate of 72.6 (69.4, 77.3) and an age-standardized incidence rate of 88.7 (85.1, 94.0) per 1,00,000 in 2016. In 2016, Telangana State had an age-standardized stomach cancer incidence rate of 9.6 per 100,000 population, the highest compared to all other cancers, with cancer of lip and oral cavity being the third most incident cancer (6.9 per 100,000) when both sexes were combined.

Stomach cancer is the leading cause of cancer-related mortality among both sexes in Telangana. Lung cancer among men and cancers of breast and cervix among women cause the highest number of cancer-related deaths in the state. The state-specific crude cancer mortality to incidence ratio (number of deaths divided by number of newly diagnosed cancer cases in a given year) was estimated to be 0.70 for females and 0.81 for males, which indicates poorer survival, especially among males. Of all the five neighbouring states, cancer-related mortality-to-incidence ratio among women in TS (0.70) is only lower than Andhra Pradesh (0.73) and Odisha (0.78). Among men, Andhra Pradesh (0.85) and Odisha (0.94) are the only neighbouring States that report poorer survival rate than Telangana (0.81) on this indicator.⁽⁴⁾

1.4. Situation in Hyderabad district

Of all cancer types prevalent among women in Hyderabad district, 35.5% are breast cancers, 8.7% are cervical cancers and 6.9% are ovarian cancers. Among all PBCRs (population-based cancer registries) in the country, Hyderabad district recorded the highest incidence rate for breast cancer – 48/1,00,000.⁽⁵⁾ Among men, the cancers with highest prevalence in the Hyderabad district are mouth, lung and tongue cancers.

2.0 DETERMINANTS OF CANCER

2.1 Modifiable risk factors

While cancers have a complex aetiology and are multifactorial in origin, at least 20 different types of cancers are caused by use of tobacco products as established by the IARC (International Agency for Research on Cancer) Monographs. 34-69% cancers among men and 10-27% cancers among women in most regions of India are tobacco-related. The IARC has also classified ethanol as a group-1 carcinogen and consumption of alcoholic beverages increases the risk. 4.2% of all cancer deaths in 2016 were attributed to alcohol. 10.9% and 6.6% of the total cancer-related DALYs in India could be attributed to use of tobacco and alcohol respectively in 2016.⁽⁴⁾

Dietary factors like consumption of processed meat, foods preserved by salting (ex: pickled vegetables) increase the risk of gastrointestinal cancers.

2.2 Non-Modifiable risk factors

Environmental factors like outdoor ($PM_{2.5} > 10 \ \mu g/m^3$) and indoor air pollution (from combustion of solid-fuels) also increase the risk of lung cancer as well as kidney, liver, brain and breast cancers. Other factors associated with increased cancer risk include genetic predisposition, ultraviolet radiation, occupation-related exposures, etc.

Chronic infections can be attributed for 13% or 2.2 million cancer cases across the globe with Hepatitis-B, C, Heliobacter Pylori and Human Papilloma Virus (HPV) largely contributing to the morbidity. HPV subtypes 16 and 18 are associated with 80% of cervical cancers in India.⁽¹⁾

3.0 NATIONAL CANCER CONTROL PLAN

3.1 National Cancer Control Programme

The WHO suggests adopting a step-wise approach to expansion of cancer care in South-Asia by duly prioritizing therapeutic services and ensuring access to the same before operationalizing population-based screening. ⁽⁶⁾

3.2 National Strategies targeting Non-Communicable Diseases

The Government of India has reiterated its commitment towards achieving a relative reduction of 25% in overall mortality from major non-communicable diseases by 2025 (as set under the National NCD Monitoring Framework) by developing a multi-sectoral action plan for the period 2017-2022. The plan includes a four-pronged strategy with major areas of action being health promotion, establishing mechanisms for inter-ministerial collaboration and involvement of development partners, strengthening health systems to ensure NCD-related services as a part of universal health coverage, effective implementation of surveillance, monitoring, evaluation and research activities.⁽⁷⁾

3.3 Cancer control activities under the National Health Assurance Scheme

With the advent of Ayushman Bharat – Comprehensive Primary Health Care Programme (CPHCP), population-based screening of all men and women above 30 years for five NCDs including three major cancers (oral, breast and cervical) has been operational since 2018.

The national guidelines recommend oral visual examination, clinical breast examination, visual inspection with acetic acid for screening adults 30-65 years every five years for the three common cancers.⁽⁸⁾ Training manuals for ANMs, ASHAs, MOs at PHC were developed by the GOI, MOHFW along with screening and management algorithms for breast, oral and cervical cancers to guide the comprehensive referral pathway from enrollment, community-based assessment and screening, through diagnosis, treatment and follow-up for suspected, potentially malignant and clinically diagnosed cases and subsequent periodic screening and medical management.⁽⁹⁾

3.4 Activities under NPCDCS and NCCP

The National Programme for Prevention and Control of Cancers, Diabetes, Cardiovascular diseases and Stroke (NPCDCS) launched in 2010 has subsumed the erstwhile National Cancer Control Programme (NCCP) initiated as early as 1975. The Tertiary Cancer Centre Scheme being implemented under the NPCDCS with a centre-state fiscal contribution in the ratio of 60:40 has budgeted Rs.120 crores for establishment of 20 State Cancer Institutes and Rs.45 crores for setting-up 50 Tertiary Cancer Centres (which include strengthening the 27 existing Regional Cancer Centres and establishing or strengthening 23 others at medical colleges, district hospitals, state government institutions and non-governmental

organizations.⁽¹⁰⁾ 218 district day-care centres are functional as of March, 2020 and NCD cells have been established in 36 states and 665 districts while NCD clinics have been operational in 637 districts and 4472 Community Health Centres.⁽¹¹⁾ As of December, 2016 chemotherapy services have been initiated in 71 district day-care centres.

The National Programme for Palliative Care (NPPC) was initiated with an overarching aim to deliver pain relief and palliative care services by enabling access to scientific and medical use of opioids in compliance to the national standards. This programme is funded through the NCD flexi-pool under the National Health Mission.⁽⁷⁾ In March, 2021 ICMR released a guiding framework for the use of telemedicine in the management of cancers including algorithm-based description for application of tele-palliative medicine.⁽¹²⁾

3.5 National Cancer registry program

The National Cancer Registry Programme commenced in 1981 under the aegis of the ICMR and currently a network of 40 (approx.) population-based registries covering 10% of the population of India and 240(approx.) hospital-based registries conduct cancer surveillance for providing insights on magnitude and time-trends to evaluate control measures, corroborate the case for financial allocations and intensify preventive efforts. There is only one functioning PBCR and one HBCR in Telangana.⁽⁵⁾

4.0 CANCER CONTROL PLAN IN TELANGANA

4.1 Measures being implemented for primary prevention

As part of implementation of National Tobacco Control Programme, district level coordination committees and enforcement squads have been set-up in 27 districts. 177 SCs/PHCs are delivering tobacco cessation services in 20 districts. Health camps are also conducted as part of *Aarogyasri* scheme providing information and guidance on available services.⁽¹³⁾

4.2 Early detection of common cancers

With regard to cancer care services, the NCD – ASHA app (available in Telugu and Hindi) enables community-health-workers to enumerate population, complete the Community-Based Assessment Checklist and mobilize all individuals above 30 years for screening.⁽¹⁴⁾

NFHS-5 data from Telangana observed that the proportion of the population who reported being screened ever is low and that there were significant rural urban differences in reported screening (Table 1).

CANCER SCREENING AMONG ADULTS (30- TO 49-YEAR-OLDS)	TOTAL %	RURAL %	URBAN %
% of women who ever underwent cervical cancer screening	3.3	3.9	2.3
% of women who ever underwent clinical breast examination	0.3	0.4	0.3
% of women who ever underwent oral cavity examination	2.5	2.1	3.2
% of men who ever underwent oral cavity examination	2.6	3.0	1.9

Table 1. Percentage of adults screened for three major cancers in Telangana (NFHS-5)

4.3 Facilities providing diagnosis and treatment

At the Mehdi Nawaj Jung (MNJ) Institute of Oncology and Regional Cancer Centre, 150,000 diagnostic tests are being conducted on an average per annum.⁽¹⁵⁾ Similar services are also provided at NIMS and other private hospitals in Hyderabad. In other districts, Aarogyasri-empanelled hospitals largely cater to the diagnostic care needs of patients.

A new L1 greenfield comprehensive cancer care centre is proposed to be set-up in Hyderabad. The government has undertaken the process of strengthening medical colleges at Adilabad, Nizamabad, Mahbubnagar and Warangal as L2 centres to provide diagnostic, treatment and follow-up services.⁽¹⁶⁾

4.4 Services under the palliative care component

The Department of Palliative Care at MNJ receives 2500 new and 8000 review patients each year for symptomatic management and end-of-life-care. Another palliative care unit has been established at the Area hospital in Chevella. Eight palliative healthcare centres have been established for in-patient services, one each in the districts of Adilabad, Janagaon, Yadadri, Warangal urban, Rangareddy, Siddipet, Khammam and Mahbubnagar. 30 mobile units in addition to 110 SCs/HWCs have been delivering home care services.⁽¹⁵⁾

In 2017, Government of Telangana decided to set up palliative care centres in all districts of the State. These centres would function by offering both in-patient and home care services. They consist of 8 to 10 beds with in-patient facility located in the premises of the local government hospital. A one-month training has been imparted to all the staff recruited at the fifteen palliative care centres launched in the districts of Karimnagar, Kamareddy, Jogulamba Gadwal and Badradrikothaguedem, Sangareddy, Mahabubabad, Wanaparthy, Jagityal, Rajanna Siricilla, Nalgonda, Kamareddy, Hyderabad (two centres) and Narayanpet.

The Government has also launched the District Cancer Control plan across districts in Telangana. Training of Medical Officers at the District hospital level has been completed on screening and palliative care. Recently work has started on providing colposcopy units at all district hospitals and to train the personnel accordingly.

4.5 State government plans for the fiscal year 2020-21

Under the supplementary PIP for 2019-20, Telangana State received administrative approval for establishment of district NCD cells at Hyderabad, Mulugu and Narayanpet. The state proposed to optimize services of existing gynaecologists and surgeons for provisional diagnosis and clinical management at cancer day care centres. To this end, Rs.295 lakhs have been approved for the financial year 2020-21 to establish mammography units and video colposcopy units in ten District Hospitals of the ten erstwhile district headquarters. The state also received approval for establishing L2 centre at District Hospital, Khammam to provide diagnostic, follow-up-treatment and palliative care for cancer patients. 16 district hubs were approved to implement free diagnostics and reduce out-of-pocket expenditure.

For implementing population-based NCD screening in sub-centres, state government has committed to provide Rs.15,000 as team-based incentive to ASHAs and ANMs involved in screening at each sub-centre or PHC. Two-day training in palliative care was planned for 1000 staff including PHC Medical Officers, nurses, paramedical workers and other health staff. Government plans to implement innovative IEC/BCC strategies (mobile-based solutions, social media and engagement of youth) under both National Tobacco Control Programme (NTCP) and NPCDCS. Orientation sessions at the District Tobacco Control Centres for law-enforcers was also approved under NTCP. ^(17–19)

4.6 Best practices implemented in Telangana

In addition to the initiatives of the Health, Medical and Family Welfare Department, Government of Telangana mentioned above, there have been some other best practices in the implementation of Comprehensive Cancer Care (Table 2).

SECTOR	PRACTICES
Public	 District level coordination committees formed for public orientation and implementation of COTPA act Teleconsultation with specialists arranged in certain urban PHCs for suspected cases and screen-positives before referral Palliative care team at district level: Physician, physiotherapist, (sometimes, AYUSH medical officer), staff-nurses, ANMs, helpers, driver Facility-based and home-based palliative care services for - Maintenance therapy / Supportive care Emotional support to allay fear and anxiety Counseling early-stage cases to continue treatment
Public Private Partnership	 Screening by ANMs and staff-nurses placed at a district hospital Continuous counseling of eligible asymptomatic women Community-mobilization - benefits of screening explained in simple terms Treatment of cervical pre-cancerous lesions (Cryotherapy, thermal coagulation)
Non- Governmental Sector	 Awareness sessions on risk factors Target population: Adolescents in government schools, children attending NCC (National Cadet Corps) camps School-based screening programmes in rural areas Instant monitoring – Cluster-based feedback Diagnostic investigations at subsidized prices Facilitation of therapeutic care in liaison with civil-servants, health department officials Plan to provide dietary supplements for paediatric cancer patients Financial support for adult patients to meet direct non-medical costs

Table 2. Best practices in planning and delivering cancer care services

5.0 JUSTIFICATION, RATIONALE, AIMS, OBJECTIVES

5.1 Rationale for undertaking the project

The healthcare infrastructure for cancer care in Telangana is predominantly urban-centric. There is a need to also look at how the services can be strengthened further in the rural areas to handle the rising burden of cancer especially at primary and secondary care levels. Therefore, an assessment of the current cancer control initiatives in the state was conducted to identify potential public health value additions to the existing plan and strengthen it further. The assessment and expert consultation complement the recent initiatives of the Government aimed at delivering a high-quality affordable comprehensive cancer care through a three-tier model.

The work led by IIPH-Hyderabad will complement the excellent initiatives of the Government of Telangana by building patient centric pathways for comprehensive cancer care alongside developing academic and research capabilities in the state.

5.2 Aim

Support the strengthening of the Telangana State Cancer Control Plan to implement a sustainable comprehensive cancer care model for Telangana, which could also be replicated in other regions/ states of the country

5.3 Specific Objectives

- Identify measures to strengthen Telangana State comprehensive cancer care plan contextualized to local priorities and learnings from global best practices/models.
- Co-create tangible interventions for implementation at the state level.

6.0 METHODOLOGY

A multi-method approach using both quantitative and qualitative research methods was used for evidence synthesis (Figure 1).



Figure 1. Methods used for evidence synthesis

6.1 Review of existing published literature

A comprehensive literature review was conducted targeting domains across the cancer care continuum to capture feasible, cost-effective, acceptable, impactful and evidence-based strategies for prevention, early detection and control of cancer. Evidence-based guidelines for cancer prevention, curative and palliative care services were reviewed. Efficient approaches to improve follow-up and linkages including technology innovations in the continuum of cancer care were outlined.

For a preliminary assessment of opportunities for and challenges related to primary and secondary prevention of cancer in the state of Telangana, accessible grey literature was also scanned. This included annual reports of the state government's Department of Health, Medical and Family Welfare.

6.2 Interviews with stakeholders

Following the review, semi-structured interviews were conducted with key-stakeholders at different levels of the health system to explore their perspectives on barriers and facilitators of comprehensive cancer care services in the state. A non-probabilistic purposive sampling technique was applied to identify oncologists, medical officers at Primary Health Centers (PHC), Community Health Centers (CHC) and District Hospital (DH), staff-nurses, Auxiliary Nurse and Midwife (ANMs), Mid-level Health Provider (MLHP), palliative care physicians and district programme officer of NPCDCS, administrative secretary of a non-governmental organization. Data was collected through telephonic interviews of 25 health care providers

after obtaining informed verbal consent. 17 patients were interviewed using the probes developed by the investigators in consultation with experts.

6.3 Projections

<u>Magnitude</u>

For estimating the cancer-specific burden in Telangana, five-year prevalence of cancer in India as reported by Global Cancer Observatory, 2020 was considered. Crude incidence rates of all cancers as estimated by the Global Burden of Disease study group for states of India in 1990 and 2016 were used to project annual incidence from 2021 to 2030 in Telangana.

Assuming the overall survival rate to be 90%, cases surviving at the end of each year were estimated which were assumed to be the baseline for the subsequent year.

Similarly, crude incidence rates for breast, cervical, oral and lung cancers over the years were projected.

Workload

Cancer being a chronic disease, the workload on the system is dependent on the number of visits made by patients during their cancer care continuum. Workload at the tertiary cancer centers was estimated based on the site and stage of cancer. Data on relative proportion of cases diagnosed in early and advanced stages was extracted from the Report on the National Cancer Registry Programme-2020 which presented information on stages at diagnoses for specific cancers from hospital-based cancer registries across India. Average number of visits required during each phase (pre-and post-diagnosis) were determined based on interviews with key stakeholders (oncologists) of both public and private hospitals. Based on estimated new cases in the respective years, cancer cases requiring chemotherapy, radiotherapy and surgery have been calculated for three assumed scenarios.

6.4 Modified Delphi – Round 1

Expert opinion was sought using a modified Delphi method using a virtual platform as in-person meetings were not possible due to COVID. An expert panel comprising oncologists, palliative care experts and behavioral scientists with expertise in the management of common cancers (breast, cervical, oral and lung) was constituted. Of the 12 experts who consented to the modified Delphi process, eight specialists completed the online form in its entirety during phase-1.

The responses were summarized and the suggestions to which more than 75 % of the experts expressed either strong agreement or agreement were considered as "strongly endorsed" recommendations. The analysis was done based on frequency counting of five categories [Strongly Agree (SA), Agree (A), Neutral (N), Disagree (D) and Strongly Disagree (SD)] that experts agreed to for each suggestion.

6.5 Modified Delphi – Round 2

Twenty-six action points were derived after removing duplications from the initial list. The 26 action points and 77 recommendations were re-categorized into 14 domains which included patient-care pathways, health workforce, training, protocols and guidelines, data and digital technology (in addition to the eight domains of the first phase – IEC to increase awareness, screening, diagnosis, treatment, follow-up and survivorship, palliative care, research and cancer care financing including schemes). Experts through the survey monkey platform ranked each of these 77 recommendations based on five criteria – **importance (due to magnitude and community concern), relevance, feasibility, affordability and expected impact.** Experts who ranked expected impact as high, were further asked to express the amount of **expected impact** on a scale of 0 to 100%.

Of the 13 experts whose participation was sought, nine responded to the online survey. Average scores for each of the five criteria (importance, relevance, feasibility, affordability and expected impact) were derived based on the frequency of responses to each recommendation using the predefined criteria. For

every recommendation, the cumulative score was computed by summation of average scores under each criterion and converted into percentage.

6.6 Ethical Approval

The project was approved by the Institutional Ethics Committee of the Indian Institute of Public Health – Hyderabad.

7.0 EVIDENCE SYNTHESIS

The project adopted a 360 – degree approach to identify the current status, future needs and areas that can be augmented further to implement comprehensive cancer care activities in Telangana State. Data was extracted from published and grey literature to assess the magnitude of cancers and the determinants, barriers to access services, skills and workload, technology innovations in the continuum of cancer care, patient journey, palliative care services and successful cancer care interventions in other parts of the world and other States in India.

7.1 Review of Existing Publications

A meticulous search was made to capture salient features that could be relevant or adaptable in the Telangana context, both peer-reviewed publications as well as grey literature.

7.2 Projected Magnitude of Different Cancers in Telangana over the next 10 years

Data was extracted from the Lancet Global Burden of Disease study conducted by ICMR to estimate the magnitude of cancers in Telangana (Table 3).

YEAR	PREVALENT CASES AT THE START OF THE YEAR	NEW CASES ADDED DURING THE YEAR	TOTAL CASES IN THE YEAR	TOTAL CASES SURVIVING AT THE END OF THE YEAR
2021	73,858	28,785	102,643	92,379
2022	92,379	29,214	121,593	109,433
2023	109,434	29,648	139,082	125,174
2024	125,174	30,087	155,261	139,735
2025	139,735	30,533	170,268	153,241
2026	153,241	30,984	184,225	165,803
2027	165,803	31,387	197,189	177,471
2028	177,471	31,794	209,265	188,338
2029	188,338	32,306	220,544	198,490
2030	198,490	32,624	231,114	208,002

Table 3. Estimated magnitude of cancers in Telangana

Available data was extracted to estimate and predict the future magnitude of specific cancers in Telangana. A 37% increase is anticipated in the crude incidence of breast cancer between 2016 and 2036 (Table 4). A 28% decrease is projected in the crude incidence of cancer of the cervix between 2016 and 2036 (Table 5). Amongst males, no change is anticipated in the crude incidence rate of oral cancers (Table 6). Regarding lung cancer no significant changes in crude incidence rates per 100,000 or magnitude is anticipated, despite demographic changes till 2036 (Table 7).

Table 4. Incidence of breast cancers in Telangana (Based on the Global Burden of Disease Study)

YEAR	2016	2021	2026	2031	2036
Crude incidence rate per 100, 000 women	13.5	14.6	15.8	17.1	18.5
New cases	2,446	2,737	3,035	3,336	3,638
No. of patients diagnosed in early stage	2,103	2,354	2,610	2,869	3,129
No. surviving from early-stage breast cancer for next five years	1,605	1,796	1,992	2,190	2,388
No. of patients diagnosed in late stage	343	383	425	467	509
No. surviving from advanced-stage breast cancer for next five years	51	57	63	70	76
Total incident cases surviving for next five years	1,656	1,853	2,055	2,259	2,464

Table 5. Incidence of cervical cancer in Telangana (Based on the Global Burden of Disease Study)

YEAR	2016	2021	2026	2031	2036
Crude incidence rate per 100,000 women	11.1	10.2	9.4	8.7	8
New cases	2,011	1,912	1,807	1,699	1,576
No. of patients diagnosed in early stage	1,864	1,772	1,675	1,575	1,461
No. surviving from early-stage cervical cancer for next five years	1,364	1,297	1,226	1,153	1,069
No. of patients diagnosed in advanced stage	147	140	132	124	115
No. surviving from advanced-stage cervical cancer for next five years	12	11	10	10	9
Total incident cases surviving for next five years	1,376	1,308	1,236	1,163	1,078

Table 6. Incidence of oral cancers in Telangana

(Based on the Global Burden of Disease Study)

YEAR	2016	2021	2026	2031	2036
Crude incidence rate per 100,000 males	3.7	3.7	3.7	3.7	3.7
New cases - males	679	702	718	728	732
Crude incidence rate per 100,000 females	7.4	7.2	7.2	7.2	7.2
New cases - females	1,341	1,358	1,393	1,415	1,427
New cases - both sexes	2,020	2,060	2,111	2,143	2,159
No. of patients diagnosed in early stage	1,848	1,885	1,932	1,961	1,975
No. surviving from early-stage oral cancer for next five years	1,112	1,131	1,163	1,180	1,189
No. of patients diagnosed in advanced stage	172	175	179	182	183
No. surviving from advanced-stage oral cancer for next five years	6	6	6	6	6
Total incident cases surviving for next five years	1,118	1,137	1,164	1,182	1,195

Table 7. Incidence of lung cancers in Telangana (Based on the Global Burden of Disease Study)

YEAR	2016	2021	2026	2031	2036
Crude incidence rate per 100,000 females	2.0	1.99	1.98	1.97	1.96
New cases - females	362	373	381	385	387
Crude incidence rate per 100,000 males	4.6	4.53	4.46	4.39	4.33
New cases - males	844	860	866	865	856
Total lung cancer cases - both sexes - Telangana	1,206	1,233	1,247	1,250	1,243
No. diagnosed in early stage	614	618	625	626	623
No. diagnosed in advanced stage	592	615	622	624	620
Total incident cases surviving for next five years	121	123	125	125	124

7.3 Workload for common cancers

For understanding the workload for managing different cancers, the magnitude of cancers alone will underestimate the workload, as cancer patients have to make a number of visits for the surviving period with cancer for treatment and follow up. The probable number of visits was computed using expert opinion. There is no documented evidence on the number of visits required for each cancer and therefore expert opinion guided the computations. These inputs were used for different cancers. It was estimated that for early-stage breast cancers, the workload will increase by nearly 33% between 2021 and 2036 (Table 8). Similarly, a 17% decrease in workload is anticipated between 2021 and 2036 for cervical cancer (Table 9). However, significant differences were not anticipated for either Oral Cavity cancers (Table 10) or Lung cancer (Table 11). Anticipated workloads for different modalities of treatment were also computed (Table 12-14).

YEAR	NEW CASES	EARLY-STAGE CASES	WORKLOAD FROM EARLY-STAGE BREAST CANCER CASES	ADVANCED STAGE CASES	WORKLOAD FROM ADVANCED STAGE BREAST CANCER CASES
2016	2,446	2,103	60,987	343	7,203
2021	2,737	2,354	68,266	383	8,043
2026	3,035	2,610	75,690	425	8,925
2031	3,336	2,869	83,201	467	9,807
2036	3,638	3,129	90,741	509	10,689

Table 8. Estimated workload from visits by new patients with breast cancer

Table 9. Estimated workload from visits by new patients with cervical cancer

YEAR	NEW CASES	EARLY- STAGE CASES	WORKLOAD FOR EARLY-STAGE CERVICAL CANCER CASES	ADVANCED STAGE CASES	WORKLOAD FOR ADVANCED STAGE CERVICAL CANCER CASES
2016	2,011	1,864	74,560	147	4,410
2021	1,912	1,772	70,880	140	4,200
2026	1,807	1,675	67,000	132	3,960
2031	1,699	1,575	63,000	124	3,720
2036	1,576	1,461	58,440	115	3,450

YEAR	NEW CASES	EARLY-STAGE CASES	WORKLOAD FROM EARLY-STAGE ORAL CANCER	ADVANCED STAGE CASES	WORKLOAD FROM ADVANCED STAGE ORAL CANCER CASES
2016	2,020	1,848	73,920	172	4,988
2021	2,060	1,885	75,400	175	5,075
2026	2,111	1,932	77,280	179	5,191
2031	2,143	1,961	78,440	182	5,278
2036	2,158	1,975	79,000	183	5,307

Table 10. Estimated workload from visits by new patients with oral cancer

Table 11. Estimated workload from visits by new patients with lung cancer

YEAR	NEW CASES	EARLY-STAGE CASES	WORKLOAD FROM EARLY-STAGE LUNG CANCER CASES	ADVANCED STAGE CASES	WORK-LOAD FROM ADVANCED-STAGE LUNG CANCER CASES
2016	1,206	604	21,744	602	14,448
2021	1,233	618	22,248	615	14,760
2026	1,247	625	22,500	622	14,928
2031	1,250	626	22,536	624	14,976
2036	1,243	623	22,428	620	14,880

Table 12. Estimated Chemotherapy requirement in Telangana

(Based on assumptions of 55%, 60% and 65% cases require chemotherapy services and six cycles per patient assumed)

		55% PATIENT REQUIRE CHEMOTHERAPY		60% PATIENT REQUIRE CHEMOTHERAPY		65% PATIENT REQUIRE CHEMOTHERAPY	
YEAR	NEW CASES	NEW CASES REQUIRING CHEMOTHERAPY	CHEMO CYCLES/ DAY	NEW CASES REQUIRING CHEMOTHER APY	CHEMO CYCLES/ DAY	NEW CASES REQUIRING CHEMOTHERAPY	CHEMO CYCLES/ DAY
2021	28,785	15,832	260	17,271	284	18,710	308
2024	30,087	16,548	272	18,052	297	19,557	321
2027	31,387	17,263	284	18,832	310	20,402	335
2030	32,624	17,943	295	19,574	322	21,206	349

Table 13. Estimated Radiotherapy requirement in Telangana

(Based on assumptions of 55%, 65% and 60% cases require radiotherapy [RT] services and 22 RT sessions per patient and 15000 sessions per machine assumed)

		55% PATIENT REQUIRE RT		60% PATIENT REQUIRE RT		65% PATIENT REQUIRE RT	
YEAR	NEW CASES	NEW CASES REQUIRING RT	LINACS REQUIRED	NEW CASES REQUIRING RT	LINACS REQUIRED	NEW CASES REQUIRING RT	LINACS REQUIRED
2021	28,785	15,832	23	17,271	25	18,710	27
2024	30,087	16,548	24	18,052	26	19,557	29
2027	31,387	17,263	25	18,832	28	20,402	30
2030	32,624	17,943	26	19,574	29	21,206	31

Table 14. Estimated Cancer Surgeries required in Telangana

(Based on assumptions of 35%, 40% and 45% cancer cases require surgeries, number per month in each scenario)

		35% PATIENT REQUIRE SURGERY		40% PATIENT REQUIRE SURGERY		45% PATIENT REQUIRE SURGERY	
YEAR	NEW CASES	NEW CASES REQUIRING SURGERY	SURGERI ES/ MONTH	NEW CASES REQUIRING SURGERY	SURGERIES/ MONTH	NEW CASES REQUIRING SURGERY	SURGERIES /MONTH
2021	28,785	10,075	840	11,514	960	12,953	1,079
2024	30,087	10,530	878	12,035	1003	13,539	1,128
2027	31,387	10,985	915	12,555	1046	14,124	1,177
2030	32,624	11,418	952	13,050	1087	14,681	1,223

7.4 Barriers in accessing cancer care services

Interviews were conducted with 17 patients and 25 healthcare providers to understand the challenges faced in accessing and delivering healthcare services across the cancer care continuum.

Delayed presentation

Presentation to a healthcare facility in advanced stages was the common barrier perceived by health care providers at all levels of the health system in both public and private sectors (Table 15).

SITE OF CANCER	STAGE AT PRESENTATION	% OF PATIENTS	SECTOR
	Ш	40	Public
Oral	11 - 111	70-80	Private
	Ш	50	Private-charitable
	Ш	30	Public
Breast	11 - 111	70	Private
	III - IV	60	Private-charitable
	Ш	30 - 40	Public
Cervix-uterine	11 - 111	80	Private
	111	50	Private-charitable
	IV	40	Public
Lung	II – IV	70	Private
_	IV	90	Private-charitable

Table 15. Major cancers in Telangana and stage at presentation to oncologists across sectors

Lack of awareness

84% of the twenty-five healthcare providers interviewed mentioned lack of awareness as the reason for delayed presentation (Figure 2). Inadequate knowledge on risk factors and screening measures such as procedure for self-examination; negligence of early symptoms and preference of local quacks to allopathic practitioners were the common patient-related barriers encountered by primary healthcare providers.



normal for pregnant and lactating women and believed cancer was a result of straining my voice at workplace"

- [Patient:1, Breast cancer]



Figure 2. Reasons enumerated by providers for delayed presentation

Inadequate knowledge about the condition and available health care services was evident across patientgroups, with women and those from rural backgrounds being disproportionately affected.

Educational status is a precursor for awareness on cancer, wherein none of the patients who were educated up to the senior secondary was aware of cancer as against 83.3% of patients among those who were graduates or more educated.

Effective and scalable approach to improve cancer literacy

- Providing cancer education training and material to healthcare providers.
- Multi-modal communication strategies to address cognitive and language barriers.

Stakeholders at the community level emphasized that stigma was the prime reason responsible for the late presentation of cancer patients at health centers as villagers have a taboo and apprehension that revealing their diagnosis may lead to them being 'labelled' by the community which results in them facing hardships due to societal norms.

Priority recommendations mentioned by stakeholders to increase awareness

- Mass communication using digital and print media to raise awareness on cancer, its risk factors, warning
 signs and symptoms was validated as a priority by the Delphi experts who also perceived its expected
 impact in reducing cancer burden to be 80%.
- Conducting community-level programmes to teach women about breast self-examination was ranked 4th of the 77 recommendations endorsed by experts, with the mean percentage of expected impact perceived to be 69%.

Other suggestions mentioned by stake holders

- Explain the procedure of self-examination to all women using flip charts and ensure adherence.
- Counsel users of tobacco and alcohol for cessation.
- Encourage private doctors and gynecologists to educate their patients and eligible couples on the risk of HPV and advise periodic screening.

Cancer care financing

60% healthcare providers cited financial constraints as the most common barrier for patients.

The National Sample Survey - 71st round reported the out-of-pocket-expenditure for cancer in India at Rs.57,232/ (Standard error: 3,885/-). Distress financing for cancer hospitalization was 42.5% (95% CI: 39.7, 45.4). This was higher in private health care settings (47.8%) as against 34.5% in public health facilities. 91% individuals who relied on distress financing for cancer hospitalization incurred CHE (catastrophic health expenditure). Overall, CHE was the highest for cancer hospitalization (79%) of all disease categories considered in the survey. ⁽²⁰⁾

Data from NSS - 75th round points to 70.3% of rural and 37.3% urban households in Telangana being covered under a government sponsored health insurance scheme. In case of cancer patients hospitalized, 83% were admitted at private hospitals in rural Telangana as against 70% in urban areas. Overall, 79% of hospitalized cancer patients in Telangana were admitted in private hospitals.⁽²¹⁾

Central-government financing schemes

Under the **Rashtriya Aarogya Nidhi Health Minister's Cancer Patient Fund,** financial assistance is provided to cancer patients who are below-the-poverty-line and are availing treatment in any of the 27 Regional Cancer Centres (includes MNJIO-RCC).

State-government sponsored schemes

Under the Telangana State *Aarogyasri*, cancer treatment covered surgery, chemotherapy, radiotherapy, palliative chemotherapy for families below-the-poverty-line (Table 17). In 2017-18, surgical oncology accounted for 8.2%, radiation oncology for 18.7% and medical oncology for 73.1% of the 71,707 oncology procedures done under the scheme.⁽²²⁾ The Employees and Journalists Health Scheme of Telangana covers State Government employees, journalists (retired or serving) and their dependent family members on similar lines.

While all the providers at tertiary level perceived financial constraints as a cause for delayed presentation, only 28.6% primary healthcare personnel had this perception. Also, 90% providers in the older age cohort perceived financial barriers delay healthcare-seeking as against 40% providers in the younger age cohort.

Although diagnostic investigations and treatment would be provided without any user-fee in the public health facilities, providers at the tertiary and secondary levels contended that indirect costs in terms of loss of wages and productive work hours is a constraint for patients from families below the poverty line, more so if patient or primary caregiver is the sole earning member. Moreover, direct non-medical costs for transportation and accommodation ought to be borne by the patient or his family and affordability is a fundamental challenge for those from peripheral areas, as cancer treatment lasts for longer duration.

47.1% of the 17 cancer patients interviewed reported receiving treatment under the state-sponsored insurance scheme. As elucidated by providers, direct non-medical costs such as expenses for travel and accommodation were the major concerns of patients and their families. Owing to the unanticipated diagnosis, patients resorted to distress financing for funding current treatment. Out-of-pocket expenditure varied from 40% to 70%, due to limited coverage of cancer-related therapies under both state-sponsored and private medical insurance schemes.

Loss of employment and livelihood for the entire duration of treatment was reiterated by caregivers. Caregiving resulted in role-conflicts and primary caregivers also experienced emotional trauma as some of them did not reveal the exact diagnosis to either the patient or other members of the family.

Priority recommendations to counter financial barriers from Delphi experts

- Converging the 'Ayushman Bharat -PMJAY Aarogyasri 'with ESIS and other schemes to enable easy access to all healthcare providers and free treatment in empanelled hospitals under either scheme in the state has been rated as a recommendation with 90% expected impact.
- Enhancing awareness of surgeons, physicians, gynaecologists, oncologists on the schemes available for financing cancer treatment was one of the top ten recommendations prioritized by experts.
- Including diagnosis, follow-up and palliative care services in all health insurance packages for the duration advised was perceived to have a mean expected impact of 83.3%.
- Conducting assessments (cost-benefit/ cost-effectiveness analyses) of innovative cancer care interventions also had a similar rating of 83.3 % on expected impact.

Other measures suggested by Delphi experts

- Providing financial assistance to cover direct non-medical costs (transportation, food, accommodation).
- Allocating funds to facilitate ambulance services for cancer patients from peripheral areas.

Innovative approaches to health financing demonstrated by States

Recently, National Health Mission Assam has included therapies like immunotherapy for the treatment of some breast cancers in the essential drug list for tertiary care. ⁽²³⁾

Moving a step forward to achieve universal health coverage, Kerala is looking into providing a scheme which will amalgamate currently existing health insurance schemes. The new scheme, Karunya Suraksha Padhati, will replace the State's current comprehensive health insurance scheme (RSBY-CHIS/CHIS Plus) and (KBF) Karunya Benevolent Fund. ⁽²⁴⁾ Similar efforts of convergence of different insurance schemes in the government sector are being planned in Maharashtra

Standardized care pathways in cancer

The clinical pathway is an organized order and detailed one based on evidence which assist the practitioner in their practice. It has been stated that in identifying treatment regimens adequate thought should be given to issues like efficacy, safety and costs.⁽²⁵⁾ To deliver effective cancer care continuum of services from awareness, prevention, screening, early detection, diagnosis (testing), referral, (affordability of and access to) treatment, follow-up, pain management and palliative care should be ensured.

Some of the key aspects which also needs to be looked into for standardized care pathways are reduction of fragmented care. ⁽²⁶⁾ It is also important to ensure equity, transparency, improved patient outcomes alongside providing an opportunity for synergy through mapping of services.

Patient care pathways

Standardized pathways for cancer management aim to ensure timely diagnosis followed by prompt and appropriate treatment. Physicians opined that referring to secondary level health centers is of limited use as there is a shortage of specialists and equipment for confirmatory diagnosis and staging at these

levels too. However, ASHAs (Accredited Social Health Activists) were entrusted to follow-up suspected and confirmed cases on a regular basis. At the secondary level, medical officers and civil assistant surgeons highlighted the need for standard protocols for providers to ensure appropriate referral of screen-positives and suspected cases.

Oncologists mentioned that patients' perception of cancer treatments and subsequent side-effects such as loss of hair during chemotherapy, propel them to default the initiated therapy and search for alternatives under the assumption that the recommended treatment is ineffective. Perceived barriers behind treatment defaulting include beliefs that cancer is incurable, or radiotherapy would result in burns or death of the patient.

"Once patients return home and after the first cycle, they feel they are completely cured and
don't return for the next cycle on time, until the disease progresses and return when they
start experiencing discomfort/difficulty."
– Provider 3

Referral and follow-up

While 20% of oncologists perceived supportive care as a barrier, 66.7% of nurses along with both the palliative care physicians and the stakeholder from community-based NGO perceived it as a barrier for patients. Coordination among clinicians (medical and surgical oncologists, primary care physicians, endocrinologists, radiotherapists), patients and caregivers therefore, is inevitable to substantially reduce the cancer burden.







Figure 3. Causes for non-compliance to recommended therapy or referral advice

Measures suggested by interviewed providers to improve adherence

- Counsel individuals on importance of healthy diet, physical activity for prevention of NCDs and adherence to medication for control.
- Post-diagnosis, counsel the patients, more importantly the caregivers about the benefits of treatment (improved chances of survival) and also the associated side-effects and risks in a language they understand for informed decision-making.

Literature suggests that care coordination is crucial at three time points⁽²⁷⁾ – 1. After initial screening, 2. During active therapy, 3. Post-treatment during survivorship.

While cancer patients who experienced accommodation/shelter barriers had an average duration of 4.5 months from noticing symptoms to being diagnosed with cancer, this duration was only 1.5 months for those without such concerns. Concerns on accommodation could have led to delayed presentation for diagnostic confirmation and this difference was significant (p-value=0.03).

In comparison to patients without transportation barriers, those with such challenges had a longer interval between first identification of symptoms and receiving the confirmatory diagnosis.

System-level barriers

System-induced barriers mainly consisted of issues concerning infrastructure and workforce essential for service-delivery (including screening), in addition to ill-effects of the pandemic.

Health care providers identified challenges in the implementation of the NPCDCS program which impacts cancer care services in Telangana.

Challenges in implementation of NPCDCS – Service delivery

- ANMs in few districts not trained in screening for cervical cancer
- Risk of missing cases at the primary level according to medical officers
- Complex reporting formats
- Multiple roles assigned to ANMs under the existing health care programmes (RMNCH+A, RNTCP, NPCDCS) in the scheduled work hours.

Lack of systematic/ organized screening programs, effect of the COVID pandemic and inadequate infrastructure were the three most important barriers identified by health care providers (Figure 4).



Figure 4. System level barriers perceived by healthcare providers

Infrastructure - Cancer care centres, drugs and equipment

Absence of histopathology labs, diagnostic equipment and chemo drugs for onco-specific treatment at the district level, including medical colleges in the public sector was identified as the principal barrier by providers at the secondary level. At the tertiary level, absence of designated areas for mixing of chemodrugs, deficit of protective gear required during the process were some of the challenges faced by nursing personnel in the public sector.

Healthcare providers shared their perspectives on how infrastructure barriers could be addressed. This information on some aspects was triangulated with published literature also.

Suggestions from providers to address infrastructure barriers

- Strengthen infrastructure at peripheral level to facilitate timely diagnosis Decentralization
- Develop cancer care centers at the district level with district hospital as the nodal center
- Establish satellite centers in tier-2 and other lower tier cities where follow-up can be done under the purview of respective tertiary cancer centers
- Set-up good pain clinics and palliative care centers at the local level with adequate availability of opioids and morphine
- Invest in quality mammogram machines with high sensitivity and install them at a particular setting PHC/CHC/DH
- Strategic purchasing of services based on public-private partnership and over time shifting to co-location model (a combination of Build, Operate, Transfer and Management Contracts) would aid operationalizing "NCD Care Facility" at district hospitals. ⁽²⁸⁾

According to data from Atomic Energy Regulatory Board, to date 2886 licensed diagnostic equipment (all types) are available in Telangana which is home to 19 centres equipped with nuclear medicine facility.⁽²⁹⁾

Initiatives of the state government (with potential impact on cancer care)

Under the T-diagnostics initiative, 36 hubs – one in each district and two in larger districts have been proposed and the State govt. plans to add imaging services after stabilizing pathological services. T-diagnostics has launched the first central laboratory (hub) in August 2018 in Hyderabad which supports more than 300 health facilities (spokes). Hub to Spoke distance has been proposed to be within 60 km reach so that the sample transportation time will be less than 5 hours.⁽³⁰⁾ Currently, only a single test for cancer detection (stool for occult blood) is a part of this model.

YEARS	MEGAVOLTAGE TELETHERAPY UNIT	BRACHYTHERAPY UNIT	CT SIMULATOR
2021	29	29	29
2024	30	30	30
2027	31	31	31
2030	33	33	33

Table 16. Requisite material resources for cancer care

Demand for equipment for the respective years (Table 16) has been estimated using the formula: $No. = Estimated new cases in the respective year \times norm/1000$

Norm = 1 per 1000 new cancer patient (31)

Human resources /Workforce

Availability in the public health system

According to an online survey most (59% of 82) of the medical oncologists in India worked exclusively in private settings. (81) 46% Indian medical oncologists (MO) had no support of chemotherapy pharmacist on-site. On delivery of clinical care, 26% Indian medical oncologists reported seeing more than 50 cases per day while similar clinical volume was reported by 12% of oncologists from other LMICs. ⁽³²⁾ Estimates indicate the need for services of 1 head nurse, 1 nurse specialist and 13 staff-nurses working on 8-hour shift, five days a week for a 24-bed oncology unit operating 24*7 in India. ⁽³¹⁾

Challenges of nursing personnel at tertiary cancer centres

Despite the presence of shift-duties, due to extensive patient-volumes at the tertiary cancer centers in the public sector, provision of quality care was a perceived barrier. In addition to patient-care, administration of chemotherapy and diet-maintenance, nurses were engaged in documentation and 'clerical work', exacerbating the problem.

"Patients mainly expect us to listen to their problems. But we can't spend enough time with each of them." - [Provider: 12]

Training

At the primary level, screening activities had been initiated in the state. Although, ANMs were conducting oral visual examination and clinical breast examination, training in VIA-based (Visual Inspection with Acetic acid) screening for early detection of cervical cancer hadn't been completed in some of the districts.

Task-sharing options

Clinical breast examination (CBE) performed by community-health workers (CHWs) is comparable to that by physicians ⁽³³⁾ indicating the plausibility of task-sharing in settings with human resource constraints.

Priority recommendations for capacity-building and competence

• Conducting regular re-orientation courses and hand-on training for ANMs to maintain their competence in screening has been ranked 6th on the list of recommendations prioritized by the expert panel.

Suggestions from providers

- Training all ANMs to conduct periodic screening regularly at all PHCs.
- Educating the general practitioners and primary doctors to step up investigations upon suspicion and refer early.
- Training primary doctors to deal with emergency and supportive care.
- Having a dedicated wing and special team for all NCDs including cancer.
- Appointing counselors within hospitals to explain the prognosis to the caregivers of patients under treatment and ensure psychological preparedness in advance.
- Employing data entry operators and receptionists for each ward to coordinate with all departments on investigation records of out-patients and maintain diet- charts of in-patients.

Human Resources for Cancer Care

Existing norms were used to compute the human resource requirement for Telangana over the period 2021 – 2030 (Table 17). Gap analysis should be undertaken to identify critical human resources that need to be trained/ skilled in Telangana.

Specialized manpower	Recommended norm for 1000 new cancer patients	2021	2024	2027	2030
Radiation/Clinical Oncologist	5	144	150	157	163
Pathologist	2	58	60	63	65
Surgical Oncologists	2	58	60	63	65
Medical Oncologists	2	58	60	63	65
Palliative care specialists	2	58	60	63	65
Clinical Pharmacists	2	58	60	63	65
Radiation therapy Technicians	12	345	361	377	391
Medical Physicists	4	115	120	126	130

Table 17. Requisite human resources for cancer care

Reference for norm - (31)

Pain Relief and Palliative Care: Barriers to accessing palliative care

- Despite their availability, palliative care services were underutilized owing to two inter-linked factors, non-acceptance of the condition by patients and perception that state-sponsored medication for pain relief are inefficacious.
- Disruption of palliative care services was observed during the pandemic.

Recommendations to prioritize palliative care

- Having designated trained palliative care staff at every public healthcare facility was perceived by the Delphi experts to be to be highly impactful and mean percentage expected impact of 90%.
- Ensuring regular availability of essential opioids at the district level and common palliative care drugs at PHC, CHC, and HWC for pain management was ranked 3rd of the 77 recommendations with the mean percentage expected impact rated as 84%.
- Providing education/awareness on pain relief and palliative care to individuals within the community was one of the top-ranked recommendations (8th).

7.5 Application of Information Technology to promote cancer care services

HIT (Health Information Technology) plays a major role for sharing patient information between providers (e.g. information exchange), between provider and system (e.g. communicating lab results) and between provider and patient (e.g. symptom management and reporting), supporting and empowering patients (e.g. online psychosocial support).⁽³⁴⁾ E-Health helps to keep a track on patient treatment and management, it builds up a network of cancer care and is feasible in the low resource settings.⁽³⁵⁾ ONCONET-KERALA, a recent telemedicine project implemented by the state helped to build a network between remote health care facilities with specialized hospitals at Regional Cancer Centre Thiruvananthapuram. It has helped in reduction of emergency patients, follow-up, unnecessary admission and visits of doctors in remote areas and improve early intervention.⁽³⁶⁾

7.5.1 Mobile-based applications

Early detection of oral cancer

Training frontline healthcare providers in m-health and deploying them for early detection of oral cancers is an effective option in resource-constrained settings through enabling mobile-based electronic data capturing of oral images. It was used in an occupational setting in New Delhi.⁽³⁷⁾

7.5.2 Audio-visual aids

Animated videos to teach self-examination

For teaching and ensuring adherence to BSE (breast-self-examination) by rural and tribal women, power point presentation of animated video describing the procedure prior to lectures, and subsequent provision of IEC materials/pamphlets was observed to be a useful strategy.⁽³⁸⁾

7.5.3 IT-enabled screening, imaging and clinical care ⁽³⁹⁾

HUB-AND-SPOKE MODEL

- Use of multi-disciplinary clinical and administrative teams to provide a range of services and reduce need for repeated visits. (oncologists, radiologists, pathologists, nurses, genetic counsellors, data managers, technologists, assistants)
- Cloud-based records to facilitate off-site expert interpretation of diagnostic findings
- Uniform distribution of workload through in-built mechanism in pacs to assign cases to radiologists. (picture archive communication system is an instant-messaging function)
- Centralized virtual tumour board
- Utilize local champions/ survivors for promotion and increase uptake of such services

Implementation in Indian Setting

In the district hospitals of Madhya Pradesh, Himachal Pradesh, Uttar Pradesh and Odisha generalist physicians and nurses who were trained in basic oncology care components under the mentorship of senior off-site oncologists, have been providing ambulatory and in-patient services for cancer patients. The hospital-based registers have been functioning as district cancer registry for target priority-sites. Surgical, diagnostic and radiation-therapy services are strategically purchased while chemotherapy is offered at no-cost to the patient. The trained physicians have been appointed as nodal district cancer officers, delivering comprehensive oncology care (from screening to palliative care support) at the district-level utilizing the available public health infrastructure and succeeded in ensuring improved clinical and patient-reported outcomes.⁽⁴⁰⁾

Differential needs in low- and middle-income countries - Case of Uganda

Designing a user-centric solution empowers cancer care centers in LMICs to effectively adopt EMRs. A unified and structured oncology-specific documentation system ensures timely scheduling of appointments to coordinate the multi-disciplinary care, assists in the entry of orders for diagnostic investigations and enables quick retrieval of reports to avoid repetition.⁽⁴¹⁾

7.6 Results of the Delphi process

As mentioned earlier, the Delphi was conducted in two sessions, which resulted in a set of recommendations and action points. A ranking exercise was then conducted and the top 25 recommendations captures (Table 18). Most of these recommendations are relevant and imminently feasible in the current context in Telangana and can result in a high impact.

Table 18. Requisite human resources for cancer care

TOP TWENTY-FIVE RECOMMENDATIONS	RANK	DOMAIN
Ensure appropriate use of medication and provide patients with pain and medication diaries	1	Palliative care
Ensure privacy through a dedicated enclosure for breast and cervical cancer screening at universal cancer /NCD screening camps	2	Screening
Ensure regular availability of essential opioids at the district level and common palliative care drugs at PHC, CHC, HWC for pain management.	3	Palliative care
Conduct community-level programmes to teach women on the procedure of breast self-examination	4	IEC to increase awareness
Asha workers to conduct clinical breast examination regularly during their home visits and incentivising them for cancer detection and appropriate referral	5	Screening
Conducting regular re-orientation courses and hand-on training for ANMs to maintain their competence in screening	6	Training
Develop guidelines for healthcare providers to enable systematic patient work flow patterns in the health system	7	Protocols and Guidelines
Provide education/awareness on pain relief and palliative care to individuals within the community	8	IEC to increase awareness
Enhance awareness of surgeons, physicians, gynaecologists, oncologists on the schemes available for financing cancer treatment	9	Financing and Schemes
Develop and implement a standard protocol at all diagnostic centres to verify validity of test results prior to communication	10	Protocols and Guidelines
Mass communication using digital and print media to raise awareness on cancer, its risk factors, warning signs and symptoms	11	IEC to increase awareness EC
Operationalize electronic medical records for tracking patients across the cancer care pathways (from screening to survivorship and beyond)	12	Digital Technology
Design and implement standardized protocols for patient-referrals	13	Patient Care Pathways
Rotation postings for students (medical and nursing) and residents/interns on pain management	14	Training
Implement regular multidisciplinary tumour board activities within the institute or centralized through cloud-based record sharing	15	Treatment
Including diagnosis, follow-up and palliative care services in all health insurance packages for the duration advised	16	Financing and Schemes
Peer-led role modelling: using patient advocates & cancer survivors to promote screening /examination and diagnosis	17	Patient Care Pathways
Training all cadres of health-care staff to deliver consistent messaging on immunization against cervical cancer (HPV sub-types 16 and 18) at every point of clinical encounter be it SC/PHC/CHC/DH/medical college- hospital	18	IEC to increase awareness

Develop standardized checklists to identify at-risk population (for early detection)	19	Research
Organize awareness campaigns by experts in local languages	20	IEC to increase awareness
Implement uniform guidelines for cancer care (i.e., national cancer grid, American society of clinical oncology, European society for medical oncology, national comprehensive cancer network etc.) And adopting/contextualizing them to Telangana state	21	Treatment
Conduct state-wide campaigns with the support of local NGOs and involving gynaecologists to provide credible information to parents on immunization against HPV, especially for those from rural backgrounds and low socio-economic status.	22	IEC to increase awareness
Incentivise private sector to augment screening services in rural areas using existing government infrastructure through a public private partnership	23	Screening
Increase penetration of health-insurance packages (individual and family-based) among middle and higher-income populations (by enabling contributory risk pooling and strategic purchasing)	24	Financing and Schemes
Introduce HPV vaccine in Telangana as part of universal immunization programme (age group 9-14years)	25	Policy

In addition to catering to the comprehensive needs of end-stage patients, palliative care services ensure holistic support from the post-diagnosis phase. Thus, further decentralization of the existing services facilitates increased compliance to recommended therapy by patients with early-stage cancers (Table 18).

For increased uptake of breast and cervix screening services, a dedicated physical enclosure which ensures privacy, is a pre-requisite and has been reiterated by specialists. Training community-health workers (ASHAs) to conduct clinical breast examination could prove worthwhile. As evident from the interviews with stakeholders and further ranked by experts, periodic training is essential to maintain competence and upgrade skills of Auxiliary Nurses and Mid-wives (ANMs) (Table 18).

Evidence-based protocols are crucial to standardize care patterns and establish linkages across the care continuum. Experts prioritized development of checklists for early detection of cancer among high-risk groups as it enables downstaging of the disease. With the National Digital Health Mission gaining momentum, the need for electronic medical records has been supported by experts. The importance of multi-disciplinary tumor board meetings was also highlighted by specialists.

While institutional tumor boards exist in both private and public tertiary cancer centers, oncologists stated that tumor board meetings were convened only for rare and high-risk (defined by age, histopathology, general conditions and high probability of recurrence) cases, twice a week and that these should cover all cancers.

Including vaccination against HPV as a part of the universal immunization programme has been consistently rated high by experts.

Expected Impact

Experts who ranked the different action points were also asked to rate how much of an impact they perceived could accrue from a specific intervention. Experts had to score these interventions on a scale of 0-100. Scores were then cumulated and the mean expected impact was computed (Figure 5).



Figure 5. Recommendations with the highest/maximum expected impact

*This recommendation although has limited direct impact on patients, was rated highly as it was perceived that it enables quality improvement of services through implementing evidence-informed interventions to ensure quality care.

7.6 Patient Journey Funnel

Patient journey funnels help us to appreciate at what levels of care leakages occur. They act like a mirror to tell us where our efforts are sub-optimal. Attention to these leakages will improve care and survival by improving follow up. For developing such funnels, a number of assumptions have to be made, most of which are anecdotal and not evidence-based. By increasing screening and improving access to diagnostic and treatment facilities, follow up rates can be improved. These measures will enhance early detection and timely treatment and this will lead to improved prognosis and survival. Early detection will also reduce the cost of care.



Figure 6. Patient Journey Funnel for all cancers - Showcasing leakages across major points

*Extrapolated from percentage screened amongst 30-49 years age-group according to NFHS-5 †Based on age-truncated case detection rate of cancers (of all sites) in India (42) ‡3610 (43%) seek diagnostic confirmation, assuming 50% of these to be cases. ‡Based on interviews with oncologists

8.0 FUTURE DIRECTIONS FOR STRENGTHENING COMPREHENSIVE CANCER CARE IN TELANGANA

Telangana state has made commendable efforts towards improving the health profile of its citizens. However, there is ample scope for improvement in the delivery of comprehensive cancer care services in the state.

It is widely known that cancer patients are diagnosed in advanced stages owing to a multitude of factors:

- Financial, socio-cultural, cognitive, linguistic, logistical barriers along with long waiting periods, inconvenient clinic hours/timings add to further delays.
- Most patients visit multiple centres across public and private sectors, leading to prolonged diagnostic and treatment intervals.

- These adversely impact the initiation of definitive treatment and in turn the clinical outcomes.
- The impact of post-pandemic transition on the health system is apparent.
- Distress financing is a common barrier for cancer patients that instigates non-compliance to treatment or default post-initiation.

To complement the state's efforts in ensuring equitable services across the cancer care continuum -

IEC to increase awareness

- Using digital and print media for mass communication on cancer (its risk factors and available services) is essential.
- Ensure affordable access to HPV vaccine for young girls and expand its reach through consistent messaging.

Screening

For encouraging the uptake of screening, diagnostic and therapeutic services and potential downstaging of the common cancers in the state:

Leveraging public private partnerships to implement organized/systematic and periodic/recurrent screening programmes across the state is crucial.

Workforce - Training

> Increased availability of competent workforce ensures early detection

Patient-care pathways

- ▶ Using peer-led role modelling strategies
- Provision of appropriate feedback to all individuals (screen-positives, negatives and diagnosed) should be mandated.

Access to comprehensive care

- Equitable distribution of comprehensive cancer care centres ensures timely access, principally for those residing in remote areas.
- > Developing standardized care pathways and establishing appropriate linkages.

Protocols and guidelines

Standardized protocols that are oncology-specific ensure operational feasibility and contribute to fiscal sustainability of the health system through optimal use of available resources.

- Contextualize the global, evidence-based therapeutic guidelines to befit the needs of Telangana population.
- > Monitor the compliance of providers across public and private sectors to standardized protocols.
- Available standardised cancer care protocols and guidelines from National Comprehensive Cancer Network (NCCN), European Society for Medical Oncology (ESMO), American Society of Clinical Oncology (ASCO), and National Cancer Grid (NCG) need to be adopted based on the available resources.

Financing and schemes

- > Enhancing awareness of healthcare providers on existing health insurance schemes.
- Convergence of all the existing schemes offered by central, state government and private sector to reduce the financial burden of the patient. Inclusion of private insurance will improve access to the middle socio-economic strata who are not covered under the *Aarogyasri* schemes or the Ayushman Bharat scheme. Implementation of comprehensive cancer care services (inclusive of diagnostic, curative and palliative therapies) for all the beneficiaries is important.

Digital technologies

Telangana State has been the pioneer in promoting digital technologies to maximize social welfare.

- > Need for designing tech-enabled cancer care services therefore, cannot be over-emphasized.
- Oncology-specific electronic medical records facilitate automation, improve patient-experience and workforce-efficiency (as the activity schedules for both clinical and administrative staff are generated in sequence), alongside enabling continuity of care.

EMR based patient navigation

- An EMR based technology platform which connects the primary, secondary and tertiary care centers will act as a backbone for standardizing care by ensuring appropriate referral to the next level of care.
- Standardised protocols can be easily followed by the caregivers using the CDS (clinical decision system) built into the EMR system.
- EMR helps in generating data on the outcomes of the patients and this will help in instituting remedial measures- actions if certain protocols are not followed or are found to be redundant.

Distributed cancer care network

- Such a network helps the cancer patients' journey from screening, diagnosis and treatment till endof-life care.
- A network of community health centers and primary health centers where ASHA's and ANM's can be given the responsibility of screening and primary care of the cancer patients will enable early detection and improve prognosis.
- In addition to the strengthening of primary care facilities, a distributed oncology care network needs to be supported at the secondary level by providing diagnostic services at district hospitals and wellestablished medical colleges of repute. This will help minimize the hardships and the financial burden faced by patients in traveling to seek care and ensures better follow up of the patient along with improved adherence to treatment.

Data and Research

Analyzing the care patterns at different settings - community, PHC/CHC, district hospital, tertiary cancer centers, etc., that patients visit across the care continuum is crucial for informed decision-making.

- > Expand the population-based cancer registry in Hyderabad district to include the entire state.
- > Consider integrating EHR data to cancer registries and further link it to claims data from AB-PMJAY.
- Consider linking cancer care centers, patients, caregivers, providers through a unique ID and aggregating the meta-data onto a health-cloud in sync with the strategy proposed by NDHM.

To benchmark, improve quality, plan and implement activities that meet patient needs across the cancer care continuum and audit outcomes.⁽⁶⁾

- > A robust monitoring and evaluation framework along with standardized procedures for data collection, analyses and timely reporting is indispensable.
- > District NCD cells could play a pivotal role as nodal cancer centres.

Shared understanding of gaps and engaging stakeholders at all levels of the social-ecological framework is critical to collectively address the challenges in comprehensive cancer control. As outlined by the implementation science framework ⁽⁴³⁾ for strengthening (preventive and curative) cancer care, generating demand at the community level (pull factors) alongside targeting health-system (push-factors) including infrastructure could be the way forward.

A framework for comprehensive cancer care was developed with verticals of Risk Factor Mitigation, Screening, Diagnosis, Treatment, Follow Up and Survivorship Care underpinned by Research and Innovation (Figure 7).

Establishing patient support groups
Promoting psycho-oncological counselling

for patients and their families

Comprehensive Cancer Care

Affordable | Accessible | Adequate | Appropriate | Equitable | Timely | Evidence-based services

Research & Innovation				
RISK FACTOR MITIGATION - Promoting cancer literacy - Promoting healthy eating habits & regular physical activity - Preventing smoking- related cancer - Reducing the harmful effect of alcohol consumption - Preventing cancer caused by infections - Preventing cancer caused by risk factors related to lifestyle and work environment	SCREENING - Promoting public awareness about cancers screening - Improving the response to common cancer screening: †availability, †access - Linking screen positive patients to diagnosis, treatment & follow up care - Ensuring the necessary resources: human, financial, & infrastructure - Periodically evaluate implementation to review delivery strategy	DIAGNOSIS - Improving the organizational & quality aspects of cancer diagnostics & treatment monitoring - Improving the access to optimal cancer diagnostic procedures to patients - decentralization - Improving collaboration & coordination among all stakeholders - Ensuring rational use of diagnostic resources - Linking to treatment & follow up care	TREATMENT & FOLLOW-UP CARE - Improving access to quality treatment: decentralization - Ensuring compliance with standard guidelines - Ensuring treatment initiation by a multidisciplinary team - Incorporating specific psycho-oncological interventions - Linking to follow up services PALLIATIVE CARE	HIP post- elop f ew n and f
			- Promoting access to quality treatment	

Figure 7. General Comprehensive Cancer Care Framework



Interactions with the wide array of experts highlighted the need to set up a cancer care advisory group to strengthen and provide technical support to the Cancer Cell in the Government. Such an advisory group should be all encompassing and invite oncology and public health and program experts from the government as well as the private sector, industry, civil society and patient support groups. This should be chaired by the Commissioner of Health and Co-Chaired by a leading non-government sector senior oncologist of repute.

9.0 IMPACT OF COVID-19 ON CANCER CARE PATHWAYS

All over the globe the pandemic has affected the delivery of healthcare services at different levels.

- Activities like awareness for early means of diagnosis have also been shut down. (44)
- The other side on the slowdown of care is due to diversion of resources for tackling the pandemic and conversion of cancer hospitals into COVID-19 facilities. ⁽⁴⁵⁾
- *Screening programs* and outreach camps were severely undermined in the last two and a half years.

"COVID-19 disrupted screening just after initiation." – [Provider: 20]

- A cohort study conducted in India found a major reduction in new patient registrations (67%), major surgeries (63%), minor surgeries (70%) and diagnostic services rendered (CT and MRI) by 57% in April and May 2020 compared to the same period in 2019. ⁽⁴⁶⁾
- The pandemic has been more challenging to the cancer patients due to their weak immune system and the mortality rate was higher for surgeries conducted amongst COVID-19 positive patient.^(47,48)
- The associated comorbidities also increase the risk for cancer patients.
- In India, cancer centres are mostly located in urban areas and are not accessible due to lack of transportation amidst lockdown and some centres were under functioning.
- Caregivers had been deserting the patients receiving treatment at tertiary cancer centers, upon cognizance of their COVID-positive status.
- Similar phenomenon was observed by palliative care physicians providing home-care, amongst family members of lung cancer patients who had been abandoning their caregiving roles upon observation of COVID-like symptoms in these patients.
- The post-pandemic situation is very challenging for cancer care centers and health care providers owing to increased waiting period for initiation of treatment under strained condition.
- Low-and-middle income countries like India could adopt learnings from other countries on pre and post pandemic preparedness.

The pandemic has also highlighted the potential and need for optimizing telehealth and remote consultations for comprehensive cancer care.

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