









RECOMMENDATION NOTE

STRENGTHENING STANDARDS OF CANCER CARE IN PM-JAY, UTTAR PRADESH



Submitted by:

Special Interest Group, convened by the State Agency for Comprehensive Health & Integrated Services





The State Agency for Comprehensive Health & Integrated Services (SACHIS), the state agency for implementing the Pradhan Mantri Jan Arogya Yojana (PM-JAY), has designed, and is implementing a multiparter initiative aimed at strengthening the provision of cancer care under PM-JAY. The initiative focuses on (i) research and analysis to build an understanding of the provision of cancer care in the state; (ii) provider engagement to understand the service delivery challenges that prevent oncology empanelled hospitals from servicing PM-JAY; (iii) facilitating capacity-building based on the standards of care and standard treatment guidelines (STGs); and (iv) promoting cross learning and advocacy.

SACHIS collaborates with King George's Medical University (KGMU), an apex institution in Lucknow that offers medical education and is a major service provider partner in the provision of health services including cancer care under PM-JAY. ACCESS Health, a not-for-profit organization, provides implementation support towards building state leadership in the evidence-based implementation and the use of efficient, multisectoral, and cost-effective interventions for strengthening PM-JAY. Roche India Healthcare Institute (RIHI) is an ecosystem partner.

A Special Interest Group (SIG) was constituted by SACHIS in November 2022 and is chaired by the Principal Secretary of Medical Health & Family Welfare, Government of Uttar Pradesh. It comprises leading oncologists from public and private empaneled hospitals as well as subject matter experts from the state (Annexure). The mandate of

the SIG was to review the existing implementation of programs and schemes and give recommendations for (i) strengthening early screening and diagnosis to reduce the late-stage presentation of the disease and improve treatment outcomes; (ii) strengthening the availability and access to cancer treatment for improved treatment outcomes; and (iii) increasing financing for cancer care.

Over the course of six months, the SIG members have participated in several rounds of discussions, reviewed the Health Benefit Packages (HBP), shared implementation challenges while servicing patients under PM-JAY, and recommended areas of consideration to further strengthen treatment for cancer. Additionally, KGMU in partnership with SACHIS and ACCESS Health conducted a qualitative study-Landscape Assessment of Provision of Cancer Care in Uttar Pradesh. The study, which is now published, is the first comprehensive study that provides an understanding of the existing continuum of care system, patient service environment—bottlenecks and challenges, the key challenges hospitals face, and areas of consideration for state and national policymakers and program managers in Uttar Pradesh.

This recommendation note aims to highlight the implementation challenges in the provision of cancer treatment under PM-JAY—synthesized from deliberations, review of literature, and the qualitative case study—and make recommendations that can be examined by the Department of Health & Family Welfare, SACHIS, and National Health Authority.

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Cancer Care Provision Under PM-JAY in Uttar Pradesh

PM-JAY provides comprehensive Health Benefit Packages for cancer treatment. Over the last five years, the packages have been reviewed by the National Health Authority and have evolved. Per the HBP 2022, 557 packages combining medical (289 packages), radiotherapy (54 packages), and surgical

Medical Oncology: 289 packages Radiation Oncology: 54 packages Surgical Oncology: 214 packages Palliative Care: XX Packages

oncology (214 packages) exist for cancer treatment. Additionally, palliative care packages were also included in 2022¹. The STGs in collaboration with the National Cancer Grid were developed and notified for PM-JAY in 2018 by the NHA.

The state of Uttar Pradesh covers close to 8 crore people through PM-JAY and state schemes. In the last five years, a network of over 3,400 hospitals has been established by SACHIS to provide services under PM-JAY². A total of 155 hospitals have been empaneled—130 private and 25 public for oncology and over 31,000 patients have received treatment for cancer.

Demand and supply-side challenges

Over the years, there have been consistent efforts by the state (Department of Medical Health & Family Welfare and SACHIS) in implementing programs for cancer care. Diagnostics and treatment are provided through medical colleges and a few district hospitals; the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases, and Stroke (NPCDCS) has also been implemented. However, these have not kept pace with the rising incidence of the disease. There are demand, supply, and systemic challenges that exist in the provision of cancer care, which lead to considerable hardships for the patient. These affect the provision of care both under PM-JAY and other schemes in the state. The SIG highlights some of the demand and supply side

challenges, which are listed below:

- Increasing incidence and mortality due to cancer in Uttar Pradesh. Six lakh persons are living with cancer and 1.9 lakh new cases are added every year³. The prevalence is 259 per one lakh population, while the incidence stands at 82 and mortality at 66 per one lakh population⁴
- Late representation of patients and poor treatment outcomes due to limited populationbased cancer awareness, screening, referrals, and follow-up support
- Delayed provision of treatment due to limited infrastructure - diagnostics and treatment are only available in medical colleges and a few district hospitals. At present there are 18 public health institutions that provide cancer diagnostics and treatment
- The NPCDCS program is fully functional, however, the focus on cancer care is very limitedPM-JAY has created a network of private hospitals providing cancer care with 130 hospitals on board—however the network is inequitable and fragmented with over 60 percent of hospitals in five big cities in the state and only 40 percent of hospitals actively participating in service provision

Service provision challenges reported by PM-JAY empaneled hospital network for cancer SACHIS has built a network of over 155 hospitals to provide cancer treatment, however, not all the empanelled hospitals service PM-JAY patients. The SIG members agree with the findings of the KGMU qualitative study and the deliberations and highlight the challenges in service provision specifically under PM-JAY.

High out-of-pocket expenditure for patients on diagnostics and investigations

While PM-JAY offers work-up diagnostics, they can only be used once the patient is diagnosed with cancer. Investigations related to staging before and during the treatment are done as outpatient services (due to a lack of beds) are not

- covered and result in out-of-pocket expenses
- The package pricing for medical oncology does not cover mandatory investigations, many of which are costly diagnostic tests. In a situation where the patient undergoes surgery, the hospital may cover the investigation cost as it falls within the package; however, in a situation where the patient undergoes chemotherapy, due to the high cost of investigations, these are not covered by hospitals and the patient is required to pay for these
- The package provides for a three-days pre-workup period for investigations and diagnosis, however, certain tests like histopathology and biopsy require 7 to 15 days
- Provision for PET Scan⁵ and FISH testing is not included

Drugs and Therapies

- No provision package for metronomic treatment, which allows administering lower doses than the maximum tolerated doses over a longer period—resulting in fewer side effects. The inability to manage the side effects is one of the main reasons for patients dropping out of treatment
- No provision for multiple myeloma
- Under certain packages, like that for urinary bladder cancer, the chemotherapy cycle intervals are quite high (21 days); reducing it by one week can be considered

Palliative care packages

A comprehensive palliative care package was launched under HBP 2022. However, the duration is very short. For example, the duration per package is 4 to 5 days. However, to treat conditions like lymphadenitis a minimum of 15 to 20 days cover is required. Similarly, there are very limited community-based palliative care programs to provide care and help with pain management at home

In addition, due to human resource shortages, a lot of hospitals have specialists who are on call and the specialist pricing is higher than offered by the PM-JAY, which can also become a deterrent.

The SIG reviewed the findings of the qualitative study conducted with patients under treatment by KGMU and partners. While the perspective is that of a small sample of 65 patients (including those covered under PM-JAY), the findings are critical to be considered for policy and program.

- Delayed identification of cancer is fueled by a lack of awareness of signs and symptoms, fear, reliance on home remedies, and limited availability of screening and diagnosis of cancer in public health facilities. This delay results in the late presentation of the disease for treatment affecting the outcome
- Delayed initiation of confirmatory diagnosis and treatment due to financial constraints, lack of information on where good treatment is available, and distance of treating facilities from their home
- Navigation barriers at the treating institutions due to overcrowding and a lack of support to help navigate between different services. At the treating institution, the time taken to initiate treatment can be anywhere between one week to 30 days. The reasons for the delay are the lack of availability of staging investigation for treatment
- High out-of-pocket expenditure incurred by patients while seeking cancer treatment. Expenses are incurred on drugs that are not available. The reported data suggests that for patients covered by PM-JAY, the average OOPE was 2.4 lakhs; for those covered by other Government schemes, the number stood at Rs 2.3 lakhs, while patients with no coverage incurred an expenditure of Rs 2.5 lakhs. On average, the expenditure ranges between 4 to 5 lakhs on tests, medicine, transportation, and treatment irrespective of insurance cover. While these findings cannot be generalized due to a small sample size, the costs incurred for diagnosis and treatment of cancer are very high
- Dropouts without completing treatment due to side effects of cancer treatment and financial burden. Not being able to afford expenses like hospital fees, medication costs, and travel costs as reasons for discontinuing the treatment altogether

Patient Pathways: Complex and delayed in absence of awareness, information and limited diagnosis and treatment

Reported average delay

6 months
(1 month to 2 years)
from onset of symptoms
to diagnosis





25-29 days on initiation of treatment once at hospital

Onset of initial symptoms and management

Delayed identification

- Lack of awareness on risk factors and symptoms
- Reliance and management of early symptoms through home remedies
- Overlooking early signs due to fear and stigma

First point of care and diagnosis

Delayed diagnosis

- First point of care local pharmacists and alternative medicine practitioners
- Dependence on informal and private for treatment due to lack of diagnosis in public hospitals
- Most out of pocket expense -multiple diagnostics

Decision making on course of treatment

Delayed reaching the right treating institution

- Lack of source of guidance on identifying the right facilities – referred to Mumbai
- Decision on treating institution on advice of family
- Time taken to arrange for money- loans and selling assets common
- Limited awareness on government schemes including PM-JAY at this point.

At treating institutions

Delayed initiation of treatment

- Limited navigation support between multiple departments
- Delay in admission and long waiting time for staging diagnosticscaseload (patients reported waiting time for CT/Biopsy/ FNAC 30 days)
- Availability of drugs due to supply chain issues
- Challenges of enrolling in scheme at the last minute
- Constrained infrastructure available for caregivers
- Expenses on staging diagnostics, drugs, food, accommodation

Post Treatment and Palliative Care

High drop out due to cost of treatment, back and forth

- Drop out due to side effects, distance of the hospital and high cost to travel
- Palliative and pain management limited

Average out of pocket spend Rs.2, 30,000 - Ranges between Rs 25,000-7,00,000
Average spend on drugs Rs 91,000 - Ranges between 2,000-4,50,000
Average spend on diagnostics Rs 60,000- Ranges between 6,000-2,00,000
Average spend on travel Rs 37,000 Ranges between Rs 30,000-2,50,000
* Mav not add to the total OOPE due to recall issues

Source: Qualitative Study - Landscape of Provision of Cancer Care in Uttar Pradesh, KGMU, SACHIS, ACCESS Health 2023

Areas of Consideration and Recommendations

Cancer care is complex and requires different moving pieces-including policy, programs, and service delivery coming together. In the current context, PM-JAY and other government-funded health insurance schemes provide an opportunity to leverage the scheme components, which include comprehensive HBPs, STGs to strengthen the public delivery infrastructure to expand the access to and availability of information, screening and early diagnostics, comprehensive treatment, and palliative care for those suffering from cancer. However, the success of these schemes is dependent on state policies, implementation of existing programs, and scaling up of infrastructure among other things. The SIG validates the increasing incidence of the disease burden, challenges and gaps that exist, and opportunities for the state. This section provides policy and programmatic recommendations for PM-JAY, and to DoH&FW and DME.

PM-JAY

PM-JAY provides a unique opportunity to leverage the private infrastructure toward increasing the

availability of quality cancer care in Uttar Pradesh. SACHIS has played an important role in increasing the availability of cancer care by leveraging the private sector and empaneling over 130 private hospitals to provide cancer treatment. Thus from a few public treating institutions, today there is a network of over 155 hospitals in both public and private sectors in the state that can service 30 percent of the eligible population. While this is good progress, there are still supply-side issues (like the limited participation of private hospitals) and several operational barriers (out-of-pocket expense and access to treatment) faced by the patients while navigating care that need to be redressed.

Provisioning an independent first line of diagnostics package as an OPD procedure under HBP: PM-JAY provides high-quality diagnostics, such as ultrasound, CT-guided percutaneous biopsy/FNAC, high-end radiological diagnostics (CT, MRI, Imaging including nuclear imaging), high-end histopathology (biopsies), advanced serology investigations, and PET scans.

	Essential	Essential & covered in PM-JAY	Suggestions for Inclusion under PM-JAY
Breast	 Bilateral Mammogram or High-Resolution ultrasonogram Trucut Biopsy/FNAC Immunohistochemistry (ER/PR/Her2) CXR/USG Abdomen and Pelvis CBC/LFT/RFT/ECG/D ECHO CT Thorax MR Mammogram Bone Scan 	 Trucut Biopsy/FNAC CBC/LFT/RFT/ECG/D ECHO (Covered within Package) CT Thorax MR Mammogram 	 Bilateral Mammogram or High Resolution ultrasonogram Immunohistochemistry (ER/PR/Her2) CXR/USG Abdomen and Pelvis Bone Scan
Cervix	 Liquid-Based Biopsy (LBC) Colposcopy Guided Biopsy/Cone Biopsy CT Abdomen-pelvis Cystoscopy 	Colposcopy Guided Biopsy/Cone BiopsyCT Abdomen-pelvis	Liquid Based Biopsy (LBC).Cystoscopy

	Essential	Essential & covered in PM-JAY	Suggestions for Inclusion under PM-JAY
Head & Neck	 CT Head & Neck MRI PNS and Face for Nasopharyngeal carcinoma and skull base tumors Direct or indirect Laryngoscopy Biopsy- Primary lesion/ Biopsy or FNAC from neck node in cases of nodal Mets USG abdomen/CXR CBC/LFT/RFT/ECG/2D ECHO Thyroid profile (CA Thyroid Bone Scan 	 CT Head & Neck MRI PNS and Face for Nasopharyngeal carcinoma and skull base tumors Biopsy- Primary lesion/ Biopsy or FNAC from neck node in cases of nodal Mets CBC/LFT/RFT/ECG/2D ECHO (Within Chemo Package) 	 Direct or indirect Laryngoscopy Thyroid profile (CA Thyroid PDL-1 Receptor Status EGFR- Receptor Status Bone Scan
Lung	 CECT THORAX CECT Abdomen-pelvis BONE SCAN Bronchoscopy CT Guided/USG and guided Biopsy CXR/USG Abdomen-pelvis CBC/LFT/RFT/ECG/2D/ECHO EGFR/ROS/PDL 1 	 CECT THORAX CECT Abdomen-pelvis CT Guided/USG and guided Biopsy CBC/LFT/RFT/ECG/2D/ECHO- (Within Chemo Package) 	 CXR/USG Abdomen-Pelvis EGFR/ROS/PDL 1 Bronchoscopy Bone Scan

However, these are only available for inpatient care. Most of the expenses incurred are on diagnostics, as these are repeated at different stages. An independent first line of diagnostics package offered as an OPD procedure can be considered and introduced by NHA to significantly reduce the cost to the patient

- Pretreatment oncology diagnostics should be unbundled from package cost and paid separately
- Expanding the diagnostics in HBP: The SIG identified a list of essential diagnostics required that are currently not covered under PM-JAY and suggested their inclusion. The table below provides additional suggestions, which can strengthen care delivery. It is recommended to NHA if these can be considered
- Partnership with private laboratories to increase access to diagnostics: The SIG members agreed that the limited availability of good quality diagnostics in public institutions, especially at the periphery, and the high cost in private facilities are major causes for delays in treatment and high out-of-pocket expense. SACHIS is recommended to empanel private laboratories through a competitive process to provide diagnostic services to the PM-JAY hospital network. The NHA has a provision for the empanelment of laboratories that can be utilized as per the state's needs.
- Evaluating cost-effective newer therapies towards better treatment outcomes and quality of life: While PM-JAY over a period has evolved and expanded therapies, there is still scope to

	Essential drugs covered under PM-JAY	Suggested molecules for evaluation
Breast	First Line Cyclophosphamide Adriamycin Regimen Paclitaxel/Docetaxel (Taxane) Traztuzumab (In Her2 positive) Second Line Gemcitabine Capecitabine SFU Methotrexate Vinorelbine	HER2-targeted therapies (Newer Agents) ⁶ Pertuzumab Ado-trastuzumab emtansine sacituzumab CDK4/6 inhibitors Abemaciclib Palbociclib Ribociclib Ribociclib HER 2 Inhibitor 1. Tucatinib Other FDA-approved drugs Alpelisib, Everolimus, Fulvestrant, Margetuximab-cmkb, Olaparib talazoparib tosylate
p]=Cervix	 Paclitaxel + Cisplatin or Carboplatin Cisplatin + 5FU Cisplatin along with RT Gemcitabine + Cisplatin 	No suggestions
Head & Neck	First Line Paclitaxel Ciplatin or Paclitaxel Carboplatin Docetaxel Cisplatin, 5FU Paclitaxel, 5FU Second Line Gemcitabine Cisplatin Carboplatin Carboplatin Carboplatin Carboplatin For NET's or small cell variants Cisplatin, Nimotuzumab	Immune checkpoint inhibitors: Pembrolizumab Nivolumab for PD L1 positive

⁶Newer Drugs- HER2 positive Breast Cancer: As the addition of pertuzumab to the neoadjuvant treatment regimen resulted in fewer patients progressing, there was an avoidance of costs associated with first line and second-line subsequent therapies. Thus, part of the upfront drug cost for the addition of pertuzumab could be recuperated through avoidance of disease recurrence.

Newer drugs like Trastuzumab and Pertuzumab FDC SC reduces preparation, administration and observation times, and the need for sequential administration—thus increasing the number of patients who can be treated in a day. Newer SC drugs reduces the resource utilization and is associated with reduced risks of infection and clot formation. It also reduces the travel and hospital times, thus the burden on patients and caregivers, and has an impact on QoL and daily activities e.g., childcare, time off work etc..

	Essential drugs covered under PM-JAY	Suggested molecules for evaluation
Lung	 Taxanes Paclitaxel Docetaxel Alkylating Agents - Carboplatin, Cisplatin Pemetrexed Gemcitabine Bleomycin Erlotinib/Geftinib for EGFR positive cases Combination of above chemo agents used e.g., Paclitaxel, Carboplatin, Cisplatin OR Pemetrexed, Carboplatin Vinorelbine Albumin bound PacliTaxel 	 ALK/ROS positive cases⁷- Certinib, Crizotinib, Alectinib, Lorlatinib Immune Checkpoint Inhibitors- Pembrolizumab, Atezolizumab, Nivolumab for PD L1 positive cases. EGFR inhibitors- Afatinib Osimertinib

strengthen the quality of cancer care. The NHA has a new technology and package inclusion initiative in which partners are invited to nominate new health technology treatments for PM-JAY. This can be leveraged to suggest new therapies for cancer. The SIG recommends the evaluation of the following therapies for inclusion: Cisplatin and Etoposide, Oncoplasty, and Octreotid, and the use of low-dose immune therapy, which is costly but has shown promising results. Chronic and lifelong treatments like thalassemia should be included in the list with comprehensive treatment. The SIG makes specific recommendations for four priority cancers for evaluation and inclusion.

Facilitating strategic purchasing of cancer drugs for PM-JAY hospital network: Despite a financial cover of PM-JAY and other state financing schemes, a key barrier remains the unavailability of drugs due to supply chain issues. Thus, it is critical that drugs and therapies for complex treatment be streamlined. It is recommended that SACHIS consider collaborating with the NCG and facilitate bulk purchases of cancer drugs on behalf of the network hospitals. With large volumes, lower prices can be negotiated with pharmaceutical companies making treatment affordable and leading to improved availability.

• Increase availability of financing beyond PM-JAY:

While the provision of the Rs 5 lakh cover that currently exists under PM-JAY is comprehensive, with the adoption of STGs and newer costeffective drugs, there may be a need to increase financial risk protection. The state may consider setting up a corpus fund like Tamil Nadu, where Rs 25 crores have been set aside for funding treatment once the Rs 5-lakh cover is over. Similarly, Odisha has expanded the health coverage from Rs 5 Lakhs to 10 Lakhs for the women of the state. It is proposed that SACHIS can consider expanding the financing cover or creating the provision of additional funds when needed.

- Establishing PM-JAY cancer registry: While at the state level, efforts towards this are taken, SACHIS with its aggregating capability can initiate a registry through the PM-JAY network of hospitals.
- Building a strong component of palliative care:

There is evidence to suggest a strong need to reduce dropouts by improving palliative care from the day the patient is identified with cancer and comes into contact with the facility to during treatments and post-treatment follow-up care

Newer Drugs in ALK+ NSCLC (Lung Cancer): ALK+ NSCLC occurs in approximately 5% of patients with advanced NSCLC and tends to be more frequent amongst younger NSCLC patients and light or non-smokers. ALK+ NSCLC patients are associated with poor prognosis. ALK+ NSCLC imposes a substantial burden to patients, caregivers, and the healthcare system overall, which becomes even higher when patients develop brain metastases. Newer drugs like Alectinib effectively treat and protect against CNS metastasis, as demonstrated in the ALEX study, which showed a greater rate of complete response in the CNS. Newer drugs like Alectinib reported clinically meaningful improvement in HRQoL for a longer duration of time and offers significant health improvements with a manageable budget impact and potential cost offsets to a clearly defined, small population. By preventing or delaying of CNS metastases, newer drugs like Alectinib can lead to cost savings.

visits. There is a strong need to link patients in lower-level facilities to palliative care, especially in managing side effects and pain. The state can pilot initiatives under the National Palliative Care Program, currently running in 30 districts, by the Department of Medical Health & Family Welfare in collaboration with the treating institution. Furthermore, the NHA can consider increasing the duration of the packages.

Department of Medical Health & Family Welfare

The SIG also recommends some policy and programmatic recommendations critical for the state health systems and will also directly improve service provision in PM-JAY.

- Pradesh: This will enable reporting of all new cases to the government, helping policymakers understand the incidence, prevalence, and trends for public health programs. In 2008, the ICMR recommended that cancer be made a notifiable disease; this was followed by a similar recommendation by the Parliamentary Committee in 2022. Several states including Haryana, Karnataka, Kerala, Tamil Nadu, Punjab, West Bengal, Assam, Mizoram, Sikkim, Gujarat, Manipur, Rajasthan, Arunachal Pradesh, and Andhra Pradesh have already made cancer a notifiable disease.
- Establishing Population-Based Cancer Registry:
 - The existing cancer registries in India include population-based cancer registries (PBCR) and hospital-based cancer registries (HBCR). PBCR collects and processes data relating to a defined geographical area, while HBCR includes data available with a specific hospital. At the systems and governance level, Uttar Pradesh has three PBCRs in Allahabad, Aligarh, and Gautam Budh Nagar. Setting up of PBCRs across the state will be critical to monitor cancer incidence, identify highrisk groups (occupational exposure, family history), and evaluate cancer treatment by tracking patient outcomes.
- Decentralized cancer care provision to provide care closer to home and reduced overcrowding in limited treating institutions: The study clearly highlights the concentration of cancer services mostly in bigger cities, including public medical colleges and private hospitals, resulting in very high patient load causing distress to both provider

and patient. Decentralization of cancer treatment aims to shift the process of providing services from cities and urban locations to peripheral and rural areas. While some efforts of task shifting (training doctors at district hospitals for the provision of chemotherapy) were attempted in 2018, they weren't successful. In the current context, with the availability and acceptance of telemedicine and the availability of human resources (physicians/surgeons) in district hospitals, task shifting should be considered an important strategy to decentralize cancer care provision. States like Assam and Kerala have empowered their district hospitals and increased the availability of care to address the issues of specialists in the state.

DoH&FW and DME can collaborate to create an Uttar-Pradesh-centric hub and spoke model in which apex institutions like KGMUSGPGI, and the likes are the hub (providing diagnostics and specialized treatment) for a network of district hospitals as spokes, which are strengthened to provide certain cancer basic (basic diagnostics, chemotherapy and follow up services). The spokes can be empowered through training and the use of telemedicine, under the supervision of the apex institutions. This can significantly improve access.

- Public-Private Partnerships for cancer care provision in public hospitals: In addition to strengthening public-sector institutions, another strategy is leveraging private-sector partnerships to increase the availability of cancer treatment in Uttar Pradesh. Many states of the country are implementing PPPs for cancer treatment. For example, Tata Memorial Centre (TMC) in Mumbai collaborated with the Maharashtra Government to establish a cancer care facility at Government Medical College and Hospital in Chandrapur. Under this, TMC provides technical assistance in design and construction, training of doctors and nurses, and equipment and supplies. The government provides infrastructure, human resources, and land. The government should consider PPPs to increase the availability and accessibility of cancer care services.
- Setting up referral pathways: The Ministry of Health and Family Welfare of the Government of India prepared a well-thought-out Operational Framework for the Management of Cancers in 2016⁸. The framework includes algorithms for

- screening and managing the three most common cancers, i.e., breast, cervix, and oral. The current referral system is almost non-existent, and patients are referred on pen and paper, requiring patient tracking and a follow-up system. Therefore, it is recommended that the state begins piloting the referral program, per the mentioned guidelines, in a few select districts, where HWC-SC/PHC/CHCs/DHs can be linked with a medical college.
- Patient navigation support mechanism for cancer patients: All studies, have highlighted the complex treatment journey for the patients, which is due to a lack of understanding of the disease, its management, side effects, and emotional stress at hospitals and after the treatment. While HWCs and ASHAs are mandated to provide the support, they are overburdened. Navigation support mechanisms for cancer patients should be developed. Through this, one-on-one support and guidance can lead to patient education and information on diagnosis, treatment, self-care, and palliative care.
- Strengthening availability and supplies of drugs and therapies in public cancer treating institutions: While public medical colleges procure cancer drugs through individual rate

- contracts, the study has highlighted supply chain issues and the availability of drugs is a challenge. In the private sector, the process of procurement and sale of drugs remains largely unregulated, thus spending on drugs is a significant out-of-pocket expense. Towards strengthening availability and economies of scale, the inclusion of cancer drugs in the state drug list for bulk purchase is recommended. Several big and small states (Haryana, Rajasthan, Tamil Nadu, Kerala, Gujarat, Karnataka etc.) procure cancer drugs through their corporations. This will be important as the state decentralizes care to district hospitals.
- Strengthening early screening and diagnosis to reduce late-stage representation and improve treatment outcomes: Awareness will not only increase the incidence of early diagnosis but in the long run also help prevent many lifestyle cancers and other diseases—reducing the disease load. There is an urgent need for training all health workers. At the community level, there could be social outreach—with a focus on cancer screenings for common cancers—mandatory for college students. Non-health organizations—like schools, colleges, banks, industries, etc.—must also be involved with accountability.

Conclusion

Improving the provision of cancer care in India will require a multi-sectoral approach in which public spending and private sector partnerships will need to be prioritized for building infrastructure, human resources, and expansion of services more equitably. The community programs on screening and diagnosis need to be innovative and engage with other sectors besides the government machinery. By adopting a comprehensive long-term vision, policymakers can significantly increase services to reduce cancer-related morbidity and mortality and improve the quality of life.

Annexure - Members of Special Interest Group

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