



# LANDSCAPE OF CANCER CARE PROVISION IN UTTAR PRADESH

## Qualitative Case Study Report



Conducted by:  
King George's Medical University, Lucknow, SACHIS and ACCESS Health

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# Table of Content

<b>Abbreviations</b>	Page 2
<b>Messages</b>	Page 3 - 4
<b>Foreword</b>	Page 5
<b>Acknowledgment</b>	Page 6
<b>Executive Summary</b>	Page 7 - 12
<b>Chapter 1: Context</b>	Page 13 - 14
<b>Chapter 2: Objectives and Methodology</b>	Page 15 - 16
<b>Chapter 3: Landscape of Cancer Care Provision in Uttar Pradesh</b>	Page 17 - 24
<b>Chapter 4: Patient Pathways</b>	Page 25 - 29
<b>Chapter 5: Areas of Consideration and Recommendation</b>	Page 30 - 35
<b>Conclusion</b>	Page 36

# List of Abbreviations

<b>ASHA</b>	Accredited Social Health Activist
<b>ANM</b>	Auxiliary Nurse Midwife
<b>AWW</b>	Anganwadi Worker
<b>CBAC</b>	Community Based Assessment Checklist
<b>CHC</b>	Community Health Centre
<b>CRD</b>	Chronic Respiratory Disease
<b>CVD</b>	Cardiovascular Disease
<b>DH</b>	District Hospital
<b>DME</b>	Department of Medical Education
<b>DoH&amp;FW</b>	Department of Health & Family Welfare
<b>FGD</b>	Focused Group Discussions
<b>FNAC</b>	Fine Needle Aspiration Cytology
<b>GBD</b>	Global Burden of Disease
<b>HBCR</b>	Hospital-Based Cancer Registry
<b>HBP</b>	Health Benefit Package
<b>HWC</b>	Health & Wellness Centre
<b>IEC</b>	Information Education and Communication
<b>ICMR</b>	Indian Council of Medical Research
<b>LEEP</b>	Loop Electrosurgical Excision Procedure
<b>KGMU</b>	King George's Medical University
<b>NCD</b>	Non-Communicable Disease
<b>NCDIR</b>	National Center for Disease Informatics and Research
<b>NCG</b>	National Cancer Grid
<b>NHA</b>	National Health Authority
<b>NPCDS</b>	National Program for Prevention and Control for Cancer, Diabetes, Cardiovascular Diseases & Stroke
<b>NSSO</b>	National Sample Survey Organisation
<b>OOPE</b>	Out Of Pocket Expenditure
<b>PBCR</b>	Population Based Cancer Registry
<b>PPP</b>	Public Private Partnership
<b>PSI</b>	Population Services International
<b>RCC</b>	Regional Cancer Center
<b>RIHI</b>	Roche India Healthcare Institute
<b>SACHIS</b>	State Agency for Comprehensive Health & Integrated Services
<b>SC</b>	Sub Center
<b>SDGs</b>	Sustainable Development Goals
<b>SGPGI</b>	Sanjay Gandhi Post Graduate Institute of Medical Sciences
<b>SIFPSA</b>	State Innovations in Family Planning Services
<b>STGs</b>	Standard Treatment Guidelines
<b>TMC</b>	Tata Memorial Center
<b>UPMSCL</b>	Uttar Pradesh Medical Supply Corporation Limited



## Message

For over a century, King George's Medical University has been one of the country's apex institutes in the field of education, research, and patient care. Our aim has been to produce outstanding leaders in health sciences, promote multidisciplinary scientific biomedical research, and provide compassionate, patient-centric care of the highest quality. With over 500 faculty members, 3,000 students, 60 departments, and 4,000 beds-KGMU has reinforced its position as one of Uttar Pradesh's premier medical universities.

KGMU's Department of Surgical Oncology, which was established in 1979, has been providing tertiary care for cancer patients from all over Uttar Pradesh, neighboring states in India, and even neighboring countries like Nepal. The Department of Medical Oncology came into being in February 2021, and offers chemotherapy, immunotherapy, and targeted therapies to both adults and children, for malignancy ranging from the brain to the extremities. With the inclusion of state-of-the-art unit for cellular therapy and bone marrow transplant-both of which are planned for the near future-KGMU hopes to strengthen its cancer care services even further to better cater to its patients.

KGMU is a proud partner of the State Agency for Comprehensive Health & Integrated Services (SACHIS) in delivering care under PM-JAY and in conducting this landscape study, with ACCESS Health. The study looks at the obstacles patients face when afflicted by the disease and implementation challenges and provides a roadmap on how the state of Uttar Pradesh can meet its citizens healthcare needs when it comes to cancer.

The recommendations that have thus been stated hope to strengthen public service delivery in the state and alleviate policy challenges that are impediments to the success of state schemes. Making cancer a notifiable disease in Uttar Pradesh, for instance, is the first step towards better understanding the incidence and prevalence of the disease in all its variations. On the other hand, decentralizing cancer care provision with a hub and spoke model with institutions like KGMU as the hub and district hospitals across the state as spokes can empower patients to seek quality care closer to home with reduced out of pocket expense.

I would like to congratulate my colleague Dr. Kirti Srivastava, Professor, Department of Radiation Oncology for leading the study and thank SACHIS and ACCESS Health for their continued support sincerely wish the myriad findings and recommendations of the report help strengthen the public health policy of Uttar Pradesh further, easing the lives of patients on their journey to seeking relief from cancer.



**Lt. Gen. (Dr.) Bipin Puri**  
Vice Chancellor,

# Message



## **Shri Partha Sarthi Sen Sharma**

*Principal Secretary, Medical Health & Family Welfare  
Government of Uttar Pradesh*

As a part of its commitment towards Sustainable Development Goals 2030, the state of Uttar Pradesh is taking big strides towards making good health and well-being a reality for its citizens. The state recognizes the need for building a resilient health system through people-centered, evidence-based, and equity-driven approaches to promote preventive, diagnostic, curative, rehabilitative, and palliative care

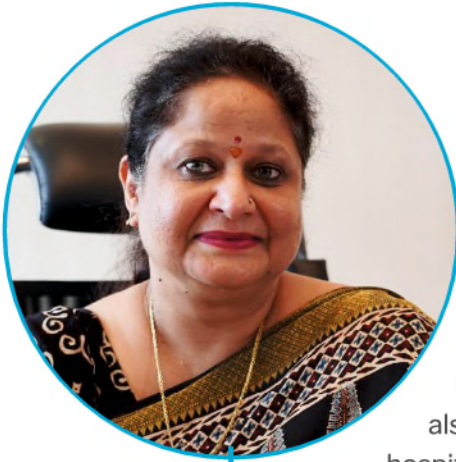
across all levels of service provision. By 2030, the state hopes to reduce one-third of premature deaths from Noncommunicable Disease, particularly through provision of early diagnosis and disease management avenues at all healthcare levels. To that end, efforts to bolster capacities of existing systems and programs are underway, particularly to the ease burden of cancer in the state.

District NCD cells have been established in 62 District Hospitals and 332 CHCs in Uttar Pradesh under the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke (NPCDCS) to help tackle the morbidity and mortality from these diseases. Similarly, 14 Sampurna Clinics have been set-up in 14 districts to specifically for cervical cancer screening—thus also ensuring a greater equity in healthcare access for women. Moreover, through the Pradhan Mantri Jan Arogya Yojana, the State is providing a cover of Rs 5 lakhs to lakhs of families in the state against medical ailments of all kinds, including cancer.

As we aim to achieve universal health coverage, there is a need to strengthen the existing network of public service delivery and make cancer-care services accessible and affordable for people of the state. This landscape study is a step in that direction, as it examines the cancer care ecosystem in the state from a nuanced perspective that encapsulates the voice of the beneficiaries while also documenting the suggestions of frontline workers and program executors.

I extend my sincerest thanks to King George's Medical University and ACCESS Health International for their efforts towards bringing this study to fruition. I'd also like to express my gratitude to SACHIS for taking this up and tirelessly working for PM-JAY beneficiaries. Academic research can inform policymaking in a myriad of ways, and I hope our partners will prioritize these findings and help the Government realize its vision for 2030.

# Foreword



## **Smt Sangeeta Singh**

*Chief Executive Officer*

*State Agency for Comprehensive Health & Integrated Services,  
Government of Uttar Pradesh*

The Pradhan Mantri Jan Arogya Yojana aims to reimagine service delivery in the state of Uttar Pradesh. As a health assurance scheme fully financed by the Government, it not only provides a cover of Rs 5 lakhs per family every year for secondary and tertiary care services-it also allows beneficiaries to access a network of private and public hospitals for their health needs. PM-JAY serves 1.18 crore families in the state, steadily working towards the vision of Universal Health Coverage in the State.

Through the empanelment of private treating institutions across the state, PM-JAY is attempting to bring healthcare closer to home for beneficiaries at little to no out-of-pocket expense. While leveraging benefits for private service providers for escalated empanelment remain a focus, SACHIS has also making organized efforts towards building capacities-especially for cancer care-with the help of partners like ACCESS Health International.

It is important for us to understand how the care under PM-JAY is provided, especially for a complex disease like cancer. And for the past one year, SACHIS in collaboration with ACCESS Health, KGMU and other partners, have tried understanding the patient's perspective, provider's operational challenges through various initiatives.

I am grateful to KGMU, an institute of excellence, and ACCESS Health for designing and conducting this study and I am confident that the findings and recommendations will strengthen our efforts to optimize the provision of cancer care services in Uttar Pradesh. I am also grateful to Roche India Healthcare Institute (RIHI) for their technical assistance in developing training modules and facilitating trainings and discussions. I'd like to urge our partners to prioritize the actionable insights from the study to create effective patient support systems, reduce costs and ensure affordable access to cancer care close to home for all beneficiaries in the state.

I hope that these recommendations will help the State make informed decisions. I believe that collectively, we can reduce the burden of cancer in the state and improve the quality of life of the patients dealing with this debilitating disease.

# Acknowledgement



## **Dr. Kirti Srivastava (Principal Investigator)**

*Professor of Radiation Oncology, KGMU*

The study on Landscape of Cancer Care Provision in Uttar Pradesh was undertaken with purpose of how care is provisioned, challenges faced by the patients and opportunities to strengthen the work. The study was done in partnership with ACCESS Health and SACHIS and attempted to understand care provision from public service delivery and the Pradhan Mantri Jan Arogya Yojna.

This study would not have been possible without the contribution of the brilliant medical minds at KGMU, SGPI, RMLIMS, Medanta, and other premier institutions in Uttar Pradesh. I'd like to thank Dr. Gaurav Agarwal, Professor and Head of Endocrinology & Breast Surgery, SGPGI, Dr. A K Tripathi, Professor and Head of Haematology & Dean, KGMU; Dr. Anand Mishra, Professor & Head, Endocrine and Breast Diseases, KGMU; Professor R K Dhiman, Director SGPGIMS & Kalyan Singh Super Speciality Cancer Institute; Dr. Amita Pandey, Professor & Head Faculty of Medical Sciences, KGMU; Dr. Madhup Rastogi, Professor & Head of Department Radiation Oncology, RMLIMS; Dr. Harshvardhan Atreya, MD - Internal Medicine, DM – Medical Oncology, Medanta Cancer Institute.

I would also like to extend my gratitude to Dr. Alka Sharma, Additional Director and NCD Nodal, Department of Medical Health and Family Welfare; Dr. Sajit, Consultant Drug, Uttar Pradesh Medical Supplies Corporation; Dr. Salil Srivastava, General Manager, Community Processes, National Health Mission, UP; Dr. Sameer Gupta, Additional Professor, Head & Neck, KGMU; Dr. Poonam Gupta, Radiation Oncologist, Hanuman Prasad Poddar Hospital; Dr. Vivek Kumar Garg, Professor, Internal Medicine & Gastroenterology, KGMU; Dr. Sushma Agarwal, Professor, Department of Radiotherapy, Sanjay Gandhi Post Graduate Institute of Medical Institute; Dr. Arun Kumar Chaturvedi, Retired Professor, Head & Neck Cancer, KGMU; Dr. Parvesh Dwivedi, Director, SAMARTH and Dr. Indushri, PM-JAY Nodal, Department of Medical Education.

Lastly, my sincerest thanks to Sangeeta Singh, CEO, SACHIS, and the team at ACCESS Health International-Himani Sethi, Manisha Tripathi, Ashish Mishra and-for their unwavering support throughout this journey.

The authors acknowledge and appreciate SAMARTH for data collection. Finally, special gratitude to the beneficiary household members who consented to take part in the household survey, gave their precious time and valuable responses for the study.

Through the findings of this study, I hope we can truly uplift patients in the state, making cancer a disease that can be cured instead of a terrifying affliction that uproots their lives.



# Executive Summary

## Context

Worldwide, cancer is the second leading cause of death after cardiovascular disease accounting for 10 million deaths in 2020. The number of new cancer cases in India was 0.95 million in 2008 and is projected to increase to 1.7 million by 2035. The incidence of cancer in India is lower than in Western nations, however the mortality is higher, suggesting low health service effectiveness<sup>1</sup>. It is estimated that approximately 2 to 2.5 million people are diagnosed with cancer annually, out of which nearly half die each year. According to the Indian Council of Medical Research (ICMR), this burden will be doubled by the year 2026. The top five cancers that affect the Indian population are breast, oral, cervical, gastric, and lung cancers. The Report of National Cancer Registry Programme 2020 suggests that the leading sites of cancer among males are lung, mouth, esophagus, and stomach, while breast is the leading site of cancer among females.

The Government of India developed the first program on cancer control as early as 1971. Over the years, 27 Regional Cancer Centers (RCCs)<sup>2</sup> have been established by the government across the country, and cancer-care facilities are also available in several Medical Colleges and private and charitable hospitals in the country. The program, however, has mainly contributed to the development of treatment services and a lot needs to be achieved for prevention and early detection of the disease. Organized screening programs are still lacking for common cancers afflicting the Indian population.

Uttar Pradesh, a state with over 22 crore population, is undergoing a changing disease burden. Between 1990 and 2016, the burden of disease due to non-communicable diseases increased from 48 percent to 75 percent nationally, and from 9 percent in 1996

to 49 percent in 2019 in the state. According to the Global Burden of Disease data published by the Institute of Health Metrics and Evaluation (IHME, 2019), Uttar Pradesh has around six lakh cancer patients, with nearly 1.9 lakh new patients diagnosed each year.

The Government of Uttar Pradesh provides cancer diagnostic and treatment facilities through public health institutions, i.e., medical colleges under the Department of Medical Education (DME) and District Hospitals under the Department of Health & Family Welfare (DoH&FW). The State Agency for Comprehensive Health & Integrated Services (SACHIS) implements PM-JAY and state schemes such as Mukhya Mantri Jan Arogya Yojna and the State Employees & Pensioners Insurance Scheme (Pandit Deen Dayal Upadhyaya scheme).

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

To further their endeavors of improving the standard of cancer care and significantly contributing to better state health outcomes, a qualitative case study was conducted to understand the status of cancer care provision in the state-including prevention, screening, diagnosis, treatment, and follow-up care and recommend areas of prioritization and strengthening.

<sup>1</sup>Daphtary M, Agrawal S, Vikram B. Human resources for cancer control in Uttar Pradesh, India: a case study for low- and middle-income countries. *Front Oncol.* 2014; 4:237

<sup>2</sup>[https://main.mohfw.gov.in/sites/default/files/48679626nccp4\\_0.pdf](https://main.mohfw.gov.in/sites/default/files/48679626nccp4_0.pdf) [Accessed on 17-04-2023]

## Objectives

1. Understanding the existing continuum of care system from screening to provision of diagnostics, therapies, and palliative care between public service delivery and PM-JAY.
2. Understanding the existing patient's service environment-bottlenecks and challenges.
3. Assessing the key challenges service providers face while providing services across different stages of cancer care patient management systems, operational barriers in adoption of Standard Treatment Guidelines (STGs), motivations, and disincentives.

The study suggests recommendations for strengthening the existing public health initiatives related to screening and early diagnosis, treatment, and palliative care.

## Methodology

The study combined methods of data analytics, desk research, and qualitative primary research using socio-ecological framework, data analysis, and validation workshops.

- **Data analysis and desk research:** This included understanding the availability of cancer care services in the PM-JAY hospital network (hospitals that have been empaneled for oncology), their participation (preauthorization raised for cancer treatment), provision of oncology services—utilization in proportion to all claims, specialty wise trend—medical oncology, surgical oncology, and radiation oncology, patient profile and portability. In addition to this, the PM-JAY Health Benefit Package 2022 in the context of cancer care and other available literature in public domain and good practices from other states was also reviewed.
- **Qualitative case study:** A critical component of the study is primary research which was conducted with the participation of cancer patients and their caregivers, service providers, managers and policy makers. The study protocols were reviewed and approved by the Institutional Review Board of KGMU. The study was conducted in five districts-Lucknow, Sitapur, Hardoi, Gonda, and Bahraich-that were selected based on the high number of PM-JAY cancer patients treated at

KGMU. Care was taken to comply with ethics, verbal, and written consent, allotting considerable time for rapport building and interviews per patient, and accounting for caregiver convenience. A total of 159 in-depth interviews and six focused group discussions were conducted. This included 65 patients and 64 caregivers. Additionally, key informant interviews were conducted with 27 ASHAs and service providers including Medical Officers and staff at NCD clinics in these districts. Five focused group discussions were conducted with ASHAs in the five study districts. At state level, officials representing the DoH&FW, DME, the Non-Communicable Disease (NCD) Program, and the Uttar Pradesh Medical Supply Corporation Representative (UPMSCL), SACHIS and the PM-JAY empaneled hospitals were interviewed.

- **Data validation workshop:** This was conducted by KGMU in collaboration with SACHIS and ACCESS Health on March 3, 2023. The findings were presented and discussed with 40 participants including oncologists from premier institutions such as the KGMU, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Medanta Cancer Institute, Ram Manohar Lohia Institute of Medical Sciences, Kalyan Singh Super Specialty Cancer Institute, Tata Memorial Hospital, Apollo Medics, Hanuman Prasad Poddar Hospital, Shri Ram Murti Smarak Institute of Medical Sciences, Balarampur District Hospital etc. Additionally, officials from DoH&FW, DME, SACHIS, NCD Program, UPMSCL as well as support partners such as Roche India Healthcare Institute (RIHI), JHPIEGO, GIZ, Uttar Pradesh Technical Support Unit were in attendance. The workshop played an important role in validating the findings and prioritizing the recommendations and solutions.

## Summary findings

The findings of the study are divided into three sections: (i) landscape of cancer care provision and related implementation and operational challenges; (ii) patient pathways in navigating cancer care, and (iii) areas of consideration and recommendations.

### Landscape of cancer care provision and implementation challenges

The landscape is understood from the demand side

(communities, patients, and caregivers) and from the supply side which includes programs, policies, infrastructure, human resources, service provision etc. Uttar Pradesh has implemented various cancer care programs launched by the Government of India, and some state initiatives, towards increasing cancer awareness, screening, and treatment for reducing cancer-related mortality and morbidity. Over the years, there have been consistent efforts by the state in implementing programs for cancer care.

**Awareness, screening, and early diagnosis:** NCD Clinics have been set up in District Hospitals (DH) and Community Health Centers (CHCs) to provide comprehensive care to patients and services include screening, diagnosis, referrals for confirmatory diagnosis and treatment, and follow-up care for the five NCDs. Over the years Uttar Pradesh has established NCD clinics in 62 DHs and 332 CHCs across 75 districts and aims to expand these. Project Sampoorna was launched in 2015 under the NPCDCS, and clinics were set up in district hospitals with an aim of increasing screening and treating women for all significant noncommunicable diseases. The State Tobacco Cell was established under the National Tobacco Control Program, launched in 2007-2008. Health and Wellness Centers (HWCs) have expanded their services to include screening and management of the NCDs. At present 11,027 HWCs are operational from the target of 20,385<sup>3</sup>.

**Cancer diagnostics and treatment:** Diagnostic services and treatment for cancer in public facilities are provided through public medical colleges, Regional Cancer Care Centers, or more recently through district hospitals (Balarampur). Over time, these medical colleges and RCCs have built infrastructure for provision of chemotherapy, surgical and radiation oncology. However, with the increasing number of cases, these institutions have been experiencing a high load. Since 2018, PM-JAY provides comprehensive coverage for all types of cancer-related treatment through a network of public and private hospitals. At present, approximately 155<sup>4</sup> hospitals (26 public and 129 private) have been empaneled to provide cancer care in the state. PM-JAY is also leveraging private hospitals to increase the availability of cancer care in the state. The National Palliative Care Program is operational in 30 districts.

**Financing schemes:** The state implements several schemes to provide financial assistance to support

the treatment of cancer patients, especially for poorer and marginalized communities. These include the Mukhyamantri Cancer Rahat Kosh, Rashtriya Arogya Nidhi, and Chief Minister Distress Relief Fund.

## Implementation challenges

Over the years, there have been consistent efforts by the state in implementing programs for cancer care; however, these have not kept pace with rising incidence. There are demand, supply and systemic challenges that exist in the provision of cancer care, which lead to considerable hardships for the patient. Some of these include.

- **Limited population-based cancer awareness, screening, referrals and follow-up support as envisioned under the NPCDCS:** While frontline workers demonstrated good understanding of the program and the signs and symptoms of the disease (they were trained before COVID pandemic), a community-based assessments are not currently conducted. Within all types of NCDs, cancer screening is less than average with little to no monitoring. ASHAs reported having sufficient information about PM-JAY, however they shared that at a population-level beneficiaries are not fully aware and don't know how to take advantage of the scheme especially when there is a health emergency or medical need.
- **Cancer services at the NCD clinics services are not available:** The clinics visited underlined that the primary focus is on hypertension and diabetes, and cancer services are not provided. This is due to limited infrastructure (including lack of space for counseling and availability of equipment and diagnostics), and gaps in human resources.
- **Public provision of diagnostics and treatment is only available in medical colleges:** More recently, a few district hospitals have started provisioning medical oncology, however mostly medical colleges offer cancer care services in the public domain. Due to lack of human resources and availability of infrastructure for diagnosis and treatment, and supply chain issues for drugs cancer services have not been operationalized at district level.
- **Cancer care provision for PM-JAY patients remains limited and difficult to navigate:** While PM-JAY has created a network of 155 hospitals

<sup>3</sup>Ministry of Health and Family Welfare's Dashboard

<sup>4</sup>Hospital Empanelment Data, PMJAY, Feb 2023

empanelled for oncology services and leveraged the private hospitals (over 100) the availability is not equitable and limited availability. Majority of the hospitals are in bigger cities and towns and only 40 percent of these have provided cancer care.

The landscape of cancer care provision can significantly change to become comprehensive with concerted efforts from the government towards addressing policy and systemic issues, by healthcare providers towards increasing the service availability and awareness, and by the citizens by focusing on their health and wellbeing.

### Patient pathways in navigating cancer care

The most important component of the study was to understand and document the complex journey of cancer patients and their caregivers in navigating the cancer care. The study explores awareness about cancer, diagnosis, treatment and recovery journey, and associated challenges. The section below provides key insights of the patient journey, challenges, resilience, and insights on how these experiences can be improved.

- **Delayed identification of cancer:** This is fuelled by a lack of awareness on sign and symptoms, fear, and reliance on home remedies. With limited availability of screening and diagnosis of cancer in public health facilities, the first point for medical aid in most cases were local doctors (formal and informal), chemists, ayurvedic doctors, and homeopathic practitioners. Only when the symptoms start affecting a patient's daily life, do they seek more formal care in private and public facilities. By this point multiple providers have been reached, with multiple diagnostics and treatments. The average delay reported was 52 days, ranging between 30 days to two years, resulting in late representation for treatment.
  - **Delayed initiation of confirmatory diagnosis and treatment:** Even when diagnosed, patients reported that it takes time for them to initiate treatment. The challenges cited are financial constraints, lack of information on where good treatment is available, and distance of facilities from their home. Most respondents reported selling their assets (motorbike, land etc), taking loans, and borrowing (from family and friends) to arrange for the funds. Moreover, they tend to have very little information
- on drugs and treatment.
- **Navigation barriers at the treating institutions:** respondents reported overcrowding, long wait time for registration, and a lack of support to help with the information to navigate between different services. At the treating institution the time taken to initiate treatment can be between one week to 30 days. The reasons for the delay lack of availability of diagnostics for staging treatment.
  - **Out of pocket expenditure on treatment:** Most respondents reported buying most of the drugs on their own as they were not available the treating institution. The findings highlight that despite patients being covered by government schemes, including PM-JAY, significant costs while seeking cancer treatment are incurred on drugs. 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. This is based on the cost reported by the patients and a significant one is on the screening and diagnostics, which was already incurred by the time they reached the treating institute.
  - **Barriers in utilizing PM-JAY:** Most of the PM-JAY respondents reported that they were not aware of the scheme and by the time they were enrolled, a considerable expenditure had already been made by them. Other operational challenges include incorrect names on the Ayushman Card leading to preauthorization rejection, PM-JAY eligibility status not declared at the time of hospital registration, and lack of information on the documentation required. There was also reported confusion about entitlement among treating doctors.
  - **High level of satisfaction reported for the treating doctors, however scope to improve overall quality of care:** The respondents reported that they were extremely happy with the services provided especially by the doctors. The treating doctors showed empathy and provided counseling in accepting the disease, treatment details, side effects, and how to take care of their physical and

mental health during the treatment.

- **Dropouts without completing treatment:** The side effects of cancer treatment and financial burden contributed to patients discontinuing treatment midway, leading to interrupted treatment. Respondents reported fatigue, pain, nausea, and extreme weakness and these debilitating side effects led to poor quality of life prompting patients to discontinue treatment. Additionally, respondents reported not being able to afford expenses like hospital fees, medication costs, and travel costs as reasons for discontinuing the treatment altogether.

The study highlighted concerns regarding long waiting times, lack of guidance and navigation support for a treatment that is complex and requires multi department coordination, limited facilities for patients and their attendants, lack of investigations and medicines at affordable prices, and in some cases poor behavior of support staff.

## Areas of consideration and recommendation

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 HBP, STGs to strengthen the public delivery infrastructure to expand the access and availability for information, screening, 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 scaled up infrastructure among other things.

The study 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 to DoH&FW, DME, and for PM-JAY to SACHIS. These have been prioritized based on several rounds of discussions with state experts.

## Areas to consider for policy

- **Making cancer a notifiable disease in Uttar Pradesh:** This will enable reporting of all new cases

to the government, helping policymakers to understand the incidence, prevalence, and trends for public health programs.

- **Establishing population-based cancer registry:** This will be critical in monitoring cancer incidence, identifying high-risk groups (occupational exposure, family history), and evaluating cancer treatment by tracking patient outcomes.
- **Decentralized cancer care provision:** This will provide care closer to home and reduced overcrowding in limited treating institutions. DoH&FW and DME can collaborate to create a Uttar Pradesh centric hub and spoke model in which apex institutions like KGMU, SGPGI etc are the hub (providing diagnostics and specialized treatment) for a network of district hospitals that serve as spokes, which are strengthened to provide certain cancer basic (basic diagnostics, chemotherapy and follow up services). The spokes can be empowered through training, use of telemedicine, and under the supervision of the apex institutions.
- **Public Private Partnerships for cancer care provision at public hospitals:** This will help to leverage private sector infrastructure to increase availability of cancer treatment in Uttar Pradesh.
- **Increased financing for building infrastructure for cancer care:** Prioritize allocation towards building cancer care infrastructure, leveraging private sector partnerships and philanthropy to build state of the art cancer treating institutions.

## Areas to consider for strengthening programs and systems

- Prioritizing cancer screening and diagnosis through the District NCD Clinics, strengthening them to serve as basic cancer prevention units.
- Rapid scaling up of cancer screening and timely referrals, and use of NCD applications.
- Targeted community screening campaigns with NGOs, private diagnostic labs, mobile vans, and District NCD Clinics.
- Opportunistic screening camps in Medical Colleges and District Hospitals to screen patients already visiting these health institutions for other concerns.
- Training of ASHAs on early identification of signs

and symptoms and use of risk assessment tools.

- Popularizing the use of NCD application for reporting and monitoring at the state level.
- Operationalizing referral pathways and testing patient navigation support mechanism.
- Strengthening availability and supplies of drugs and therapies in public cancer treating institutions through state procurement.

## Areas of consideration to strengthen implementation of PM-JAY

PM-JAY offers a unique opportunity to leverage private infrastructure towards increasing 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 125 private hospitals to provide cancer treatment. If adopted, the areas of consideration provided below can positively impact the landscape of cancer care provision in the state.

- **Provisioning confirmatory cancer diagnostics under the Health Benefit Package:** While PM-JAY HBP provides high quality diagnostics, these are available only for inpatient care. The study establishes most of the expenses incurred are on diagnostics, as these are repeated at different stages. An independent first line of diagnostics package offered as OPD procedure can be introduced, which will significantly reduce the cost to the patient.
- **Partnership with private laboratories to increase access to diagnostics in PM-JAY network:** Availability of cancer diagnostics even in private sector is fragment, to improve availability SACHIS can empanel private laboratories to provide diagnostic services to the PM-JAY hospital network.
- **Increase availability of financing beyond a five-lakh cover:** While provision of the Rs 5 lakh cover that currently exists under PM-JAY is comprehensive, and still not completely utilized

with the adoption of STGs and newer cost-effective drugs, there may be a need to increase financial risk protection. State may consider setting up of corpus fund like Tamil Nadu, where 25 crores has been set aside for funding treatment once the 5-lakh cover is over. Similarly, Odisha has expanded the health cover 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 provision of additional funds when needed.

- **Establishing PM-JAY cancer registry:** SACHIS with its aggregating capability of creating the private network can initiate a registry through its network of hospitals or encourage the private hospitals to report in the national registry.

## Programmatic

- Increase awareness among beneficiaries on provision of cancer treatment under PM-JAY.
- Improve access to cancer treatment by expanding the hospital network and encouraging servicing PM-JAY beneficiaries.
- Facilitating strategic purchasing of cancer drugs for PM-JAY hospital network by collaborating with the National Cancer Grid.
- Evaluating cost effective therapies towards better treatment outcomes and quality of life.

The provision of continuum of cancer care is fragmented, with little understanding and visibility of patient journey and outcome. Improving the provision of cancer care in Uttar Pradesh will require multi-sectoral approach in which the 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, the state can significantly increase services to reduce cancer related morbidity and mortality and improve the quality of life.

# Chapter 1: Context

The morbidity and mortality burden due to non-communicable diseases (NCDs) is rising in India. A report, India: Health of The Nation's State, estimated that the proportion of deaths due to NCDs has increased from around 38 percent in 1990 to 62 percent in 2016. Cardiovascular Diseases (CVDs), Cancers, Chronic Respiratory Diseases (CRDs), and diabetes are rapidly increasing due to various reasons—including behavioural risk factors. A global burden of disease (GBD) study found that cancer contributed to 8.3 percent of the total deaths in India, with a 12 percent point increase in deaths due to cancer from 1990 to 2016. The Indian Council for Medical Research (ICMR) estimates that approximately 2 to 2.5 million cancer cases are reported annually in India; of these, nearly half die each year, a number which is expected to double by 2026. Most patients (70 - 80 percent) are diagnosed with cancer in the late stages—which means by the time they start receiving treatment, the disease has advanced rapidly in the body, leading to poor patient survival. In India, tobacco-related head and neck cancers among men and cervical cancer among women are the predominant types of cancers.

Uttar Pradesh experienced a surge in the overall incidence rate of cancer patients from 1990 to 2019, as it increased from 72 to 79 per one hundred thousand people. Although the state's incidence rate is lower, these figures translate to 1.9 lakh cases annually<sup>5</sup>. The five most common cancers among females in the state are cancers of the breast, cervix, stomach, lip, oral cavity, and colon. The top six most common cancers among men are cancers of the lip, oral cavity, pharynx (other than nasopharynx cancer), stomach, lung, and colon and rectum.

Cancer care-related treatments are costly and tend to have devastating impacts on patients and their families. Studies have shown that households with a family member with cancer have a 2 - 3 percent lower work participation rate. On the other hand, their borrowing and selling rate stands at 50 percent to raise funds for the treatment—which is

considerably higher than households without a member with cancer (16 percent). Data from the 71st round on the Key Indicators of Social Consumption in India: Health by the National Sample Survey Organisation (NSSO) shows that approximately one-third of households with cancer patients spend more than 10 percent of their per capita household expenditure on cancer treatment<sup>6</sup>. Almost three-fourths of the expenditure on cancer is out of pocket. Other studies have shown that patients with cancer have a higher risk of incurring catastrophic health expenditures than those diagnosed with noncommunicable diseases. Hence, delivering affordable cancer care is the need of the hour, and will require a high level of commitment and prioritization from the Government.

To achieve the globally agreed Sustainable Development Goals (SDGs) of Universal Health Coverage, the Government of India introduced Ayushman Bharat reforms with two components to provide a continuum of care. These reforms have a provision for comprehensive primary healthcare services, free essential drugs and diagnostics, and preventive healthcare through 1.5 Lakh Health and Wellness Centers (HWCs). The second component is the Pradhan Mantri Jan Arogya Yojana (PM-JAY), tax funded health insurance scheme, that provides financial protection for hospitalization expenses to 10 crore families or approximately 50 crore individuals who have been identified as vulnerable. PM-JAY provides hospitalization services for 26 specialities, including cancer care, which can be availed through a network of empaneled private and public hospitals. The Health Benefit Package (HBP) for cancer treatment has expanded in the last four years and provides 557 packages combining medical (289 packages), radiotherapy (54 packages), and surgical oncology (214 packages). Additional palliative care packages were also included in 2022.

The Government of Uttar Pradesh provides cancer diagnostics and treatment through public health institutions, i.e., medical colleges under the

<sup>5</sup>Dandona, L. (2018). The burden of cancers and their variations across the states of India: The Global Burden of Disease Study 1990–2016. *Lancet Oncol*, 19: 1289–306.

<sup>6</sup>Datta, A. (2013). Study finds that half of Indian households affected by cancer must sell assets to fund care. *BMJ*.

Department of Medical Education (DME) and District Hospitals under the Department of Health & Family Welfare (DoH&FW). Additionally, the State Agency for Comprehensive Health & Integrated Services (SACHIS) covers approximately eight crore people through PM-JAY, Mukhya Mantri Jan Arogya Yojna (a state health insurance scheme), and the State Employees & Pensioners Insurance Scheme (Pandit Deen Dayal Upadhyaya scheme). SACHIS has created a network of over 3400 public and private hospitals and has covered over 20 Lakh<sup>7</sup> hospitalizations so far—including cancer treatment in the last four years of implementation.

King George's Medical University (KGMU) is an apex institution in the state that offers medical education and is a major provider of health services with an annual patient load of 15 lakh patients and 1 lakh indoor admissions. KGMU partners with SACHIS in the provision of health services including cancer care under the PM-JAY. ACCESS Health, a not-for-profit organization, provides implementation support to SACHIS towards building state leadership in evidence-based implementation and the use of efficient, multisectoral, and cost-effective interventions for strengthening PM-JAY.

Cancer care is complex and there are challenges related to lack of awareness and social cultural barriers that results in low uptake of screening services, issues of infrastructure and accessibility that results in long waiting times, incomplete treatment and limited follow up, out of pocket expenditure and emotional and physical distress. Even though PM-JAY has provided an opportunity to address some of the supply issues, however there are several policy and programmatic challenges that affect the demand and supply and need urgent attention in Uttar Pradesh.

Towards this end, KGMU in partnership with SACHIS and ACCESS Health designed and conducted a qualitative landscape study to understand the current scenario of cancer care provision in the state to further their endeavour to improve the standard of cancer care and significantly contribute to better state health outcomes. The study covered both the provision of cancer care through public hospitals and through PM-JAY (both public and private) and suggests recommendations for prioritization and areas of strengthening related to screening and early diagnosis, treatment, and palliative care.



# Chapter 2: Objectives and Methodology

The objective of the study is to understand the status of cancer care provision in the state, including prevention, screening, diagnosis, treatment, and follow-up care. To that end, the following areas have been studied:

1. Understanding the existing continuum of care system from screening to the provision of diagnostics, therapies, and palliative care between public service delivery and PM-JAY.
2. Understanding the existing service environment for patients-bottlenecks and challenges.
3. Assessing the key challenges faced by providers in service provision, patient management systems, operational barriers in the adoption of Standard Treatment Guidelines (STGs), their motivations, and incentives.

Specifically for PM-JAY, the study aimed to provide insights on the operational challenges faced by the providers in cancer care provision under the scheme and obstacles along the patient journey to address both demand and supply challenges. The study also offers areas of recommendations to the DoH&FW towards prioritizing cancer care especially improving service provision, identification, management, and follow up care towards strengthening standards of care for cancer patients.

## Methodology

The study combined methods of data analytics, desk research, and qualitative primary research using socio-ecological framework, data analysis, and validation workshops.

### Data analysis and desk research

The data analysis was conducted by SACHIS with support from ACCESS Health and focused on understanding the availability of cancer care in PM-JAY hospital network (hospitals who have empaneled for oncology), their participation (preauthorization raised for cancer treatment), provision of oncology services--utilization in proportion to all claims, specialty wise trend - medical oncology, surgical oncology and radiation oncology, patient profile and

portability. Additionally, 100 sample cases were identified to conduct in-depth understanding of utilization and understanding the level of compliance of STGs. The analysis was conducted for the timeframe of 2018 – 2021 and data sources included Transaction Management System (TMS) and Hospital Empanelment Module (HEM).

In addition, the PM-JAY Health Benefit Package 2022 in the context of cancer care and other available literature and practices from other states in public domain were also reviewed.

### Qualitative case study

A critical component of the study was the primary research which was conducted in participation with the cancer patients and caregivers to understand and document the patient experience, challenges, expenses, and insights. Additionally interviews and focus group discussions with state and district implementers and managers, service providers (public and private), and frontline workers were conducted to understand the supply side challenges in provisioning cancer care.

The socio-ecological framework was used to design the qualitative case study to understand how cancer screening, management, and follow-up care interact within the context of the larger social and environmental factors. This theory-driven framework considers the multiple spheres of influence (individual, interpersonal, organizational, community, and policy) that impact health-seeking behavior. These spheres of influence do not interact linearly with each other, but in complex ways. This approach offers additional insights into gaps in service delivery or why one implementation strategy might be chosen over others. The case study primarily used the life history method to understand the cancer patient's journey. A checklist was developed and pretested for the range of caregivers associated with cancer patients.

- **Study setting:** The study was conducted in five districts-Lucknow, Sitapur, Hardoi, Gonda, and Bahraich-that were selected based on the high number of PM-JAY cancer patients treated at KGMU.

- **Selection of patients and caregivers:** The patients were shortlisted from the Hospital-Based Cancer Registry (HBCR) of KGMU under three categories (i) PM-JAY patients; (ii) patients covered by Prime Minister, Chief Minister schemes and other insurance coverage; and (iii) patients with no insurance cover. Patients above the age of 18 years, diagnosed between June 2021 -2022 and being treated for any of the five types of cancers-- Cervix, Breast, Oral, Oesophagus, and Gallbladder were considered. Patients with advanced metastasis and with a history of mental illness were not considered. Using the above criteria, a shortlist of patients was developed, and those who consented to participate in the study were recruited. All care was taken to comply with ethics, verbal and written consent, considerable time was allotted for rapport building and interviews per patient, and caregiver convenience was followed.
- **Tools:** The following tools were developed, field tested, and translated in Hindi.
  1. In-depth interview guide for patients
  2. In-depth interview guide for caregivers
  3. In-depth interview guide & Focused Group Discussions Guide (FGD) for ASHAs
  4. In-depth interview guide for Program Managers/Nodal officers under PM-JAY
  5. In-depth interview guide Medical Officers and Chief Medical Superintendent.
- **Training and field practice:** A four-day training was conducted with the research team to develop a common understanding of the objectives, methods, and data collection. The training included orientation and field practice in Community Health Centers (CHCs) and Primary Health Centers (PHCs) in Lucknow. Post the field sessions, their feedback about the tools was incorporated.
- **Ethics review board:** The detailed protocol of the study along with the tools were submitted to the Institutional Review Board of KGMU, that reviewed the study protocol and tools and consented to proceed. On August 11, 2022, the ethics committee at KGMU approved the study titled "Understanding the Continuum of Cancer Care in UP: A Qualitative Case Study Approach" with reference number 117th ECM IB/ P3.
- **Data collection:** A total of 159 in-depth interviews and six FGDs were conducted. This included 65 patients and 64 caregivers. Additionally, key informant interviews were conducted with 27 ASHAs and service providers including Medical Officers and staff of NCD clinics. Five FGDs were conducted with ASHAs in the five study districts. At state level, officials representing the Department of Health and Family Welfare, the Department of Medical Education, the Non-Communicable Disease (NCD) Program, and the Uttar Pradesh Medical Supply Corporation Representative, SACHIS and the PM-JAY empaneled hospitals were interviewed.
- **Data validation workshop:** Considering the qualitative nature of the responses, which are subject to individual interpretation, a data validation workshop was conducted by KGMU in collaboration with SACHIS and ACCESS Health on March 3, 2023. The workshop was conducted with over 40 representatives including oncologists from premier institutions such as the KGMU, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Medanta Cancer Institute, Ram Manohar Lohia Institute of Medical Sciences, Kalyan Singh Super Specialty Cancer Institute, Tata Memorial Hospital, Apollo Medics, Hanuman Prasad Poddar Hospital, Shri Ram Murti Smarak Institute of Medical Sciences, and Balarampur District Hospital etc. Additionally, officials from DoH&FW, DME, SACHIS, Non-Communicable Disease Program, UPMSCL, support partners such as RIHI, JHPIEGO, GIZ, and Uttar Pradesh Technical Support Unit were also a part of the workshop. The workshops played an important role in validating the findings and prioritizing the recommendations and solutions.

## Limitations of the study

The study sample size is limited, and thus the findings cannot be generalized for the entire state of Uttar Pradesh. The study findings should be interpreted with caution and cannot be extended to other populations or contexts. For instance, reporting the out-of-pocket expenditure may suffer from recall bias and other individual biases, so the findings must be substantiated carefully. Additionally, evaluations of hospital care quality are subjective and dependent on the patient's expectations. However, the insights gained from this study can guide further studies or programs in the field and enhance our understanding of the phenomenon in the state.

# Chapter 3: Landscape of Cancer Care Provision in Uttar Pradesh

The landscape of cancer provision is understood from the demand side (communities, patients, and caregivers) and from the supply side which includes programs, policies, infrastructure, human resources, service provision etc. This section captures the provision of cancer care, in which the key actors in public service delivery include DoH&FW, DME, National Health Mission (NHM), the National Program for Prevention and Control of Cancer, Diabetes, Cardiovascular diseases and Stroke (NPCDCS), Uttar Pradesh Medical Supplies Corporation Limited (UPMSCL), SACHIS, and a network of public treating institutions. On the private service delivery side, there are private medical colleges and hospitals, supply chain partners whose primary focus is on diagnostics, treatment, and palliative care with little emphasis on health promotion, screening, and early diagnosis. In addition, there are patient advocacy groups and community organizations which complement the public and private initiatives.

The findings presented below combine the insights from secondary data review of policies, program implementation plans, research studies, primary data based on the field visits to the 10 NCD clinics, and discussions providers, managers, and frontline workers.

## Implementation of cancer care programs

Uttar Pradesh has implemented various cancer care programs launched by the Government of India and some state initiatives towards increasing cancer awareness, screening, and treatment for reducing cancer-related mortality and morbidity. More recently, initiatives on palliative care have been designed and are in the early stages of implementation. One of the major programs Uttar Pradesh implements is the NPCDCS, which was launched by the Government of India in 2008 on a limited scale (100 districts), and then extended across the country in 2017.

The NPCDCS provides detailed operational guidelines for the development of infrastructure,

deployment of human resources, training etc. towards health promotion, screening and early detection, timely affordable and accurate diagnosis, access to affordable treatment and rehabilitation. In addition, guidelines for screening and management for three common cancers were also released in 2017. A paradigm shift proposed under the program included population-based screening close to the community by ASHAs and Auxiliary Nursing Midwife (ANMs), the use of NCD application for capturing patient-wise data with referral of high-risk cases to Primary Health Centers (PHCs), Community Health Centers (CHCs), and District Hospitals (DH) on the availability of services for examination and confirmation. The intent was early screening and comprehensive management of cancers. Under the umbrella of NPCDCS, several initiatives have been implemented in the state for screening, diagnosis, and treatment. Some of these include:

### Programs on awareness, screening, referrals and early diagnosis

- **Setting up of NCD clinics:** NCD Clinics are set up in DHs and CHCs to provide comprehensive care to patients. Their services include screening, diagnosis, referrals for confirmatory diagnosis, and treatment and follow-up care for the five NCDs. Over the years, Uttar Pradesh has established NCD clinics in 62 DHs and 332 CHCs across 75 districts. NCD clinics receive funding from the National Health Mission. The state intends to expand this to all 75 DHs, 427 CHCs as provisioned under program implementation for the current year.
- **Sampoorna clinics:** Project Sampoorna, launched in 2015 under NPCDCS, is aimed towards increasing screening and treating women for all significant NCDs. The project was implemented by the NHM, State Innovations in Family Planning Services (SIFPSA), and Population Services International (PSI). The clinics were established at district women hospitals and selected CHCs in 28 districts. At present not much is known about the functioning of these clinics, however the

discussions highlighted that Sampoorna Clinics are still operational in 14 districts and the state plan to scale these to all districts.

- **Dedicated tobacco control cell:** In Uttar Pradesh, the State Tobacco Cell was established under the National Tobacco Control Program launched in 2007-2008 to enforce tobacco control strategies. The state implements and monitors various anti-tobacco initiatives, like public awareness through local Information Education and Communication (IEC) activities and tobacco cessation services at the DH Outpatient Department. The tobacco control program is running in the 75 districts of the state.
- **National palliative care program:** This was launched nationally in 2012 to address the issue of care due to poor treatment outcomes due to late-stage presentation of cancer patients for treatment. In Uttar Pradesh, the palliative program is in the inception stage. It was reported that the program is operational in 30 districts with a budgetary provision for renovation of Outpatient Departments, training of staff, IEC, travel, and drugs.
- **Health and wellness centers:** In 2018 with the Ayushman Bharat reforms, the mandate of the PHCs expanded to include screening and management of NCDs. Their services include population-based screening through ASHAs, referrals, confirmation and follow up support. At present, 11,027 HWCs are operational from the target of 20,385<sup>9</sup>. The Community Health Officers at HWCs reported having been trained on NCDs, including cancer.

**Balarampur district hospital:** This is one of the District Hospitals in Uttar Pradesh, which has started offering Medical Oncology services from August 2022 onwards. The center has diagnostics Computed Tomography (CT), Fine Needle Aspiration Cytology (FNAC), Biopsy, and Histopathology. It also offers cancer drugs.

Services are provided free of cost to patients below poverty line. For others, diagnostics are paid, while treatment is free. The center has provided treatment to over 275 cancer patients so far.

The challenges reported at the Balarampur DH include the unavailability of drugs due to

individual indenting by the center. This results in delay of initiating treatment and patients end up buying drugs from the market leading to OOOPE.

Areas of strengthening include improve supply of drugs (through medical colleges), radiological investigations, setting up stronger hospital information system to ensure follow up.

### Provision of cancer diagnostics and treatment

- **Public institutions:** Diagnostics and treatment for cancer in public facilities is provided through public medical colleges also known as the Regional Cancer Care Centers (8 RCCs)<sup>9</sup>, and more recently through district hospitals (Balarampur). Over a period, the medical colleges or RCCs have built infrastructure for the provision of chemotherapy, and surgical and radiation oncology. However, with the increasing number of cases, these institutions experience high loads.
- **Pradhan Mantri Jan Arogya Yojana:** PM-JAY provides comprehensive coverage for all types of cancer-related treatments including palliative care. The HBP 2022 released has 25 new chemotherapy therapy treatments includes covers CA Breast, Ovary, Endometrial, metastatic cancer etc, 9 radiation procedures, 89 surgical procedures, 32 palliative procedures that cover medical, surgical and radiation oncology. The special packages with multiple procedures and therapies, cross specialty packages, list of implants and high-end consumables and any preventive packages are available to the treating institution to provide care. More importantly PM-JAY has been able to create a network of private hospitals in the state which provide care. At present, approximately 155<sup>10</sup> hospitals (26 public and 129 private) have been empaneled to provide cancer care in the state. Of these 155 facilities, 17 are medical colleges (11 public and six private).
- **The national cancer grid:** The NCG is a network of cancer centers, research institutions, and healthcare professionals who work together to improve availability of good quality cancer care services. Institutions from the state are part of the network and through these work towards improving quality of care and research. Some of

<sup>9</sup>Ministry of Health and Family Welfare's Dashboard

<sup>9</sup>Dr. Ram Manohar Lohia Institute of Medical Sciences, Lucknow, King George's Medical University, Lucknow, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, Regional Cancer Centre, Kamla Nehru Memorial Hospital, Allahabad BRD Medical College, Gorakhpur, Mahamana Pandit Madan Mohan Malviya Cancer Centre, Varanasi, Motilal Nehru Medical College, Allahabad, Lala Lajpat Rai Memorial Medical College, Meerut

<sup>10</sup>Hospital Empanelment Data, PMJAY, Feb 2023

the institutions parts of network are Dr. Ram Manohar Lohia Institute of Medical Science, Lucknow, SGPGI, Tata Memorial Center, Varanasi.

## Government schemes

The state implements several schemes to provide financial assistance to support the treatment of cancer patients especially for poorer and marginalized communities. Some of these include:

- **Mukhyamantri Cancer Rahat Kosh:** This provides financial assistance for upto Rs 2 Lakh to cancer patients below poverty line.
- **Rashtriya Arogya Nidhi:** An umbrella scheme that includes the Health Minister's Discretionary Grant and the Mukhyamantri Cancer Kosh, this provides one-time financial assistance up to 15 lakh including post treatment assistance to poor patients suffering from any life-threatening illnesses, including cancer. However, the treatment can only be taken in the network of 27 government cancer treating hospitals across India. In Uttar Pradesh, the Sanjay Gandhi Post Graduate Institute (SGPGI) and Kamla Nehru Memorial Hospital, Allahabad participate in the scheme. Patients covered by PM-JAY are exempted from the benefits for this scheme.
- **Chief Minister Distress Relief Fund:** This provides financial assistance to patients needing medical treatment for life threatening diseases.

While these schemes exist and are used to a certain extent, there is limited awareness on how to avail them. Most patients come to know of them just prior to beginning treatment. Furthermore, the coverage provided may not be enough. It's important to note that there is little information available on impact of these schemes on the treatment outcomes.

Over the years, the state has prioritized cancer care significantly; however, considering the increasing incidence of and assessment of programs, there exists a few significant implementation challenges, which have been presented in the next section.

## Implementation challenges

This section captures the implementation challenges reported during the qualitative study by the frontline workers, service providers at the NCD Clinics and

district and state level officials. The section includes insights on the community's perception towards cancer, their knowledge on the availability of treatment, their role and capacity in providing cancer care, awareness on PM-JAY, and the challenges faced in service provision. It also captures challenges faced in the provision of cancer care through various programs.

### Limited population-based screening, referrals and follow up support:

A key component of NPCDCS is population-based screening which is meant to be implemented by frontline workers. ASHAs play an important role in this, offering referrals for high-risk patients and any support during the treatment. ASHAs are required to conduct a Community Based Assessment Checklist (CBAC) for all women and men over 30 years in their population. The assessment captures data related to age, family history, treatment for any of the NCDs, waist circumference, and high-risk behaviors. For conducting the assessment, an ASHA is provided an incentive of Rs 10, which increases to Rs 100 for patient follow-up. The key takeaways on community-based interventions are:

- **Communities believe that cancer is a "deadly disease that cannot be cured."** It is a disease with little awareness, a lot of myths, misconceptions (especially of it being communicable) and fear are associated with it, which leads to delay in dealing with it. Even when symptoms become a problem the reliance remains on local doctors and use of home remedies.
- **Limited availability of cancer care services in the lower level of public facilities** and no services for screening and diagnosis available in CHCs and DH. This is a barrier for people to seek timely care as diagnostics and treatment are only available in medical colleges in cities.
- **ASHAs demonstrated good understanding of the NCD program but do not conduct CBAC or use NCD applications.** Some level of trainings on NCD including cancer is provided to them just before the COVID pandemic. However, with the complexity of the disease management, the ASHAs suggested that refresher trainings and provision of job aids (checklist /IEC) can improve their functioning.
- **High awareness on PM-JAY and related entitlements among ASHAs.** Most ASHAs know about the scheme, range of health services it offers, and that beneficiaries can go to

empaneled private hospitals also for seeking care. They however reported that even after years, beneficiaries are not very sure how to get enrolled and use the scheme at the time of medical emergency.

#### **Inadequate service provision at the NCD clinics:**

The assessment covered 10 NCD clinics in five study districts to understand the implementation challenges in the provision of cancer care through the clinics. Interviews were conducted with Medical Officers, NCD Nodal Officers, Counselors, and Block Program Managers under NHM. The focus was to understand the operational challenges and community behavior. The key takeaways are:

- **Cancer services are not available** or provided through NCD clinics, the primary focus is only on hypertension and diabetes.
- **Limited infrastructure and inadequate human resources** are the reported barriers hindering full functioning of the clinics. As per the guidelines, an NCD clinic should be equipped with a six-member staff comprising of a Physician, General Nursing Midwife, Physiotherapist, Technician, Counselor, and Data Entry Operator: however, the study found that out of 10 NCD clinics visited only two clinics have full staff, and the remaining eight clinics had partial staff availability. The staffing at clinics in District Hospitals are better. No doctors are available at any of the clinics in the CHCs.
- **At the district level, only 23 clinics in district hospitals have the positions of physicians filled.** The gap in staffing was attributed to a poor payment structure provided under the program. Lack of physical space at the clinics especially service provision of examination and counselling was also reported.
- **Gaps in the availability of equipment and diagnostics also exist.** For instance, the service provision at NCD clinic includes risk assessment, clinical examination, and investigation Visual Inspection (VIA/VILI for Cervix and Oral). The study identified gaps in the availability of equipment and basic diagnostics. For instance, the VIA method necessitates specialized equipment, and not just acetic acid, which were not available.
- **Lack of comprehensive training** was reported by the NCD staff. The last training was provided three

years ago; this results in limited knowledge on cancer screening and protocols of the program.

- **Manual system for recording and referrals** leads to lack of tracking and follow-ups. In some clinics, referral cards were available.

The above findings are corroborated with a similar but much larger study for strengthening of District Health Management Systems for Non-Communicable Diseases in Uttar Pradesh, which was conducted by Department of Community Medicine, KGMU in 2018-2019. The study was conducted with the participation with 36 District Hospitals, 72 Primary Health Centers, and 72 Sub Centers across 18 select districts. The study highlighted similar challenges, signifying the gradual and slow progress under NPCDCS. Similar findings included lack of provision of cancer screening services, with a higher focus on hypertension and diabetes; lack of human resource deployment (physician and support staff), training, availability of screening protocols, referral guidelines, limited availability of diagnostics and consumables (no provision of histopathology in District Hospitals), and poor documentation at NCD clinics for tracking the patients.

Other studies have also assessed different components of the cancer care program to highlight the implementation challenges faced. A study of the NPCDCS services in Lucknow<sup>11</sup> found that at the population level, there is low awareness and utilization of services. An assessment of implementation of NPCDCS in a district of Uttar Pradesh<sup>12</sup> found several implementation challenges faced by the program such as limited funding, inadequate human resources, weak monitoring and evaluation, and limited partnerships.

**Inadequate cancer diagnostics and treatment in public hospitals:** Out of the 40 public medical colleges in Uttar Pradesh, 36 colleges are under the DME, two are All India Institute of Medical Sciences (AIIMS) and Banaras Hindu University and Aligarh Muslim University are under the union government institutions. Cancer care is provisioned through 18 medical colleges (14 under DME, AIIMS and union government medical colleges) and have a cancer department called the Radiation/ Oncology department. In the remaining 22 colleges under DME, the departments have been set up, however they are not fully functional. Thus, provision of cancer care is

<sup>11</sup>Sandhya Gupta, et al. (Journal of Family Medicine and Primary Care, 2019)

<sup>12</sup>Ramesh Chandra Sachan, et al. (Indian Journal of Community Health, 2018).

limited to a few medical colleges and very few district hospitals (Balarampur). This is both due lack of human resources and the availability of infrastructure for diagnosis and treatment.

Government data available from various sources reveal that Uttar Pradesh is grossly lacking physicians at the DHs and lower levels. According to rural health statistics published by the Ministry, only 72 percent of the sanctioned positions at the District Hospital are currently filled. Similarly, only 42 percent of CHCs have occupied positions.

It was reported the state attempted implementing the suggestions from Dr. Rohit Pendarkar model of patient centric care<sup>13</sup> in 2018-2019, to increase the availability of cancer treatment by training doctors in District Hospitals to administer chemotherapy drugs. However, there was a resistance from District Hospitals and doctors who did not feel equipped to provide cancer treatment and feared legal action. As a result, the initiative was not successful. Thus, inadequate human resource is barrier. In general, only a handful of institutions provide confirmatory diagnostics in public sector for the state of over 22 crore population.

**Non-availability and timely availability of cancer drugs:** At present, medical colleges providing cancer treatment have their independent rate contracts through which cancer drugs are procured. UPMSCL procures only essential drugs from the drug list (286) provided by the Directorate and rate contracts are available for 264 drugs. The drugs are supplied only to the public sector facilities including some medical colleges, which are not autonomous. It was reported that cancer drugs form only 1 percent of drugs in the Higher Drug List availability, thus highlighting that availability of drugs is a major barrier for patients, who must procure these from outside and pay out of pocket. The study found that in 2019-2020 cancer drugs were procured but no indents were raised by the District Hospitals (in absence of human resource to administer the treatment) and the drugs were wasted. Since then, procurement for the cancer drugs by UPMSCL has been stopped. While apex institutions have a stable internal system of procurement, in the absence of government procurement other facilities (District Hospitals) face challenges in individual indenting, which leads to delay and patients buying drugs out of pocket.

**Cancer care provision under PM-JAY remains limited and difficult to navigate:** While PM-JAY has provided an immense opportunity to advance the agenda for cancer care, there are supply side challenges that affect optimum utilization.

- **Limited availability of hospitals empaneled for oncology services:** In the last 4 years, there are approximately 155 hospitals which have empaneled to provide cancer treatment, which accounts for only 5 percent of the hospital network. There are approximately 129 private hospitals that have been empaneled for the provision of cancer care. Majority of these are in bigger cities and towns leading to unavailability in several areas of the state. Analysis highlights that over 90 percent of beneficiaries were treated in Lucknow, Varanasi, Bareilly, Gorakhpur, Allahabad, Meerut, and Kanpur Nagar, which has the highest availability of hospitals empaneled for cancer treatment.
- **Limited participation of private hospitals in servicing PM-JAY patients for cancer treatment:** An analysis done by SACHIS to understand the provision of cancer treatment through PM-JAY highlights that not all hospitals empaneled have been provisioned for oncology services. There are less than 40 percent hospitals that have serviced beneficiaries despite being empaneled for cancer treatment. Reasons include the lack of specialists (Oncologist) in their hospitals, limited availability of infrastructure per the STGs to provide care, inadequate understanding of the provisions of the HBPs and fear of delayed payment cycles. The hospital also reported lack of awareness among patients about the private hospitals that have been empaneled for cancer treatment because of which they end up going outside the state. Thus, while a network of private hospitals has been created, real availability is still limited.
- **Lack of information and understanding on how to utilize the scheme by the patients:** Patients covered under PM-JAY are entitled to comprehensive treatment (diagnostics during inpatient care and drugs and therapies by the HBP). However, there are challenges in awareness on coverage and how to utilize the benefits.
- **High portability:** Many patients travel outside their home district or state to get treatment. Cancer

<sup>13</sup>Dr. Rohit Pendarkar, a radiation oncologist developed a patient centric model that focused on personalized care and support to patients, a multidisciplinary team approach, developing infrastructure, patient accommodation and support services and capacity building. The model has been adopted by many hospitals such as the Tata Memorial Centre, Rajiv Gandhi Cancer Institute and Research Centre, Christian Medical College which improved care quality of care for patients.

treatment under PM-JAY sees over 30 percent portability to other states such as Madhya Pradesh & Uttarakhand, which increases both out of pocket expenses and chances of patients dropping out of treatment due to logistical issues.

### Challenges in administration of NPCDCS

The NPCDCS program is implemented by the DoH&FW in coordination with NHM. The State Nodal Officer is supported through four staff positions (State Program Officer, Program Coordinator, Finance cum Logistics Consultant, and Data Entry Operator). A similar structure is proposed at the district level, however there are issues of under staffing due to vacancies at both state and district level, which affects implementation, specially monitoring. There are competing health priorities which affects the implementation of NPCDCS. Within the NPCDCS, cancer is the most under serviced focal area. While budgets are available through program implementation plans, their utilization could not be studied.

### Challenges reported by provider empanelled under PM-JAY

The providers (oncologist and physicians) from hospitals empaneled under PM-JAY highlighted issues related to the health benefit packages, need to expand therapies, and diagnostics and operational issues faced while servicing the PM-JAY beneficiaries.

- Diagnostics under health benefit package – PM-JAY packages are for post diagnosis treatment of the patient. It has two packages one each for serological and imaging, however they are available only for in patient care, thus highlighting the need to de-bundle the diagnostics component that can be exercised for pre work up and detection phase. Further the package provides for three days pre work up period for diagnosis, however certain tests like histopathology and biopsy require 7 to 15 days. Provision of chemotherapy requires investigations during and post treatment, which are not currently included, similarly PET Scan<sup>14</sup> and FISH testing is not included.

*A senior oncologist cited 'our experience with patients is that a cost of Rs 2000 for core-biopsy causes hardships for them when they have the lump for even more than 2-3 months. Therefore,*

*the pre-diagnosis examinations too must be covered by PM-JAY.*

- Therapies under the health benefit package - there is no package for metronomic treatment, which allows administering lower doses than the maximum tolerated doses over a longer period and resulting in fewer side effects. Inability to manage the side effects is one of the main reasons for dropping out of treatment. Similarly, multiple myeloma is not included. Chemotherapy cycle intervals under certain packages such as urinary bladder are high (cycle interval is 21 days, however it could be reduced to one week. While palliative care packages are comprehensive, however the duration is very short. For example, duration per package is 4 to 5 days, however, to treat conditions like lymphadenitis a minimum of 15 to 20 days. Reducing the per day rate and increasing the duration can be considered.
- Need for additional packages such as head and neck, electro beam radiotherapy under radiation oncology, rehydration, and supportive treatment for patients with chemotherapy and radiotherapy. package for recurrent disease occurring after mastectomy and Ca ovary and packages for post-chemotherapy complications.
- The current package cost of concurrent chemotherapy is discouraging for private sector, which results in referrals to public health institution leading to patient distress and out of pocket expenses.
- Patient related challenges – result in primary delay (by patient or family), secondary delay (delay by doctors of first point of contact - family physician or quacks/alternative medicine practitioners), tertiary delay (delay in treating institutions - waiting list, delayed reporting, doctors on leave, strikes) and quaternary delay (patient hopping from provider to the other or mid-course attrition to alternative treatment). Further providers cited that a lot of patients do not know where services under PM-JAY are available.

### Conclusion

Over the years, there have been consistent efforts by the state in implementing programs for cancer care, however these have not kept pace with rising incidence. There are demand, supply and systemic

<sup>14</sup>During the study, the PET Scan was included in the HBP by NHA



challenges that exist in provision of cancer care, which cause considerable hardship to the people. At an information level, there is limited state data available for cancer. While at the national level there are 38 Population-Based Cancer Registries (PBCRs) and 189 HBCRs registered under the ICMR and the National Center for Disease Informatics and Research (NCDIR). Uttar Pradesh has PBCRs at only three sites—Allahabad, Aligarh, and Gautam Buddha Nagar (NCDIR, 2022). There is an urgent need to have more and real time data on prevalence for the state to be able to plan. A state-wide cancer registry which helps collate data on incidence, prevalence, and mortality can be considered. Thus, a population-based registry under PM-JAY might be a good idea to begin or if hospitals can be encouraged to report on the national registry.

At a program level, the NPCDCS program, which was supposed to result in increased awareness, early identification, and diagnosis has not led to the desired results. There is limited awareness on signs and symptoms, lack of screening (population and opportunistic) for early identification, and lack of diagnostic infrastructure. While 394 NCD clinics have been established in DHs and CHCs, service provision for cancer is not available and the program has only been able to roll out services for diabetes and hypertension. The program implementation reports of NHM suggests that around 16 lakh people above the age of 30 years have been screened for oral cancer, 6 lakh women for breast cancer, and 2.6 lakh women for cervical cancer; however, in relation to the state population, these numbers are not optimum. Additionally, there is little information post screening on people identified at risk for cancer. The National Family Health Survey-5 corroborates the poor coverage of screening of the common cancers with only 1 percent of women aged 30–49 ever

undergoing screening for cervix cancer, 0.3 percent for breast cancer and 0.6 percent screened for oral cancer.<sup>15</sup>

The health system challenges include lack of human resources (only 23 out of 62 NCD clinics have a physician deployed), availability of screening equipment, system of referrals, and non-use of NCD application. At a community level ASHAs, are overwhelmed with other health-related tasks, limited training, job aids, and lack of monitoring affecting the awareness and screening programs.

Thus, population-based screening may not be the solution for the state; instead, the strategy could be opportunistic screening programs in districts reporting higher incidence. The PM-JAY data provides information on districts from where higher patients are coming, these could be prioritized, and screening could be intensified. Besides frontline workers, partnerships with private sector and civil society organization needs to be explored.

At service provision level, the number of public and private hospitals remain limited and affected with shortages of human resources especially specialist (oncologist, radiotherapist, oncology nurses). An analysis in Uttar Pradesh highlights that state has only 20 radiation oncologists<sup>17</sup> per 1 crore population, compared to ideal ratio of 50 per crore as recommended by World Health Organization. Even at a physician level only 23 out of the 62 NCD clinics have Medical Officers deployed. There is an urgent need to understand the current availability of human resources and estimate the requirements. The table shows the estimated human resources and infrastructure that need to be built in Uttar Pradesh to respond to the increasing incidence of cancer. This requires increase availability of funds, policy action and leveraging the private sector. In long-term,

## Estimated Resource for Cancer Care in Uttar Pradesh<sup>16</sup>

Human Resources	Equipment
<ul style="list-style-type: none"> <li>▪ 570 – 760 Radiation Oncologist</li> <li>▪ 380 Medical Oncologist</li> <li>▪ 380 Surgical Oncologist</li> <li>▪ 380 Pathologist</li> <li>▪ 1140 to 1330 Radiotherapy Technician</li> </ul>	<ul style="list-style-type: none"> <li>▪ 1 Megavoltage tele therapy unit (Linear or Cobalt) per 1000 new cancer cases</li> <li>▪ 1 Brachytherapy Unit per 1000 new cancer cases</li> <li>▪ 1 CT stimulator per 1000 new cancer cases</li> </ul>

<sup>15</sup>[http://rchiips.org/nfhs/NFHS-5Reports/Uttar\\_Pradesh.pdf](http://rchiips.org/nfhs/NFHS-5Reports/Uttar_Pradesh.pdf) [Accessed on 18.04.2023]

<sup>16</sup>As per Daphtary et al published study for cancer control in UP & International Atomic Energy Agency

<sup>17</sup>"Human Resource Gaps in Cancer Control in India: A 2014 Analysis" conducted by authors Arora et al. 2017.

increasing the number of seats in different oncology specialty needs to be considered and in near-term training the existing district level providers in providing medical oncology under the supervision of medical colleges could be planned.

Public investment in strengthening the infrastructure with diagnostic tools, such as imaging machines, laboratory equipment in public medical colleges, and 18 divisional district hospitals can play an important role in reducing geographical inequities. Additionally, the state has private diagnostic infrastructure, which can be leveraged through public private partnerships.

There is evidence that PM-JAY has led to an increase in utilization for cancer treatment among low-income

households<sup>18</sup>. Thus, strengthening PM-JAY implementation by empanelling more private hospitals that provision for cancer care, encouraging the existing hospital to increase participation, empowering beneficiaries with information, and focusing on preventive health and wellbeing will be critical.

The landscape of cancer care provision can significantly change to become comprehensive with concerted efforts from the government towards addressing policy and systemic issues, by healthcare providers towards increasing the service availability and awareness, and by the citizens by focusing on their health and wellbeing.

# Chapter 4: Patient Pathways

The most important component of the study was to understand and document the complex journey of cancer patients and their caregivers in navigating cancer care. It explored awareness about cancer, diagnosis, treatment, and recovery journey and associated challenges. Though the study interacted with a small sample it provides invaluable insights to supply side stakeholders on strengthening provisioning of cancer care in the state. Sixty five cancer patients treated at KGMU participated in the study (22 with PM-JAY cover, 20 through national and state schemes, and 23 with no financial protection). The mean age of the patients was 52 years (24-90 years), with 52 of the 65 patients under 50 years 40 being female. Households' income ranged between Rs. 1,000-45,000. Thirty-two patients had completed treatment, 15 dropped out of the treatment (received partial treatment), and 18 were continuing treatment at the time of the study. The section below provides key insights of the patient journey, challenges, resilience, and insights on how these experiences can be improved.

- **Delayed identification of cancer due to lack of awareness on sign and symptoms, fear, and reliance on home remedies:** Respondents reported ignoring early symptoms and only seeking treatment when the symptoms worsened and started to interfere with their daily routine. Initial symptoms reported were of lumps in the breast and stomach, persistent body pain, scars, white patches, high fever, blisters, and difficulty in swallowing food etc. However, patients did not seek medical care. In addition, there is stigma and the fear of testing positive for cancer as it is considered a “**deadly disease with no survival chances**”. Women especially delayed seeking medical help because of the stigma and fear. A respondent cited:

“I never told my family about the lump because of fear, and it was not painful initially. When it grew painful, I told my neighbors, who informed my family. They took me to the hospital against my wish”

Another said,

“I wish I had not delayed seeking help, my treatment chances would have improved”

Respondents reported use of home remedies (alum water in the case of oral cancer, Ayurvedic medicine, heat fomentation, use of banana leaves to treat lumps, drinking juices like pomegranate etc) to treat their symptoms before reaching out for appropriate medical treatment. A respondent said:

“Over time, my voice started changing, I thought it was because I was drinking cold water. I tried many home remedies for about 15 to 30 days, like drinking tea and ‘kaadha’, thinking it was cold or cough”

- **Limited availability of screening and diagnosis of cancer in public health facilities, preference for informal and other practitioners resulting in delay:** The first point for medical aid in most cases were local doctors (formal and informal), chemists, Ayurvedic doctors, and homeopathic practitioners. While some respondents pointed out that they prefer seeking care from local practitioners, others cited the non-availability of government facilities nearby as a reason to go to other practitioners who are more accessible. A patient with oesophageal cancer said,

“I was taking medicines for gas and acidity from a pharmacy and was told the issue is due to congestion in my chest, I believed him and continued the treatment for long and ignored that it could be something serious”

Additionally, a lack of information on the required tests to confirm cancer and their unavailability in public hospitals was reported, which led to multiple investigations and prescription of

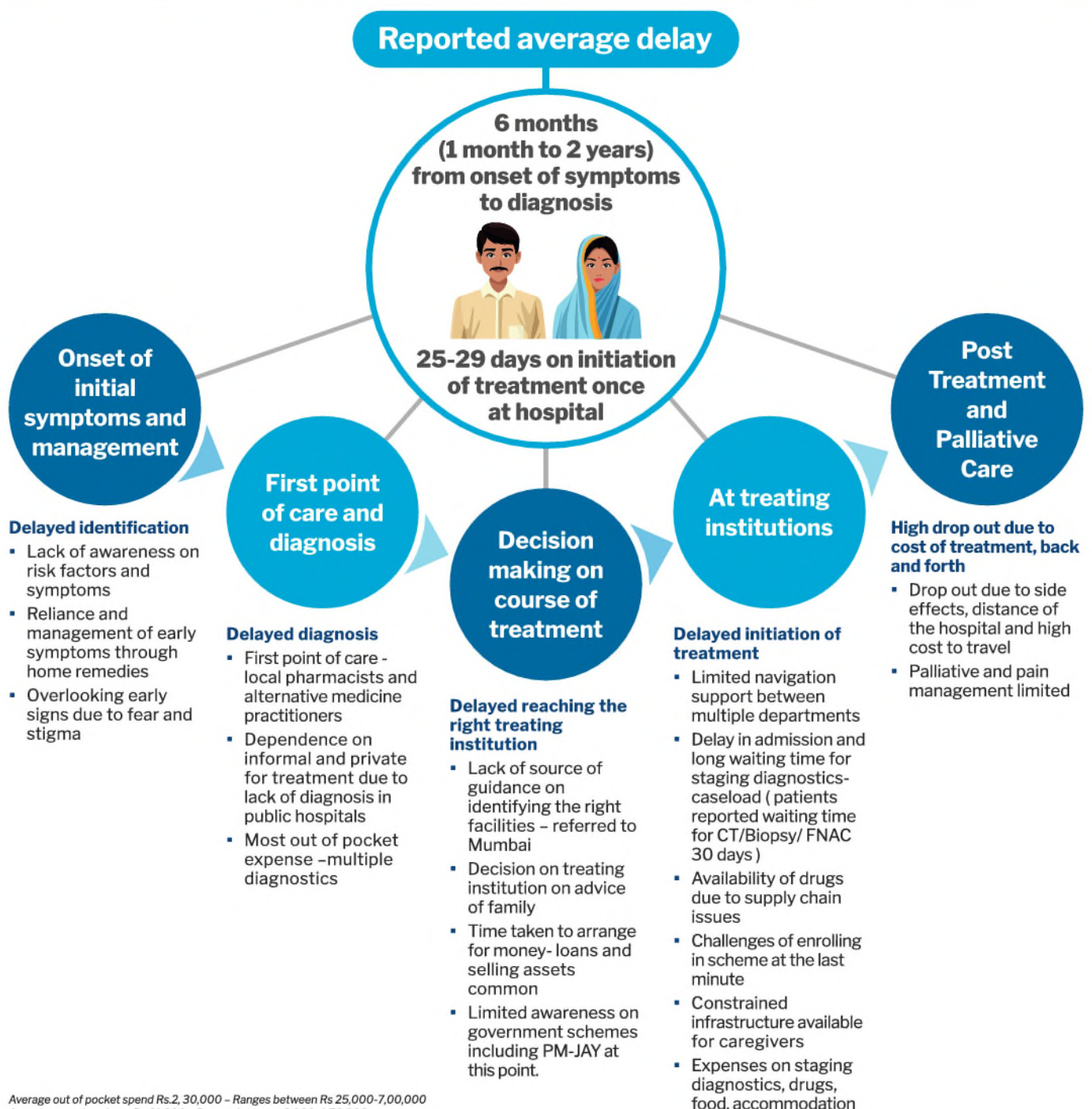
medicines at private hospitals. A patient with oral cancer said,

“I went to a private doctor in Allahabad, and was prescribed medications for around 7-8 months, but it did not bring me any relief. It was only after this that I went to KGMU ”

Another patient reported,

“At a private nursing home I was given 7 injections, after which a biopsy was done. Once, I received the report, I was told they do not have the appropriate treatment facilities available and I should go to a government hospital ”

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



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  
 \* May not add to the total OOPPE due to recall issues

This corroborates with the provider challenges who cited 'botched up treatment' before the patients reach medical colleges, making medical recourse difficult, and considerable delay in seeking right care.

- **Concentration of treating hospitals in bigger cities, financial constraints, and lack of information delay initiation of treatment:** Even when diagnosed, patients reported that it took them time to initiate treatment. Some of the factors they cited include distance from the home, making logistics very difficult, availability of money (respondents reported selling assets like motorbike and land, took loans, borrowing from family), to arrange for the funds, little information on drugs and treatment. No system exists either between public and private hospitals, and the patients reported seeking treatment in multiple hospitals. Almost all respondents reported seeking care in multiple hospitals before reaching KGMU. Thus, the patient's journey includes several diagnostics, which may be repeated and were reported to be stressful and time-consuming.
- **Navigating treatment at treating institution is challenging:** The treating hospitals for cancer see high patient load in the absence of treatment at periphery institutions. KGMU on an average sees 500 patients per day in the cancer outpatient department, highlighting huge load, resulting in patients dealing with access challenges.
  - Long wait time for registration due to high case load and a lack of support to help with the information to navigate between different services. For instance, a patient-reported

“he felt lost after reaching the facility and spent 4-5 hours in searching the right place”

Another patient reported that

“my husband and his brother went to KGMU after a few days, but they saw the crowd there and thought they will not be able to get him treated without any reference, thus they decided to get him treated in a private hospital”

- Delayed initiation of diagnosis for staging treatment due to high patient load is also a significant problem. Respondents reported

diagnostics and investigation can take anywhere from one week to more than 30 days, followed by a waiting period to get the reports (CT, Biopsy and FNAC can take up to 30 days). Most patients reported getting investigations done from outside.

- Shortages, limited number of cancer drugs, and non-functional radiotherapy machines have also been reported as obstacles. Respondents reported buying most of the drugs from outside as they were not available at the institution; they also cited occasional outages of the radiation machines.
- **Barriers in utilizing PM-JAY - continuing high OOPE & other concerns:** The findings suggest that despite patients being covered by Government schemes, including PM-JAY, significant costs while seeking cancer treatment are incurred. Most of the respondents reported that they were not aware of PM-JAY and by the time they were enrolled, a considerable expenditure had already been made by them. The Cancer Sahayta Kender offers support in helping the poor patients avail various financing scheme, however information remains limited. The reported data suggests that for patients covered by PM-JAY, the average OOPE was 2.4 lakhs, 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 an average, expenditure ranges between 4 to 5 lakhs on tests, medicine, transportation, treatment irrespective of insurance cover. Some PMJAY patients reported not receiving the full benefits, a few could use upto Rs 10-15 thousand, while others could use Rs 70000-80000. However, most patients reported spending between 2 to 7 lakhs on their treatment despite having a PMJAY card.

While beginning treatment, PM-JAY respondents reported barriers in using the scheme. These included, incorrect names on the Ayushman Card leading to preauthorization rejection, PM-JAY eligibility status not declared at the time of hospital registration, and lack of information on the documentation required. Confusion about entitlement was also reported among the doctors.
- **High level of satisfaction reported for the treating doctors, however scope to improve overall quality of care:** The respondents reported

that they were extremely happy with services provided, especially by the doctors. The treating doctors showed empathy and provided counseling in accepting the disease, treatment details, side effects and how to take care of physical and mental health during the treatment. The respondents recalled the names of their treating doctors, nurses, and counselors highlighting a positive recall and following the instructions given by doctors at home. Most patients recalled receiving treatment on time except in some cases when the machines stopped functioning.

However, the study also highlighted concerns regarding long waiting times, lack of guidance and navigation support for a treatment that is complex and requires multi department coordination, limited facilities to patients and their attendants, lack of investigations and medicines at affordable prices and in some cases poor behavior of support staff.

- **Dropouts without complete course of cancer treatment:** Side effects of cancer treatment and financial burden contributes to patients discontinuing treatment midway and leading to interrupted treatment. Respondents reported fatigue, pain, nausea, and extreme weakness and these debilitating side effects that lead to poor quality of life lead to patients discontinuing treatment. A patient cited

**“I was advised to undergo 28 radiotherapy sessions, however by the 14th session I had blisters in my mouth. I could not eat or drink anything and could not deal with the pain and stopped taking treatment ”**

Respondents attribute high OOPE as another factor for opting out of treatment. Some respondents reported not being able to afford expenses like hospital fees, medication costs, and travel costs as reasons for discontinuing the treatment altogether. A patient said

**“since we could not afford to buy blood, we decided to quit the treatment ”**

Patients also cite the lengthy nature of cancer treatment like multiple chemotherapy and radiation cycles that contribute to poor quality of life, and the fear of succumbing to the treatment as reasons for dropping out.

This is corroborated with the data from the cancer registry. The data of the year 2018-2019 shows a total of 11,963 patients diagnosed with cancer at the institute. (55 percent locally advanced disease, 15 percent metastatic cases, and 30 percent early-stage disease). Notably, 20 percent of patients left the facility after the first visit. Out of the remaining 80 percent, 30 percent completed their treatment, while 70 percent dropped out, highlighting a significant loss to follow-up. This highlights the need to understand the reasons for high dropouts. The study highlights the need to understand the treatment related issues specially management of pain and side effects better and provision pain management and palliative care.

## Conclusion

From the onset of the symptoms and diagnosis to the initiation of the treatment--the patient pathway is riddled with complexity, lack of information, uncertainty, and little navigation support from home to treating hospitals. Patients interfaced with multiple providers (formal and informal), paid for the service, sold belongings, took loans, and received information from multiple sources which were not necessarily actionable over prolonged period. The average time from the onset of symptoms (significant and affecting daily life) to confirmed diagnosis is 6 months, ranging from 1 month to 2 years. Once at the treating institution, there are delays and it can take up to 25-29 days to begin the treatment due to issues of availability beds, diagnostics, and drugs. The experience during the period is of panic, fear, and confusion and dealing with painful medical symptoms. Many report being unable to accept their situation and gathering information independently, leading to additional delays in treatment initiation. Patients fear the treatment and procedures, particularly chemotherapy. In many instances, the fear stemmed from the question of surviving the disease. The satisfaction from the treating hospital is high, however there is significant expenditure incurred despite financial risk protection due to availability of diagnostics and drugs, which is the key factor in drop out from the treatment.

A significant finding is that financial protection through PM-JAY and other schemes, have made no difference in the operational challenges faced by the patient. The pathway of getting to treatment remained complex and hard. Even with simple documentation to enrol, due to the nature of disease and their soci-

economic background patients found it hard to avail the benefits. Due to a lack of treatment infrastructure at the lower level, medical colleges and treating institutions are burdened. The human resources, infrastructure, availability of diagnostics and drugs remain a challenge even for the treating institution. It is evident that despite PM-JAY cover, non-availability of drugs in treating institutions led to patients buying these from

outside. The system of capturing patient data is not robust enough to track and follow up. Majority respondents have taken loans, sold their assets to get treated and have dropped out of treatment as they could not continue to afford the medicines. While PM-JAY offers palliative care packages however, these are for institutional care, however the state palliative program is limited and needs to be strengthened.

# Chapter 5: 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 HBP, STGs to strengthen the public delivery infrastructure to expand the access and availability for information, screening, 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 study validates the increasing incidence of the disease burden, challenges and gaps that exist and opportunities for the state. The section provides policy and programmatic recommendations to DoH&FW, DME and for PM-JAY to SACHIS. These have been prioritized based on several rounds of discussions with state experts.

Department of Medical Health & Family Welfare		SACHIS	
Policy	Programs and systems	Policy	Programs and systems
<ul style="list-style-type: none"> <li>▪ Making cancer a notifiable disease</li> <li>▪ Increasing population based registries</li> <li>▪ Decentralizing cancer care provision to district level</li> <li>▪ Private partnerships for cancer care provision at public hospitals</li> <li>▪ Increasing financing to build infrastructure</li> </ul>	<ul style="list-style-type: none"> <li>▪ Empowering NCD Clinics as basic cancer prevention care units</li> <li>▪ Rapid scaling up of cancer screening and early detection and use of NCD application                             <ul style="list-style-type: none"> <li>▪ Targeted community screening campaigns</li> <li>▪ Opportunistic screening camps in medical colleges and district hospitals</li> <li>▪ Refresher training of frontline workers</li> <li>▪ Popularizing the full use of NCD application</li> </ul> </li> <li>▪ Setting up of referral pathways</li> <li>▪ Setting up patient navigation support systems</li> <li>▪ Strengthening availability and supplies of drugs</li> </ul>	<ul style="list-style-type: none"> <li>▪ Provisioning an independent first line of diagnostics package as an OPD procedure under HBP</li> <li>▪ Partnership with private laboratories to increase access and availability to diagnostics</li> <li>▪ Establishing PM-JAY cancer registry</li> <li>▪ Facilitating strategic purchasing of cancer drugs for PM-JAY hospital network</li> </ul>	<ul style="list-style-type: none"> <li>▪ Evaluating cost effective newer therapies for better treatment outcomes and quality of life</li> <li>▪ Improve access to cancer treatment by expanding the hospital network and encouraging servicing PM-JAY beneficiaries</li> <li>▪ Increase awareness among beneficiaries on provision of cancer treatment under PM-JAY</li> </ul>



## Areas to consider for policy:

### ▪ **Making cancer notifiable disease in Uttar Pradesh**

At present, cancer is a disease which can pose significant risk to the population and Uttar Pradesh and making it a notifiable disease should be considered by the state. 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, ICMR recommended that cancer be made a notifiable disease; this was followed by a similar recommendation of 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 and hospital-based cancer registries. PBCR collect and process data relating to a defined geographical area, while HBCR include data available with a specific hospital. At the systems and governance level, Uttar Pradesh has three PBCR in Allahabad, Aligarh, and Gautam Budh Nagar. Setting up of PBCRs will be critical to monitor the cancer incidence, identify high-risk groups (occupational exposure, family history), evaluate the cancer treatment by tracking patient outcomes. While the government evaluate this proposition, in near-term SACHIS can consider setting up registry of PM-JAY beneficiaries and can guide cancer programs in the state or encouraging the private hospitals to report on national registry.

### ▪ **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 provision of chemotherapy) were attempted in 2018, they weren't successful. In the current context, with the availability and acceptance of telemedicine, availability of human resources (physicians/surgeons) in district hospitals, task shifting should be considered as an important strategy to decentralize cancer care provision. KGMU has initiated the Cancer Care Network through which periphery public health institutions (CHCs) in districts sees high volume of cancer patients to KGMU that have been brought together to create a network of hospitals that provide follow up support to the patients closer to home.

There are states like Assam and Kerala, which have empowered their district hospitals and increased the availability of care to address the issues of specialist in the state. A pilot study conducted in rural Tamil Nadu<sup>19</sup> found that decentralized model of cancer care is feasible in rural settings. With training primary care providers were able to identify and diagnose cancer early and provide palliative care.

DoH&FW and DME can collaborate to create a Uttar Pradesh centric hub and spoke model in which apex institutions like KGMU, SGPGI etc 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, use of telemedicine and under the supervision of the apex institutions. This can significantly improve access.

### ▪ **Public Private Partnerships for cancer care provision at public hospitals**

While one strategy is strengthening public sector institutions, another strategy is leveraging private sector partnerships to increase 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 collaborates with the Maharashtra government to establish cancer care facility at Government Medical College and Hospital in Chandrapur. Under this, TMC provides technical assistance in design and construction, training of doctors, nurses, provides equipment and supplies. The government provides

<sup>19</sup>Decentralized Cancer Care in Rural India: Pilot Study Rangarajan et al. 2017

infrastructure, human resources, and land. Other examples are Apollo Cancer Institute in Hyderabad is partnership between Apollo and state government, Max Healthcare in Delhi is partnering with the Government of Delhi to set up cancer care in Lok Nayak Jai Prakash Narayan Hospital, SRL Diagnostics provides cancer diagnostics in Delhi State Cancer Institute. The government should consider PPPs to increase availability and accessibility of cancer care services.

- **Increased financing for building infrastructure for cancer care**

The government of Uttar Pradesh has increased the spending on healthcare over the years. The state fiscal allocation on healthcare has increased from Rs 17,761 crores to Rs 5,50,270 crores in 2021-2022<sup>20</sup>. This is a significant increase. This budget is expected to be utilized for strengthening healthcare infrastructure and improving equipment and technology, and it will be critical to prioritize this for increasing public provisioning of cancer care. States like Assam, Kerala, Rajasthan, and Odisha have increased the allocation towards building cancer care infrastructure, have leveraged private sector partnerships, and philanthropy to build state of the art cancer treating institutions.

### Areas to consider for strengthening programs and systems:

- **Prioritizing cancer screening and diagnosis through the district NCD clinics – NCD clinics as basic cancer prevention units**

At present, most NCD clinics are facing operational challenges due to shortages of human resources and lack of infrastructure and equipment, which prevents provision of NCD services. Also, services for cancer are not being currently provided at these clinics. NCD Clinics can be developed as basic cancer prevention units by strengthening the available infrastructure, equipment, supplies, and deployment of full team of human resources and their training. Provision of risk assessment clinical examination, and visual inspection (VIA/VILI for cervix and oral cancers) facilities with a strong referral to treating institutions can help decongest the apex institutions.

For training, collaboration with the National Institute Cancer Prevention and Research and ECHO India can be forged to rapidly scale up

trainings. The training curriculums are available for medical officers, gynecologists, pathologists, dental surgeons, and nurses.

Considering the complexity of cancer, it is also suggested that the cancer program should be independent and not combined along with other NCDs.

- **Rapid scaling up of cancer screening and timely referrals and use of NCD applications**

Both population based and opportunistic screening is limited in the state. To significantly increase awareness on sign and symptoms and screening high risk population the screening and referrals should be rapidly scaled up. This can be achieved by strengthening the NPCDCS program with a special emphasis on cancer screening. The program should consider.

- **Targeted community screening campaigns**

with NGOs, private diagnostic labs, mobile vans, and District NCD Clinics. The state of Assam implements 'Universal Screening and Control of Five common NCDs through a mobile team of dentists, nurses, health camp managers, and data entry operators along with HWC staff. Rajasthan deployed mobile vans for mass screening and diagnostics, including mammography, digital X-ray, colposcopy, pap smear, and video endoscopy of the head and neck. They also provide genetic counselling in case family history of cancer is present, and if genetic mutations suggestive of familial link.

- **Opportunistic screening camps in Medical Colleges and District Hospitals:**

This provides an opportunity to screen the patients who are already visiting the health institutions. Swasth Assam Kiosk at OPDs of medical college hospitals provides opportunistic check-up of blood pressure and diabetes and risk assessment.

- **Training of frontline field force (ASHAs, ANMs, and AWWs) on early identification of signs and symptoms**

and use of risk assessment tools. The National Health Systems Centre has developed a master trainers' program to train and equip ASHAs, which can be leveraged by the state.

- **Popularizing the use of NCD application:**

At present the NCD application is not optimally

used for reporting and monitoring at the state level. The application provides an opportunity to record and keep a track of high-risk patients for follow up. Several states have effectively used the screening and use of NCD applications to create accurate information on screening on the ground. Some examples include Shylee, a digital app that has been developed for ASHAs in Kerala to collect information on the prevalence of lifestyle diseases and its risk factors among all those above 30 years in the State as a part of the population-based screening program. The application uses AI to provide risk scores, and those above four are referred for further medical examination and investigation. Andhra Pradesh has launched an NCP Pro which provides risk assessment, health education and referral pathways. Tamil Nadu launched NCD Care that provides patient registration, risk assessment and patient management tools. Maharashtra uses an application called Maha-Arogya and Rajasthan M-Swasthya. The NCD Application developed by Government of India, can be utilized by training the frontline workers.

#### ▪ **Setting up referral pathways**

The Ministry of Health and Family Welfare of the Government of India has prepared a well-thought-out Operational Framework for the Management of Cancers in 2016. The framework includes algorithms for screening and managing the three most common cancers, i.e., breast, cervix, and oral. PHCs and HWCs can be considered the first screening point, and patients who test positive can be referred to CHCs or DH for further confirmation. The DH should be the first referral point from lower-tier institutions. The guideline states that the district hospital is expected to have the capacity to provide diagnostic services such as breast ultrasound, colposcopy, cryotherapy, Loop Electrosurgical Excision Procedure (LEEP), and additional diagnostic services, including biopsy. It also suggests that every district hospital should be linked with a Medical College to facilitate referral and follow-up and serve as a mentoring and support institution. However, these guidelines are yet to be implemented on the ground.

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. The Balarampur district hospital can be considered a pilot for the first referral unit, linked with KGMU/RML. To ease patients' navigation, the state may strengthen the referral mechanism by guiding patients at the first point of contact by providing them with information on the right hospital, department, and OPD days, so that they do not feel lost in the health system.

#### ▪ **Patient navigation support mechanism for cancer patients**

The current study, and almost all other studies, have highlighted the complex treatment journey for the patients, which is due to lack of understanding on the disease, its management, side effects, and emotional stress they go through at the hospitals and after the treatment. While HWC and ASHAs are mandated to provide the support, they are overburdened. However, navigation support mechanism for cancer patients should be developed. Through this one-on-one support and guidance can provide 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 RCCs and autonomous public medical colleges procure cancer drugs through individual rate contract, the study has highlighted that there are supply chain issues and the availability is challenge. In the private sector the process of procurement and sale of the drugs remains largely unregulated, thus and expense on drugs is a significant out of pocket expense. Towards strengthening availability and economies of scale, 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 decentralize care to district hospitals.

#### **Areas of consideration to strengthen implementation of PM-JAY**

PM-JAY is a unique opportunity to leverage the private infrastructure towards increasing 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 empanelling over 125 private hospitals to provide cancer treatment. Thus from a few public health institutions there is a network of over 150 hospitals in both public and private in the state which can service 30 percent of the eligible population. While this is good progress, there are still supply side issues (limited participation of private hospitals) and several operational barriers (out of pocket expense, access to treatment) faced by the patients while navigating care which need to be redressed. The areas of consideration are provided, which if adopted, can address these and can impact the landscape of cancer care provision in the state.

#### ▪ **Policy Level**

##### **- Provisioning confirmatory cancer diagnostics under HBP**

PM-JAY HBP provides high quality diagnostics, such as ultrasound, CT-guided percutaneous biopsy/FNAC, high end radiological diagnostic (CT, MRI, Imaging including nuclear imaging), high-end histopathology (Biopsies), advanced serology investigations and PET scans. However, these are only available for inpatient care. The study establishes that 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 introduced, which will significantly reduce the cost to the patient. The National Health Authority (NHA) has designed an intervention called e-RUPI, a paid voucher which would enable a beneficiary to avail free diagnostic service at any empaneled lab—which can also be explored.

##### **- Partnership with private laboratories to increase access to diagnostics**

The study highlights limited availability of good quality diagnostics in public institutions, especially at the periphery. The availability in private is fragmented and leads to high cost. It is proposed that through competitive process diagnostic labs can be empaneled by SACHIS to provide diagnostic services to the PM-JAY hospital network. The NHA has a provision for empanelment of laboratories, and this can be utilized per state needs.

##### **- 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 cost-effective drugs, there may be a need to increase financial risk protection. The state may consider setting up a corpus fund like Tamil Nadu, where 25 crores has been set aside for funding treatment once the 5-lakh cover is over. Similarly, Odisha has expanded the health cover 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 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 its network of hospitals or encourage them to report at the national registry.

#### ▪ **Programmatic**

##### **- Increase awareness among beneficiaries on provision of cancer treatment under PM-JAY**

Despite high enrolment, there is a reported lack of information and awareness on how to access cancer care and what is covered. SACHIS can collaborate with the NPCDCS program and private hospitals towards increasing awareness on scheme and promoting preventive health and wellness.

##### **- Improve access to cancer treatment by expanding the hospital network and encouraging servicing PM-JAY beneficiaries**

A targeted empanelment of private hospitals to increase availability of cancer treatment in the state can address the inequities that exist. With attractive pricing of the HPB 2022, a targeted approach can be executed and hospitals with all three services (medical, surgical and radiation) should be encouraged.

##### **- Facilitating strategic purchasing of cancer drugs for PM-JAY hospital network**

SACHIS, can consider collaborating with the NCG that does bulk purchasing of cancer drugs

on behalf of the network hospitals. With large volumes lower prices are negotiated with pharmaceutical companies making treatment affordable and accessible. This is like approach of group purchasing organization (GPOs) in other countries which negotiate with suppliers on behalf of multiple hospitals to obtain lower prices of medical products.

**- 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 potentially a scope to strengthen this. The NHA has a new technology and package inclusion initiative in which partners are invited to nominate new health technology treatment for PM-JAY. This can be leveraged to suggest new therapies. The study engaged with several senior oncologist from the states and there are suggestion to consider following therapies: Cisplatin and

Etoposide, Oncoplasty, and Octreotid, and the use of low dose of immune therapy which is costly but has shown promising results.

**- Building the strong component of palliative care**

There is evidence that suggests 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, during treatment and post-treatment follow-up care visits. This includes informing patients about the stage of the disease, time, type, and cost of treatments, as well as do's and don'ts. There is a strong need to link patients with lower-level facilities for palliative care, such as 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 in collaboration with the treating institution. Further advocating with NHA to increase the duration of the packages can be considered.

# Conclusion

Improving the provision of cancer care in Uttar Pradesh will require multi- sectoral approach in which the 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 innovative and

engage with other sectors besides the government machinery. By adopting a comprehensive long-term vision, the state can significantly increase services to reduce cancer related morbidity and mortality and improve the patients quality of life. Through the report the research partners urge the government to prioritize cancer care in the state.



