

FIRST Cancer Care: Leveraging Fourth Industrial Revolution technologies for cancer care

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Abbreviations

AI: artificial intelligence

AR: augmented reality

CCVP: cancer care value pathways

CEA: carcinoembryonic antigen

DALY: disability-adjusted life-years

EHR: electronic health record

FHIR: fast health interoperability resources

GDP: gross domestic product

GPS: Global Positioning System

HER2: human epidermal growth factor receptor 2

HER2 ER: human epidermal growth factor receptor 2 with (o)estrogen receptor

HER2 PR: human epidermal growth factor receptor 2 with progesterone receptor

HPV: human papillomavirus

ICMR: Indian Council of Medical Research

IoT: internet of things

MOOCs: massive online open courses

MR: mixed reality

MRI: magnetic resonance imaging

MRO: master record of oncology

NDHM: National Digital Health Mission (renamed as ABDM – Ayushman Bharat Digital Mission)

NCDIR: National Centre for Disease Informatics and Research

NCRP: National Cancer Registry Programme

NPCDCS: National Programme for the Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases and Stroke

ODM: oncology data model

OPD: out-patient department

OOPE: out-of-pocket expenditure

PET positron emission tomography

POC: point of care

PPP: public-private partnership

USG: ultrasound sonography

VR: virtual reality

WHO: World Health Organization

Preface



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“We must develop a comprehensive and globally shared view of how technology is affecting our lives and reshaping our economic, social, cultural and human environments. There has never been a time of greater promise, or greater peril.”

– Klaus Schwab

The Fourth Industrial Revolution has ushered in a new era of innovations to address some of the greatest challenges that humanity faces today. It is transforming health and medicine thanks to the extraordinary advances in artificial intelligence, blockchain, robotics, data science and genomics. Industry is often at the forefront of the development of these transformative technologies, with the broader stakeholder community of policy-makers, civil society, international organizations and, ultimately, patients grappling with ethical and sustainable adoption.

The FIRST Cancer Care initiative based out of the Centre for the Fourth Industrial Revolution in

India explores how technological advances can revolutionize cancer care, and drives action to ensure equitable and sustainable healthcare for populations affected by cancer. The initiative reflects the Forum’s stakeholder-centred approach and grounds the work in the expectation that outcomes will benefit society broadly. This report represents a major milestone for the initiative. It articulates a cancer care agenda for India that spans preventive and curative care, using Fourth Industrial Revolution technologies to address foundational healthcare governance issues. Going forward, continuing to foster a multistakeholder approach to integrating technology into cancer care will ensure that successful results are scaled rapidly across the country. We anticipate that the insights generated will have relevance for cancer care globally.

We hope that the insights in this report will demonstrate how technological interventions can transform the healthcare landscape and make services more precise, timely and affordable.

Foreword



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Healthcare is a critical national priority for India, which has a population of over 1.3 billion and ranks low on the global health security index. Despite efforts made by the government under the National Health Mission and by the private sector, the country still faces huge challenges including shortage of health professionals and health infrastructure, low public expenditure on healthcare and a huge urban-rural divide in access to health services.

At the same time, the incidence of cancer in India is increasing, owing to a mix of causes such as dietary and lifestyle changes and ageing of the population. To address the complex challenges that the healthcare ecosystem faces, we must harness emerging technologies to transform India's cancer care landscape. India needs a comprehensive matrix of prevention through treatment to palliative care, and clearly, we must do more with less by optimizing our resources.

The Fourth Industrial Revolution for Sustainable Transformation (FIRST) Cancer Care report is the result of deliberations among more than 30 stakeholders including clinicians, academics, IT and pharmaceutical companies, public health professionals and civil society, who have brainstormed in over 45 meetings to build a robust strategy. This strategy identifies the gaps in current cancer care and recommends interventions including use of Fourth Industrial Revolution technologies to create an oncology data model, as well as a framework to execute these interventions with multistakeholder engagement.

We are optimistic that this report will make a significant difference to the patient journey by providing a roadmap for a technology-led transformation of cancer care in India.

Executive summary

Harnessing new technologies to prevent, diagnose and treat diseases is an important global challenge for the next decade, the World Health Organization has declared. Looking further ahead to 2050, the World Economic Forum strives to ensure that the estimated 9.7 billion population would have equal access to the highest standards of care, and aims to assist the industry in its efforts to transform healthcare delivery systems.

To this end, the Centre for the Fourth Industrial Revolution in India has designed FIRST Healthcare, a strategy to enable the Fourth Industrial Revolution for Sustainable Transformation (FIRST) in the healthcare sector. This strategy seeks to align all the stakeholders in the healthcare ecosystem with the aim of addressing critical challenges by utilizing Fourth Industrial Revolution technologies.

Of the 18 themes that FIRST Healthcare has identified, cancer has been prioritized due to its increasing incidence, a challenge compounded by the shortage of infrastructure and expert resources. A core group of experts working on the FIRST Cancer Care project in India has identified the critical gaps in the existing healthcare system and assessed various technologies to recommend a set of interventions.

The critical gaps have been identified in the following areas:

- Early diagnosis and continuum of care.
- Knowledge and skill development.
- Financing solutions.
- Interoperable, standardized data.

In particular, the lack of data has been identified as a serious gap across the entire landscape.

This report lays out the project's recommendations for creating an Oncology Data Model, covering aspects including data capture, standards, protection and alignment with the Digital Health Mission. This model would ensure data capture at every step of the patient journey, while avoiding duplication and ensuring privacy. An Oncology Master Record thus created would be accessible to all authorized stakeholders.

This will require the adoption of technological solutions and interventions at the patient, provider and system levels. These interventions have been clustered into four Cancer Care Value Pathways for planning and implementation:

- Population health pathway.
- Health professional education pathway.
- Provider pathway.
- Data pathway.

The feasibility and viability of all interventions has been assessed individually, and those that promise to be gamechangers are accorded the highest priority and are to be rolled out first, on a pilot basis.

Two to three pilots are proposed for each state, to be implemented at the district level. Once a pilot demonstrates success, it can be scaled up across the state(s).

The success of the FIRST Cancer Care initiative will hinge on the top leadership's commitment, a multistakeholder approach, a consistent focus on impact, and the cost effectiveness of the technologies. The central and state governments have a vital role to play.

Introduction

India's healthcare system consists of both public and private actors. To improve public healthcare provision, the National Health Mission was launched in 2013 to take some key steps, including the institution of a community health worker programme,¹ introduction of quality standards,² provision of free drugs³ and free diagnostic initiatives,⁴ strengthening of infrastructure and an increase in the availability of human resources. These concentrated efforts have improved some critical indicators of maternal and child health⁵ – the infant mortality rate has reduced to 32 from 50 (per 1,000 live births) in a span of 10 years⁶ and the maternal mortality ratio to 113 from 130 (per 100,000 live births) in four years.⁷

To strengthen the public health facilities to address the growing burden of non-communicable diseases, the National Programme for the Prevention and Control of Cancer, Diabetes, Cardiovascular

Diseases and Stroke (NPCDCS) was launched in 2010.⁸ This programme was expanded in 2017 to introduce population-based screening and management of common non-communicable diseases (such as hypertension, diabetes and some cancers) at primary healthcare facilities.⁹

In 2018, the Ayushman Bharat initiative was launched to deliver a more comprehensive range of healthcare services and to realize the vision of universal healthcare coverage. As part of this initiative, existing primary health centres are being upgraded to “Health and Wellness Centres” and new centres are being established to create a network of 150,000. These centres will provide comprehensive primary healthcare including cancer screening. Through the Pradhan Mantri Jan Arogya Yojana, the initiative also provides financial assurance for secondary and tertiary care to the 40% households that are India's most marginalized.¹⁰



The challenge

Despite the gains made under the National Health Mission and through the private sector, India faces enormous challenges such as shortage of health professionals and health facilities, low public spending on healthcare (1.3% of GDP), and a huge urban-rural divide in access to health services.

Meanwhile, poor health literacy, malnutrition, air pollution, consumption of tobacco and poor dietary habits are increasing the burden of disease – including in terms of the financial cost and the loss of wellbeing and productive life-years – calling for a greater focus on preventive care and wellness.



The opportunity

India needs to optimize the limited resources available to improve healthcare at a faster pace, especially as the deadline for meeting Sustainable Development Goals is drawing near. An excellent opportunity lies in deploying technologies at population scale. The Centre for the Fourth Industrial Revolution in India has developed a Fourth Industrial Revolution for Sustainable Transformation (FIRST) Healthcare strategy that

provides a roadmap for bringing into play frontier technologies such as artificial intelligence (AI), internet of things (IoT) and blockchain to transform healthcare delivery. For instance, AI can enable faster and more accurate diagnosis, wearables can promote wellness, IoT devices can support remote management and AI-enabled clinical decision support (CDS) can enhance the efficiency and effectiveness of health professionals.



The FIRST healthcare strategy

While the need and the opportunities are enormous, the FIRST Healthcare strategy recognizes the imperative to prioritize so as to derive maximum impact from optimal and coordinated efforts. To this end, the strategy has identified 18 themes along the three streams of preventive care, curative care and governance. Top experts in the medical,

public health and health-tech areas have advised on this prioritization, and suggestions from the ministries of health, information technology (IT) and biotechnology, as well as the pharmaceuticals industry and representatives of the Indian systems of medicine, have been incorporated.



The vision and agenda

The vision of the FIRST Healthcare strategy is to enable India to achieve better health outcomes – defined as improved patient care and population health, and reduced cost of healthcare provision – through responsible use of emerging technologies.

It aims to realize this vision through the coordinated efforts of multistakeholder communities to be built around 18 prioritized themes.

FIGURE 1 18 themes of FIRST healthcare

Prevention and early detection	Curative care (diagnosis, medication)	Governance
<ul style="list-style-type: none"> – Immunization – Health screening – Awareness and education – Improved child and maternal nutrition – Wellness practices 	<ul style="list-style-type: none"> – Cardiovascular disease – Cancer – Diabetes – Tuberculosis and chronic respiratory disease – Eye diseases – Mental disorders – Skin diseases – Neonatal disorders 	<ul style="list-style-type: none"> – Data governance – Capacity building of field health workers – Health service delivery – Public health intelligence – Capacity building of doctors
<p>These themes can be executed through multiple projects in three phases</p>		

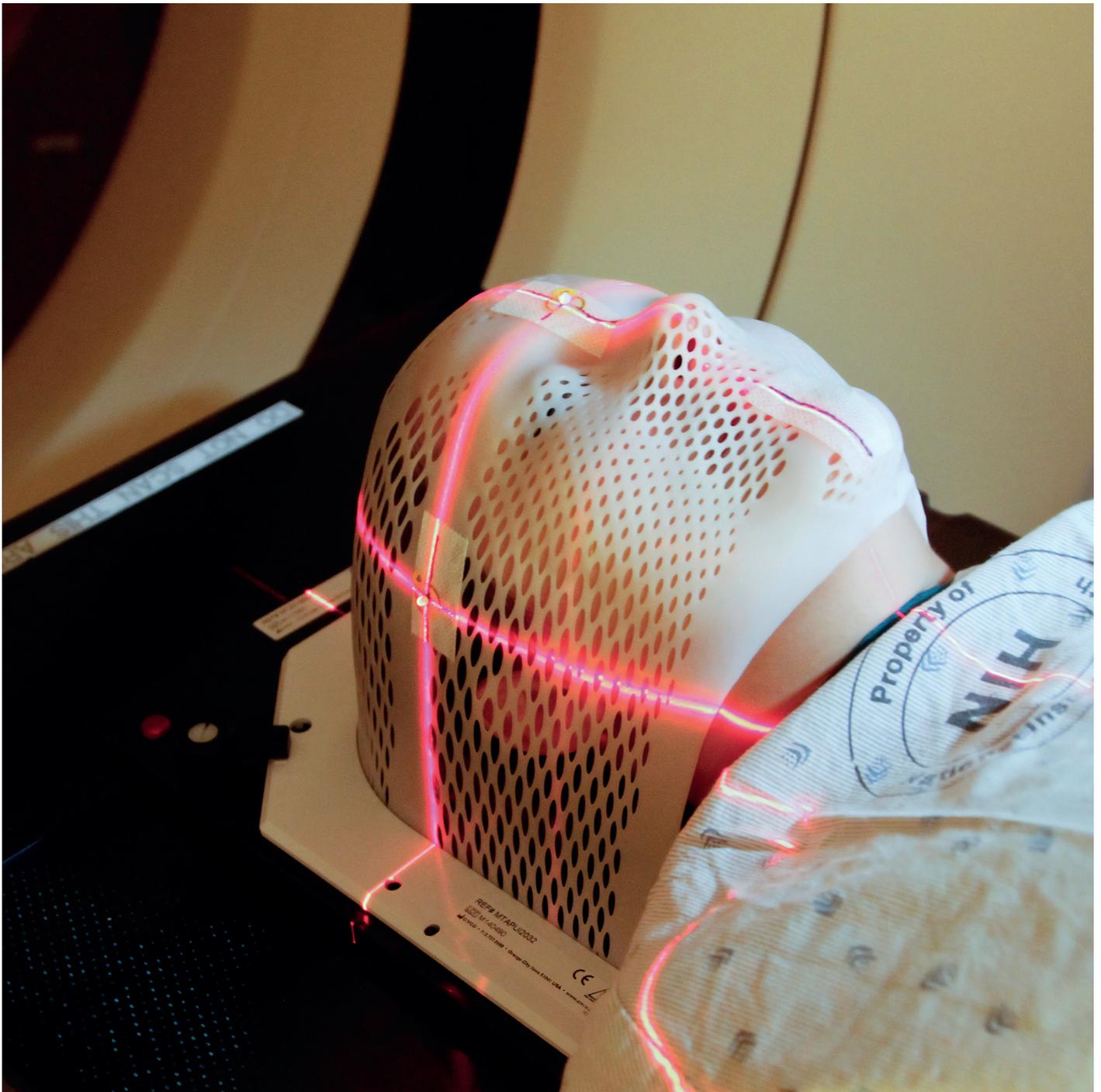


The FIRST cancer care strategy

Cancer is among the largest contributors to the burden of non-communicable diseases in India and to out-of-pocket expenditure.¹¹ Cancer is the first theme that the FIRST Health portfolio will address, and the initiative has been named FIRST Cancer Care.

The initiative will identify the gaps in policy and governance, collate the national and global best practices in the deployment of emerging technologies (AI, IoT, blockchain) in cancer care, identify specific opportunities for transforming the cancer care regime and patient journey, develop required frameworks and, above all, implement scalable pilots through partnerships.

This large and complex initiative will require a multistakeholder approach to ensure that efforts converge, an environment of openness, co-design and co-creation is created, interests are balanced, and business needs are synchronized with innovation. Accordingly, a core group was established in April 2021 that includes, in addition to clinicians, representatives from the government, industry, academia and the start-up community. The overarching goal of the initiative is to “solve for India, solve for the world”.



1

Landscape survey and gap analysis



The Forum’s project methodology typically consists of four phases: landscape survey and gap analysis; opportunity mapping and development of frameworks; piloting the frameworks; and scaling up the initiative.

Gap analysis identifies the problem(s) that the initiative needs to address. This section presents an overview of the cancer landscape in India and identifies the major gaps in policy, governance and technology.

1.1 Cancer spread in India

The incidence of cancer in India is increasing, owing to a mix of reasons including changes in diet and lifestyle, tobacco consumption and ageing of the population. This last factor is important as cancer predominantly affects the aged in India. The number of new cancer cases recorded every year, called the crude incidence rate, increased 28.2% from 63.4 per 100,000 in 1990 to 81.2 per 100,000 in 2016. Kerala and Mizoram had the highest crude incidence rates for cancer in 2016 (figure 2).¹²

The crude incidence rate of breast cancer among women increased by 39.1% from 1990 to 2016, with the increase observed in every state. Although the rate of some cancers fell during this period, the burden remains high in terms of absolute numbers. The total number of cancer cases in India in 2020 was 1.39 million (100.7 per 100,000 population) and is likely to rise to 1.57 million by 2025 (108.6 per 100,000 population) as per a 2020 report of the National Cancer Registry Programme.¹³

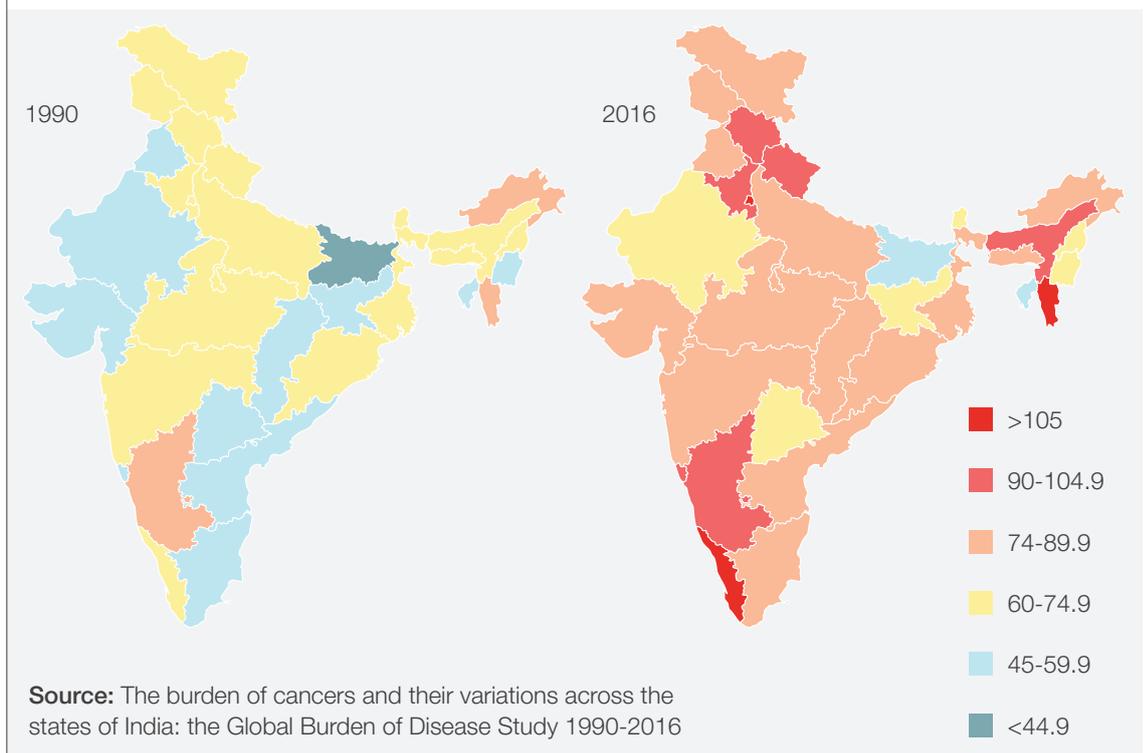
The disability-adjusted life-years (DALY) lost to cancer increased 25.3% from 1990 to 2016.

“Among females, breast, cervical, and stomach cancer were responsible for the highest DALYs in 2016. The highest cancer DALYs among males in India in 2016 were due to lung cancer, followed by lip and oral cavity cancer, pharyngeal cancer, and stomach cancer.”¹⁴ (One DALY refers to the loss of the equivalent of one year of full health.)

“The 10 cancers contributing the highest DALYs in India include cancers of the stomach, lung, pharynx other than nasopharynx, colon and rectum, leukaemia, oesophageal, and brain and nervous system, in addition to breast, lip and oral cavity, and cervical cancer,” the report said, adding that the last three are currently the focus of screening and early detection programmes.

The incidence rate of different types of cancers varies widely across India due to differences in the distribution of important risk factors. Varying patterns of tobacco consumption, alcohol consumption, diet, biological and environmental factors lead to variances in the incidence of related cancers.¹⁵

FIGURE 2 Crude annual incidence rate of all cancers in the states of India, 1990 and 2016



1.2 Critical gaps in cancer care

The core group has identified critical gaps in cancer prevention and care along six dimensions: data,

diagnosis, knowledge and skills, financing, patient journey and human resources.



Data

India has made substantial improvement in cancer registration, but a lot of work is needed to ensure that records are complete and up-to-date. Cancer is not a notifiable disease, except in a few states, so physicians are not required by law to report it to the government. At the same time, the lack of a reliable internet connection is a major bottleneck for real-time digital capture of cancer screening data in rural and hard-to-reach areas.

Since the healthcare industry has been relatively slow in adopting information technology, outside of a few urban pockets, India's medical professionals have not yet embraced electronic health records.¹⁶ Health facilities that have the infrastructure may fail to upload data due to the high workload on healthcare providers. Further, cancer data gets fragmented due to the long and complex nature of cancer treatment and care – diagnosis can include multiple procedures, treatment may involve numerous therapies, often in combination, and services may be delivered by various providers at different points along the patient journey.

As a result of all these factors, most patients face the lack of accurate and timely information.

Meanwhile, the large volume of patient-related data currently available is heavily under-utilized for research and development. A proper clinical research environment, founded on anonymized and annotated datasets on different types of cancer and built from trustworthy sources, is much needed.

In the absence of national digital health systems, numerous uncoordinated sources have emerged to fill individual requirements on an *ad hoc* basis. These often lack clear standards and end up duplicating work done elsewhere. Various government programmes also end up duplicating data-entry efforts. The National Digital Health Mission, renamed as the Ayushman Bharat Digital Mission, aims to “develop the backbone necessary to support the integrated digital health infrastructure of the country and bridge the existing gap amongst different stakeholders of the healthcare ecosystem.”¹⁷



Diagnosis

Many communities have little awareness about cancer and its early warning signs, despite ongoing initiatives such as population-based screening programmes. Patients and families, especially in rural areas, are often deterred from seeking care for fear of losing daily wages, by the high cost of diagnostic services and by worries about a potential financial crisis.

One of the predominant reasons why cancer diagnosis gets delayed is the lack of awareness and training among community physicians. They often misclassify disease severity and misinterpret the symptoms.

Various institutions, such as the Indian Council of Medical Research and the National Cancer Grid, have published guidelines for diagnosis of different kinds of cancer. But general physicians at primary health centres and in private clinics and hospitals, who are at the frontlines and are often the first point of contact for cancer patients, have not fully adopted the guidelines.

In areas with inadequate resources, where appropriately sensitive digital diagnostic tools are not available, screening populations for cancer becomes more difficult. Most diagnostic platforms are invasive,

expensive or require highly trained operators, making them unsuitable for deployment in low-resource settings. Overall, challenges pertaining to logistics, cost, training of providers and socio-cultural behaviours have impeded the adoption of newer technologies.

At the same time, in India's highly fragmented diagnostics sector, where large chains coexist with standalone centres and hospital-based laboratories, resources for diagnosis and treatment are either unavailable in many parts of the country or are used ineffectively. At present, unorganized laboratory service providers cater to the unmet demand for diagnosis. When patients migrate between publicly-funded health centres and private facilities, the sharing of patient information is suboptimal at best, further complicating the already disjointed and fragmented data capture due to the complex nature of cancer care pathways.

Quality assurance of the services is a major concern in the face of inadequate regulation and lack of quality norms. This makes for easy access to unlicensed/unregulated private entities, with widely varying quality and compliance with clinical standards.



Knowledge and skills

The diversity of the Indian population requires bespoke models of digital interventions. A prerequisite is to make knowledge available and accessible – the English language is predominant on the internet and in digital applications, whereas users may not be familiar with it as they speak and understand their own different languages. Improving language accessibility for all information related to health is key to narrowing digital inequalities.

Another gap lies in the low capacity for continuing professional development and skill-building in pathology and laboratory technologies. The rapid advancement of medical knowledge in diagnosis and treatment is creating an urgent need for providers to undertake continuing professional development so as to maintain their clinical competence. To ensure access to training and skill enhancement avenues, integrated education and training programmes must be developed as part of a national plan, some experts have suggested.¹⁸

Meanwhile, general physicians must be trained in recognizing the early signs and symptoms of cancer, and be made aware of the importance of palliative care and pain management.¹⁹ Although standard referral and follow-up protocols are available, these are far from being effectively institutionalized and completely implemented. Counselling and follow-up services are either non-existent or of indifferent quality, particularly in public health facilities.²⁰

The result of all these factors is that the quality of care at all levels is uneven. This is also true of community-based cancer hospitals, whether run by local governments or private enterprises. The Ayushman Bharat programme is trying to address these inadequacies.



Financing cancer care

India has one of the highest levels of out-of-pocket expenditure (OOPE) on healthcare, which entails catastrophic expenditure and poverty for millions of patients and their families. Over two-thirds of the households that seek care in the private sector incur OOPE in excess of 20% of their annual per capita household expenditure.²¹ Since the poorest sections of society thus suffer the hardest financial hardship, including for cancer care, important equity issues arise.

Distress financing, such as from borrowings, sale of household assets and contributions from friends and relatives, is high across private and public health facilities. Nationally, more than 40% of households use such means to pay for cancer treatment in public hospitals. Distress financing is widespread especially in rural areas, with 48.7% and 58.4% of households using such funds for treatment in public and private hospitals, respectively.²²

Most health insurance packages cover all major grave illnesses, including cancer, but these policies usually pay only for treatment and hospitalization. India trails the world in insurance coverage of the

cost of outpatient department (OPD) services, including drugs and diagnostic tests. These costs are borne through OOPE.

Covering OPD costs under the publicly funded health insurance programmes could make it possible for more patients to get tested and treated, increasing the uptake of these programmes and services in the private sector, initiating a positive feedback loop by making it more feasible for private facilities to offer these services.

While published data on the cost of cancer treatment is limited, the amount covered by insurance is generally considered small. Studies have found that the decision to reimburse is based on consultation with experts rather than on scientifically driven cost information.²³

One way to avoid the high rates of catastrophic health expenditure due to cancer treatment could be to enhance the coverage of risk pooling mechanisms that reduce patients' need to pay out of pocket.²⁴



Patient journey

In the Indian context, most patients do not recognize the signs and symptoms of cancer, or know about diagnosis and treatment options. This delays treatment and care, with poor outcomes for patients and families.

On an average, patients spend more than nine months from the appearance of a symptom to first discussion with friends and family members. Four more months are spent, on average, in consultation with other health systems such as alternative systems of medicine and traditional healers.²⁵ By the time a patient consults an allopathic doctor and eventually an oncologist, the disease has progressed to advanced stages.

Due to India's suboptimal doctor-patient ratio, doctors treat huge numbers of patients, so that

each patient receives little time and attention. Early signs and symptoms of cancer that could otherwise be identified are often overlooked. Even after correct diagnosis, proper and timely treatment may not begin – too often, patients have no financial means to access specialists, for instance.

Knowledge sharing on diagnosis and treatment options is limited, as noted before, particularly disadvantaging remote geographical locations and poorer socioeconomic strata.²⁶

Overall, the quality of cancer care varies widely between regions, between rural and urban settings, and across socio-economic groups.



Governance

Inadequate public funding and planning for cancer care have created gaps in public healthcare that have been bridged to some extent by the private sector,²⁷ but this has created challenges of oversight and referral pathways because most cancer facilities operate in an autonomous manner.

The advancement of medical tourism, and a focus on deregulation and privatization, have hampered the much-needed growth in public provision of cancer treatment facilities.²⁸ For primary services,

patients with non-communicable diseases rely mostly on the private sector, where challenges of overpricing and quality assurance are rampant.

Initiatives to develop cancer care facilities, in both public and private sectors, are currently fragmented and uncoordinated. *Ad hoc* review missions have impeded the long-term planning and commitment needed for a national network of public cancer centres.²⁹



Human resources

India has a large deficit in the number of oncologists, nurses and technicians that would be needed to create an equitable and quality cancer care system for the wider population.³⁰ The skilled workforce sits at the top of the pyramid of the cancer care delivery system, which is very weak at the base.

According to the World Health Organization (WHO), India had only one oncologist per one

million people in 2018, while the United States had 161.³¹ Despite the increase in the number of seats in medical colleges, the gap in patient-to-oncologist ratio is likely to remain high compared to developed countries.

A gap also exists in the density and geographic spread of oncologists in India – nearly 50-60% of oncologists are concentrated in the top 9-10 metro or tier 1 cities, according to a 2015 EY report.³²

2

Interventions recommended



This section recommends the Fourth Industrial Revolution technologies that can play a pivotal role in addressing the gaps in cancer care such as late diagnosis; the thin spread of diagnostic and treatment centres, especially in rural areas; the financing of expensive care; and the skill development of health personnel.

The core group followed five steps to make its recommendations: a) categorizing the challenges b) identifying the interventions c) defining the interventions d) prioritizing the interventions, and e) recommending sets of interventions that comprise specific value pathways.

The core group held numerous interactions with a wide range of solution providers and start-ups, and bolstering its findings with research into the areas in which emerging technologies are being deployed for cancer care, arrived at potential interventions.

The interventions were then prioritized based on impact, feasibility, cost effectiveness and scalability. Finally, inter-related interventions were combined into value pathways.

2.1 Challenges

Having identified the critical gaps in the cancer care space, this section highlights the most

prominent challenges that technology-based interventions can address.

FIGURE 3 Mapping identified gaps to potential interventions

Patient-centric interventions	Provider-based interventions	System-based interventions
<ul style="list-style-type: none"> – Awareness and education – Access to services – Streamlining patient journey – Palliative care, remote management 	<ul style="list-style-type: none"> – Knowledge – Skills – Diagnostics – Clinical decision support – Quality of care – Mainstreaming technologies into standard treatment workflows 	<ul style="list-style-type: none"> – Data <ul style="list-style-type: none"> – Registries – Mass or targeted screening – Continuum of care, clinical pathways – Capacity building at all levels – Financing cancer care – Framework for PPP
Emerging technologies are horizontal across all intervention levels		

2.2 Patient-centric interventions

Awareness and education

Since lack of knowledge and awareness as well as paucity of resources are key challenges for early detection of cancer in India, an approach targeted at identifying cancers in high-risk populations could be deployed, using AI to segment the population on the basis of risk factors and age.

Technology can be used to set up health awareness platforms to improve health seeking behaviour among specific groups, such as those at high risk, and their care-givers and communities.

Content could be designed in the form of audio-visual packages to disseminate key science-

backed messages on, for instance, the chewing of tobacco, genital hygiene, breast self-examination and information on where to seek help. The content could be personalized based on user-specific interests and risk factors.

Networks of community-based organizations and NGOs could be encouraged to use technology to disseminate these messages in the community and among patients.

Screening through point-of-care testing

Early detection of a tumour is essential to effective treatment. Point-of-care testing using handheld devices powered by AI and/or machine learning (ML) could deliver quick diagnosis. No specific expertise is required for deploying such solutions in low-resource areas.

comparison to *in vitro* diagnostics, which take time and require complex laboratory infrastructure and skilled technicians. Ground-breaking approaches in point-of-care diagnosis using smartphone interfaces, lab-on-a-chip technology and biosensors are expected to revolutionize the healthcare landscape.

Point-of-care cancer diagnostic devices give better results for cancer biomarker detection in

Continual and easy access to care

Various technologies can be leveraged at various stages to ensure a continuum of care from screening and early detection through diagnosis, treatment and follow-up to palliative care.

Automated reminders and feedback can be set for appointments for screening, treatment schedules and follow-up assessments.

2.3 Provider-centric interventions

Telemedicine

Telemedicine has the potential to reduce healthcare expenses, improve services in remote areas and support modern, home-based healthcare. It can improve diagnosis by, for instance, making it possible to consult experts located in urban centres or distant countries, or even multidisciplinary tumour boards in difficult cases.

The following stages of cancer care can use teleconsultation:³³

- Prevention and screening
- Diagnosis
- Treatment
- Follow-up and rehabilitation

- Referral
- Second opinion
- Palliative and end-of-life care

Teleradiology can address the shortage of radiology experts, as well as the general lack of expertise in this specialty. It can particularly be used in the early detection of lung cancer using AI/ML algorithms.

Telepathology improves speed of diagnosis, in addition to improving access and reducing cost. It can be used particularly in the early detection of cervical cancer.

Automated generation of records

When clinicians are required to enter patient data, it disrupts their work flow and adds to their work burden. Technologies are now available to automate the process of creating medical records conforming to e-data standards. For instance, speech-to-text

software can be used for automated generation of patient health records and electronic health records. This finds better acceptance among clinicians as it enables the creation of a complete case record with the least additional effort by the clinician.

2.4 System-level interventions



Training, upskilling of health professionals

Traditional systems of training only reach a small number of health professionals and are time consuming. Ensuring lifelong upskilling of large numbers of health personnel at different levels of the system needs technology solutions.

Online teaching is one possibility for training general physicians and specialists, and courses are now widely available. Massive online open courses (MOOCs) are being effectively used in many health programmes now, especially since the pandemic.

Since some skills have to be demonstrated in person, blended or hybrid models of skill transfer

must be initiated. At the same time, augmented reality (AR), virtual reality (VR) and mixed reality (MR) can be used for imparting higher-order skills that can be imparted through life-like experiential learning.

Training programmes should be accredited by national benchmarking bodies and certificates issued to those who meet the attendance or learning criteria. Assessments can be made more interesting through the use of innovative formats such as gamification and simulation.



Skilling of field workers

Retention of skills wanes over time unless there is constant support, monitoring and mentoring. Good mentoring also improves the quality of services that healthcare providers deliver.

Currently, no structured programmes exist for mentoring trainees or assessing their skills in a non-formal manner. Going ahead, digital applications such as video-calling could be developed for mentoring and supporting continuous professional skill upgradation at periodic intervals. Non-formal assessments and motivational support can be delivered through gamification and simulation. Smart assessment tools and interactive needs-based learning can be provided using AI in education.

In the Indian context, frontline public health workers such as auxiliary nurse-midwives and

accredited social health activists must be skilled and re-skilled constantly. Some ways in which technology could be used to do this include:

- Appropriate print, digital and/or audio-visual training materials could be created and translated into all the main Indian languages, with easy-to-grasp and interesting content.
- Interactions of trained personnel with the community could be captured using GPS trackers.
- Hub-and-spoke models could be created from state to district level for effective delivery of digital content.



Comprehensive insurance packages

In a developing country, the affordability of comprehensive cancer care determines to a large extent whether patients can access it. Affordable cancer care matters most to the low-income groups for whom public health insurance coverage doesn't cover all the treatment costs and to the middle-income groups that are not covered by public health insurance at all. India needs seamless and adequate insurance coverage for all to fulfil its aspirations for universal health coverage.

A pilot could be undertaken to study how a seamless group insurance cover could be offered to all individuals or families who are not covered

by any health insurance programmes. The pilot group could be facilitated to undergo screening for different cancers based on their risk profiles, and appropriate insurance packages and products could be designed. These could then be replicated or scaled up.

Some options based on target groups' spending capacity:

- In-patient hospitalization for Rs 3-5 lakh (\$4,000 to \$6,700) could be offered depending on the target group's spending power, which could be availed of in a cashless manner in selected public or private hospitals.

- A fixed payout could be issued for the 15 major surgeries. For instance, a sum of Rs 3 lakh (\$4,000) could be paid if a patient undergoes a surgery and submits documents such as discharge summary.
- A per-day hospitalization cash payout of Rs 1,000-2,000 (\$13-27) could be paid, limited to 15-20 days a year.

This intervention would enable:

- Seamless integration of risk screening, insurance solution integration and continuum of care.
- Increased awareness of risk factors and what should be done to mitigate them.
- Early detection and treatment.



AI in insurance

The insurance industry is a treasure trove of data. This data is unstructured but can be leveraged with the help of AI to customize personalized services, increase customer engagement, target the right customer and formulate personalized messages for promoting health-seeking behaviour.

AI can help determine the optimal pricing models designed per customer needs, and can recommend

useful products to customers. Similarly, machine learning can be used to recognize fraud and reduce fraudulent claims. Finally, chatbots can be developed using neural networks to answer customer queries.

All these capabilities can enhance customer insurance coverage at a lesser cost.



Public-private partnership frameworks

In India's resource constrained setting, public-private partnerships (PPP) between public sector institutions, private healthcare service providers and not-for-profit entities can help optimize resource use and results. This will require a receptive political mindset and public buy-in, but the potential rewards are many.

Some models of potential interventions:

Overflow care

A panel of private organizations could be established to cater to the overflow of cancer patients from the public sector. This could take the shape of an end-to-end treatment model at public sector rates. Or, the private sector could be engaged to take care of patients after they are referred for diagnosis or for treatment.

While patients would get rapid access to care and treatment, the private sector would be able to optimize its assets, enjoy efficiencies of scale and generate additional revenue. For the public sector, it would reduce the burden on health facilities and service providers.

Shared infrastructure

The private sector's diagnostic capacity could be utilized to expedite diagnosis or treatment wherein cancer suspects would be referred to pathology, radiology, chemotherapy or radiotherapy departments in private facilities. This approach has

three-pronged benefit: for the private sector, optimal asset utilization, including out-of-hours patient testing, and additional revenue streams; for the patient, speedy diagnosis and expedited treatment; and for the public sector, increased capacity and better patient outcomes through early case detection and accelerated treatment.

Technology would enable an optimal utilization of capacities through integrated scheduling and record-keeping, more efficient management of public sector funds and effective monitoring of outcomes.

Digital continuum of cancer care

In this model, a public healthcare organization would partner with a private technology partner to automate screening, diagnosis, treatment planning and monitoring through the continuum of care. The healthcare partner would work with the technology provider to design and deploy (at risk) a unified cancer care platform. The cost savings from preventing late-stage detection and costly care would justify the investment in the development of such a digital ecosystem.

Table 1 displays the interventions, with the technologies used and some illustrative examples of the solutions being tried out in the field. The core group went through presentations from various start-ups and technology majors to explore this landscape of solutions.

TABLE 1 | Interventions at a glance

Challenges	Intervention	Description	Technologies used	Expected impact on health outcomes	Illustrative solutions
 Citizen-centric interventions					
Lack of awareness and knowledge about cancer in high-risk groups and general public	Awareness generation; targeted messaging	Technology platforms to be established to improve health- and wellness-seeking among citizens	Digital, AI	Help patients recognize the early signs and symptoms of cancer	Saathealth CancerU
Absence of testing in screening programmes	Point-of-care testing	Point-of-care testing using AI/ML-powered handheld devices enables quick diagnosis	AI	Early detection and monitoring of the tumour can provide more effective treatment and better prognosis	Niramai iBreastexam
Absence of care pathways for patients	Continual and easy access to care	Continuum of care can be designed from screening, early detection to treatment	AI	Improved prognosis and patients' quality of life	Karkinos NCD programme (Indian government partnering with Dell)

 Provider-centric interventions					
Access to specialized care	Telemedicine	Early detection, referral and post-treatment follow-up at the local level	AI	Reduced healthcare expense, improved healthcare service in remote areas	Karkinos mFine Wellthy
Absence of low-cost diagnostics	Teleradiology	Machine learning algorithms detect lung cancer	AI	Early detection of lung cancer	Qure.AI
Absence of low-cost diagnostics	Telepathology	Remote viewing of microscopic images	Telecommunications, AI	Early detection of cervical cancer	Onwardhealth
Incomplete patient records	Automated generation of electronic health records and patient health records	Automation of patient history, clinical data and findings	AI	Complete, efficient data entry and a complete health record compliant with standards	Simbo.AI Zeedoc Comprehend Medical M16 labs

Challenges	Intervention	Description	Technologies used	Expected impact on health outcomes	Illustrative solutions
 System-based interventions					
Updated cancer-specific skills	Online and digital training modules	Massive online open courses, audio-visual and 3D aids	Digital, AI, AR, VR, MR	Skilling of the formal workforce in specialized procedures and practices in cancer care	Medisage apoQlar
Inadequate skills for cancer diagnosis and care	Skilling of health workers	Video-calling for continuous professional skill upgradation at periodic intervals	Digital tools	Mentoring and monitoring of professional development of frontline workers	Saathealth
Absence of cancer-specific insurance packages for all education groups	Formulation of comprehensive insurance packages	Seamless group insurance cover for all	Digital tools, AI	Seamless integration of risk-based screening, insurance solution integration and care continuum	To be designed and developed
Low penetration of insurance in lower-income and marginalized groups	Increased insurance penetration	Partnerships to be developed with banking and existing insurance agencies to increase penetration in rural areas and urban middle-income populations	Digital tools, AI	Lower out-of-pocket expenditure on cancer care	To be designed and developed
Absence of effective PPP frameworks in cancer care	Development of PPP frameworks	Creating shared PPP infrastructure and digital care continuum	Digital tools, GPS, AI/ML	Inclusive treatment across spectrums	To be designed and developed

3

Oncology data model and standards



3.1 Overview

Oncology data needs to be harnessed for delivering value to patients, care providers and health policy-makers. As a first step towards achieving this goal, the core group has suggested an Oncology Data Model (ODM).

This section elucidates the steps to design the proposed ODM, starting with the core principles that must inform the process.

3.2 Core principles

To reduce the complexity of data flows in cancer care and enable interoperability across multiple service providers, a set of principles is required. The principles proposed below would leverage the

1. Align with National Digital Health Mission (now Ayushman Bharat Digital Mission).
2. Align with international standards on health data.
3. Collect data “once only”.

developments in the Indian digital health ecosystem and are compatible with the relevant global standards.

4. Collect minimal data.
5. Design for the best user experience.
6. Ensure data protection and security.

3.3 The data model

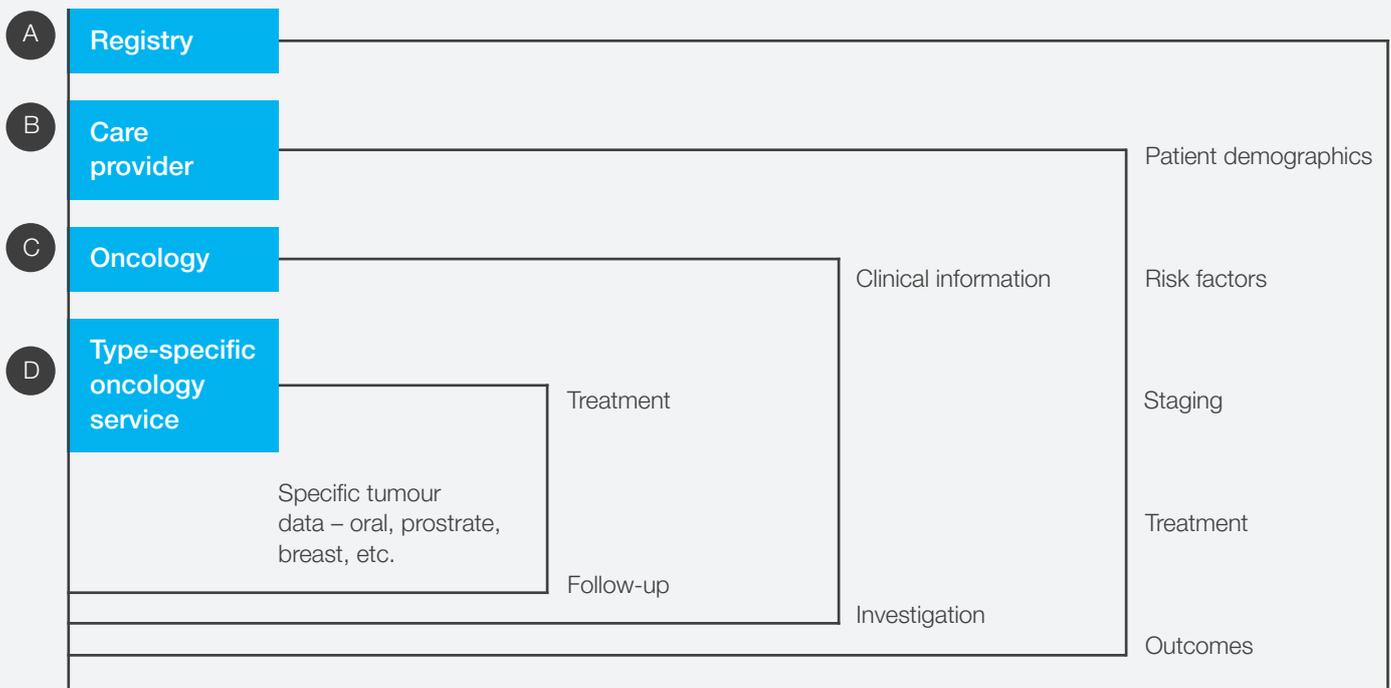
The model would consist of an onion-layer structure (Figure 4) with four layers:

1. Registry: A meta-resource of key data in cancer care, captured in an automated manner from the primary sources of cancer data.
2. Care provider: A person or an organization authorized to provide medical or surgical care at any level, i.e. primary, secondary or tertiary.
3. Oncology department: A cancer care provider.

4. Type-specific oncology service: A service specific to the type of cancer such as breast, oral or prostate.

The layers guide the design of the data model and do not necessarily represent the sequence in which data are generated in oncology.

FIGURE 4 | Oncology data model



The framework in Figure 4 reduces the complexity and duplication of data entry by proposing what kind of data may be gathered at what point. These portable implementations would interoperate with each other to populate oncology data and make it accessible in a contextually relevant manner, observing the principle of least privilege.

While ensuring minimal and optimal entry of patient data as shown in Figure 4, the data model would guide the design of databases and data entry templates.

3.4 Oncology master record

The above data model would create a Master Record of Oncology (MRO). Each of the components of the master record would be required to follow the *once only* entry principle.

The proposed MRO would have the fields shown in Annexure 1, with both minimal (light blue) and

optional (green) elements to support data collection for multiple use cases of oncology.

Implementations could begin with capturing, processing and exchanging minimal data initially, and could be expanded to cover the optional data in a phased manner.

3.5 Guidelines for implementation

The implementation framework for the ODM would be:

1. Paperless by design.
2. Open source, extensible and customizable.
3. Based on use of normalized schemas.
4. API-based access-enabled.
5. Supportive of automation at all stages of data processing.
6. Designed to leverage Fourth Industrial Revolution technologies.

3.6 Safeguards for privacy of health data

Data protection, privacy and security should be patient-centric to ensure:

1. Informed consent.
2. Explicit communication.
3. Disclosure and use of data only for the purpose for which it has been collected.
4. Secure technology implementations for de-identification, anonymization and pseudonymization to prevent linking, singling out and identification of individuals and their details.
5. Administrative controls.
6. Conformance to the standards prescribed by the National Digital Health Blueprint.

3.7 Guidelines for adoption of standards

In alignment with the principles defined for ODM, the following guidelines are recommended for implementing the standards in relation to oncology data.

Optimal data definition

The best or most accepted validated data should be captured to ensure completeness and enhance the quality of data for clinical usage. The ODM should allow the flexibility to capture all essential and optional data in different use cases of treatment, and to create views for different entities in the healthcare ecosystem.

Conformance to healthcare data standards

Conformance to the standards ensures and enhances the quality of data, avoids duplicate collection or storage, and also brings interoperability and enables advanced research. By adopting existing standards like Fast Health Interoperability Resources (FHIR), the same resource structures should be utilized to create multiple views for different entities including patients, clinicians, organizations and the registry. The elements of the Master Record of Oncology are mapped to the FHIR in Annexure 2.

Sharing of contextual and quality clinical information

The aim would be to enable clinicians to refer to the appropriate, up-to-date clinical information for use in the different fields in the ODM. It should help in achieving quality data capture and adoption of best practices in the industry.

Support for minimal-to-highest semantic interoperability

In line with the approach of the National Digital Health Blueprint, the ODM data structures should be designed to support legacy data and systems and be fully interoperable with future healthcare systems.

Fulfilment of national/local requirements

The specifications of FHIR should be customized and extended to meet the local/national requirements. The adoption should ensure compliance with policy and regulatory requirements.

Reuse and reference of existing efforts

The existing national and international efforts should be referred and reused before defining new data structures, value sets and guidelines for adoption.

4 Implementation framework and roadmap



4.1 Objectives of the implementation framework

The core group has identified what needs to be done to transform the state of cancer care in the country. An implementation framework and a roadmap are crucial for initiating the next steps to describe how to do it.

In all, 30 interventions, mostly technology-driven, were identified. These interventions have been

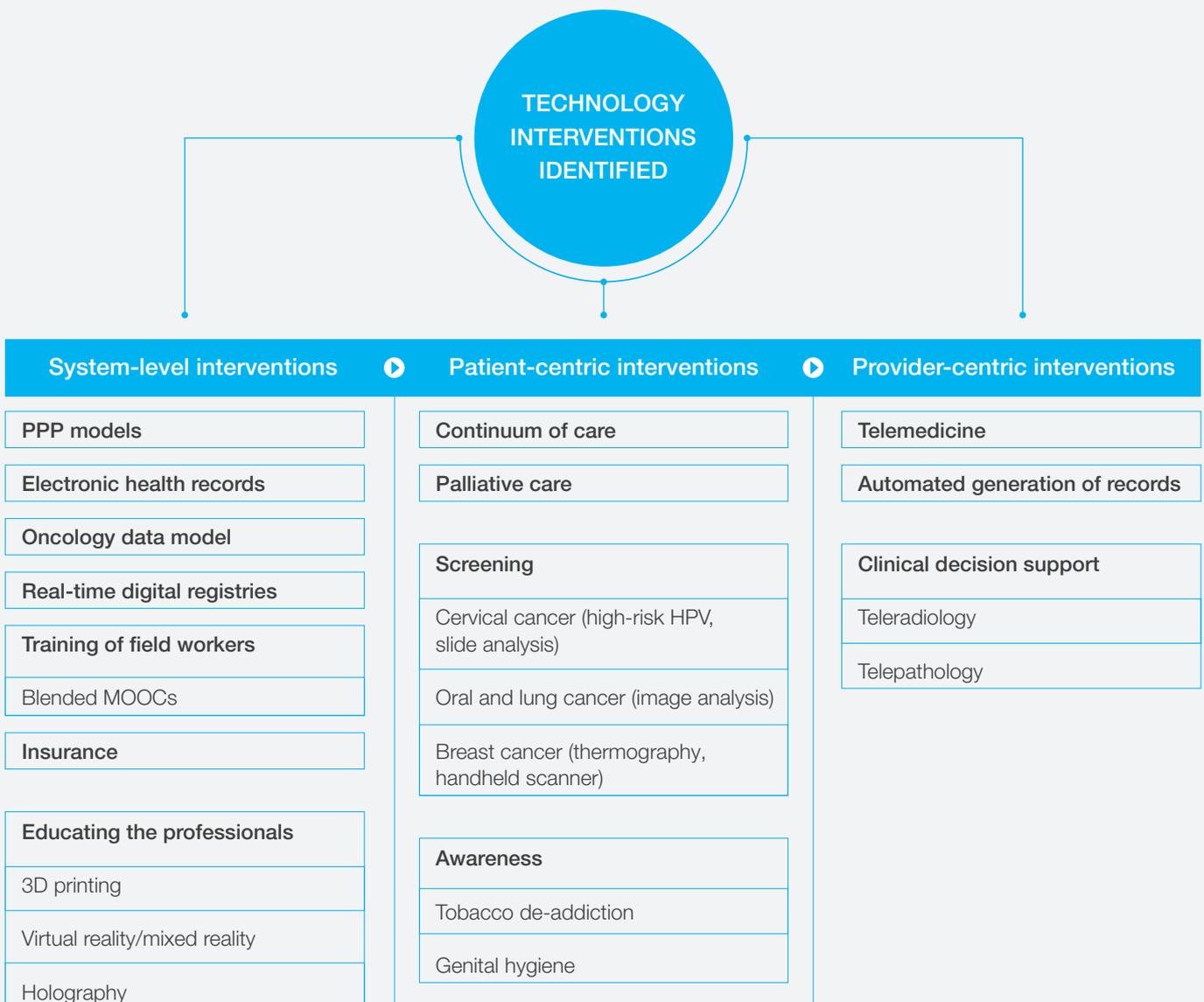
described in detail previously (see the section “Interventions recommended”), and the next section provides an overview of some shortlisted interventions. These call for a coordinated, multistakeholder effort designed and undertaken in a sustainable way across the entire continuum of cancer care. This is best achieved by formulating an appropriate implementation framework.

4.2 Overview of the interventions

The implementation framework suggests ways of converting the identified interventions into a set of actions on the ground.

Figure 5 is a visual representation of 18 of the 30 interventions that make significant use of Fourth Industrial Revolution technologies.

FIGURE 5 | Intervention map



4.3 Cancer care value pathways

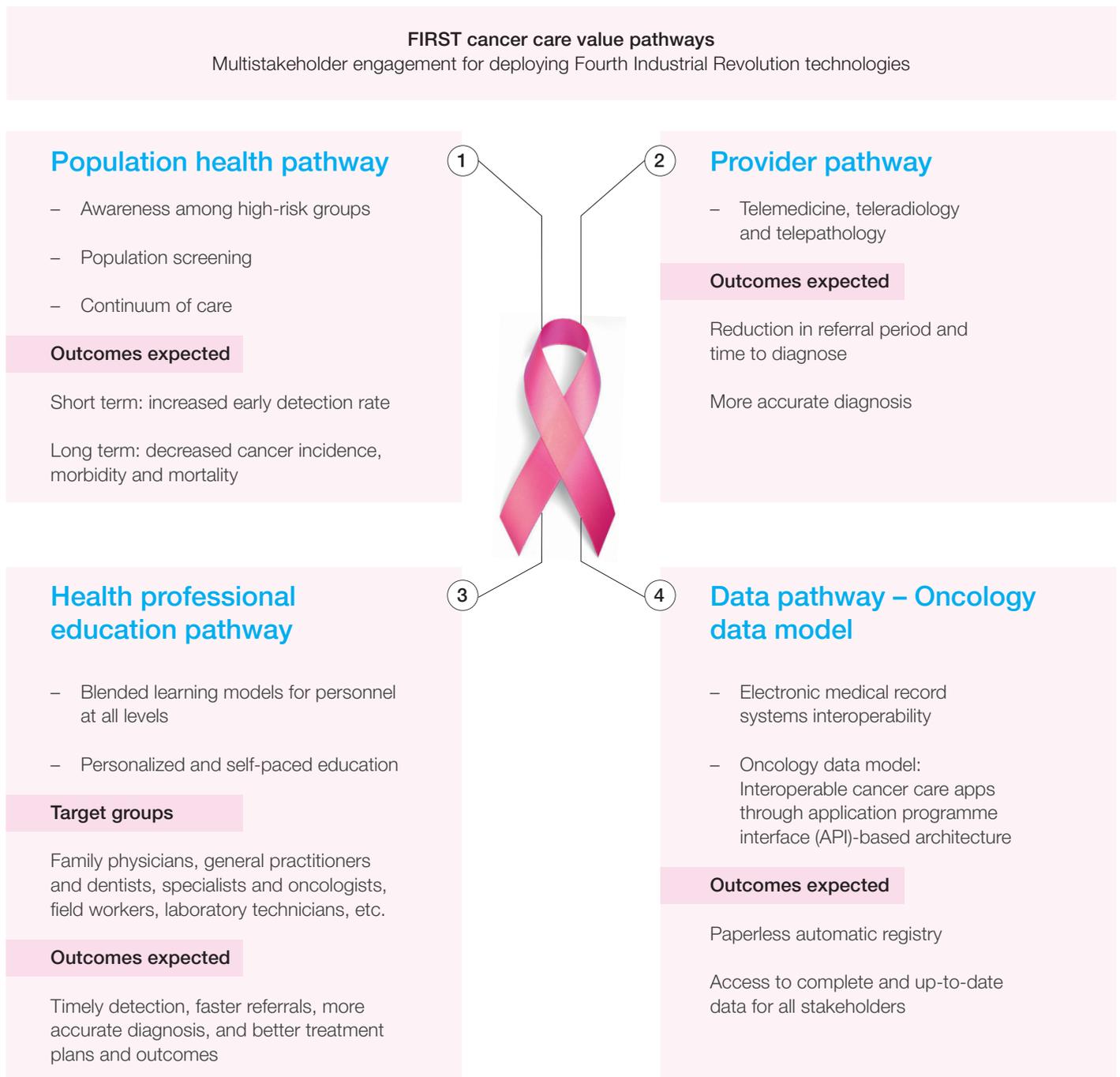
A cancer care value pathway (CCVP) is a specified segment of the cancer care value chain that can produce tangible and measurable outcomes for the stakeholders concerned. Value pathways can be imagined as distinct modules of the cancer care ecosystem that can be designed, developed and deployed independently of the other pathways, but in an interoperable manner to facilitate continuum of care. A value pathway is a combination of digital and physical processes.

The value pathways approach enables ecosystem players to think bigger than implementing point

solutions for addressing specific gaps and problems, and to adopt a more holistic and integrated approach to the continuum of care.

Figure 6 depicts four indicative cancer care value pathways. These pathways could be fleshed out by (i) defining the scope of each value pathway (ii) specifying the technologies to be deployed, and the standards and specifications for the same, and (iii) supplementing each value pathway with phygital (a combination of digital and physical) interventions, where required, to ensure the continuum of care.

FIGURE 6 | Cancer Care Value Pathways



4.4 Prioritization of interventions for piloting

Keeping in view the objective and scope of the FIRST Cancer Care project, key interventions have been prioritized so as to produce maximum impact quickly and surely. The prioritization has been done by mapping the interventions along the dimensions of impact (Y-axis) and viability (X-axis).

Potential impact is defined by scalability, inclusivity, sustainability and social benefit, while viability is defined by the technological innovation, financial viability, acceptability and policy intervention needed.

The interventions fall into four quadrants after the mapping:

Potential game changers

These have the potential to cause a transformative shift in cancer screening. The ODM falls under this category.

Incremental interventions

These can be carried out in conjunction with the other initiatives recommended. Field workers' capacity building, telemedicine, telepathology and teleradiology are included in this.

Easy wins

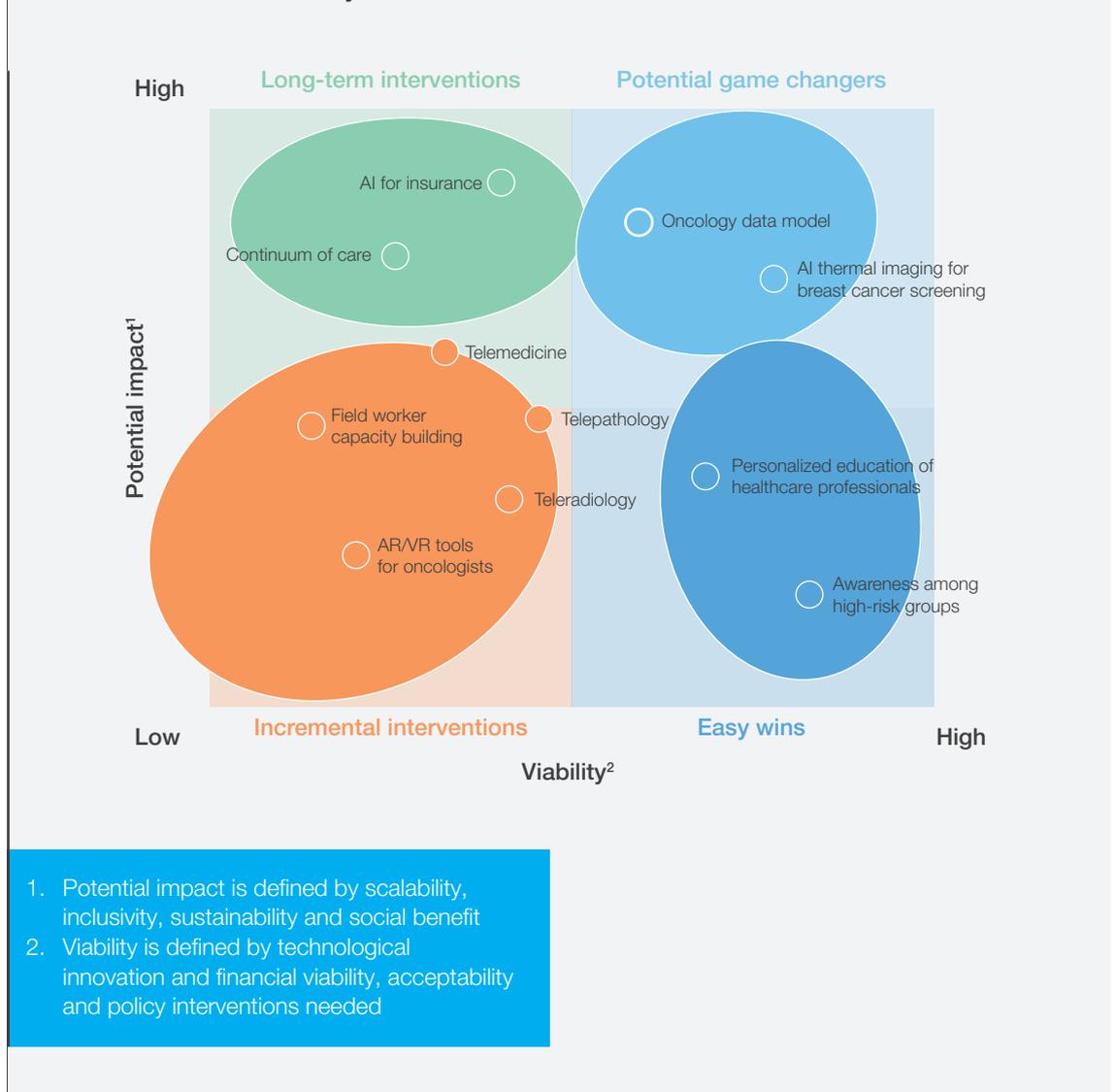
These can be easily scaled by supporting primary healthcare institutions. Personalized education of healthcare professionals and creation of awareness among high-risk groups are included under it.

Long-term interventions

These are difficult to initiate but reap significant returns if implemented. AI for insurance and continuum of care are included in this category.

FIGURE 7

Cancer Care Value Pathways



4.5 Designing pilots

The insights gained in the first phase of the FIRST Cancer Care project need to be validated through a pilot study in a limited geography. The section

below describes how such a pilot could be designed and implemented.

Geographic scope

The geography of the pilot should be just large enough for validating the proposed interventions and solutions. It should be a unit of administration so that the state government can facilitate coordination and implementation. A typical district would satisfy these criteria. The following considerations should guide the selection of pilot districts:

1. The districts should be selected in two or three states that are willing to support the pilots and, preferably, have reasonably well-established digital health systems.
2. Each district should have a tertiary healthcare centre with a well-established oncology department.
3. It is desirable that the district have a reputed medical college, independent or attached to a tertiary care centre.
4. The district should have a spread of private and public healthcare providers at the primary and secondary levels, comparable in number to the national average. Its doctor-population

ratio, nurse-population ratio and bed-population ratio should also compare well with the national average.

5. It would also be prudent to consider the districts or states known to have a higher incidence of the types of cancers prioritized in FIRST Cancer Care to demonstrate the impact of the initiative, and the aspirational districts identified by the NITI Aayog, to derive synergies from the other programmes being implemented in those districts. (The core group has identified the following cancers for according high priority: pan-India – head and neck, lung, breast, cervical and haematological; and regionally - oesophagus and stomach, gallbladder cancer and colorectal.)

During the design phase of the pilot, an analysis of the health profiles of potential districts may be carried out in association with a national institution like the Public Health Foundation of India to shortlist the states and districts. The states concerned may be approached for an in-principle agreement to support the pilot.

Functional scope

The scope of the interventions identified is wide. Despite packaging the interventions into logically compact groups and pathways, implementing such a large portfolio would need careful calibration. While all four cancer care value pathways may not

be implemented in each pilot district, an attempt may be made that all four are covered in the two or three pilot districts together. The interventions within each pilot may be phased to match with the resources and capabilities available.

The crucial aspects of defining the functional scope include the following:

1. A shared vision may be developed in an iterative and consultative manner, involving all the key stakeholders.
2. A set of outcomes may be designed for each pilot, after an in-depth interaction with the key stakeholders of the pilot area.
3. A set of key performance indicators may be defined for each outcome.
4. A responsibility assignment (RACI) matrix may be prepared along with a communication plan.

5. The pilot structures should be designed to be part of the district health administration, not as disparate external teams working on their own mandates.

While the broad contours of the functional scope can be prepared already, the steps suggested above can be taken only after the pilot states come on board and the districts are identified.

Design considerations

The following are some of the design considerations that are to be built into the pilots, independent of the scope.

1. An ethics framework should be put in place, as part of the pilot design. Each pilot should be appraised by a neutral third party for conformance to the ethics framework. Constituting ethics committees at the appropriate level would be an important step to ensure that the ethical requirements are continually met during the execution of the pilots.
2. While the 30 interventions identified in this report are the most important, these need to be supplemented with other activities/interventions that may be non-technological so that each value chain or cancer care value pathway is complete and holistic.
3. The approach should be to build on what is already existing in the pilot geography, rather than reinventing the wheel.
4. The district administration, especially the office of the district collector or district magistrate, should be central to the implementation plan.

Pilot implementation partner/lead partner

FIRST Cancer Care is an ambitious project with a wide and varied scope. Its implementation calls for coordinated action by a multistakeholder community. This cannot happen without an

orchestrating mechanism. A lead partner must play this critical role during the pilot phase. The pilot state may be requested to select the lead partner in line with its internal processes.



Conclusion



The increasing contribution of cancer to the disease burden in India is a powerful reason for more systematic and large-scale approaches to improving cancer care at the population level across the country. These efforts should include improved infrastructure and resource distribution, along with adequate financial protection.

With a population of 1.3 billion scattered across urban and rural areas, India faces a unique healthcare challenge. If it is to realize its goal of universal health coverage, it is imperative that technology and healthcare interact with each other seamlessly. Adding infrastructure and medical professionals alone will not solve India's huge unmet needs in healthcare. It needs to be supported by technology.

The interventions recommended in this report call for a coordinated, multistakeholder effort designed

and undertaken in a sustainable way across the entire continuum of cancer care. Given the intricate relationships, roles and responsibilities spread across various levels, a multi-tier institutional structure should take forward the interventions outlined in this report.

Implementing this ambitious project with a wide and varied scope involving a multistakeholder community needs an orchestrating mechanism. Given the altruistic nature of the initiative, this role is best performed by a not-for-profit foundation, preferably working in the health sector. A foundation is recommended as it would provide more flexibility and agility in evolving the designs and plans, besides enabling collaboration with multiple commercial entities.

Appendix 1

Master Record of Oncology

Demographics	Risk factors	Investigations	Treatment plan	Follow-up	Outcome
Consent	History	Method of diagnosis – Histology – Imaging	Surgery (yes/no) If yes, name of surgery	Status	Alive
Name	Tobacco (yes/no) If yes, – Chewing or smoking – Frequency per day – Duration	Final diagnosis	Planned chemotherapy (yes/no/unknown) If yes, – Neoadjuvant – Adjuvant – Palliative	Recurrence (yes/no/unknown) If yes, – Local – Regional – Locoregional – Distant – Both local and distant	Dead
UHID	Alcohol (yes/no)	Staging classification	Hormonal therapy (yes/no/unknown)	Treatment if recurrence	
Date of birth	Other addictions	Final stage	Planned targeted therapy (yes/no/unknown)		
Gender	Comorbidities	Blood investigations	Combination		
Permanent address		Genetic markers			
Marital status		– HER2, ER, PR (Breast)			
Mobile number		– P16 (Oral)			
Occupation		– CEA (Colon) – USG/MRI/PET (Cervix)			

Appendix 2

Oncology data model (ODM) categories and corresponding fast health interoperability resources (FHIR)

ODM categories	Corresponding FHIR
Demographic	Patient, RelatedPerson, Person, Group
Care provider identity	Practitioner, PractitionerRole, Organization
Investigations	DiagnosticReportRecord (DiagnosticReportImaging, DiagnosticReportLab, Observation)
Clinical data (diagnosis, risk factors, tumour classification, tumour stage)	Family Member History, Allergy Intolerance, Condition, ClinicalImpression, Observation; MedicationAdministration, ServiceRequest, ObservationBodyMeasurement, ObservationGeneralAssessment, ObservationGeneralAssessment, ObservationLifestyle, ObservationPhysicalActivity, ObservationVitalSigns, ObservationWomenHealth
Outcomes	Procedure
Treatment plan, follow-up	Care Plan, MedicationRequest, Goal

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