Title:
Develop a framework for the overall cost of treatment or burden of cancer (and not just anti-cancer drugs) for pharmacoeconomic or cost-effectiveness evaluation.

Full Name:
Sakthi Vignesh D

Name of the Institution:
Government Kilpauk Medical College, Chennai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):

The key objective is to establish a National Oncology Data Commission—which serves as an authority for cancer data stewardship. This serves to host all the data involving cancer patients all over India. This can be done by empaneling all diagnostic centers, private corporate hospitals, and government institutes (mandatory reporting like done for TB), tracking patients from diagnosis onset to treatment and follow-up, and end-of-life care. By integrating all data, we can identify region-wide disparities and areas of lacunae, needing more focus, for optimizing fund allocation and areas of research guidance.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):
To ensure proper functioning of the National Oncology Commission—all diagnostic centers, private corporate and small hospitals, government institutes and hospitals should be empaneled in a single system. Patients diagnosed with cancer with imaging or biopsy should be provided with a Unique Oncology ID—generated at the first point of diagnosis. This number can be used after that, wherever the patient goes and gets treatment, so that the complete profile of the patient, from diagnosis to treatment completion or end-of-life care, is available to us. In this way, we can track the clinical profile and total expenses incurred and other crucial data required for research. To protect patient identity and rights, a deidentification layer can be used and data encrypted, so that identity is preserved. This system serves as a transparent system to analyses the Pharmacoeconomics, areas where extra research and strengthening are required, and methods by which potential time delays can be eliminated are analysed. A real-time dashboard can be created, by which anonymous data can be seen for research purposes and general information. Researchers requiring additional details can be offered a tiered access protocol to access sensitive data, after proper verification. Cloud data should be stored in a protected firewall environment, and steps should be taken to ensure no data leak happens. In this way, we can ensure that cancer burden in India is mitigated by evidence-based policy decisions and specific targeted research.

Full Name:
Himaprathyusha Parupalli

Name of the Institution:
MNJIORCC Osmania Medical College, Hyderabad

State:
Andhra Pradesh and Telangana

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):

Title: Access-Driven Precision Oncology: A Cost-Optimized, Tiered Molecular Testing Framework for Resource-Constrained Settings.

Objective of the Solution:

To develop a structured, cost-efficient framework for molecular testing that prioritizes high-impact diagnostics, ensures equitable access, and minimizes financial burden while maintaining clinical effectiveness.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

In resource-constrained settings, a major barrier to precision oncology is the inability of patients to afford even essential molecular tests. This leads to delayed or suboptimal treatment and contributes to inequitable care.

This proposal introduces a tiered molecular testing framework:

- Priority 1 (Essential): Tests directly impacting first-line treatment decisions
- Priority 2 (Conditional): Tests used in selected clinical scenarios
- Priority 3 (Advanced): Tests reserved for refractory or research settings

A pooled funding mechanism involving government schemes, NGOs, and industry partnerships subsidizes essential tests for eligible patients.

Testing is centralized through regional laboratories to reduce costs and improve turnaround time. MDT-based approval is required for higher-tier testing to ensure rational utilization.

Example: A lung cancer patient receives subsidized EGFR testing under Priority 1, enabling targeted therapy instead of empirical chemotherapy.

This model ensures rational allocation of limited resources, improves access to precision medicine, and reduces financial toxicity.

Full Name:
Dr. Chilamkurty Maitreyi

Name of the Institution:
Stanley Medical College, Chennai

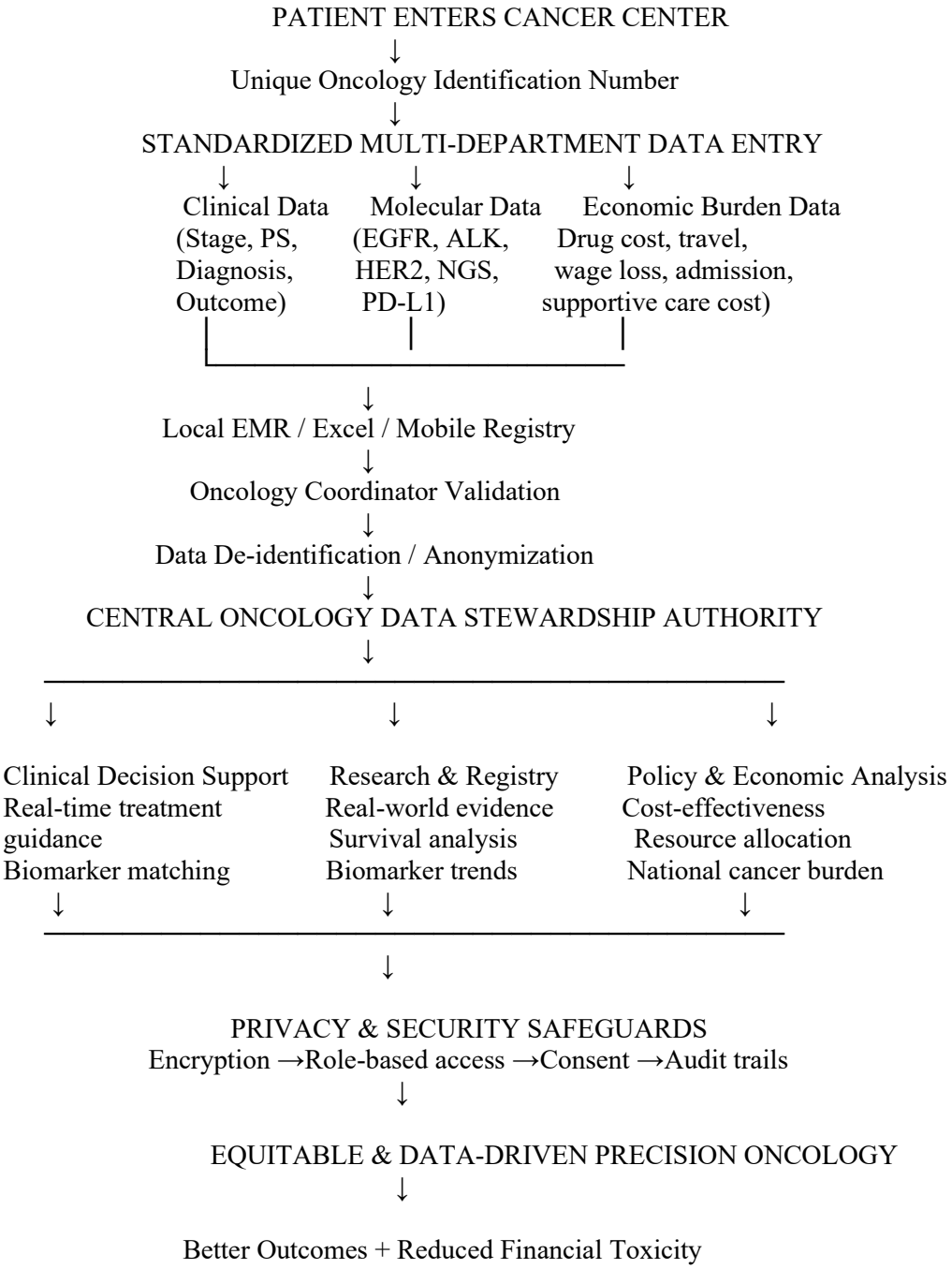
State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
To establish a unified and secure oncology data system that records the overall medical and financial impact of cancer care, supports informed clinical and research decisions, and promotes safe, ethical, and responsible sharing of healthcare information across institutions.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):
Problem statement: A 56-year-old farmer undergoing treatment for metastatic colorectal cancer at a government oncology center faces multiple challenges during his care journey. His medical information is maintained separately in pathology reports, radiology records, pharmacy logs, billing sections, and handwritten case sheets, making coordinated care difficult. Although expenses related to chemotherapy are recorded, several important components of cancer burden such as transportation costs, loss of daily income, nutritional support, hospitalization expenses, caregiver burden, and delays in treatment are not systematically documented.
In addition, molecular diagnostic reports remain isolated within individual departments and are not easily available for clinical review, research analysis, or health policy planning because of disconnected data systems and concerns regarding patient privacy. Due to the absence of a unified and secure oncology data framework, the institution is unable to accurately assess the true economic burden of cancer, analyze treatment effectiveness, identify gaps in access to care, or optimize healthcare spending. At the same time, uncontrolled sharing of patient information increases the risk of confidentiality breaches and misuse of sensitive medical data.

These limitations significantly affect evidence-based cancer care delivery and create major obstacles for both advanced and resource-limited healthcare systems.

Solution: Integrated Oncology Data Stewardship & Cost Intelligence Framework (IODS-CIF)



A tiered accessibility model:

- Clinicians →real-time treatment support
- Researchers →anonymized datasets
- Policymakers →cost-effectiveness and burden analysis
- Pharma/public health agencies →biomarker prevalence, drug utilization trends, and access-gap analysis without patient identification

Full Name:
Foram Joshi

Name of the Institution:
Kidwai Memorial Institute of Oncology, Bangalore

State:
Karnataka

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
The biggest fear of denying treatment for Cancer and preference towards best supportive care is because of financial toxicity and the need for caregiver support for Cancer treatment in the majority of middle-income and economically weaker sectors. Financial challenges begin as soon as patients have symptoms, starting from repeated visits to local physicians for persistent symptoms, and sometimes unnecessary investigations as well, doctor shopping, and finally getting diagnosed with cancer after a long wait time. The majority of finances get exhausted in this journey with no options for funding treatment. Hence is a need for a country-wide framework to break disparity and ensure Quality Standard of Care treatment for all rather than just for Elites of society.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):
The framework should begin with basic awareness campaigns and early diagnosis strategies. If these strategies are properly implemented, cost-effectiveness can also be improved. Access to oncology services must be made available at the community level, with specialists trained in basic oncology services for patients living in remote areas. This will help reduce costs associated with travel and caregiver support.

Availability of diagnostic services may be challenging at times. Therefore, governments must prioritize collaborations between public and private sectors with adequate funding and supportive strategies to overcome these challenges, ensure equitable care, and reduce the burden of patient load on Regional and Central Cancer Centres.

At times, delivering quality cancer care at the community level may become difficult, and appropriate referrals to Regional Cancer Centres should be made on a case-by-case basis. One of the biggest challenges in resource-limited countries in delivering community cancer care is poor pay scales for specialists and lack of government action in filling vacancies. Therefore, it is essential to develop a structured framework to address these issues.

There is a tremendous need to improve framework algorithms for cost-effectiveness at Regional Cancer Centres where the patient load is extremely high. It is equally important for us to embrace newer technological advancements and artificial intelligence to develop cost-effective healthcare models. AI can assist in quicker diagnosis and support diagnostic algorithms, thereby reducing workload. It can also help develop precision oncology algorithms, reducing unnecessary investigations, saving time, and minimising manual work. AI and digitalisation can also support data entry and reduce the requirement for manpower.

Another important challenge is the cost associated with prolonged hospitalisation, repeated admissions, ICU care, ventilator support, sepsis management, and treatment-related side effects. Therefore, cost-effective strategies must evolve in every aspect of cancer care, along with careful clinical decisions balancing standard treatment choices with patient tolerability and affordability.

We must encourage the use of biosimilars to reduce financial toxicity and ensure quality cancer care. Regional Cancer Centres often face resistance from administrative systems, and corruption may also become a major issue. There should be a regulatory board supervising drug procurement, pharmaceutical

company tenders, availability of cost-effective biosimilars, and most importantly, equal access to clinical trials for all eligible patients.

Cancer is a chronic disease, and financial toxicity also continues throughout treatment monitoring and reassessment. In resource-limited countries, it is extremely important to provide quality services while minimising unnecessary investigations and promoting cost-effective strategies. There should also be affordable surveillance strategies with access available at the community level.

We must realize that cancer affecting one family member impacts the entire family financially, psychologically, and socially. The greatest burden is often financial toxicity. Therefore, cancer care services must also focus on the well-being of caregivers. There is a need for caregiver allowances to help manage daily expenses. Regional Cancer Centres should provide facilities for patient and caregiver accommodation along with food and water facilities. This should be considered a cornerstone of every cancer centre because of the chronic nature of the disease and prolonged duration of treatment.

It is also important to support employment opportunities for family members, especially when the earning member of the family is diagnosed with cancer. We must understand that cancer care should not be judged only by the price of treatment but by the overall impact it has on patients, families, and the healthcare system.

We must also realize that resource-limited healthcare systems function differently in every country, which has become a major limitation in creating a universal treatment algorithm. Eligibility for free cancer treatment, even for economically weaker sections, varies from state to state, which creates serious healthcare inequalities.

For example, in India, if a cancer patient resides in one state but possesses a Below Poverty Line card from another state, the patient may not be able to access cancer treatment benefits in the current state. This highlights the need for universal access to cancer treatment. Unless this issue is addressed, treatment for all cannot be achieved.

There are also economically weaker sections of society who do not possess any government cards and therefore pay completely out of pocket for treatment. Hence, there is a need for proper regulation of healthcare policies and affordable insurance schemes for these vulnerable groups.

In many countries, cancer patients can broadly be divided into four groups. The first group includes the elite class who can afford any treatment modality. The second group includes patients with health insurance coverage. The third group includes economically weaker patients who still pay for treatment from their own resources. The fourth group includes the poorest sections of society who are dependent on government-funded treatment programmes. This classification itself is one of the biggest barriers to achieving equity in cancer care.

Full Name:
Habeeb K A

Name of the Institution:
VPS Lakeshore, Kochi

State:
Kerala

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):

- Establish a National Oncology Data Trust for standardized, ethical, and centralized cancer data stewardship.
- Enable structured, interoperable data collection across hospitals covering clinical, genomic, imaging, outcomes, and cost data.
- Improve real-world evidence generation for survival outcomes, treatment effectiveness, and cost-effectiveness in India.
- Ensure secure, privacy-protected data sharing using de-identification, consent systems, and strong cybersecurity frameworks.
- Build a learning health system where patient data continuously improves clinical decision-making, research, and policy planning.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

Cancer generates enormous data—clinical, genomic, imaging, outcomes, and costs. Yet in India, much of this remains fragmented across hospitals, unused for improving care. Building a robust data-sharing ecosystem is not just a technical need—it is a moral responsibility to ensure every patient's journey contributes to better outcomes for others.

1. Central Data Stewardship—A Trusted Custodian

A National Oncology Data Trust, aligned with the National Cancer Grid, should serve as a neutral, non-profit custodian. It standardizes data definitions, ensures quality, prevents duplication, and enables national-level insights on outcomes and costs. Most importantly, it builds public trust, ensuring data is used ethically and not commercially exploited.

2. Structured Data Collection and Integration

A three-tier model ensures scalability:

- Tier 1 (Source level): All cancer centers submit structured, de-identified data—diagnosis, stage, treatment, toxicity, outcomes, and out-of-pocket costs—through standardized EHRs and registries.
- Tier 2 (Regional hubs): Validate, clean, and anonymize data; integrate with insurance (e.g., Ayushman Bharat) to capture real-world costs.
- Tier 3 (Central repository): Secure national database generating annual reports, survival benchmarks, and cost-effectiveness insights.

Interoperability using open standards (OMOP/OHDSI) and APIs allows integration of radiology, pathology, genomics, and pharmacovigilance systems—creating a longitudinal patient journey dataset.

3. Balancing Access with Privacy and Security

Accessibility: Tiered access—aggregate data for researchers, limited patient-level data with consent for trials, dashboards for policymakers.
Privacy: De-identification (k-anonymity, differential privacy) with patient-controlled consent (opt-in/opt-out).
Security: Encrypted storage, role-based access, audit trails, and strict penalties for breaches.

4. Human-Centered Enablers

Patient helplines, multilingual consent tools, and community oversight boards ensure transparency. AI analytics can guide treatment and policy, while training clinicians in digital systems ensures adoption.

In my view, the future is a learning health system, where every patient's data improves the next patient's care.

Conclusion:

Data is not to be hoarded—it is a patient's gift to science. A transparent, ethical system must honor that gift while protecting dignity and privacy.

Full Name:
Shashanka K S

Name of the Institution:
Manipal Hospital, Bengaluru

State:
Karnataka

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
What constitutes the cancer care cost? It is testing, travel costs, supportive care, caretaker expenditure; the major share of it is the treatment cost. It looks simpler on the outlook; however, it has hidden layers to it. The cost of research has a lion's share in the cost of a new drug or treatment. It is everyone's wish that the newer medical innovation should not be expensive. Fact which is not highlighted enough is the expenditure the pharmaceutical or manufacturer must bear in negative trials and failed research as well, especially in the field of oncology, where finding a breakthrough is like finding an "oasis in a desert". In contrast, what is more shocking is the fact that more than 90% of clinical data in India does not translate into research material, which is a lost fortune for medical innovation. This solution is an attempt to connect the dots, establishing a system for better magnitude and quality of research output for the betterment of humanity.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):
Framework for the establishment and functioning of "National medical data collection, storage, research and regulatory body".

- STEP 1: ESTABLISHMENT of an autonomous central regulatory body under the Ministry of Health, Govt of India, whose only goal is improving data stewardship (data collection, storage, utilization and regulation).
- STEP 2: DEVELOPMENT OF UNIQUE ID: It can be linked to ABHA / digital health id which is already in use by the govt.
- STEP 3: UNIVERSALITY: Upon registration at any hospital with Aadhaar card, a unique health ID is generated, which can be used across hospitals and institutions; it should reflect in patients' OPD prescriptions, IP discharge summaries, other than the hospital number provided by the hospital. This is a “health Aadhaar number or ID"
- STEP 4: DATA COLLECTION: By linking the central data center portal to the hospital HIMS with firewall protection, the central data center software captures only clinical data, without personal information, to safeguard patients' privacy. Hospitals are reassured by firewalls to protect against any violation of their privacy.
- STEP5: ADDRESSING THE CHALLENGES of data collection in high-volume centers and Govt hospitals, most of it is still on paper.
  Options - Development of a health app by the Govt health department which has multiple sections for uploading reports, symptoms, etc., which later can be used for many purposes like completely digitalizing the healthcare system.
  This data uploaded by patients will be organized and summarized by AI, saving the time of doctors and healthcare professionals. Doctors/ hospitals can access patient inputs with the help of an OTP sent to the patient or a permission-to-access option in the app, ensuring the privacy of the data. During consultation, with the help of an AI speech-to-text converter and real-time data capture, clinical decisions and plans are incorporated into digital data; alternatively, many centers are already documented digitally. Illiterate patients/persons who need assistance can use the assistance of dedicated social workers or AI chatbots at hospital counters (this can be integrated in a few hospitals as pilot projects before larger implementation).
- STEP 6: DATA STRUCTURING: At the central level - Data is organized in a structured manner, stratified and stored with the help of AI and cloud computing.
- STEP 7: ADDRESSING ETHICAL ISSUES: A central body should have an ethical committee formulating guidelines for ethical use of this data,

- STEP 8: DATA SHARING: Any researcher wishing to obtain this data for medical research should submit a proposal to the body about their study details, and a reasonable fee based on the type of medical data will be charged by the body; revenue will be transferred to the Ministry of Health, and the audit of which will be available in the public domain. This revenue generated should be strictly utilized for health budgets in addition to regular allocations to provide treatments, to increase reach of Ayushman Bharat programs, and to build health infrastructure.
- STEP 9: RESEARCH ID: Each research project, after clearance from the body, will be given a unique research ID. Researchers can access the data through the central portal till the completion of the study. AI technology will be used in data stratification and segregation of the incomplete data. These models require the help of AI and cloud computing, which are possible in this era.
  Based on data proficiency patterns, the central body must prepare formats for each disease or specialty to tailor the need and enhance the quality of data. Eg: oncology, family history details, and genetic profiles are missing many times; if a format is created, it's more likely that data is collected or AI can pick information based on previous records.

Advantages

- FOR MANUFACTURERS AND INNOVATORS: For example, Roche can get real-world data of Phesgo in India with this method easily and bring out more studies; with time and adequate validation, this can be an alternative to exorbitant phase IV studies. This will reduce the cost of research, indirectly making not only oncology care but medical care affordable in India.
- FOR INDIAN MEDICAL RESEARCH: We are the most populous country on earth. Our clinical data not aiding in medical research and innovation is a crime against humanity and the medical field. The most difficult part of research is data collection. By building a robust, self-sustained data handling system, we will open gates for numerous research papers, retrospective studies, metanalysis by independent researchers. This will also help in looking into unknown patterns of association.
- FOR PATIENTS AND GENERAL PUBLIC: Everyone will be beneficiaries of enhanced research and rapid innovation. Revenue generated by research helps to build Indian healthcare and provide treatment for "people of India".
  - Option of refusal to consent should be provided to safeguard individual sovereignty. Such individuals may not be eligible for certain health schemes provided by the Government.
  - Throughout the process, most precautions are taken to maintain the privacy of data and transparency of the system.

Challenges:

- Data security against attempts of hacking.
- Initial infrastructure/ system building/ training of staff and patients.
- Preventing lobbying in research allocation and avoiding red tape.
- Usage of the same data by the hospital (clinician for individual research. which can be addressed by making intimation to the body mandatory; however, all these challenges can be addressed.
- Outcome assessment will still be challenging considering heterogeneity in treatment and supportive care; however, this can be minimized by AI-based stratifications to extract the subset data.

Full Name:
Vaidya Vedant Shripad

Name of the Institution:
JIPMER, Puducherry

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
India possesses an unprecedented volume of clinical data, and the integration of CDAC systems in government hospitals marks a critical first step in digital oncology. However, raw data without stringent quality control is insufficient for policymaking. Our objective is to develop a centralized, AI-driven framework for data stewardship that captures the comprehensive pharmacoeconomic burden of cancer—extending far beyond standard anti-cancer drug costs. By balancing seamless data accessibility for advanced research with rigorous privacy protocols, this framework will generate high-fidelity Real-World Evidence (RWE), empowering oncologists and administrators to perform precise cost-effectiveness evaluations and optimize care on a national scale.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

To effectively harness India's vast data potential and evaluate the true pharmacoeconomic burden of oncology, a structured data policy framework must be implemented.

1. The Case for Centralized Data Stewardship

Fragmented healthcare infrastructure inevitably leads to siloed, heterogeneous data. Establishing a central data stewardship authority is paramount for standardizing oncology terminologies, enforcing uniform data entry protocols, and maintaining strict quality control. This central body would govern the CDAC system's utilization, ensuring that the clinical, demographic, and financial variables fed into the registries are pristine. High-quality inputs are the bedrock of any reliable cost-effectiveness evaluation, preventing flawed conclusions in national health policy and trial design.

2. Framework for Integration and AI-Driven RWE

Data collection at the central level must seamlessly integrate Electronic Health Records (EHRs) with national cancer registries. By deploying advanced AI algorithms at this integration layer, the system can automatically curate vast, unstructured datasets to generate robust Real-World Evidence (RWE). AI can specifically track and analyze indirect treatment costs—such as prolonged hospital stays, loss of wages, and supportive care requirements—calculating the holistic burden of cancer. This comprehensive, integrated data stream is essential for developing accurate pharmacoeconomic models that reflect local realities.

3. Balancing Accessibility with Stringent Privacy

To advance targeted therapy research without compromising patient rights, the framework must utilize a "privacy-by-design" architecture. Implementing federated learning allows AI models to analyze data across multiple regional centers without extracting or exposing raw, identifiable patient information to a central server. Coupled with dynamic data anonymization and strict, role-based access controls, this ensures researchers and policymakers can seamlessly access critical macro-level RWE, while the integrity and security of individual patient data remain fully protected under national privacy frameworks.

Full Name:
Monish Balaji S

Name of the Institution:
Kilpauk Medical College, Chennai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):

Title:

Access-Driven Precision Oncology: A Cost-Optimized, Tiered Molecular Testing Framework for Resource-Constrained Settings

Objective of the Solution:

To develop a structured, cost-efficient framework for molecular testing that prioritizes high-impact diagnostics, ensures equitable access, and minimizes financial burden while maintaining clinical effectiveness.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

Cancer economics goes beyond measuring drug prices alone to capturing the "total burden of cancer," including diagnostics, surgery, rehabilitation, productivity loss, mental health, survivorship, and end-of-life care. A National Oncology Data Stewardship Grid can aid this through centralized yet federated governance. At the core, an independent public data trust should function as the national steward, standardizing clinical, genomic, insurance, and patient-reported outcome data into operable formats, preferably using AI-enabled harmonization, thereby creating a dynamic pharmacoeconomic ecosystem capable of real-time cost-effectiveness evaluation across diverse conditions.

Data collection should follow a three-layer architecture: hospitals and laboratories generate encrypted raw data; regional centres validate and anonymize datasets; and the central intelligence platform integrates the longitudinal patient journeys through audit trails and unique digital health IDs. Integration with wearable devices and social determinants of health would allow dynamic estimation of financial toxicity and quality-adjusted life years beyond conventional models.

To balance accessibility with privacy, the framework should adopt a zero-trust oncology cloud—where researchers access only de-identified, purpose-specific datasets through secure data sandboxes. Federated learning can enable AI models to train across institutions without transferring sensitive patient data. Dynamic consent systems should allow patients to control how their data is used. High-level encryption and algorithmic bias audits must become mandatory safeguards.

This framework can fuel precision oncology, equitable policy, and sustainable healthcare financing while preserving patient dignity, autonomy, and trust.

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Full Name:
Jarfin I M

Name of the Institution:
Gleneagles Health City, Perumbakkam—Chennai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
To build a cancer cost and data framework that measures the true burden of cancer while protecting patient dignity, privacy, and trust.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

Cancer cost evaluation must go beyond drug price. It should include diagnostics, surgery, radiation, hospitalization, ICU care, supportive medicines, blood products, travel, accommodation, lost wages, caregiver burden, rehabilitation, palliative care and end-of-life expenses. Without this full picture, Pharmacoeconomics becomes incomplete and unfair.

A central data stewardship body is essential, preferably linked to state cancer registries, National Cancer Grid-style systems and Tamil Nadu government oncology networks. This body should define what data is collected, how it is validated, who can access it and how it benefits patients. Data must include stage, treatment, toxicity, outcomes, costs, abandonment, quality of life and survival.

Collection should happen through standardized digital templates across government medical colleges, private centres and district hospitals. Integration with CMCHIS claims data can reveal real treatment burden and gaps in reimbursement. This can guide policy decisions on which diagnostics, surgeries, radiation techniques and systemic therapies deserve priority funding.

Privacy must be non-negotiable. Data should be de-identified, encrypted and accessed only through ethics-approved systems. Patients should know how their data may help improve care, and consent processes must be simple.

Roche can support responsibly through registry infrastructure, health-economics expertise, real-world evidence generation and access programs.

A visionary oncology system must measure not only how long patients live, but what cancer costs them physically, emotionally and financially. Only then can policy become truly humane.

Full Name:
Dr Mohamed Thanish

Name of the Institution:
Stanley Medical College, Chennai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
To propose a federated oncology data governance framework for India, anchored in the Digital Personal Data Protection Act 2023, that enables centralized health technology assessment and pharmacoeconomic evaluation of cancer treatments by integrating real-world clinical, financial, and patient-reported outcome (PRO) data across NCG institutions without requiring the movement of patient-identifiable information beyond institutional boundaries.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

India cannot currently perform its own health technology assessment for cancer treatments. The pharmacoeconomic analyses that drive formulary decisions, reimbursement policies, and Ayushman Bharat coverage determinations are overwhelmingly imported from NICE, ICER, or FDA review bodies that assessed cost-effectiveness against economic thresholds, population characteristics, and healthcare cost structures that bear no meaningful resemblance to India's. The root cause of this dependency is not analytical incapacity. It is the absence of centralized, integrated, trustworthy oncology data from which Indian calibrated analyses could be performed.

The case for central data stewardship rests on a straightforward observation. Every NCG member institution generates valuable data: daily treatment patterns, drug costs, hospitalisation rates, adverse event frequencies, survival outcomes, and patient-reported experiences. None of this is currently aggregated in a form that enables national-level health technology assessment. Each institution is an island. The data that could power an Indian ICER (Institute of Clinical and Economic Review) analysis equivalent, calibrated to our INR 2 to 2.5 lakh per QALY (Quality Adjusted Life Year) willingness-to-pay threshold, exists in fragmented form across 300 institutions and is never synthesised.

The framework I propose is federated rather than centralised, which resolves the privacy problem structurally rather than through policy promises. In a federated model, patient data never leaves the originating institution. Standardised analytical queries are distributed to each institutional node, run locally against local data using a common data model- the OMOP (Observational Medical Outcomes Partnership) Common Data Model, used by the global OHDSI (Observational Health Data Science and Informatics) network across 80 countries, provides a proven template and only aggregated statistical outputs are returned to the central coordinating body. No patient-identifiable record crosses an institutional boundary. This architecture is fully compliant with India's Digital Personal Data Protection Act 2023, which requires purpose limitation and data minimisation in exactly this way.

(PTO)

The data collection framework at each institutional node needs to capture four categories that together enable a complete cost-effectiveness analysis. Direct medical costs include drug acquisition at institutional procurement prices, diagnostic costs, procedure costs, hospitalisation duration and intensity, and supportive care utilisation. Direct non-medical costs transportation, accommodation, caregiver services should be captured through a brief validated patient-reported instrument administered at each clinic visit, because this data does not exist anywhere in India at scale and its absence makes every economic analysis systematically incomplete. Clinical outcomes including overall survival, progression-free survival, and ECOG performance status trajectory should be entered into a structured registry field, not buried in clinical notes. And quality of life should be measured using the EQ-5D-5L with Indian population utility weights, which have been validated and published in Value in Health by Prinja and colleagues in 2019, a resource that exists and is almost entirely unused by Indian oncology practice.

The privacy and access balance is maintained through tiered data access levels. Aggregated anonymized outputs are accessible for academic research and health technology assessment. Institutional-level benchmarking data is accessible to NCG governance for quality improvement. Individual patient data never moves. Researchers proposing access to institution-level data undergo a standardized data access agreement process modelled on the UK Biobank governance framework.

The output of this system is an annual Indian Cancer Cost Effectiveness Report, produced jointly by ICMR and NCG, that uses Indian cost data, Indian outcomes data, Indian utility weights, and an Indian WTP(Willingness to Pay) threshold to tell policymakers which treatments deliver genuine value in our economic context and which do not. That report would be the most consequential document in Indian oncology policy, and the data infrastructure to produce it can be built within existing NCG institutional relationships without requiring new legislation or new funding of a scale that is politically unrealistic.

Full Name:
Rajarajan

Name of the Institution:
Madurai Medical College, Madurai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
Decentralized healthcare data creates silos, resulting in fragmented patient records and inconsistent standards. Centralized stewardship enforces uniform data models, ensuring information is harmonized and accurate.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

- A robust framework aggregates heterogeneous clinical and molecular data across four logical layers:
- Ingestion & Orchestration: To access data from e-health records and lab values in a live manner
- Harmonization & Mapping: Standardizing clinical concepts to global ontologies (SNOMED-CT, RxNorm, LOINC) and genomic variants to GA4GH standards.
- Hybrid Repository: Stores structured data (demographics, treatments) in an indexed data warehouse, while unstructured data (DICOM imaging, genomic sequencing files) resides in scalable object storage.
- Governance & Access: A centralized metadata catalog allows authorized researchers to view cohort availability without exposing patient-identifying data.
- Privacy vs. Accessibility Solutions: To advance research while safeguarding patient rights, a multi-layered security strategy is essential:
- Multi-Tiered De-identification: Trusted Research Environments (TREs): Data remains in a secure, central cloud platform. Researchers analyze data within monitored virtual workspaces, preventing raw data downloads.
- To add mathematical noise to query outputs, allowing researchers to extract population-level trends while protecting individual identities.
- To restrict data access based on user role, project approval, and IRB mandates.

Logs all queries into tamper-evident audit trails to guarantee full compliance transparency.

Full Name:
Shashanka K S

Name of the Institution:
Manipal Hospital, Bengaluru

State:
Karnataka

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
What constitutes the cancer care cost? It is testing, travel costs, supportive care, caretaker expenditure; the major share of it is the treatment cost. It looks simpler on the outlook; it has hidden layers to it. The cost of research has a lion's share in the cost of a new drug or treatment. It is everyone's wish that the newer medical innovation should not be expensive. Fact which is not highlighted enough is the expenditure the pharmaceutical or manufacturer must bear on negative trials and failed research as well, especially in the field of oncology, where finding a breakthrough is like finding an "oasis in a desert". In contrast, what is more shocking is the fact that more than 90% of clinical data in India does not translate into research material, which is a lost fortune for medical innovation. This solution is an attempt to connect the dots, establishing a system for better magnitude and quality of research output for the betterment of humanity.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

Framework for the establishment and functioning of "National medical data collection, storage, research and regulatory body".

- STEP 1: ESTABLISHMENT of an autonomous central regulatory body under the Ministry of Health, Govt of India, whose only goal is improving data stewardship (data collection, storage, utilization and regulation).
- STEP 2: DEVELOPMENT OF UNIQUE ID: It can be linked to ABHA / digital health id which is already in use by the govt.
- STEP 3: UNIVERSALITY: Upon registration at any hospital with Aadhaar card, a unique health ID is generated, which can be used across hospitals and institutions; it should reflect in patients' OPD prescriptions, IP discharge summaries, and other than the hospital number provided by the hospital. This is “health Aadhaar number or ID"
- STEP 4: DATA COLLECTION: By linking the central data center portal to hospital HIMS with firewall protection, the central data center software captures only clinical data, without personal information, to safeguard patients' privacy. Hospitals are reassured by firewalls to protect against any violation of their privacy.
- STEP5: ADDRESSING THE CHALLENGES of data collection in high-volume centers and Govt hospitals, most of it is still on paper.
- Options - Development of a health app by the Govt health department which has multiple sections for uploading reports, symptoms, etc., which later can be used for many purposes like completely digitalizing the healthcare system.
- This data uploaded by the patient will be organized and summarized by AI, saving the time of doctors and healthcare professionals. Doctors/ hospitals can access patient inputs with the help of an OTP sent to the patient or a permission-to-access option in the app, ensuring the privacy of the data. During consultation, with the help of an AI speech-to-text converter and real-time capturing of data, clinical decisions and plans are incorporated into digital data; alternatively, many centers are already documented digitally. Illiterate patients/persons who need assistance can use the assistance of dedicated social workers or AI chatbots at hospital counters (this can be integrated in a few hospitals as pilot projects before larger implementation).

- STEP 6: DATA STRUCTURING: At the central level - Data is organized in a structured manner, stratified and stored with the help of AI and cloud computing.
- STEP 7: ADDRESSING ETHICAL ISSUES: A central body should have an ethical committee formulating guidelines for ethical use of this data,
- STEP 8: DATA SHARING: Any researcher who wishes to obtain this data for medical research should submit a proposal to the body about their study details, and a reasonable fee based on the type of medical data will be charged by the body; revenue will be transferred to the Ministry of Health, and the audit of which will be available in the public domain. This revenue generated should be strictly utilised for health budgets in addition to regular allocations to provide treatments, to increase the reach of Ayushman Bharat programs, and to build health infrastructure.
- STEP 9: RESEARCH ID: Each research project, after clearance from the body, will be given a unique research ID. Researchers can access the data through the central portal till the completion of the study.

  AI technology will be used in data stratification and segregation of incomplete data. These models require the help of AI and cloud computing, which are possible in this era.

  Based on data proficiency patterns, the central body must prepare formats for each disease or specialty to tailor the need and enhance the quality of data. Eg: oncology, family history details, and genetic profiles are missing; if a format is created, it's more likely that data is collected or AI can pick information based on previous records.

Advantages

- FOR MANUFACTURERS AND INNOVATORS: For example, Roche can get real-world data of Phesgo in India with this method easily and bring out more studies; with time and adequate validation, this can be an alternative to exorbitant phase IV studies. This will reduce the cost of research indirectly, making not only oncology care but medical care affordable in India.
- FOR INDIAN MEDICAL RESEARCH: We are the most populous country on earth. Our clinical data not aiding in medical research and innovation is a crime against humanity and the medical field. The most difficult part of research is data collection. By building a robust, self-sustained data handling system, we will open gates for numerous research papers, retrospective studies, metanalysis by independent researchers. This will also help in looking into unknown patterns of association.
- FOR PATIENTS AND GENERAL PUBLIC: Everyone will be beneficiaries of enhanced research and rapid innovation. Revenue generated by research helps to build Indian healthcare and provide treatment for "people of India".

  The option of refusal to consent should be provided to safeguard individual sovereignty. Such individuals may not be eligible for certain health schemes provided by the Government.

  Throughout the process, most precautions are taken to maintain the privacy of data and transparency of the system.

Challenges:

- Data security against attempts of hacking.
- Initial infrastructure/ system building/ training of staff and patients.
- Preventing lobbying in research allocation and avoiding red tape.
- Usage of the same data by the hospital (clinician for individual research. which can be addressed by making intimation to the body mandatory; however, all these challenges can be addressed.
- For outcome assessment, it will still be challenging considering heterogeneity in treatment and supportive care; however, this can be minimized by AI-based stratifications to extract the subset data.

Full Name:
Devarakonda srujana

Name of the Institution:
Kidwai Memorial Institute of Oncology, Jayanagar

State:
Karnataka

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):

- Taking one of the common cancers in India, Oral cavity malignancy as an example, treatment costs 4.5 lakh (average) to >8 lakh in Tier 1 hospitals. OOPE (out-of-pocket) accounts for 58.7% of India's health expenditure, thereby increasing financial toxicity. Advanced-stage treatment costs 42% more than early-stage treatment.
- Travel, lodging, and nutrition expenses account for 23.6% of costs.
- Indirect costs contribute 21% of the total economic burden due to loss of income and caregivers' loss of wages. (1)
- The lack of a centralised system for collecting and integrating clinical, cost, and outcome data leads to fragmented information, limiting accurate assessment of the true burden of cancer. Most of the focus is on treatment costs, but not on non-medical expenses, productivity losses, and quality of life.
- This lack of comprehensive data hinders pharmacoeconomic analyses, evidence-based policymaking, resource allocation, and price negotiations for cancer care.

This highlights the need to have a centralised data stewardship framework to capture the full cost of cancer, support health technology, and improve affordability in India.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):
Establishing centralized data stewardship:

1. Overcoming Data Fragmentation

A central data steward (NCG/KCDO) ensures that all hospital EMRs comply with ABDM standards, making exchange of data across public and private healthcare systems possible.

2. Standardising Indian-Specific HTAIn (2)

Centralized data collection supports Cost-of-Illness and Cost-Utility registries by integrating medical and non-medical data. Combining EQ-5D-5L tariffs (3) enables QALY estimation.

3. Use data for pooled procurement of drugs and diagnostics to reduce treatment costs, decrease out-of-pocket expenditure, improve affordability, and enhancing equitable

Balancing Privacy and Accessibility

Implement an architecture that is compliant with India's Digital Personal Data Protection (DPDP) Act:

1. De-identification at Source: Local EMR and chatbot servers automatically strip personally identifiable information and replace it with a decentralized, randomized Patient ID token.
2. Federated Data Queries: Instead of sending patients' medical records to a central database, hospitals keep their data within their own system. When needed, the central platform analyzes data locally and receives only summarized, anonymized results, helping protect privacy while supporting research and decision-making.
3. Dynamic Consent Ledger (My Data Vault) (4): patients retain full control over their records and can grant, deny, or revoke access to their datasets.

I propose a dual-force digital ecosystem SOLUTION FRAMEWORK designed for low-EHR settings: The "Sahayata" & "CDSS" Integrated Ecosystem.

1. The "CDSS" App

In hospitals lacking Electronic Health Records (EHRs), oncologists can use a mobile-first Clinical Decision Support System (CDSS).
Give basic clinical data and the family's financial profile.
Socioeconomic Matching by mapping the clinical profile to standardised, cost-optimized NCG guidelines. If the family is self-paying and at high risk of financial distress, the system suggests validated, evidence-based alternatives such as metronomic chemotherapy, hypofractionated radiotherapy, or local surgical packages (saving up to 50% compared to corporate protocols) without compromising survival outcomes.
Scheme Integration: automatic reference and match with active state-sponsored packages like Ayushman Bharat (PM-JAY) or regional schemes (e.g., Rajiv Aarogyasri) to provide cashless care.

2. The "Sahayata" FTX Tracker

To manage ongoing non-medical and indirect financial shocks, the family is enrolled in "Sahayata," a multilingual WhatsApp chatbot (5)
The caregiver expenditures via simple, multilingual voice or text prompts are noted.
Financial Toxicity (FTX) & Mitigation: chatbot takes inputs to calculate FTX Index, which If crosses the 10% household capacity-to-pay threshold, an alert is pushed to the hospital's social worker, who connects the family with localized charitable trusts, CSR programs, or pharmaceutical PAPs to subsidize therapies by 60% to 90%, ensuring treatment continuity.

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Full Name:
Livin T

Name of the Institution:
Madurai Medical College, Madurai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
The system should automatically sync hospital electronic health records directly with state insurance databases like PM-JAY.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

Trying to figure out the actual cost-effectiveness of oncology care by just staring at the sticker price of a new biologic is honestly completely useless. The real financial toxicity for a family here in Tamil Nadu goes way beyond the pharmacy bill. They are constantly bleeding cash for supportive interventions. Things like expensive growth factors or specialized enteral nutrition just destroy their savings. And you have to factor in the brutal non-medical costs, like paying for long-term lodging near our Madurai clinics and the complete loss of their daily wages.

But right now, we have absolutely no structured way to actually map this total economic burden. Our current NCDIR registries are a decent starting point. But they mostly just track basic disease incidence instead of capturing the actual ground-level financial hemorrhage. This is exactly why we desperately need aggressive data stewardship at the central level. We have to build a unified national framework to integrate all this incredibly messy data. The system should automatically sync hospital electronic health records directly with state insurance databases like PM-JAY.

And yet, dumping all this highly sensitive clinical data into one massive registry is a total security minefield. We absolutely cannot just hand the keys over to external researchers. Finding the balance requires a heavily locked-down, tiered access protocol. For general population research, the data must be rigorously anonymized. But if an academic group is trying to validate trial outcomes against ASCO guidelines, we really need to learn on federated learning architecture. That way, the raw patient data stays safely behind our local hospital firewall. Only the encrypted algorithmic insights ever travel to the central server. It protects their privacy while finally letting us analyze the true, grueling cost of cancer survival.

Full Name:
Rishika Goyal

Name of the Institution:
Kidwai Memorial Institute of Oncology, Bengaluru

State:
Karnataka

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
Formation of a unique but standardized model that measures real cancer load, which goes beyond the cost factor of treatment pertaining to cancer and gives practical evidence for pharmacoeconomic evaluation, decisions for reimbursement, and policy planning in health care domains

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

Existing Gap

The real cost of cancer burden for an individual includes multiple factors mentioned as follows, apart from treatment and drugs costing like

- Expenses for diagnostic and biomarker testing
- Costs for travel and accommodation
- Treatment-related hospitalizations and toxicities
- Loss of income source for patients and caregivers
- Treatment interruptions due to financial hardship

Hence, the real socio-economic impact of cancer is often neglected, creating incomplete assessments of value and affordability.

Solution formulated

I suggest the development of a Cancer Burden Score (CBS), which is a simple but standardized tool. It can be administered at the point of diagnosis and during follow-up visits.

This score would encompass six areas that are frequently missed from the pharmacoeconomic aspect:

1. Diagnostic burden
2. Treatment-related expenditure
3. Travel and accommodation costs
4. Patient and caregiver productivity loss
5. Treatment interruptions due to financial reasons
6. Financial toxicity and distress

The CBS can initially be piloted across selected National Cancer Grid centres and linked to routine clinical outcomes. By correlating Cancer Burden Scores with treatment compliance, hospitalization, survival, and quality of life, India can generate real-world evidence on the true cost of cancer beyond drug expenditure alone.

A central data stewardship body under the selected major National Cancer Grid hospitals can oversee standardization, anonymized data integration, and controlled access for researchers and policymakers. Patient privacy can be protected through de-identified data collection, role-based access, and ethical oversight mechanisms.

Other important aspects linked to CBS, like standardization of the procedure, integration of anonymized data, and controlled access for researchers and policymakers, can be managed by a central data management body within the National Cancer Grid. Patient privacy would be safeguarded through de-identified data collection, role-based access, and ethical oversight.

The final and ultimate aim is to integrate Cancer Burden Scores into health technology assessment of India, Pradhan Mantri Jan Arogya Yojana reimbursement decisions, and future oncology policy frameworks, ensuring that therapies are evaluated not only by their cost but also by the burden they alleviate.

Full Name:
Dr. Chilamkurty Maitreyi

Name of the Institution:
Stanley Medical College, Chennai

State:
Tamil Nadu

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):
To establish unified, secure, and patient-centered oncology data stewardship that captures the complete clinical, molecular, and economic burden of cancer care across healthcare settings and to support evidence-based clinical decision-making, real-world research, and precision oncology through standardized interdepartmental, operable data collection, ethical data sharing, reducing financial toxicity, optimizing healthcare resource allocation, and improving equitable cancer care outcomes at institutional and population levels.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):
Problem statement: Mr. X, a 56-year-old farmer diagnosed with metastatic colorectal cancer, travels 120 km every 2 weeks for chemotherapy at a government cancer center. While his treatment costs are documented, the hidden burden of cancer remains invisible, loss of daily wages, transportation charges, nutritional support costs, caregiver burden, repeated hospital visits, and treatment delays. His pathology reports, molecular testing results, pharmacy records, billing information, and insurance exist in separate systems. Oncologist struggles to obtain a complete picture of his journey; researchers cannot accurately evaluate outcomes, and policymakers underestimate the true economic burden of cancer.
Solution: CARENET oncology addresses this gap by transforming fragmented data into actionable intelligence while protecting patient privacy

- C- Capture: A unique oncology ID links clinical records, Histopathology reports, pharmacy, molecular reports, data, and patient outcomes.
- A-Assess both direct and indirect cancer costs: drugs, travel, wage loss, nutrition, caregiver burden, hospital admission, treatment delays
- R-Responsible data stewardship by undergoing deidentification, encryption, consent verification, and ethical sharing.
- E- Empower clinical care by real-time dashboards for treatment history, biomarker profiles, toxicity monitoring, follow-up alerts, precision oncology trials, and recommendations.
- N-Network intelligence - pharma partners like Roche can help in collecting data from Institutes and contribute anonymized data to a central oncology registry, generating real-world evidence on survival, treatment patterns, and access disparities.
- E- Economic insights reduce financial toxicity, NGOs support, social assistance programs
- T-transform health care policy -cost effective analysis, resource allocation, national cancer burden estimation, biomarker prevalence mapping, healthcare infrastructure planning.

CARENET Oncology converts Fragmented cancer information into a secure national learning health system where every patient encounter contributes to better care, stronger research, smarter policy decisions, and reduced financial hardship.
Every cancer journey counted. Every data point protected. Every decision informed

Full Name:
Dr. Chirag Gajera

Name of the Institution:
JNMC, Belagavi

State:
Karnataka

Objective of your solution: (Briefly define the primary outcome of your solution to this challenge):

1. Establish a national framework for comprehensive cancer burden assessment.
2. Capture the complete economic impact of cancer beyond drug expenditure.
3. Generate high-quality real-world evidence for policy decisions.
4. Enable cost-effectiveness evaluation of cancer interventions.
5. Promote equitable allocation of healthcare resources.
6. Facilitate innovation through responsible data sharing.
7. Protect patient privacy, confidentiality, and data rights.
8. Improve cancer outcomes through evidence-based healthcare planning.

Describe your solution/proposal: Provide a detailed account of your solution/ proposal to this challenge. You could type your solution/ proposal here. (Disclaimer: Solution/proposal should not exceed more than 300 words):

The proposed solution is a centralised oncology data stewardship framework integrating clinical, genomic, economic, and patient-reported outcome data from cancer care centres. The National Oncology Data Governance Authority will establish uniform data standards, interoperability protocols, and ethical guidelines for data collection and utilisation.

The platform will capture the complete cancer burden, including treatment costs, supportive care expenses, hospitalisation, adverse event management, indirect societal costs, productivity loss, and quality-of-life outcomes. This will enable accurate pharmacoeconomic evaluations based on real-world evidence rather than drug costs alone.

A secure digital infrastructure using encryption, anonymization, role-based access, and audit monitoring will ensure patient privacy. A tiered access model will allow researchers, policymakers, and healthcare providers to access appropriate levels of information while protecting individual identities.

Integration with electronic health records, cancer registries, insurance databases, and genomic platforms will create a comprehensive national oncology intelligence system. This framework will support evidence-based policy decisions, improve affordability and accessibility of cancer care, accelerate research, and ensure that innovation reaches patients in a sustainable and ethical manner.