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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.
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