

Peer Review

Review of: "Indian Health Ministry Refuses to Make Cancer a Notifiable Disease Despite ICMR's Recommendation"

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The concern of the authors is genuine and well-placed. A functional comprehensive cancer registry is a need of the hour. It will help in many ways for policy making, public health actions, and funding prioritization.

There are some suggestions for this review article.

- It appears that the authors are taking “disease with national registry” and “notifiable diseases” as synonymous concepts. After the occurrence of a notifiable disease, there is a plethora of actions and investigations that need to be done for the prevention of further spread of the disease. This notification warrants immediate action. To start with, India had only three diseases in this category- Plague (a deadly disease with more than one pathway of spreading), Yellow fever (a vector-borne viral disease with the whole Indian population immunologically naive and vulnerable), and Cholera (a fast-spreading deadly water-borne disease, with historical large epidemics). All of these diseases have a high potential of causing large outbreaks, high mortality, high morbidity needing institutional care, and high economic cost.
- There is an addition to this list of diseases. However, one must understand that when such a case is reported, what all actions happen at the preparation level- Arrangement of diagnostics (updating and improving the existing ones as well), deciding on the best treatment protocols- standardizing them and disseminating them to the physicians, making related medications available by various policy means (import, production, raw material subsidy, etc.), keeping hospitals ready to absorb

possible new cases, and making related changes in daily operations as well as in outreach activities.

- For cancer, such actions are not needed. It does not spread, nor is there one treatment for various types and stages of cancers. What action will you take when some hospital notifies a cancer patient?
- Maintaining a registry is a different thing altogether. To notify a disease to this registry system is aggregable to most agencies, and it is very different from making a disease notifiable. That's why I suggest changing the title.
- Now coming to the issues with the national cancer registry in India. Unlike western countries (where health care is provided by a single entity), in India, health care is provided by many different stakeholders like- state & center-run hospitals; state, center, and city corporation-run medical colleges; center agencies like railways, defense, research centers, etc., which have their own hospitals; and the private sector in its various levels of hospitals. Most of them are run by various mandates and are overburdened. They will need dedicated additional manpower and incentives to add data with all the required details. For the TB-related portal (NIKSHAY), incentives are provided to patients, doctors, and data entry operators to enter the data on the portal. It is a fairly successful program where all the TB patients under treatment (both at private and govt. centers) can be tracked. For cancers, such investments and incentivization can help. But apart from epidemiologists and the pharma industry, who else will use the cancer registry? Unlike TB (tracking a patient is crucial to make sure that s/he has completed the treatment and is cured and done mandatory tests), physicians and the public health system may not have a greater interest. Authors can consider an in-depth discussion on some of these challenges in the article.
- The authors can emphasize more on the benefits of the registry and its possible uses at the start. The problems can be discussed, and later, evidence-based examples to solve such problems may be useful.

Declarations

Potential competing interests: No potential competing interests to declare.