

## Commentary

# Indian Health Ministry Refuses to Make Cancer a Notifiable Disease Despite ICMR's Recommendation

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**Cancer in India is not a notifiable disease at the central level. The Indian Ministry of Health and Family Welfare refuses to declare it as a notified disease despite recommendations from the Indian Council of Medical Research. The reason given by the ministry is that cancer is not a communicable disease and does not have community spread, which is why it cannot be made notifiable in the current circumstances. With a rise in cases in India, the notification of cancer will give impetus to the decades-old National Cancer Registry Program and enable proper and mandatory recordkeeping of cancer cases, as seen in many developed nations.**

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Cancer, an uncontrolled growth of the cells in the body, is a non-communicable disease and can spread to other parts of the body. Close to half of the cancer deaths can be avoided by prevention and control of risk factors. These include issues like smoking, mineral dust like asbestos, and other exposures. To manage cancer, the government must first know its incidence, prevalence, morbidity, and mortality rates in the country. This happens through proper record-keeping, which enables proper allocation of resources, highlights the areas in the country where priority must be given to first record and then reduce cancer. It also enables the right data to reach national and international agencies and development sectors to prioritise the focus on particular issues. This data may be key to ending conjectures like ‘arsenic causing cancer in Bihar or pesticides causing a cancer surge in India’ and provide real-time epidemiological evidence<sup>[1]</sup>.

Such record-keeping is made possible through registries, which are operated either individually by hospitals or as a collective of many hospitals, where a big hospital records cases in a common database

from the other smaller hospitals in its catchment area. Since 1981, the Government of India's run cancer registry has been operating under the National Cancer Registry Program, which is run by the Indian Council of Medical Research's run National Centre for Disease Informatics and Research, Bengaluru, or ICMR–NCDIR. But the problem with the ICMR–NCDIR–run registry is that despite being operative since 1981, it only covers 16% of the total population of the country. This fact has even been noted by a parliamentary committee report on health set up to deal with cancer, which expressed ‘it’s deep displeasure’ over this fact<sup>[2]</sup>. The primary reason for this low coverage by the National Cancer Registry Program may be that there is no legal mandate or requirement for hospitals and healthcare providers to provide this data to the central government registry.

Making cancer notifiable has been recommended by ICMR–NCDIR itself in its 2020 policy brief, which recommends ‘*Making cancer a notifiable disease to enable increased coverage by registries and establishment of registries in areas hitherto uncovered regions.*’<sup>[3]</sup>

In a case filed before the National Human Rights Commission of India or NHRC (59/30/3/2024) on this matter of making cancer notifiable in India, the NHRC disposed of the matter with a direction to the Secretary of the Ministry of Health and Family Welfare to ensure that such an action, as deemed appropriate, in the matter, is taken’ (See Supplementary Files).

The Ministry replied that ‘Cancer is a type of non-communicable disease’ and that it is not an infectious disease that does not spread from one person to another or does not have any community spread. The Ministry of Health and Family Welfare further stated that ‘In the present circumstances, it may not be declared as a notifiable disease.’ This was also reaffirmed by the same Parliamentary Committee, which took back its recommendations in the face of a response from the Ministry of Health (See supplementary files)<sup>[4]</sup>.

This is despite the fact that 17 states in India have already made cancer notifiable at the state level. Some of these states, even in the absence of public health legislation, used the administrative order instead of a gazette notification to give action to the notification of cancer. Some states, like Tamil Nadu, operate a comprehensive state-level registry program.

The Tata Memorial Centre, or TMC in Mumbai, in order to solve the debate of communicable vs non-communicable disease, came up with a semantic solution. TMC recommended that the parliamentary committee declare cancer a “documentable disease” so that it can still be compulsorily reported and rigorous recordkeeping can still take place<sup>[2]</sup>. It can be speculated that the Ministry may be influenced

by the disease control organisation of India (under the health ministry), which may have the mindset that only communicable diseases should be made nationally notifiable. This is despite the recent step where another non-communicable disease, i.e., snakebite (also non-communicable), was declared notifiable by the central government, urging states to use their local public health acts to do so<sup>[5]</sup>. Making cancer notifiable nationally is all the more relevant when India is facing a double burden of disease from communicable as well as non-communicable diseases. While cancer may not be communicable, there may well be common exposure factors in communities leading to many cases.

Among the other non-communicable diseases, cancer, the ‘emperor of all maladies,’ must be specifically focused on in India (as named in a Pulitzer-winning book by Mukherjee S. titled ‘The Emperor of all Maladies: The Biography of Cancer’). This is because a latest report now calls India the ‘cancer capital of the world’ as cancer cases are on a sharp rise<sup>[6]</sup>. But even this calculation of the rise in cases may show an incomplete picture. This is because the data available may represent a small percentage of actual cases. That is characterised by the fact that in a study where hospitals were actually keeping records of cases and having numbers of cancers in their books, 75% of these were not part of the population-based cancer registry programme run by ICMR-NCDIR<sup>[7]</sup>. Data collected by ICMR-NCDIR is reported to international agencies like the International Agency for Research on Cancer or IARC<sup>[8][9]</sup>. IARC data may be used for policy focus.

A large number of cases recorded due to the notification of cancer and subsequently more robust and accurate recordkeeping may cause a temporary setback in terms of large numbers of cancer incidence/prevalence coming on record. But in the long run, having registries will pave the way for proper management of cancer prevention, as has been accomplished in Nordic countries where registries have been operating since 1942 (Denmark). Around the time when India’s cancer registry program’s predecessor started in 1964, a study reports that ‘there were several well-established cancer registries in Europe (Finland, Scotland, and Denmark), North America, and South America (Brazil), Asia (China and Singapore), and Oceania (Australia and New Zealand)<sup>[10]</sup>.’ Notification of cancer at the national level as a ‘magic bullet’ may provide the impetus needed to make the 4-decade-old Indian cancer registry programme work better and impact the future prevention of disease.

## *Abbreviations*

ICMR: Indian Council for Medical Research

## Statements and Declarations

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## **Declarations**

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