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ICMR drafts policy to safeguard medical records

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The National Centre for Disease Informatics and Research (NCDIR), Bengaluru, under ICMR, has developed a draft policy on data processing and disclosure that aims to protect patient confidentiality and privacy in disease registries.

The registry data comes from hospitals and laboratories and are extracted from medical records, pathology reports, radiotherapy charts etc. that have been collected for several years.

ICMR has mandated that the data will only be used for research purposes or in the larger public interest. The third party, i.e. legal person, public agency or any other body, shall use the data strictly in compliance with the terms of the policy, and cannot further share or transfer the data with any other individual or organization within or outside India. Only after ICMR-NCDIR approval shall this research be released for publication.

According to ICMR, such a policy is much needed. In the near future, there may be a statutory mandate for hospitals and other sources to supply data on non- communicable diseases such as cancer, cardiovascular diseases, diabetes, stroke to the ICMR-NCDIR.