

## National Quality Registry for India: Need of the Hour

When it comes to the need of having correct and reliable information on various parameters including morbidity and mortality, the only logical solution seems to be the system of robust registry in any country. These registries are maintained at the local, regional, national, and international levels. A patient registry is a well-organized system with a predetermined scientific, clinical, or policy goal, in which standardized data are gathered to assess certain outcomes for a population characterized by a disease, condition, or exposure.<sup>[1]</sup> These registries are the source of generating good quality data. If data are compiled well, it helps in strategizing better policies which are based on facts and evidence.

At the local level, data captured through electronic health records (EHRs) can also be used to generate patient registers. Although in principle, the purpose of EHR and registers is a bit different, the information gathered through these registries can be used for understanding disease epidemiology and for developing health-care strategies to minimize morbidity and mortality.<sup>[2]</sup>

In India, the Indian Council of Medical Research (ICMR) established the first such registry program in December 1981, which was a network of cancer registries spread across the country.<sup>[3]</sup> In the recent past, the process of establishing new registries for stroke, chronic kidney disease, diabetes, and cardiovascular disease registries has also been initiated.<sup>[4]</sup> The National Clinical Registry for COVID-19 was launched by the ICMR in collaboration with the Ministry of Health and Family Welfare, AIIMS, and ICMR-NIMS, New Delhi, to maintain a clinical database of COVID-19-related data pertaining to symptom profile, clinical progress, treatment received, and outcome of hospitalized COVID-19 patients. This registry is being created to help guide the evolution of COVID-19 management rules at the national level. This registry has served as a platform for developing ideas, conducting clinical trials, and evaluating the efficacy of various therapy approaches currently in use.<sup>[5]</sup>

Currently, India is also maintaining the registries of health-care facilities. The establishment of the National Health Resource Repository (NHRR), the country's first registry, which comprises authentic, harmonized, and up-to-date geospatial data of all public and commercial health-care facilities, is one such example. NHRR was launched in 2018 by the Union Ministry of Health and Family Welfare, Government of India along with the Indian Space Research Organisation a partner organization who ensures data security.

India has achieved substantial progress in developing disease registries but still more efforts are needed. Low coverage, quality assurance in data, lack of follow-up and survival data,

timeliness, and nonlinkages in registries pose challenges.<sup>[6]</sup> The main purpose of a registry is to aid health-care providers in their efforts to provide evidence-based solutions for a wide range of medical disorders.<sup>[5]</sup> For this, registries should contain individualized data concerning patient problems, medical interventions, and outcomes after treatment, within all health-care settings.<sup>[1]</sup>

For utilizing registries to its full potential, there seems a need of National Quality Registries (NQRs) which has a potential to improve health-care management and delivery. NQRs could be utilized in an integrated and active manner for continuous learning, reform, research, and management to help individuals in achieving the greatest possible health and care.<sup>[7]</sup>

If the registries contain information about the entire population/individual in the population such as demographic detail, process, and outcome of health care, then these registries can serve as a gold mine for research. In India where every citizen has ADHAR unique ID generated based on factors such as demographic and biometric data can be utilized to link with these quality registries to continuously improve and provide good health care.<sup>[8]</sup>

For developing and implementing properly designed disease registries, India, could work on the lines of Sweden. Sweden has been recognized as a role model, with over 80 NQRs, many of which are well-established.<sup>[8]</sup> Individual data entries on specific disorders or diagnoses, therapeutic treatments, and results are collected through the NQRs. These registers are run by health professionals and are subsidized by national agencies.<sup>[9]</sup>

Sweden has developed a network of over a hundred NQRs that enables the Swedish health-care system to track quality and health-related outcomes.<sup>[7,10]</sup> The registries are designed and administered by members of the professional groups that utilize them, but they are primarily financed and operated by local authorities and regions.<sup>[7,10]</sup> Individual-level data on problems or diagnoses, treatment interventions, and outcomes can be found in these registries.<sup>[7,10]</sup> They are utilized for general planning and management as well as at the local level, providing unique opportunities to monitor and enhance health care.<sup>[7,10]</sup> Moreover, Sweden has also six competence centers for NQRs where registries share the various costs of staff and systems that a single registry could not afford.<sup>[7]</sup> These centers also help in assuring the continued development of the registries.<sup>[7]</sup> India could also develop this type of quality registry system by utilizing the opportunity provided by the National Digital Health Mission and collaborations such as “Sweden–India Health Hub” at AIIMS, Jodhpur, established under India Sweden partnership for a sustainable future.<sup>[11]</sup> The

information from these registries can be used by health-care providers to assess and benchmark their quality of care and to undertake improvement programs.

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