Taking a leaf out of Amul's textbook to help rare-disease patients

Just as Amul and the other cooperatives it inspired made India milk-secure and secured the livelihoods of millions of farmers, so too could a patient data collective have an outsized impact on drug discovery for most rare diseases, contributing to the health of many patients who currently have few treatment options

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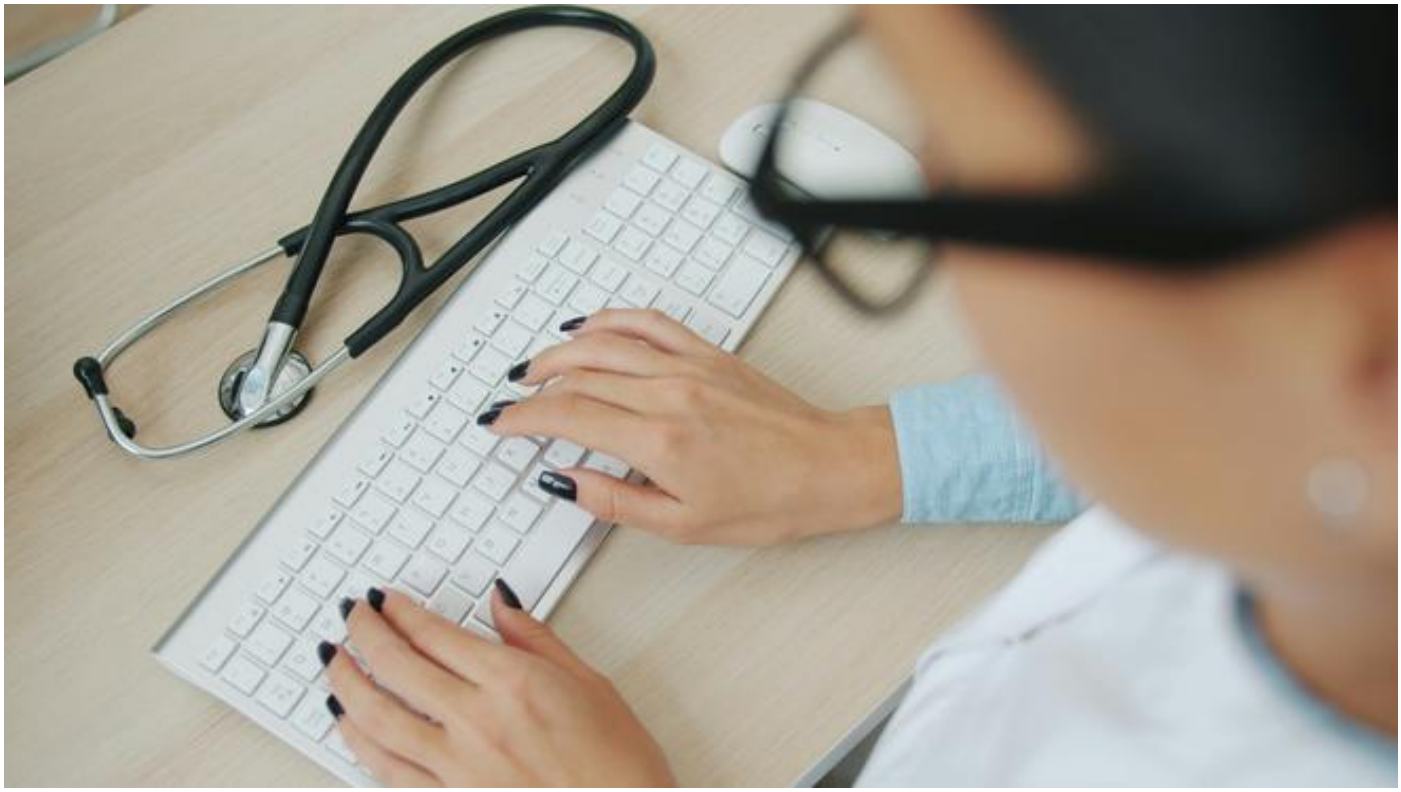

A patient data collective for rare diseases in India can serve as a cooperative that holds patients' data on their behalf to facilitate research, and which returns most, if any, of the revenue back to them. Representative image. | Photo Credit: Vitaly Gariev/Unsplash

Patient data, including medical records and patient experiences, are essential for scientists to develop new treatments, especially for rare diseases. The data help identify

diagnostic biomarkers, predict disease progression, and help investigators design better clinical trials.

This is important because clinical trials are required to show that a new treatment is safe and effective before a country's regulators approve it. Conventional clinical trials involve a large number of participants and include both treatment and control groups. However, for rare diseases, too few people are eligible to participate, and it is not possible to have a control group.

In these situations, patient registries and natural-history studies can provide real-world data that can serve as 'external' controls. Natural-history studies record clinical parameters, including those reported by patients, over time, allowing clinicians to model disease progression in the absence of treatments. Patient data can also help scientists identify suitable participants and meaningful clinical endpoints to properly evaluate complicated treatments.

Thus, by improving trial design and reducing uncertainty, comprehensive patient datasets can help researchers develop drugs faster, increase the chances of their receiving regulatory approval, and ultimately help bring safe and effective treatments to patients with rare diseases more quickly.

Patient data collective

For example, patient information collected over many years helped doctors understand how spinal muscular atrophy — a rare genetic condition that damages the spinal cord — progresses, identify the best ways to measure improvement, design good clinical trials, prove treatments work, and show that treating patients early gives the best results.

Recent advances in artificial intelligence (AI) models now make these goals possible in new ways — provided good patient data are available. Researchers can collect this data in two steps: first, create a community of patients with a given condition; and second, collect a range of medical and diagnostic records for those patients.

To implement this, the authors propose a cooperative model to create a 'Patient Data Collective' (PDC). The inspiration comes from the dairy cooperative Amul, which serves lakhs of farmers in India and ploughs back most of the profits from milk and milk-derived

products to them. Amul also offers veterinary care and at-cost feed for cattle.

Similarly, a PDC for rare diseases in India can serve as a cooperative that holds patients' data on their behalf to facilitate research, and which returns most, if any, of the revenue back to them. And the PDC can act on behalf of patients just as Amul does on behalf of farmers. It will access data from patient advocacy groups, the Ayushman Bharat Digital Health Mission, hospital records, the Centres of Excellence for Rare Diseases, clinicians, and other repositories.

In addition to its centralised repository, the PDC could have AI-based data analytics, with safeguards in place. That is, once a patient is registered, their consent to have their data collected, stored, analysed, and, indeed, protected.

Worldwide, patient advocacy groups are already helping research communities accelerate the development of drugs for rare diseases and navigate the approval ecosystem. This movement has also reached India, and active disease-specific groups could play a critical role in setting up and operating the PDC as well.

Setting up a collective

The Indian Council of Medical Research (ICMR) has already set up a rare disease registry based on data uploaded by a few experts from 19 specialised hospitals. The registry has collected data on around 4,000 patients with select diseases over the last five years.

Valuable though this resource is, it is also minuscule compared to India's population. Given Indians' experience with public registries, the data collection exercise behind the PDC should be flexible and inclusive, while maintaining accuracy and abiding by the highest ethical and legal standards.

This, in turn, is possible only as a patient-centric initiative with support from non-governmental organisations. Although setting up the proposed portal and backend database to accept data from all stakeholders while adhering to standards about accuracy, ethics, safety, and legality will be difficult, it is feasible, as demonstrated by the Citizen Health Platform operating in the U.S.

Once the portal is set up, patient data will need to be made easily available to the PDC

through digital health records maintained by both public and private health providers. To aggregate scattered medical histories, genetic reports, and clinical notes, India can leverage its Ayushman Bharat Digital Health Mission: to mandate a clear governance model for a specialised, secure digital health locker or for the PDC to maintain patient records as such a locker.

Alongside a data repository, generative AI can be used as a tool to synthesise from large volumes of medical records medically relevant patterns that can inform doctors' and patients' decisions. Indeed, if an AI model is trained to engage with users in their local language, it can help analyse medical information to suggest possible diagnoses and lay out the various options, and thus encourage participation from diverse groups of patients.

Attracting drug developers

Support from the government or philanthropic organisations is needed to develop a platform with such AI capabilities, with clear governance and oversight.

In fact, the PDC should deliberately attempt to generate useful data. The authors suggest encouraging natural-history registries led by patient advocacy groups to generate longitudinal real-world evidence datasets. The groups can be funded to initiate natural history studies for their target diseases, with the data then channelled to the PDC.

Aggregating granular, everyday patient-reported metrics across India's unique, genetically diverse endogamous populations could also attract drug developers from abroad seeking ethnically specific target-validation cohorts.

With recent updates to India's New Drugs and Clinical Trials Rules, which embrace advanced computational modelling and non-animal testing models, Indian biotechnology and pharmaceutical companies can use the PDC to rapidly pre-screen and construct virtual synthetic control groups, making small-batch orphan drug evaluation clinically and financially viable within domestic budgets.

Just as Amul and the other cooperatives it inspired made India milk-secure and secured the livelihoods of millions of farmers, so too would a PDC have an outsized impact on drug discovery for most rare diseases, contributing to the good health of many patients who currently have few treatment options.

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