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When Research Is Invisible to Patients

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Clinical trials shape the medicines and treatments we rely on every day. India runs thousands of clinical trials every year, yet most patients never hear about them. This lack of information affects patients who can get access to new treatments.

The day my father's neurologist uttered the words *PSP*, our world was shaken.

Progressive Supranuclear Palsy (PSP) is a rare, brutal neurodegenerative disease, often mistaken for Parkinson's. But Parkinson's medicines do not work on it. Patients lose their faculties, slowly, one by one, until they are trapped in their own body, unable to move or communicate. The most cruel part is that their minds often stay active and lucid.

There is no cure; even symptom relief is limited.

As a scientist, I know clinical trials exist precisely for situations like this-where current treatments fall short and scientists are testing new ideas. So, it felt impossible to accept that the story simply ended with *there's not much we can do*. If not treatment, surely there was something-a trial testing a new molecule, a device, a rehabilitation protocol. Something, somewhere.

I started looking for clinical trials in India for PSP and similar neurodegenerative conditions, assuming it would be easy to find out if any were happening. Instead, I found that even if such trials existed, there was no reliable way for us to find them. The troubling truth was that even when research exists, patients often have no way of seeing it.

Finding Trials

Clinical trials often sound mysterious or risky to the public, but they are how modern medicine works. They are the backbone of every pill we swallow and every procedure we trust. Any new drug or medical device goes through careful testing in clinical trials to make sure it is safe and that it actually works before it reaches patients. The results from these trials are reviewed by government regulators, who decide whether the treatment can be made widely available.

The process starts long before patients are involved. In the pre-clinical stage, scientists test the treatment in laboratories, often on cells or animals (under the core ethical guidelines of 'replace, reduce, refine' to minimise harm to animals in scientific studies). This helps them understand possible risks and see whether the treatment shows enough promise to move forward. Only after this data is reviewed and approved by regulatory authorities and ethics committees can human testing in clinical trials begin.

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Clinical trials are conducted in phases, each of which has a distinct objective. Phase 1 is safety-focused, with a small number of patients receiving the treatment to allow researchers to observe how the body reacts, and determine safe dosage. Phase 2 continues to monitor side effects while examining whether the treatment is truly beneficial for those with the illness. Phase 3 compares the new treatment with current ones and looks for less frequent side effects using much larger groups, often spread across multiple locations. Even after a treatment is approved for general use, studies continue in Phase 4 to see how it works in real life, over longer periods and in more diverse groups of people.

Patient safety always comes first at every stage. Strict regulations, oversight, and ethical safeguards are made part of the process. Each phase builds on the one before it, step by step, to ensure that new treatments move from the lab to patients as safely and responsibly as possible.

This is a vast effort. According to the World Health Organization, there were over 540,000 clinical trials registered globally as of mid-2025. Clinical trials are complex, expensive, and time-sensitive, and running these is not easy. One of the biggest challenges is finding and retaining participants. Studies from the US and Europe show that nearly 80% of trials are delayed because they fail to recruit enough participants, and around 20% are terminated early for this reason alone. This leads to delays in approvals and higher

development costs, meaning newer treatments take longer to reach the patient.

Despite a large population and high disease burden, India has a low trial participation rate per million people compared to the US. While there are many factors affecting this, a survey-based study in India from 2016 found that lack of awareness about clinical trials in patients is a major contributor.

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Limited Options

In most Western countries, trial information is everywhere. Hospitals display posters and patient groups circulate emails. In many countries, patients can search for clinical trials themselves. Public registries like ClinicalTrials.gov (US) or the EU Clinical Trials Register show up on a simple Google search. You can filter by disease, location, recruitment status. Each entry explains, in simple language, what the study is trying to find out, how it will be done, who can take part, and who to contact if someone wants to know more. In the US, for example, the government-run registry ClinicalTrials.gov receives tens of millions of visits each year, many from patients and caregivers.

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India works differently. Here, clinical trial enrolment is mostly led by doctors. Patients usually learn about trials only if they happen to be seeing a doctor at a hospital where a trial is running, and if that doctor thinks the patient may be suitable. If not, the patient may never hear of the trial. There are no posters in most hospitals, nor is there concerted public outreach. There is also no easy way for patients to search by disease or location on any online search engine for such trials.

This caution perhaps is not misplaced. India has varied literacy rates, and its relationship with medical research has not always been smooth.

In the early 2000s, some clinical trials in India were found to have taken place unethically, without proper consent or adequate oversight. This raised public alarm, and rights groups questioned whether volunteers were truly being protected. In response, the Supreme Court issued a landmark ruling in 2013 that made rules on participant safety, informed consent, and compensation much stricter. At that time, ethics committees and consent processes were still evolving. Over the last decade, regulators and researchers have continued to strengthen these protections, with a major update to the system in 2019 through the New Drugs and Clinical Trials Rules.

Against this backdrop, it becomes even more important for patients to have access to clear, reliable information that comes from a trusted, regulator-mediated source.

Clinical trials are complicated, and doctors play a key role in guiding patients-helping them understand risks, deciding what is appropriate, and protecting them from poorly designed or exploitative studies. The current system in India, however, relies on doctors being closely connected to research networks and having the time to track ongoing trials.

In reality, India has relatively few clinician-scientists, and most doctors are overwhelmed with clinical workloads. Awareness of ongoing trials, especially those outside one's own institution, is uneven. As a result, some eligible patients may never hear about research opportunities simply because information does not travel far beyond institutional or professional networks. For patients with common conditions, this may not matter much. For those with rare, chronic, or degenerative diseases, where treatment options are few, this can mean missing the only chance to try something new.

The real challenge therefore is not to get rid of caution, but to make sure it does not turn things opaque, where the effort to protect people also ends up limiting awareness, conversation, and patient choice.

In India, all clinical trials must be registered with the Clinical Trials Registry-India. It is overseen by the Indian Council of Medical Research and the Drugs Controller General of India. This rule has made clinical research more regulated and transparent than it was in the past.

From a patient perspective, however, it is not an easy system to navigate. The registry is hard to use, trial descriptions are highly technical, often not updated, and difficult to find through a simple online search. There is also no clear requirement to explain studies in jargon-free language or to share results once a trial is over.

The irony is that some of the information the patients need already exists in the Indian registry. It just is not presented in a way that patients can easily find, understand, or use. In contrast, trial registries in the US, Europe, and the UK are built with the public in mind, not just regulators.

Offering Choice

Many people believe that joining a clinical trial automatically means getting a new treatment. That is not always the case.

In most trials, participants may receive either the standard treatment already in use or the new treatment being tested. Some studies compare different doses or different ways of giving the same treatment, and participants are usually assigned to these options at random. Importantly, many treatments being studied do not end up working. Throughout the process, safety is watched very closely. In India, trials are monitored by ethics committees and the Drugs Controller General of India, with clear rules to minimise risk to participants. If unexpected side effects appear, a trial can be paused or stopped. This is not a failure; it is how patient safety is protected.

So why would someone still choose to take part?

Clinical trials offer choice. They give patients a chance to look beyond routine care, to contribute to knowledge that may help others in the future, and sometimes to access treatments that are not yet widely available. But this choice should be informed and voluntary. It should not depend on luck, personal connections, or being in the right hospital at the right time.

This issue goes far beyond individual stories. It has an impact on how medical knowledge is developed and who it benefits.

Representation in medical research has long been a problem. Gender, genetics, body type, diet, and disease patterns can all have a significant impact on how a drug works. However, individuals from low- and middle-income countries, including India, remain under-represented in the clinical trials that influence international treatment recommendations. In other words, much of the evidence doctors rely on in India comes from studies done in populations very different from ours, where the way drugs are absorbed and act in the body can be quite different.

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This is happening even as India's clinical research landscape is expanding rapidly. More pharmaceutical companies are conducting studies here, and the government has shown strong interest in building research capacity. Approximately 18,000 new clinical trials were registered in India in 2024 alone, which was roughly 50% more than the previous year. India is now the third largest clinical trial destination in the world thanks to this expansion. This increase is a result of a large and diverse patient population, lower costs, a skilled workforce, and increased funding for research.

However, growth alone is not enough.

When studies carried out in India are difficult to find, poorly updated, or missing results, their findings often do not become part of the international evidence reviews that influence treatment recommendations. As a result, even though India accounts for a sizeable portion of the global disease burden, global medical recommendations may not fully apply to Indian patients.

This is where clinical trial registries matter. They help researchers find studies that were never published (for example, those with negative results), reduce publication bias, and improve the reliability of medical evidence. Today, this is considered essential. Guidelines now clearly recommend searching trial registries as part of any serious evidence review. Registries also list ongoing trials, making it possible to update evidence as new results emerge.

In India, registering a trial with the Clinical Trials Registry is mandatory. But updating recruitment status or sharing results is not consistently required. As a result, a large amount of valuable data from trials happening in India never feed into the evidence that guides medical care, both at home and globally.

It is widely recognised that failing to make clinical trial results accessible through registries is a major source of research waste and a grave ethical problem. If clinical trial results are not shared, other researchers might unintentionally repeat the same studies, investing time, resources, and energy on questions that have already been answered or shown not to work. This type of duplication hinders advancement and takes funds away from exploring novel and more promising therapies.

This also raises ethical concerns, because patients take part in trials believing their effort and risk will contribute to knowledge. So, when results remain hidden, participants' time and health risks are wasted.

Matters to Everyone

You do not need to be sick today to care about clinical trials. At some point, most of us will depend on medicines that were an outcome of research either for ourselves or for our loved ones. If that research comes from narrow or unrepresentative groups, its gaps show up in everyday care-how drugs are prescribed, how well they work, and what side effects people experience.

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There is no medicine without research, and no progress without participation. Clinical trials are part of our public health system. When information about them is easy to find and understand, science moves faster and benefits more people. When it is not, important opportunities are lost. Patients should not have to discover research by accident. They should be able to see what science is doing and decide for themselves whether they want to be part of it.

Looking at how other countries share clinical trial information shows that this can be done better. In many places, trial registries are built not just for regulators and scientists, but for patients and families. They require trials to update their status and share results, whether the study succeeds or fails.

In India, information in the registry is often hard to find, hard to understand, and sometimes outdated. This is not a complex problem to fix. Making trial listings searchable online, improving the registry's own search feature, adding simple language summaries, making it obvious whether a trial is open, recruiting, or closed, and mandating that results be shared after a trial is completed or stopped are just a few small, useful changes that could have a significant impact. In addition, encouraging hospitals and patient groups to actively share trial information would further help ensure that research is visible to the people it is intended to serve.

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Making trials easier to find will not solve every problem. Not everyone will want to take part. Not every study will be right for every person. Doctors will always play a key role in guiding decisions. But visibility is where things begin. It helps patients ask better questions. It helps researchers reach the people they are trying to study. And it shifts participation away from chance and toward informed choice. This is not just good policy; it is good medicine.

My father was not a scientist, and science could not ease his disease or his suffering. But he believed deeply in contributing to knowledge. He pledged to donate his eyes, his body, and his brain to medical research. Today, his brain tissue is housed at a leading national institute, and our family finds some comfort in the thought that it may one day help advance understanding of PSP-if not during his life, then through what he chose to give after it.

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