Title

A Cross-Sectional Survey to Assess Awareness and Perception to Clinical Research: Unbox Research

Authors

Pooja Sharma, Rhea Aggarwal, Niti Mittal, Durga Chougule, Ritu Bhalla, Deeksha Kapoor, Kuldeep Kumar Chauhan, Padam Singh, Manish Kumar Singh

Abstract

Clinical trials help advance medical science, but participation in India remains low due to lack of awareness and safety concerns. This study surveyed 852 participants (median age 21 years) to assess their awareness, perception, and willingness to participate in clinical research.

Over 85% were aware of clinical trials, with hospitals (44.2%), social media (40.2%), and print media (40.2%) being key sources of information. Many saw trials as a way to access new treatments (63.4%), but concerns about safety (59.7%) and fear (50.8%) limited participation.

To improve involvement in clinical research, addressing safety concerns and building trust is essential.

Acknowledgments

The authors appreciate the support of Mr Pankaj Sahni (CEO), Mr Rajiv Sikka and the IT team at Medanta, Clinical Research Department, Ms. Arunima Choudhary, Ms. Nikita Sharma, Mr. Sajid Alam, Ms. S Parvathi, Ms. Gargi Singh, Ms. Chetna Shinde and all the participants from participating institutions (Medanta – The Medicity, Gurugram, Lotus Valley School, Gurugram, Mahatma Gandhi Institute of Medical Sciences Sevagram, Wardha, Delhi Public School, New Delhi, Pandit Bhagwat Dayal Sharma Post Graduate Institute of Medical Sciences, Rohtak, Navy Children School, New Delhi, Shree Guru Gobind Singh Tricentenary University Gurgaon, Gurugram, CanKids…KidsCan, New Delhi, Miranda House College, New Delhi, Bangalore Baptist Hospital, Bengaluru, Citizenry Cybersuraksha Association, Bengaluru).

Title

Patient Advocates for Clinical Research (PACER): A Step Toward Ethical, Relevant, and Truly Participatory Clinical Research in India

Authors

Poonam Bagai, Pooja Sharma, Aala Ansari, Nirbhay Singh, Sonal Sharma, Padam Singh,

Durga Chougule, Manish Kumar Singh, Gargi Singh, Sanjeev Singh

Abstract

Clinical research can improve healthcare in India, but lack of trust, awareness, and fear of being a “guinea pig” remain challenges. This study aimed to train Patient Advocacy Groups (PAGs) to educate patients and make them active partners in research.

The PACER program included an online course and workshops on clinical research, ethics, and informed consent. 48 participants from 20 PAGs (focused on cancer, diabetes, and rare diseases) took part. 30 participants completed the course with an average score of 23.9/30, and 140 participants joined focus group discussions.

The program led to a 9.4% improvement in knowledge, showing that training PAGs can increase patient awareness and trust in clinical research.

Acknowledgements

The authors appreciate the support of the capacity-building and strengthening educational program PACER by an Educational Grant from Pfizer Limited (India).

Title

Emphasizing Patient-Centricity Through a Tailored Training Program to Empower Patients, Advocates, and Ethics Committees in Good Clinical Practice

Authors

Poonam Bagai , Pooja Sharma , Aala Ansari , Nirbhay Singh , Sonal Sharma , Padam Singh ,

Durga Chougule, Manish Kumar Singh , Gargi Singh , Sanjeev Singh

Abstract

Good Clinical Practices (GCP) are vital for ethical, patient-centric research, but standard training may not fully prepare ethics committee members, especially laypersons and social scientists. This study explores a patient-driven training program (PACER) to improve awareness of research ethics and GCP among patients, advocates, and ethics committee members.

A workshop with 116 participants was conducted, with 91 completing pre- and post-training assessments. Before the workshop, only 16.5% understood ethical considerations for vulnerable populations, while 69.2% were aware of data governance. Post-workshop results showed a 5.4% improvement in knowledge.

PACER training helps bridge knowledge gaps, ensuring better ethical oversight and patient engagement in clinical research.

Acknowledgements

The authors acknowledged the support of APAR Health for providing the expertise throughout the PACER project execution and medical writing support.

Title

Perspective of Patient Advocacy Groups on Clinical Research and Outcomes of Their Involvement

Authors

Poonam Bagai, Pooja Sharma, Aala Ansari, Nirbhay Singh, Rhea Aggarwal, Durga Chougule, Sonal Sharma, Padam Singh, Manish Kumar Singh, Gargi Singh, Sanjeev Singh

Abstract

Patient Advocacy Groups (PAGs) help bridge the gap between patients, researchers, and clinical trials, but they need proper training to raise awareness. This study assessed the knowledge, awareness, and impact of PAGs through the PACER awareness program using a questionnaire and focus group discussions (FGD).

Among 185 participants, 97.8% were aware of clinical trials, and 90.3% understood that trials happen before a drug reaches the market. Key barriers to participation included safety concerns (82.2%), limited knowledge (67.6%), and fear (58.9%). Participants emphasized the need for greater patient involvement (59.5%) and more clinical trials. 88.6% believed PAGs in clinical trials benefit patients. The program led to PAGs joining ethics committees and helped enroll 14 patients in trials within six months.

This study highlights the power of training PAGs in boosting clinical trial awareness, participation, and collaboration for better healthcare outcomes.

Acknowledgments

The authors appreciate the support of the capacity building and strengthening educational program PACER was supported by an Educational Grant from Pfizer Limited (India).

The authors acknowledge the support of APAR Health

Title

PARTAKE Survey of Public Knowledge and Perceptions of Clinical Research in India

Authors

Tal Burt, Savita Dhillon, Pooja Sharma, Danish Khan, Deepa MV, Sazid Alam, Sarika Jain, Bhavana Alapati, Sanjay Mittal, Padam Singh

Abstract

Public awareness and trust in clinical research are essential for ethical and effective studies, yet many people remain uninformed or misinformed. The PARTAKE program aims to increase public knowledge and engagement in clinical research.

A survey of 175 individuals (ages 18–84) in New Delhi assessed awareness and perceptions. While 26.3% had heard of research, only 2.9% had participated, but 58.9% were willing to participate. Most believed research benefits society (94.1%), but many were unaware of compensation (62.3%) and had concerns about confidentiality (33.5%) and government protection (16.9%).

The findings highlight support for clinical research but also gaps in awareness and trust. Larger studies and educational programs are needed to improve public understanding and participation.

Acknowledgments

The authors would like to acknowledge the contributions of Sabrena Mervin-Blake, Dr. Robert Noveck, to the conceptualization of the survey, Pullaiyya Naidu Surapureddy, Sachin Shedge, Md. Muneeb Ahsan,Kuldeep Chauhan, Santhosh Joseph, Shahid Karim, Hari Ballabh Gupta,Joseph John, and Prashant to the testing, administration, and processing of survey data, and Drs. Truls Ostbye and Rahul Malhotra for their helpful comments. The authors would also like to acknowledge PARTAKE Steering Committee members .