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ICMR Bioethics Unit

People-Centric Approaches in Medical Research

REPORT: August 2025

WHO Collaborating Centre for Strengthening Ethics in Biomedical and Health Research

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FOREWORD

Indian Council of Medical Research (ICMR) Bioethics Unit extends its deepest appreciation to all participants, speakers, and panelists who enriched the discussion on "People-Centric Approaches in Medical Research" during the 13th International Conference on Ethics Education on June 12, 2025, at St. John's National Academy of Health Sciences, Bengaluru. This meeting reaffirmed the critical need to embed the voices of patients, communities, and stakeholders into the core of biomedical and health research.

As a WHO Collaborating Centre for Ethics in Biomedical and Health Research, ICMR remains steadfast in its commitment to advancing ethical, inclusive, and participatory research practices. The meeting echoed our shared vision—that research must be by the people, for the people, ensuring their perspectives shape study design, implementation, and outcomes. We recognize that meaningful engagement fosters trust, enhances relevance, and ensures equitable benefits.

This consultation reinvigorated essential dialogues on patient partnership, community-led research, and proactive ethical oversight, setting the stage for transformative change. Moving forward, we must translate these insights into action—strengthening policies, refining ethical frameworks, and cultivating a research culture that truly serves India's diverse population.

We hope this report inspires researchers, institutions, and policymakers to champion participatory, ethical, and impactful health research, leaving no one behind.

Dr. Roli Mathur, Scientist G & Head, ICMR Bioethics Unit, Bangalore

EXECUTIVE SUMMARY

The meeting on "People-Centric Approaches in Medical Research" held on June 12, 2025, at St. John’s National Academy of Health Sciences, Bengaluru, as part of the 13th International Conference on Ethics Education, brought together experts to discuss integrating patient and community perspectives into medical research. Discussions highlighted the need to shift from a traditional researcher-driven model to one that prioritizes transparency, trust, and equitable collaboration. Patient advocates stressed the importance of true informed consent, respectful communication, and treating participants as partners, particularly for vulnerable groups. Researchers explored successful engagement models like Community Advisory Boards (CABs), addressing challenges such as trust-building, funding, and ensuring community ownership of research. Ethics Committees (ECs) were urged to evolve from oversight bodies to proactive facilitators by adopting culturally sensitive consent processes, ethical training in medical education, and frameworks for meaningful patient involvement. Key takeaways included the necessity of co-designing studies with communities, disseminating results responsibly, and embedding ethical principles at every stage. The meeting concluded that achieving truly people-centric research requires systemic changes in study design, ethical governance, and a cultural shift toward trust and shared decision-making. By centering patients and communities as active collaborators, medical research can become more equitable, relevant, and transformative in addressing real-world health needs.

PEOPLE-CENTRIC APPROACHES IN MEDICAL RESEARCH

JUNE 12, 2025

INTRODUCTION

On June 12, 2025, thirty multidisciplinary experts convened for a discussion on "People-Centric Approaches in Medical Research" at St. John's National Academy of Health Sciences, Bengaluru, as part of the 13th International Conference on Ethics Education. Experts included patient advocates, Ethics Committee members, researchers, policymakers, and community representatives, among others. The discussion aimed to transform the traditional paradigm of medical research by positioning patients and communities as partners rather than mere participants in research.

The comprehensive program was structured around three critical perspectives that collectively address the fundamental shift needed in contemporary medical research practices. The first session explored what people want from research, grounding the discussion in lived experiences and authentic participant perspectives. The second session examined what researchers must actively do to implement meaningful engagement strategies throughout the research lifecycle. The third session focused on how Ethics Committees can evolve from compliance gatekeepers to proactive facilitators of people-centric approaches. This tripartite structure ensured comprehensive coverage of the systemic changes required across all stakeholders in the research ecosystem.

OPENING REMARKS

Speaker: Dr. Roli Mathur

Dr. Roli Mathur welcomed all participants and opened the meeting by highlighting the importance of people-centric approaches in medical research. She emphasized that meaningful engagement of patients, caregivers, and communities throughout the research process helps ensure relevance, improves outcomes, and promotes equitable benefit-sharing.

She stressed the need for true collaboration, where people help design studies, set research agendas, and identify outcomes that matter to them. This makes research more robust, acceptable, and grounded in real-life needs.

Dr. Mathur concluded her opening remarks by reiterating that the meeting aims to rekindle dialogue on people-centric approaches in medical research and to hear perspectives from people/patient advocates, researchers, and ethics committees. She urged participants to actively contribute so that ICMR can take forward actionable steps to make future research more inclusive and impactful for the people of India.

SESSION I - THROUGH PEOPLE'S EYES: WHAT THEY WANT FROM RESEARCH?

Co-Chairs: Dr. Amar Jesani and Dr. Durga Gadgil

Speakers: Mr. Gautam Dongre and Ms. Ritu Bhalla

The opening session prioritized the voices of those most directly affected by medical research, research participants themselves. The session aimed to ground all subsequent discussions in the lived experiences and needs of the people that research purports to serve. Two patient representatives shared insights that challenged conventional research approaches and their vision of true collaborative partnerships with participants in medical research.

Representing over 2 lakh sickle cell patients in India, Mr. Gautam Dongre (Secretary, National Alliance of Sickle Cell Organization - NASCO) emphasized the need for research focused on more effective, safer, and personalized treatments, and improved quality of life for those living with sickle cell anaemia. He also stressed the prioritization of patient needs, preferences, and experiences, along with accurate and reliable information for informed treatment choices. Mr. Dongre asserted that patients should be treated as partners, not just participants, advocating for full transparency on benefits and risks, and adequate support during and after participation in research. Experiences of insufficient information and follow-up have led to mistrust, underscoring the importance of ethical and transparent research to restore faith and encourage participation.

As a two-time blood cancer survivor and patient advocate, Ms Ritu Bhalla (Lead, Patient-driven research, CanKids, New Delhi) shared her journey from being a patient to an advocate for patient rights. She highlighted the challenges in patient-led research, such as facing resistance in publishing her research due to her non-medical background, which emphasized systemic barriers. Ms. Bhalla articulated that patients and advocates desire engagement in research priority setting and protocol drafting, involvement in Ethics Committees (ECs) for exposure and capacity building, and patient-friendly initiatives like painless procedures, simple language information, and home visits. Furthermore, she called for simplified ways for patients to understand research, ongoing training for advocates, patient-friendly research registries, true and informed consent, and access to trials that genuinely benefit them.

The discussion in Session I underscored the significant stigma against diseases like sickle cell anaemia and cancer, necessitating a focus on neglected diseases in vulnerable populations. Transparency and informed consent were highlighted as essential for building trust and ensuring voluntary, respectful participation.

Public education was identified as vital to dispel misconceptions about research. The discussion concluded that meaningful engagement with research participants includes their proactive participation in all study phases, research priority settings, membership in ECs, community engagement, recognition, platforms for feedback, and research training.

SESSION II: MEANINGFUL ENGAGEMENT: WHAT RESEARCHERS MUST DO?

Co-Chairs: Dr. Shalini Bharat & Ms. Aparna Mittal
Panelists: Dr. Manisha Gate, Dr. Naro Chandola, Dr. Sandip Mukhopadhyay, Dr. Ananya Samajdar

This session focused on the fundamental transformation required in research methodology, shifting from hierarchical structures to genuinely collaborative processes where research is conducted with people rather than on them. The panelists emphasized that meaningful engagement demands sharing control and ownership while leveraging the expertise that comes from the lived experiences of people, to improve research outcomes for greater relevance.

Dr. Manisha Ghate emphasized that trust emerges from sustained engagement throughout the research lifecycle rather than superficial interactions. Her team's approach involved spending months in community visits before initiating any research activities, actively listening to concerns and meaningfully involving Community Advisory Boards in shaping their research approach. During active research phases, they empowered participants to develop educational materials, recognizing that communities possess unique capabilities to communicate health information effectively to their own members. Crucially, engagement continued after research conclusion, with efforts to connect participants to relevant government programs such as free treatment services, acknowledging that research relationships extend far beyond mere data collection. Her team also reimagined logistical arrangements for participant convenience, operating clinics during weekends and conducting blood collection in participants' homes, demonstrating genuine respect for participants' time constraints and preferences.

Dr. Naro Chandola brought valuable perspective from clinical trials, noting that working with urban poor populations requires different engagement strategies due to their unique individualistic characteristics compared to rural communities. She advocated for Community Advisory Boards as powerful operational tools, comprising trusted community members including school teachers and residents' welfare association leaders who effectively bridge researchers and communities. These CABs successfully countered harmful myths, such as unfounded claims about vaccine-induced infertility, provided essential reality checks on scientific protocols including concerns about frequent blood draws, and contributed to designing culturally appropriate awareness materials using local knowledge and communication preferences. However, she acknowledged challenges including maintaining CAB focus on research objectives while managing expectations regarding their influence on operational decision-making processes.

Dr. Sandip Mukhopadhyay introduced two practical frameworks designed to operationalize people-centric principles in research practice. The CARE framework for public health research and the HEART framework for clinical studies:

CARE:

- **C**ollaborative engagement with communities from the very beginning, not as an afterthought or requirement to check off.
- **A**ddressing real-world needs to improve lives rather than purely academic questions without meaningful outcomes.
- **R**espect for values and diversity, ensuring that research designs acknowledge and accommodate different cultural contexts.
- **E**ngaging ethically, empathetically, and transparently, sharing not just risks but goals and results.

HEART:

- **H**uman-centric approaches that prioritize dignity and individual rights.
- **E**mpowerment through ethical engagement that builds rather than exploits.
- **A**ccessibility across all societal strata, education levels, and financial circumstances.

- **R**esults focused on real-world impact rather than just publication metrics.
- **T**wo-way communication that creates meaningful dialogue rather than unidirectional information transfer.

Dr. Ananya Samajdar advocated for genuinely grassroots-led research where communities actively define research questions, collect relevant data, and interpret findings, moving decisively beyond tokenistic engagement toward authentic partnership. This comprehensive approach involves communities defining research priorities to ensure studies address their actual needs, training community members as data collectors to build peer-to-peer relationships that enhance data quality and participant comfort, and involving community members in interpreting research findings to ensure cultural relevance and accuracy. Dissemination of research outcomes becomes community-driven, with collaborative creation and sharing of results using culturally resonant formats including folk songs, street theatre performances, and compelling social media storytelling that reaches target audiences effectively.

The panel collectively emphasized that people-centric research transcends tokenistic engagement to create partnerships that truly matter, demanding comprehensive systemic changes that improve both ethical standards and scientific quality. By partnering with people and communities, researchers can gain access to deeper insights, reduce various forms of bias, and produce findings that are significantly more likely to be adopted and sustained by the communities they aim to serve.

SESSION III: HOW ETHICS COMMITTEES CAN FOSTER PEOPLE-CENTRIC APPROACHES?

Chairperson: Dr. Sudha Ramalingam
Panelists: Dr. Keshar Kunja Mohanty, Dr. Shifalika Goenka, Dr. Vikrant Bhor, Ms. Aarti Kumar

This session focused on the urgent need for Ethics Committees (ECs) to evolve from their traditional role as compliance gatekeepers to proactive facilitators of people-centric research. The discussion emphasized that ECs must actively involve participants as partners in research while ensuring culturally sensitive consent processes are implemented from project inception rather than as afterthoughts.

Dr. Mohanty's framework emphasized shifting from procedural compliance to substantive ethical engagement in research. This involves prioritizing and simplifying participation protocols to reduce barriers, ensuring representation across socioeconomic strata. Research quality is enhanced by treating participant engagement as a validity measure and aligning study designs with community needs for greater impact. However, current academic incentives and perceived operational delays from participatory approaches create resistance. Structural requirements include institutional policy changes, funding mechanisms supporting longer engagement timelines, and revised performance metrics for researchers.

Dr. Shifalika Goenka's work highlighted critical limitations in current informed consent processes, particularly in multicultural research settings. She emphasized that consent documents require cultural adaptation, not just literal translation, to ensure meaningful participant understanding. She highlighted that autonomy depends on a person’s ability to make decisions, which can be limited by poverty or discrimination, so ethics committees must carefully check whether study protocols allow for genuine informed consent. Consent forms should also clearly distinguish between the study’s effects and any direct benefits, enabling participants to make realistic, informed decisions.

Dr. Vikrant Bhor's contributions grounded the discussion in practical realities, acknowledging the gap between good intentions and executable strategies. He observed that community engagement proves more manageable in public health research compared to clinical settings. Bhor proposed concrete frameworks and checklists as a pragmatic approach to systemic change, emphasizing the documentation of engagement efforts. The call for continued oversight and monitoring acknowledged that guidelines without enforcement mechanisms often remain aspirational rather than transformational.

Ms. Aarti Kumar identified that most ethical challenges in research originate during medical education rather than at the Ethics Committee (EC) stage. Ethical deficiencies often arise in undergraduate training, as early education shapes attitudes toward patients and research participants, highlighting the need for fundamental reform in how healthcare professionals are trained and acculturated to interact with patients and research participants. Medical culture can “infantilize” patients, treating patients as if they lack autonomy, while ECs frequently function only as final checkpoints after researchers' attitudes are already formed. Kumar emphasized the importance of context-sensitive, participant-centered approaches in India, considering its social, cultural, economic, and religious diversity and structural inequalities.

INTERACTIVE DISCUSSION: HIGHLIGHTS

Coordinated by: Dr. Raajasiri Iyengar

The interactive discussion was conducted using Mentimeter, allowing all 30 participants and the audience to provide real-time input on various aspects of people-centric research. The results revealed valuable insights into current practices, participant needs, researcher blind spots, and communication strategies.Community Advisory Boards, informed and understood consent, and involving patients as partners were identified as current practices. For meaningful participation, clear communication of risks and benefits, ethical treatment, and community relevance were emphasized.

Figure 1: Interactive discussion response to “mention three people-centric approaches in research that you have come across”.

Major researcher blind spots included poor communication, lack of empathy, limited respect for autonomy, and prioritizing researcher convenience over participant needs. Overall, the session underscored the gap between ethical ideals and actual practice, calling for improved researcher training, institutional reforms, and culturally responsive engagement strategies to make research truly people-centric.

Figure 2: Interactive discussion response to "What aspects researchers often overlook while working with research participants?"

SESSION IV: SUMMARIZATION & WAY FORWARD

Speakers: Ms. Poonam Bagai, Dr. Shalini Bharat, Dr. Sudha Ramalingam

The concluding session synthesized insights from all previous discussions and articulated a comprehensive path forward for implementing people-centric approaches throughout Indian medical research. The overarching consensus emphasized a fundamental reorientation of medical research toward genuine people-centredness that extends beyond superficial modifications to existing practices.

This transformative approach involves treating patients and communities as partners rather than passive participants, fostering an environment of transparent communication and culturally appropriate informed consent processes that ensure complete understanding rather than mere procedural compliance. The speakers emphasized that this transformation requires moving beyond traditional power structures that position researchers as experts and participants as beneficiaries, toward partnerships where expertise flows multidirectionally and decision-making authority is appropriately shared.

Critical recommendations emerging from the session included comprehensive empowerment of patient advocates through systematic training and meaningful inclusion in research design processes, promoting the establishment and effective utilization of Community Advisory Boards as a standard practice rather than exceptional additions, and ensuring robust mechanisms for post-research access to benefits and culturally appropriate dissemination of findings that reach and benefit target communities. The speakers emphasized that these recommendations require structural changes in funding mechanisms, institutional policies, and researcher evaluation criteria to create incentives for people-centric approaches.

Furthermore, the session issued a call for Ethics Committees to function as proactive facilitators of people-centric research, embedding ethical principles from foundational stages of medical education rather than treating ethics as advanced specialization. The need for sustained efforts to educate both researchers and the general public about the benefits and requirements of people-centric research approaches, and developing clear, actionable frameworks for meaningful engagement that promotes partnership with research participants.

RECOMMENDATIONS:

Ten specific, actionable recommendations for implementing people-centric approaches in medical research were suggested:

1. Include Public Representatives in Ethics Committees
2. Ensure ‘Understood Consent’ not just ‘Informed Consent’
3. Provide Plain Language Result Summaries for All Research
4. Offer Training for Researchers & ECs for People-Centricity
5. Embed Ethical Reflexivity in Medical Education
6. Develop stakeholder checklists/ toolkit for people-centric research
7. Educate stakeholders through dedicated workshops
8. Gather participant feedback in annual reports to ensure accountability
9. Standardize data and sample collection processes to maintain ethical standards
10. Empower patient advocates by involving them in research design to ensure their perspectives are integrated from the outset.

CONCLUSION

The discussions demonstrated clear consensus that transforming medical research requires fundamental systemic changes rather than superficial modifications to existing practices. The active participation of thirty experts from diverse backgrounds—including patient advocates, researchers, ethicists, and institutional representatives—ensured that recommendations emerged from multi-stakeholder dialogue rather than unilateral academic perspectives. The recommendations provide actionable pathways for institutions, researchers, and Ethics Committees to implement meaningful changes that respect participants' autonomy while advancing scientific knowledge.

REFERENCES

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ANNEXURES

Annexure I: Meeting Agenda

PEOPLE-CENTRIC APPROACHES IN MEDICAL RESEARCH

Venue: St. John's National Academy of Health Sciences, Bangalore

AGENDA

Date: 12 June 2025 **Time: 1:30 to 4:30 PM**

Time	Topics	Speaker
Group Photo		
1:30 – 1:40 PM	Welcome and Opening remarks	Roli Mathur
SESSION-I		
1:40 – 1:45 PM	**Chairpersons:** Amar Jesani & Durga Gadgil	
1:45 – 2:05 PM *7 minutes each*	*Presentation* Through People's Eyes: What they want from research?	Gautam Dongre Ritu Bhalla
2:05 – 2:20 PM	*Discussion/ Q & A*	
SESSION-II		
2:25 – 3:05 PM *40 minutes*	**Chairpersons:** Shalini Bharat & Aparna Mittal	**Panelists:** Manisha Ghate Naro Chandola Sandip Mukhopadhyay Ananya Samajdar
	Panel Discussion Meaningful engagement: What Researchers must do?	
SESSION-III		
3:10– 3:50 PM *40 minutes*	**Chairpersons:** Sudha Ramalingam	**Panelists:** Keshar Kunja Mohanty Shifalika Goenka Vikrant Bhor Aarti Kumar
	Panel Discussion How ECs Can Foster People-Centric Approaches?	
3:55 – 4:10 PM	Interactive Discussion	ICMR Bioethics Unit
SESSION-IV		
4:15 – 4:25 PM	Summarization & Way Forward	Poonam Bagai Shalini Bharat Sudha Ramalingam
4:25 – 4:30 PM	Closure	ICMR Bioethics Unit

Session led by: ICMR Bioethics Unit

Annexure II: List of Contributing Members

1. Dr. Roli Mathur, Scientist-G & Head, ICMR Bioethics Unit
2. Prof Shalini Bharat, Former Director, TISS, Mumbai
3. Dr. Amar Jesani, Editor, Indian Journal of Medical Ethics, Mumbai
4. Dr. Sudha Ramalingam, Professor & HOD, Dept of Community Medicine, PSG, Coimbatore
5. Dr. Durga Gadgil, Consultant, TRAC, Tata Memorial Hospital, Mumbai
6. Dr. Naro Chandola, Senior Scientist and Senior Deputy Director, Centre for Health Research and Development, Society for Applied Studies (SAS), Delhi
7. Dr. Ananya Samajdar, Deputy Director – Research, GRAAM, Bengaluru
8. Dr. Shifalika Goenka, Head, Physical Activity & Health Promotion, Centre for Chronic Disease Control (CCDC), Delhi
9. Ms. Aarti Kumar, CEO & Co-founder, Community Empowerment Lab, Bengaluru
10. Mr Gautam Dongre, Secretary, National Alliance of Sickle Cell Organizations (NASCO), Nagpur
11. Ms Ritu Bhalla, Lead, Patient-driven research, CanKids, New Delhi
12. Ms Aparna Mittal, Founder and CEO, PatientsEngage, Mumbai
13. Ms Poonam Bagai, Founder – CanKids, New Delhi
14. Dr. Keshar Kunja Mohanty, Sci-G, ICMR-NJIL&OMD, Agra
15. Dr. Manisha Ghate, Sci-G & Head, Division of Clinical Sciences, ICMR-NITVAR, Pune
16. Dr. I.P. Sunish, Sci-F, ICMR-RMRC, Sri Vijaya Puram, Andaman & Nicobar Islands
17. Dr. Vikrant Bhor, Sci–E, EC Member Secretary, ICMR NIRRCH, Mumbai
18. Dr. Snehal Chavhan- Sci- E, ICMR NIV, Pune
19. Dr. Sandip Mukhopadhyay, Sci-E, ICMR-NIRBI, Kolkata
20. Dr. Anjali Sharma, Professor, EC Member Secretary, ICMR-BMHRC, Bhopal
21. Dr. S. Srikanth, Sci – C, ICMR – VCRC, Puducherry
22. Dr. Mamta Pandey, Sci-C, ICMR-NARFBR, Hyderabad
23. Dr. Shrinivasa B, Sci-B, ICMR-NIOH, Nagpur
24. Dr. Jayasankar, Sci – B, ICMR-NCDIR, Bengaluru
25. Dr. Dileep G, Scientist-C, ICMR Bioethics Unit
26. Dr. K Md Shoyaib, Scientist-B, ICMR Bioethics Unit
27. Dr. Elna Paul Chalisserry, Consultant, ICMR Bioethics Unit
28. Dr. J Raajasiri Iyengar, Project Research Scientist- II, ICMR Bioethics Unit
29. Dr. Aswini Madhavan, Project Research Scientist- II, ICMR Bioethics Unit
30. Mr. Arjun R Y, Young Professional Admin – II, ICMR Bioethics Unit