



## Community Engagement and Involvement (CEI) Charter

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**List of amendments to the CEI Charter based on recommendations from the committee**

Date change suggested	Changes made	Page number

## Introduction

Community engagement and involvement (CEI) in research is key to the success of research projects as community members can guide projects through their lived experiences and make the outputs more relevant to the needs of the population. People with lived experience - and the organisations that represent - researchers and health and care practitioners will all have distinct, though often overlapping research priorities. By working together we can develop a shared agenda. An active partnership will enable us to learn from each other and agree on the research priorities together through a shared decision making process. The purpose of this charter is to define the responsibilities of the MaatHRI CEI committee, list the members, describe purpose and frequency of committee meetings, provide the procedures for ensuring confidentiality, standards, proper communication, reimbursements, and CEI impact evaluation and reports.

**MaatHRI** (<https://www.npeu.ox.ac.uk/maathri>) is a UK-India collaborative research platform established in September 2018 to undertake epidemiological studies to improve care and outcomes of mothers and babies. There are three broad objectives of MaatHRI:

1. Conduct repeated monthly surveys of cases and deaths due to severe maternal complications.
2. Undertake epidemiological studies to improve clinical outcomes of mothers and babies.
3. Build research capacity in the MaatHRI collaborating hospitals and encourage mutual learning.

The results of the epidemiological studies are used to develop pregnancy care guidance and interventions to reduce severe complications and death among pregnant women and babies in India. The research project is sponsored by the University of Oxford and funded by the Medical Research Council (MRC) UK, Nuffield Department of Population Health and Ultromics Limited through Fellowship and grants to Dr. Manisha Nair. Dr. Manisha Nair is the Chief Investigator for MaatHRI and is based at the University of Oxford. The Indian Site Investigators are based at the following locations and a list of the investigators is included in Appendix1:

- Srimanta Sankaradeva University of Health Sciences, Guwahati, Assam
- Assam Medical College and Hospital (AMCH), Dibrugarh, Assam
- Jorhat Medical College and Hospital (JMCH), Jorhat, Assam
- Guahati Medical College and Hospital (GMCH), Gwahati, Assam
- Silchar Medical College and Hospital (SMCH), Silchar, Assam
- FAA Medical College and Hospital (FAAMCH), Barpeta, Assam
- Tezpur Medical College (TMC), Tezpur, Assam
- Mahendra Mohan Choudhury Hospital (MMC), Gwahati, Assam
- Makunda Christian Leprosy and General Hospital, Karimganj, Assam
- Mahatma Gandhi Institute of Medical Sciences, Wardha, Maharashtra
- Institute of Medical Sciences, Banaras Hindu University, Varanasi, Uttar Pradesh
- Nazareth Hospital, Shillong, Meghalaya
- Dr Rajendra Prasad Government Medical College, Tanda, Himachal Pradesh

A MaatHRI steering committee comprised of the Chief Investigator and Statistical Epidemiologist at Oxford, and all Site Investigators in India oversees the general scientific direction of the research project. The Community engagement and involvement (CEI) committee will provide independent advice for planning new research, implementing and monitoring projects and research outputs, developing policy and community briefs from the research outputs, and evaluate the impact of CEI on MaatHRI's work. This document outlines the formal operating procedures for the MaatHRI CEI committee and is adapted from the INVOLVE guidance (<https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research>).

## **What is community engagement and involvement (CEI) in research?**

CEI in research can be defined as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. It is an active partnership between patients, people with lived experience of one or more health conditions (whether they’re current patients or not), carers, members of the public and organisations that represent people who use services with researchers that influences and shapes research.

Here are examples of how members of the CEI committee might get involved in research:

- as joint grant holders or co-applicants on a research project
- identifying research priorities
- as members of a project advisory or steering group
- commenting on and developing patient information leaflets or other research materials
- undertaking interviews with research participants
- participate in science festivals open to the public with debates and discussions on research open days at a research centre where members of the public are invited to find out about research
- raising awareness of research through media such as television programmes, newspapers and social media
- dissemination to research participants, colleagues or members of the public on the findings of a study

## **Why involve members of the public in research?**

CEI can improve the quality and relevance of research, as well as serving the broader democratic principles of citizenship, accountability and transparency.

### [Democratic principles](#)

People who are affected by research have a right to have a say in it. It can also help empower people who use health and social care services, by providing the opportunity to influence research that is relevant to them.

### [Providing a different perspective](#)

Members of the public might have personal knowledge and experience relevant to research topic or be able to provide a more general societal perspective. They might have lived experience of one or more health conditions or of using services. Members of the public will also bring their experiences of being part of specific communities or groups.

### [Improving the quality of the research](#)

Involving members of the public helps ensure that research focuses on outcomes that are important to the public. It is also a good way of tailoring research to the needs of specific communities and ensuring that research methods are sensitive to the needs, customs and circumstances of the community.

## **Why members of the public get involved in research**

Members of the public get involved in research for a variety of personal and social reasons. For some, these are linked to personal experiences of health or social care services and a desire to bring about change in the quality of care or to improve treatments either for themselves or for others with a similar condition. For others it might be a way to have a ‘voice’ and influence the processes that affect people’s lives. Some people have had difficult experiences and appreciate being able to do something positive with that experience. Others have had very good experiences, and see their involvement as an opportunity to ‘give

something back'. Other people get involved to ensure the voice of their community/communities are represented in research. Well planned and resourced involvement in research can also be valuable to those involved by increasing their confidence and knowledge and helping them to develop new skills.

### **Six Standards of community involvement in research (adapted from INVOLVE)**

**Inclusive opportunities** –community involvement opportunities should be accessible and reach people and groups according to research needs.

**Working together** – work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

**Support and learning** –promote support and learning opportunities that build confidence and skills for community involvement in research.

**Governance** – involve the public in research management, regulation, leadership and decision making.

**Communication** – use plain language for well-timed and relevant communications, as part of involvement plans and activities.

**Impact** – seek improvement by identifying and sharing the difference that community involvement makes to research.

### **Organisation of the MaatHRI CEI committee**

#### **Composition of the CEI committee**

The CEI membership will include patients, people with lived experience of one or more health conditions (whether they're current patients or not), carers, members of the public and organisations that represent people who use services, and others with keen interest in improving the health and wellbeing of mothers and babies.

#### **Selection of CEI committee Members**

The CEI Chair and 6-8 members will be selected by the Chief Investigator, Project Manager and the Indian Site Investigators. In the event that a member is unable to continue participation, a replacement will be recommended. The committee members will be from diverse backgrounds with an inclusive representation (gender, region, experience, others) to represent an extensive range of experiences, views and opinions.

#### **CEI committee Membership**

CEI committee members will be required to declare any conflict of interest and be cleared of any real or potential conflicts of interest in accordance with the provisions in this Charter. The Chief Investigator and MaatHRI steering committee will assure that the members do not have any conflicts of interest. The initial duration of membership will be for a period of 5 years. The membership will be reviewed and members will be replaced every 5 years to give opportunity to a larger section of the community. Membership of the CEI committee is a voluntary non-binding commitment, and members can contribute as much as they want. They are also free to leave at any point or consider continuing for more than the expected term of five years.

### **CEI committee meetings**

There will be at least 1-2 CEI meetings per year. Additional meetings might be required if urgent consultation is required for a new project or for developing dissemination materials, etc, or if any mitigation measures are required for MaatHRI research projects. The meetings will be online using appropriate and secure video conferencing facilities. The Chair of the CEI committee along with Chief Investigator and Project Manager of MaatHRI will set the agenda for each meeting and decide a date that would be convenient for a majority of

the members. A pre-meeting consultation via telephone or email will be organised to discuss the agenda and papers with all members. MaatHRI Project Manager will support the CEI Chair to organise the meetings and also help in drafting the minutes of the meeting. The CEI Chair will be responsible for submitting the minutes of the meeting to the MaatHRI steering committee. MaatHRI Project Manager and Chief Investigator will be present in all meetings and Site-investigators will be invited to join based on their availability.

#### Guidance for conducting the meetings

- Meetings will be conducted in the form of consultations
- CEI Chair will ask members to introduce themselves at the beginning of the meeting
- Members will agree ground rules for how a meeting will be conducted so that everybody has an equal opportunity to contribute
- Members agree to rules of mutual respect, confidentiality and the six standards of community involvement in research
- Chair to make sure that everybody has an equal voice on the committee
- Chair to encourage the use of clear language, explain jargon and acronyms
- Chair to regularly check that people understand the language used and the content of the meeting
- Plan for breaks in the agenda if the meeting is for more than 45 minutes
- Consider different ways of conducting meetings, such as time in small group sessions (breakout rooms online) as well as meetings in a larger group to allow people the opportunity to contribute in different ways
- Create a mentor or buddy system to support the members, if required
- Discuss the CEI charter in the first meeting to ensure that each member has read the Charter and agrees to its content, and thereafter discuss the Charter in each meeting and note any further amendments
- Ask for feedback from members and if they have any suggestions for improvement for future meetings

#### **CEI committee reports**

In addition to the minutes of the regular meetings, the CEI committee will also submit a short 1-2 page annual report on its activities, suggestions for new research priorities, engaging the wider public and processes by which the research outputs could be made usable to benefit the population.

#### **Confidentiality**

All committee members will treat as confidential the reports, meeting discussions, and minutes. Master copies of the CEI committee reports and recommendations will be kept in a limited access, locked file cabinet.

#### **Remuneration**

Remuneration will be provided by the University of Oxford. Each member will be paid INR 2000 per meeting that they attend. MaatHRI Project Manager will oversee the remuneration process. The fee will be reviewed every five years.

#### **Responsibilities and functions of the CEI committee**

This CEI will be coordinated by the University of Oxford. Members will be involved in a whole range of research activities. These include helping to develop the research priorities, applying for funding and ethical approval, sitting on advisory groups, carrying out the research and disseminating the research findings.

A research topic may be proposed by the MaatHRI steering committee or the CEI committee. The topics will mainly focus on clinical research as MaatHRI is a hospital-based platform, but community-based studies may also be proposed.

People with lived experience - and the organisations that represent - researchers and health and care practitioners will all have distinct, though often overlapping research priorities. By working together we can develop a shared agenda. An active partnership will enable us to learn from each other and agree on the research priorities together.

- ❖ Members will be asked to contribute and review MaatHRI project proposals for funding applications.
- ❖ Members might be invited to join as co-investigators in projects.
- ❖ Members will be involved in the design of the research to -
  - identify aspects of the research that raise ethical considerations and provide a broader set of perspectives on solutions
  - suggest ways that people can be meaningfully involved in the various stages of the research
  - suggest ways to ensure that diversity and inclusion are addressed in the research, for example in ensuring that volunteers can be recruited from certain communities
  - ensure that the recruitment process is practical and feasible
  - help develop written information in user friendly and plain language, which is appropriately targeted at specific communities
- ❖ Members will be involved in managing the research to ensure that -
  - a public and societal perspective is maintained throughout an individual project or a programme of work
  - CEI involvement in the project is properly budgeted and funded
  - effective support is developed for members of the public involved in the study
  - advice is available on improving the recruitment of participants to the study
  - there is involvement in the selection process of staff and researchers for the study – particularly helpful if members are going to be working with research participants
- ❖ Members will be involved in analysing and interpreting the results of the studies to –
  - help to identify themes that researchers might miss
  - help check the validity of the conclusions from a public perspective
  - highlight findings that are more relevant to the public
- ❖ Members will be involved in widely disseminating the research outputs so that they can influence and change practice for the better. To support public engagement in research, members will help to–
  - develop progress reports or newsletters to keep people informed throughout the project, reporting both negative and positive results
  - feedback results to everyone consulted and collaborated with as well as participants
  - work with members of the public to develop dissemination plans – they will often have access to groups and forums that researchers are not aware of
  - involve people in presenting at conferences, speaking to patients, support groups and service providers
  - acknowledge the contribution of members of the public made to the research when writing journal articles and reports
  - write short sections for the MaatHRI newsletter and reports



- ❖ Members will contribute to build the evidence base and let others know about what worked well and what didn't and the impact of public involvement in MaatHRI research.

#### **APPENDICES**

Appendix 1: MaatHRI investigators, Project Manager and study hospitals

Appendix 2: List of CEI members and duration of membership

## Appendix 1: MaatHRI Investigators, Project Manager and study hospitals

Chief Investigator		Dr Manisha Nair, National Perinatal Epidemiology Unit, Nuffield Department of Population Health, University of Oxford, Richard Doll Building, Old Road campus, Headington, Oxford, OX3 7LF Phone: +44-1865617820; Email: <a href="mailto:manisha.nair@npeu.ox.ac.uk">manisha.nair@npeu.ox.ac.uk</a>	
Project Manager		Ms Rupanjali Deka, Srimanta Sankaradeva University of Health Sciences, Assam. Narkashur Hilltop, Christian Basti Bhangagarh, Guwahati, Assam 781032. Phone: +91 (0) 8811842882, 9864060259; Email: <a href="mailto:maathripm@gmail.com">maathripm@gmail.com</a>	
Sl. No.	Name of hospital	Coordinating institution	Name of site investigators
<b>Assam</b>			
1	Assam Medical College and Hospital, Dibrugarh	Srimanta Sankaradeva University of Health Sciences, Assam	Vice Chancellor is the coordinating PI for these hospitals. List of Site investigators – i. Dr. Saswati Sanyal Choudhury, Gauhati Medical College and Hospital, Guwahati, Assam ii. Dr Farzana Zahir, Assam Medical College and Hospital, Dibrugarh, Assam iii. Dr. Robin Medhi, F.A.A Medical College, Barpeta, Assam iv. Dr. Swapna D Kakoty, F.A.A Medical College, Barpeta, Assam v. Dr. Ratna Kanta Talukdar, Jorhat Medical College and Hospital, Jorhat, Assam vi. Dr Pranabika Mahanta, Jorhat Medical College and Hospital, Jorhat, Assam vii. Dr Gitanjali Deka, Tezpur Medical College and Hospital, Tezpur, Assam viii. Dr Bandana Das, Silchar Medical College and Hospital, Silchar, Assam ix. Dr Seeresha Rao, Silchar Medical College and Hospital, Silchar, Assam x. Dr Amrit Bora, MMC hospital, Gwahati, Assam
2	F.A.A Medical College and Hospital, Barpeta		
3	Gauhati Medical College and Hospital, Guwahati		
4	Jorhat Medical College and Hospital, Jorhat		
5	Tezpur Medical College and Hospital, Tezpur		
6	Silchar Medical College and Hospital, Silchar		
7	Mahendra Mohan Choudhury (MMC) Hospital		
8	Makunda Christian Leprosy and General hospital, Karimganj		

Meghalaya			
9	Nazareth Hospital, Laitumkhrah, Shillong	Nazareth Hospital	Dr. Indrani Roy, Senior Consultant and Head of the Department of Obstetrics and Gynaecology
Maharashtra			
10	Kasturba Hospital, Sevagram	Mahatma Gandhi Institute of Medical Sciences, Wardha	Prof. S Chhabra, Director Professor, Department of Obstetrics and Gynaecology
11	Dr. Sushila Nayar Hospital, Utavali, Melghat		
Uttar Pradesh			
12	Institute of Medical Sciences, Varanasi	Banaras Hindu University, Varanasi	Dr. ( Major ) Anjali Rani, Assistant Professor, Department of Gynaecology and Obstetrics
Himachal Pradesh			
13	Dr. Rajendra Prasad Government Medical College, Kanga, Tanda	Dr. Rajendra Prasad Government Medical College	Dr Ashok Verma; Professor, Department of Obstetrics and Gynaecology  Dr Omesh Kumar Bharti; State Epidemiologist, State Institute of Health and Family Welfare, Government of Himachal Pradesh  Dr Sita Thakur; Professor and HoD, Department of Obstetrics and Gynaecology

## Appendix 2: List of CEI members and duration of membership

Sl No	Name	Short bio	Contact email and phone	Membership
1	Rashmi Mohanty	Has worked for more than 30 years in the field of public health, humanitarian response and development. She has worked with several grass-root organisations, international and national organisations in several Indian states/UTs and in South Sudan at all levels (from community to national level).	<a href="mailto:rashmi.kalahandi@gmail.com">rashmi.kalahandi@gmail.com</a>	Start: November 2021 End date: Ongoing
2	Akashdeep Chowdhury	Is currently Project Officer (Operations) at United Nations Development Programme. Experienced Operations Officer with a demonstrated history of working in the international affairs industry and public health projects. He is skilled in project management, last mile delivery, inventory, logistics, and has a Master's degree in business administration.	<a href="mailto:akash100294@gmail.com">akash100294@gmail.com</a> Phone: +91 7735466463	Start: November 2021 End date: Ongoing
3	Devachandana Oja	Is currently looking after the advertising and marketing segment at Oja Hyundai Limited (Self Employed). Previously, she was a lecturer at the North-eastern Regional Institute of Management. She is enthusiastic to work with people who she thinks will help her to enhance knowledge and skills.	<a href="mailto:neoroja@gmail.com">neoroja@gmail.com</a> Phone: +91 9864021157	Start: November 2021 End date: Ongoing
4	Dimpi Phukan Neog	A former teacher now a proud homemaker by choice. Having been into teaching for 10 long years, she began to lose interest after the birth of her 2nd daughter. She is a graduate in arts from Guwahati University. Her two lovely daughters, aged 12 and 15, are the joy of her life. She is also a keen gardener.	<a href="mailto:dimpyphukan@gmail.com">dimpyphukan@gmail.com</a> Phone: +91-9864032847, +91-7002649587	Start: November 2021 End date: Ongoing
5	Dr Kshama Metre	Is popularly known as "Doctor Didi". She is a Padma Shree and the National Director of Chinmaya Organization for Rural Development (CORD). She is a paediatrician by training, but now has dedicated her life to CORD which is a participatory, comprehensive, integrated and sustainable rural development project. Her work through CORD is impacting 60,000 beneficiaries directly and 300,000 indirectly in rural India.	<a href="mailto:cordsidhbari@gmail.com">cordsidhbari@gmail.com</a> Phone: +91-980-546-8721	Start: November 2021 End date: Ongoing

Notes