Engaging with low- and middle-income countries (LMICs):

A global code of conduct

Based on principles of bidirectional, equitable partnership *(Pratt et al., 2023)*

Encephalitis International
The brain inflammation non-profit

Purpose of this code of conduct

This code of conduct recognises the specific challenges and considerations associated with working in low- and middle-income countries (LMICs) and provides a clear framework for effective, ethical and meaningful engagement. It is intended to guide research and patient engagement activities in lower-resource settings, with a particular focus on health and encephalitis research.

While resource constraints exist globally, they are more prevalent in LMICs and can shape power dynamics, access to care and research capacity. This code therefore sets out practical, achievable principles for engagement that aim to mitigate unequal power relationships and differences in financial or institutional capacity. It is grounded in trust, respect, inclusivity and adaptability, and seeks to foster partnerships that are reciprocal exchanges, equitable, culturally sensitive and mutually beneficial.

As a global non-profit organisation, Encephalitis International (EI) is committed to co-strengthening capacity, knowledge and leadership across all partners including EI, LMIC partners and key stakeholders, such as governments, research institutions, patients and families. This code provides shared principles to support collaborative working, promote meaningful community engagement, and ensure that activities are appropriate to the context in which they take place.

Global collaboration is essential to addressing health inequities, reaching diverse populations and improving understanding, diagnosis and treatment of encephalitis worldwide. Developing strong, respectful working relationships with LMIC partners is therefore a strategic priority for EI.

EI's engagement with LMICs

EI has a longstanding and growing commitment to working with LMICs. Our collaboration on the World Health Organization (WHO) Technical Brief demonstrates our capacity to work effectively at an international level while continuing to advocate for people affected by encephalitis globally. This work provides an example of EI adapting our priorities because of LMIC collaboration: our engagement with clinicians, researchers, and policymakers from LMICs during development of the WHO Technical Brief highlighted that many of the greatest barriers extend beyond scientific evidence and relate to delayed diagnosis, workforce shortages, surveillance, laboratory infrastructure, and rehabilitation. As a direct result we pivoted our international work to focus on: surveillance, community burden and practical clinical education aimed at LMICs.

This includes funding bursaries for delegates from LMICs to attend the annual Encephalitis Conference, facilitating international connections among clinicians and researchers, supporting research studies conducted in LMICs, and commissioning online training modules with the British Medical Journal specifically designed for professionals working in low-resource settings, among many other initiatives. EI currently supports a professional membership of over 600 clinicians and researchers from LMICs.

Our global conference provides another example of how we changed our practice as a direct result of learning from LMIC collaborators and more visibly recognising that expertise is globally distributed. We did this by increasing bursaries, involving more LMIC speakers, highlighting diseases particularly relevant to LMICs, and showcasing work led by LMIC investigators.

EI is also supported by its global lay community, including Team Encephalitis Volunteers from multiple countries. We actively share patient and caregiver experiences from across the world, reflecting the full spectrum of encephalitis aetiologies seen globally. EI's lay membership from LMICs now exceeds 500 individuals, contributing to one of the largest patient and professional encephalitis networks worldwide.

How EI facilitates research in LMICs

As a patient organisation, EI ensures that the voices and experiences of people affected by encephalitis are embedded within research activity. EI acts as a co-applicant on international encephalitis research projects and provides recruitment, engagement and dissemination support to studies worldwide. Our CEO Dr Ava Easton is also co-author on many peer-reviewed papers exploring various aspects of encephalitis in LMICs.

Since 2019, EI has funded ten seed research projects in LMICs including Cameroon, Brazil, Senegal, India, Uganda and Peru. These projects support locally led capacity strengthening in encephalitis diagnosis, treatment and rehabilitation.

EI's research team, led by CEO Dr Ava Easton MBE, provides tailored support for patient and public involvement in international research, connecting researchers with patients and families across diverse settings. Given EI's extensive engagement in LMICs, it is essential that this work is guided by a clear framework that recognises the realities of lower-resource health systems and varying levels of research infrastructure. The following sections set out the principles that underpin this global code of conduct.

Framework for engagement with LMICs

This framework is structured around five interdependent principles: trust, respect, inclusivity, adaptability and reciprocity. Together these principles promote equitable partnerships in which knowledge, expertise, leadership and benefit are shared across all collaborators.

Health research in LMICs must address locally relevant priorities and contribute tangible social and medical value. Research activity should be responsive to local health needs, particularly in resource-limited settings, to ensure that it delivers meaningful and sustainable benefit.

EI recognises that this work is a shared learning process and that we will not always get it right. We commit to learning alongside our LMIC partners, responding openly to feedback and adapting our practices to do better.

Building trust

Trust is foundational to all effective engagement. Researchers, policymakers, community leaders, patients and carers must feel confident that partnerships are transparent, ethical and genuinely collaborative.

Good practice includes:

- Co-creating governance, research priorities, success measures and decision-making.
- Collaborating with local leaders early and in an ongoing manner, including at idea-generation and planning stages.
- Ensuring that research proceeds only with appropriate local consent and approval.
- Establishing clear mechanisms for feedback, concerns and complaints.
- Identifying and mitigating potential risks of stigma linked to research participation.
- Developing collaboratively agreed roles and responsibilities for volunteers, patients and community members.
- Establishing shared and accessible understandings of research processes.
- Establishing shared and accessible public and patient involvement.
- Valuing participant contributions and demonstrating their impact.
- Maintaining engagement and support beyond the end of individual projects.

Prioritising respect

Engagement must be a mutual exchange of expertise, which can also acknowledge and actively address potential power imbalances between high-income and lower-resource settings. Respect for local knowledge, expertise and lived experience is essential.

This includes:

- Valuing traditional knowledge, practices and existing community resources.
- Ensuring cultural sensitivity and ethical appropriateness of research design.
- Following local ethical approval and consent procedures.
- Implementing additional safeguards where participation could lead to stigma or harm.
- Adhering to the principle of "do no harm" and avoiding extractive research practices.
- Actively including marginalised or hard-to-reach populations.
- Establishing clear, locally appropriate data governance, ownership and management processes.
- Co-developing research outcomes in accessible formats that are meaningful for local communities.
- Considering the cultural and social relatability of the research team.
- Using iterative approaches to ensure ongoing relevance and appropriateness.
- Recognising LMIC innovation as globally relevant.

Ensuring inclusivity

Inclusive engagement strengthens trust, relevance and impact. Research should be co-designed and co-delivered with, and not merely in, LMIC communities.

An inclusive approach includes:

- Co-leadership, equitable budget authority, joint-priority setting, fair authorship and opportunities for LMIC investigators to lead publications and conference presentations.
- Meaningful involvement of local leaders throughout development of research questions, study design, agenda-setting, methodological design, planning, delivery and evaluation.
- Inclusion of local researchers and use of existing local infrastructure and expertise.
- Use of mixed methods to understand local contexts, priorities and barriers to engagement.
- Transparent budgeting that reflects the true costs of engagement, including fair reimbursement.
- Proactively addressing language barriers through interpreters, translators and accessible materials.
- Building on existing skills to support long-term sustainability of outcomes.
- Supporting skills co-development and capacity strengthening within communities, including the distinction between, and acknowledgement of, short-term training activities and longer-term institutional training (examples might include: embedding joint data analysis sessions, integrating training in study design, manuscript development mentorship, protocol co-development, skills transfer in diagnostics, analyses and/or patient involvement methodologies and support for early-career LMIC researchers).
- Clearly communicating benefits of participation and how burdens will be minimised.
- Dissemination of results to research participants.

Maintaining adaptability

Engagement in LMICs must remain flexible in response to changing social, economic and political contexts. Competing priorities and constraints should be accommodated rather than treated as barriers.

Adaptable practice includes:

- Community-based approaches to awareness and recruitment.
- Consideration during study design in respect to future access to interventions and diagnostics, training, or improvements in care generated by the research.
- Providing information in formats that are locally appropriate and accessible. This includes consideration of language accessibility, translation of key outputs, and structured local dissemination, including adaptation of education materials to local clinical realities and resource constraints.
- Supporting and compensating local support roles, such as interpreters and administrators.
- Remaining responsive to shifting local priorities throughout the research cycle.
- Maintaining two-way communication channels.
- Actively seeking, listening to and acting on community feedback.
- Being mindful of national, regional and historical factors that may influence engagement.

Reciprocity

Reciprocity means recognising that every partnership creates opportunities for mutual learning, shared leadership and lasting benefit. EI believes that expertise exists in every setting and that global collaborations should strengthen all partners, regardless of geography or resources. Partnerships should therefore be characterised by openness, humility and a willingness to adapt based on the knowledge and experience of others.

Reciprocal practice includes:

- Co-developing research priorities, ensuring that questions address locally identified needs while contributing to global knowledge.
- Recognising that knowledge exchange should flow in all directions, with lessons from LMIC partners informing EI's own organisational practices and assumptions in response to its learning from partners.
- Promoting shared leadership through equitable representation on steering groups, advisory panels and governance structures.

- Supporting equitable authorship and recognition of intellectual contributions in accordance with international best practice (lead presentations, publications, educational activities and international collaborations).
- Ensuring transparency in decision-making around priorities, budgets, resource allocation and dissemination activities.
- Investing in long-term institutional relationships rather than project-specific collaborations wherever possible.
- Sharing learning, resources and innovations across the global encephalitis community so that successful approaches developed in one setting may benefit others.
- Recognising and valuing innovation developed in resource-limited settings, including approaches that may improve practice within higher-income health systems.
- Considering success not only in terms of research outputs, but also through strengthened partnerships, mutual trust, shared capability and sustainable networks.
- Celebrating the achievements and leadership of partner organisations, ensuring visibility and recognition are shared fairly.

Controls, reviews and safeguards

Sustainability and exit planning

EI is committed to sustainable engagement that leaves lasting benefit. Research and engagement activities should identify a minimum standard versus any aspirational standards to avoid ethical drift when timelines or funding might be under pressure. There should also be early consideration of sustainability, knowledge transfer and responsible exit planning, ensuring that local partners are not disadvantaged when projects conclude.

Fair authorship, recognition and intellectual contribution

EI supports fair recognition of contributions, including equitable authorship, acknowledgement and intellectual ownership for local researchers, community members and partners, in line with international best practice.

Safeguarding and duty of care

All engagement must adhere to robust safeguarding principles, including clear procedures to protect children, at-risk adults and research participants, and to respond appropriately to exploitation, harm or risk.

All research should include a decision-making and escalation pathway for issues that might arise, for example, in relation to disputes on authorship, budget allocation or financial inequities, misuse of data, or community harm.

Where disputes cannot be resolved internally EI commits to providing an ethics advisory group or external mediation.

Monitoring, accountability and learning

EI will measure partnership quality using indicators such as mutual benefit, perceived influence, shared decision-making and institutional strengthening- not only research outputs.

EI will review and update this code of conduct regularly, informed by feedback from LMIC partners and communities, to ensure it remains relevant, effective and responsive to emerging challenges.

We expect studies to commit to tracking capacity outcomes beyond publications (e.g. new ethics approvals, new local protocols, sustained services) and to commit to documenting and sharing lessons learned from study challenges (internally or publicly where appropriate).

Concluding remarks

EI recognises that effective global partnerships require us to learn as well as lead. We therefore commit to regularly reflecting on how collaboration with our LMIC partners has influenced our own strategy, programmes, educational resources and research priorities. We will actively seek opportunities to embed this learning within our organisation and to share examples of reciprocal impact with our partners.

Strong, respectful co-working relationships between researchers, communities, policymakers and governments are essential to improving outcomes for people affected by encephalitis. These relationships must acknowledge cultural, political and structural differences while focusing on shared goals.

This code of conduct reflects EI's commitment to ethical, inclusive and sustainable partnerships with LMICs. While challenges such as limited resources, logistical barriers and ethical complexity are recognised, they must not detract from the overarching goal of improving health equity, strengthening research capacity and reducing death and disability from encephalitis worldwide.

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