

Epilepsy Climate Change (EpiCC) Memorandum of Understanding

EpiCC is an affiliation of like-minded professionals involved in epilepsy who consider that climate change will likely have disproportionately adverse consequences for people with epilepsy (PWE). The purpose of EpiCC is to share knowledge, disseminate information and promote practices that reduce contributions to climate change and help mitigate its effects with a view to effects on epilepsy. EpiCC is a venue for discourse, dissemination of useful activities, encouraging change from within the epilepsy community, and supporting research.

Members act in their capacity as professionals with a duty of care. Members may choose to undertake similar activities as private individuals, but this is not within the scope of EpiCC.

Whilst evidence for an effect of climate change on epilepsy is currently circumstantial or anecdotal, members accept that it is better to act now as we see the effects of climate change around us. Where possible, EpiCC will act as a ready-made consortium that can help develop research into the effects of climate change on epilepsy.

EpiCC encourages all those who are interested to take part. Members are encouraged to follow the principle of thinking globally and acting locally. EpiCC will have a guiding executive, with the following properties:

- A small group (~6 members) that is responsible for day-to-day, operational matters of EpiCC as an entity, serving as the point of contact and primary source for EpiCC-related communications.
- The composition of the executive will aim to maximize the opportunity for effective interactions with funding agencies, the ILAE, IBE, and other relevant entities.
- Each member of the executive must be a senior representative of their field with substantial experience in networking.
- Meets monthly by methods of minimal climate impact.
- Reaches decisions by informal consensus of those participating in calls, not by formal vote.
- Term limit of three years, renewable.

No member is required to undertake any activity in which they do not wish to participate. Membership is subject to the following, limited, requirements:

1. Members will act to promote the interests of PWE in the context of climate change. It is recognised that many important activities in epilepsy, such as scientific workshops, can contribute to climate change but are often essential for progress in the delivery and improvement of best practice. Members are not expected to abandon all such activities, but should think about their possible consequences and the development of newer ways of working that support the aims of EpiCC.

2. Members of EpiCC will not bring it into scientific disrepute. In an era of increasing bias, partisan fragmentation, and threats to scientific integrity, EpiCC activities should be based wherever possible on realistic estimations of the evolution and impact of climate change, whilst recognising that actions are required now.

3. Where EpiCC is involved in research activity, members will follow principles now well established in several global epilepsy research consortia, whilst recognising that EpiCC is fundamentally different. These principles include:

- Membership of EpiCC carries advantages for which some sacrifices of autonomy are considered to be a reasonable price – the collective benefits considerably outweighing the individual restrictions.
- The principle of “no surprises” extending to all analyses, poster and oral presentations, manuscripts and other tools of the trade. In the context of EpiCC, this equates to the dissemination and promotion of best practice and due recognition of its source, but also to free use of material (in the spirit of Creative Commons).
- Amongst other advantages, benefits of EpiCC approach are expected to include the strengthening and improving of preliminary ideas via discussion with experts in epilepsy, climate change and other fields, the possibility of attracting resources in support of proposed projects, access to larger data sets, better analytical tools, and sharing of complementary skills.

I AGREE:

- To consider participation in EpiCC activity, subject to constraints or limitations that I can impose in each case.
- To openly declare conflicts of interests that will arise during the participation in EpiCC.
- To try and solve any conflicts in EpiCC jointly and peacefully. If a joint decision cannot be reached, the decision of the group as a whole (one member, one vote) is binding.
- To abide by this MOU.
- That failure to uphold this agreement may result in my expulsion from the EpiCC.

Signature

Date

Please print name
