

Curing Coma Campaign Administrative Policies

1. Mission Statement

The Curing Coma Campaign (CCC) was developed by the Neurocritical Care Society (NCS) with the goal of improving the lives of patients with Disorders of Consciousness (DoC) and coma resulting from severe acute neurological conditions. The plan is to accomplish this by advancing the science of coma and DoC through new research endeavors and advancing the clinical care of patients through education and outreach. This is recognized as a “grand challenge” that will bring together many collaborators across these domains and will only succeed if there is open and enthusiastic cooperation in research, education, and outreach endeavors. It is the stated principles of the CCC that aspects that derive from the work done collaboratively be available for open use by CCC participants, be recognized as collective work of the CCC, and that CCC participants receive appropriate credit for their work and participation. It is anticipated that aspects may potentially arise in several different domains including research data, publications, educational or other outreach product development, and intellectual property from inventions. Each CCC participant is expected to abide by the principles in this Policy document as allowable based on restrictions from their primary employer (most often a university).

2. Roles and Responsibilities

Many individuals are involved in the CCC in a variety of different roles. Each specific role has unique duties, obligations and responsibilities. This includes members who serve on the CCC scientific steering committee, scientific advisory committee and working groups, CCC modules, and sites and individuals who enroll patients in research studies and registries. This Policy document is intended to apply uniformly across all participants. The specific governance structure of the CCC is described below.

- a. CCC Project Executive Committee (the “CCC-EC”).** The CCC-EC (also known as Mission Control) will have a minimum of six (6) members, is responsible for overall direction of the CCC and is the final arbitrator for decisions and dispute resolution for CCC issues.
- b. CCC Project Scientific Steering Committee (the “CCC-SSC”).** The CCC-SSC consists of all of the members of the CCC-EC plus a minimum of six (6) additional members. The CCC-EC has the power to make any changes to the size, membership and duties of the CCC-SSC. Members of the CCC-SSC are responsible for the overall scientific direction and strategy for the CCC.
- c. CCC Project Scientific Advisory Committee (the “CCC-SAC”).** The CCC-SAC consists of all members of the CCC-SSC as well as additional members convened at the initiation of the CCC (Vancouver 2019 NCS meeting) and added as necessary. Members of the CCC-SAC are responsible for attending periodic calls and meetings of the entire CCC-SAC to review status, re-assess research, and help frame the long-range scientific agenda of the CCC. Specific scientific working groups will be developed out of the CCC-SAC and will include members beyond the CCC-SAC as needed to accomplish the mission of the CCC.

- d. CCC Project Modules.** The CCC includes distinct operational modules (eight (8) at the initiation of the CCC), each having a specific focus related to execution of the various aspects of the mission of the CCC. Each Module has two co-leads who are responsible for ensuring active participation of Module members and completion of Module responsibilities as defined in the CCC Manual of Procedures. Each Module should include a minimum of five (5) members including co-leads.
- e. Member Sites.** Individual institutions may contribute to the CCC through studies that involve submission of data at the individual patient-level, provider-level, or overall institution. Each Participant Site will have a designated Principal Investigator (PI) who will be responsible for coordinating CCC research activities at that institution.
- f. CCC Project Collaborator (“Collaborator”).** Individuals may participate in the mission of the CCC in a variety of ways that may include membership in the above noted committees, as a member of a scientific working group or module, or as a member site for the CCC to contribute research data or participate in educational or outreach activities. Every individual participant who contributes to a CCC Project, and/or CCC Project work products, is deemed a Collaborator.
 - i. In addition to their other roles and obligations, each Collaborator agrees that as a participant in the CCC, the Collaborator will be open with ideas and will share results of their individual research efforts related to coma with the various CCC Committees, including: data, conclusions, intellectual property conceived, and publications.