International Progressive MS Alliance

People Affected by Progressive MS Engagement Coordination Team

**Terms of Reference**

Updated 12 February 2020

**Purpose:**

The People Affected by Progressive MS Engagement Coordination Team (ECT) convenes people affected by progressive MS and other stakeholders to provide perspectives, leadership, and recommendations regarding applying the MULTI-ACT Patient Engagement Guidelines to the research agenda of the International Progressive MS Alliance (the Alliance).

The Coordination Team will be formed to accomplish two objectives:

* Evaluate the current Alliance efforts to engage people affected by MS
* Develop recommendations for applying the MULTI-ACT patient engagement framework to increase the impact of the Alliance research agenda
  + Design and put in place a plan to engage people affected by progressive MS in the Alliance research agenda (based on the selected priority)
  + Consistently monitor and review performance and engagement

**Reporting to:**

The People Affected by Progressive MS ECT reports to the Executive Committee through the ECT Co-Chairs on a quarterly basis or when otherwise required. Input may be solicited from the Industry Forum, Scientific Steering Committee and other patient engagement initiatives. The Scientific Steering Committee provides scientific oversight and feedback to this committee and facilitates final recommendations to the Executive Committee.

**Authority:**

The ECT is the body responsible for developing and making key recommendations. The Scientific Steering Committee will be consulted for feedback. Final materials, recommendations, and resources will be approved by the Executive Committee. Decisions and recommendations will demonstrate a commitment to engaging people affected by progressive MS, specifically to enable science with and of patient input.

The Executive Committee will evaluatethe “GO/NO GO”, renewal and implementation of 2nd phase of the MOU, which may be renewed for 3 years.

**Composition:**

**Members:**

* Co-Chair, person living with progressive MS (1)
* Co-Chair, MULTI-ACT leader with trained to provide “MULTI-Act training®” focused on capturing experiential knowledge (1)
* Scientific Steering Committee representative (1)\*
* Industry Forum representative (1)\*
* People living with or affected by Progressive MS (with a gender, geographical, and language balance) (7)
* Scientific Staff leaders – MULTI-ACT (1) and Alliance (1)\*
* Alliance Staff Leader (1)

\*Members should have expertise in priority topic(s): e.g. Implementation Planning Team Co-Chair/team member (e.g. Enhancing Wellbeing Implementation Planning Team member)

**Competencies of ECT Members:**

* Good understanding of the general state of science in MS and the confidence to ask for clarification if necessary along with a sound understanding of the principles of high-quality research and ethics
* Willingness to think broadly about MS and consider the questions and priorities that are most important to the diverse range of people affected by progressive MS, including the drug development process
* Confidence to voice opinions and actively participate in discussions with health professionals and scientists
* Ability to listen, understand and respect differing opinions, demonstrate empathy and active listening compassion
* Communication skills, motivator and coaching abilities
* Experience taking an active role in decision-making in panel or committee meetings (including teleconferences)
* Supportive of the Alliance policies, culture and values.
* Expertise in patient engagement strategies & methods (online and offline)
* Fluent in English (meetings and documents are all in English)

The ECT should be trained on how to gather people affected by progressive MS’ stories and information and translate them into Experiential Knowledge useful in the context of Research & Innovation (R&I) (mission/selected Alliance’s prioriy). MULTI-ACT is developing a training module (**MULTI-ACT Training module®**) that will serve for the scope.

**Terms of Office:**

All standing members will serve a 1-year term. Terms of non-staff delegates are renewable to a maximum of 3 terms, unless an extension is determined by the Executive Committee, and as long as the requirements for membership are fulfilled. Staff delegates may serve as long as the requirements for membership are fulfilled by their organisation.

**Scope and Mandate:**

The Coordination Team shall:

* **Advise** onthe current patient engagement strategies of the Alliance (baseline assessment)
* **Define** areas where patient engagement is instrumental to the Alliance mission and develop the **P**eople Affected by Progressive MS **E**ngagement Plan (PE Plan) for the identified Alliance priority, focusing on the 7 steps of the R&I path
* **Coordinate** the implementation of the PE Plan and constantly **monitor** the performance and return on engagement (RoE), assuring the sustainability of the plan, monitoring risks and proposing mitigation actions
* **Engage** the community of people affected by progressive MS to ensure representativeness
* **Exchange** clear information among people affected by progressive MS and other team members to ensure shared understanding of processes, expectations, experiences and research findings
* **Motivate** people affected by progressive MS to stay engaged along the development of the PE Plan and assure that they “feel valued” by facilitating team interaction and setting up an inclusive research environment
* **Mitigate** challenges such as ethical conflicts in research design, tokenism, power struggles, difficulties in engaging different people affected by progressive MS, additional time, cost
* **Moderate** the dialogue between interdisciplinary and different (and sometimes competing) voices and experiences and settle a dispute resolution system
* **Direct** the people affected by MS’s experiential knowledge so that it is transformed into outcomes that matter to people affected by progressive MS and are “scientifically” validated
* **Inform** patient engagement strategies in future Alliance initiatives and research
* **Collaborate** and **provide feedback** on the MULTI-ACT framework for multi-stakeholder health research initiatives, including on tools and resources
* **Provide feedback** to the Industry Forum, Scientific Steering Committee and Executive Committee on additional initiatives involving regulators and other patient engagement groups
* **Draft** principles, policies, and processes needed to measure impact of research and treatments on patients
* **Facilitate** the rollout, publishing and adoption of the Alliance patient engagement principles to key stakeholders
* **Provide** counsel as requested by the Executive Committee

**Meetings:**

Meetings of the ECT, either by phone or videoconference will be held at least 4 times a year and may be held more frequently at the discretion of the Co-Chairs. The ECT will convene in-person as a stand alone meeting or in connection with the Annual scientific meetings of the Alliance at least once a year. The Co-Chairs will ensure that a draft agenda for each meeting and the required documentation is circulated one week prior to teleconferences and two weeks prior to in-person meetings.

**Quorum and Voting:**

* Consensus agreement is desired for all committee decisions and recommendations, meaning that all opinions are heard and understood and a decision has the full support of the group. Members have a commitment to the group decision above self interests. If consensus is not satisfactorily reached, voting may be used as a last resort.
* A simple majority of members of the ECT shall constitute a quorum for the transaction of business.
* Unanimous agreement is desired, however, decisions may be made by majority vote.

**Support and Resources:**

* Convening and other administrative support for the ECT shall be provided by the Sr. Specialist, Progressive MS Alliance and National MS Society - US. There will be a summary of meetings.
* MULTI-ACT staff with competencies and capacity to serve as Co-Chair of the ECT and related activities for phase 1 (i.e. design the PE Plan). MULTI-ACT will provide person months staff leadership for the presentation of the Patient Engagement guidelines
* Alliance pays travel and expenses of committee members to attend in-person meetings and expenses of convening activities to bring together key stakeholders (other patient engagement initiatives, industry)

Acronyms:

ECT – Engagement Coordination Team

RoE – Return of Engagement

R&I – Research and Innovation, including 7 steps on path

PE - **P**eople Affected by Progressive MS **E**ngagement Plan

[MULTI-ACT Guidelines](https://www.dropbox.com/s/1nhmhtgs49kdaxm/Multi-Act%20guidelines.pdf?dl=0)