**CONSUMERS’ EXECUTIVE REPORT TO THE STEERING GROUP**

**Document prepared by:** Liz Whamond, Co-Chair, Cochrane Consumer Network (CCNet)

**Submitted to the Steering Group:** September 13, 2012

**Purpose:** To update the Steering Group on activities of the Consumers’ Executive

**Urgency:** Low

**Access:** Open

**Work of the Consumer Network:** The Consumer’s Executive continues to meet monthly via teleconference call to discuss issues pertinent to consumers and deal with policy issues. It is the Consumer Coordinator’s responsibility to implement policy once developed.

We continue to engage our Geographic Advisory Group in helping us establish policy. A long term goal is to have one representative from each of the Cochrane Centres from around the world as members of this group. Needed is a policy on roles and responsibilities of the Geographic Advisory Group and will be next on our agenda.

Several policy papers are in various stages of development. The CCNET governance document has been finalized, a policy with respect to speaking on behalf of CCNet has been developed and another policy with respect to strategies for supporting and strengthening non-English language consumer’s participation in the Cochrane Collaboration is ready to circulate to our Geographic Advisory Group.

The Plain Language Expectations for Authors of Cochrane Summaries (PLEACS – pronounced Pleeks) working group led by Catherine McIlwain have developed a draft set of standards that have been approved by the MECIR team. Those standards have been circulated for comment by internal and external stakeholders and comments are currently under review. The PLEACS team will meet by teleconference in October 2012 to discuss the feedback and finalize their recommendations for the standards.

CCNet has created a new checklist for consumer referees that has been reviewed and approved by the ERC. This checklist has been circulated to several CRGs who will begin piloting the checklist this year. Gill Gyte has led the creation of a guidance document which will accompany the checklist to education new consumers on the expectations of consumer referees.

Catherine McIlwain, Gill Gyte and Silvana Simi, in addition to several CCNet members from the European Union, have been engaged in the work of the European Communication on Research Awareness Needs (ECRAN) project. This project achieves several of CCNet’s objectives, and consumers will be involved at each point through the guidance of the Consumer Co-ordinator. The work includes an inventory and assessment of existing clinical trial educational materials for patients and the creation of a multilingual website containing a searchable database with these tools. The project has allocated funds to CCNet which will be managed by the Consumer Co-ordinator (under the responsibility of David Tovey) to ensure consumer contribution to the work packages.

Catherine’s employment contract has been extended for three years. The Consumer Coordinator position is essential to the progress of the Consumer Network, and we are grateful to Catherine for her work in advancing the consumer agenda and to those who granted final approval on the renewal.

Social media outreach has been successful in both recruiting and engaging consumers in CCNet. Catherine McIlwain’s work remains pivotal to this outreach.

CCNet Info continues to be prepared by Gill Gyte and is being distributed monthly to consumers to keep them up-to-date on activities. A quarterly newsletter is produced and distributed by the Consumer Co-ordinator.

Respectfully submitted,

Liz Whamond

**Recommendations:** None

**Resource implementations:** None