



Core Outcome Measures in Effectiveness Trials (COMET) Initiative

People and Patient Participation, Involvement and Engagement (PoPPIE) Working Group – Terms of Reference

1. Remit

1.1 The COMET People and Patient Participation, Involvement and Engagement (PoPPIE) working group's role is to lead and oversee the public participation, involvement and engagement work of the COMET Initiative, as set out in the COMET Public Involvement Strategy (http://www.comet-initiative.org/assets/downloads/COMET%20Public%20Involvement%20strategy_website.pdf). In line with the agreed priorities of the working group, the group will also contribute to the development of patient and public involvement, engagement and participation resources and research articles, posters and presentations (as set out in the COMET PPI action plan). The strategy was developed as a direct result of the contributions at the COMET Involving People event in March 2014. This was a collaborative meeting between UK-based public involvement organisations, core outcome set developers and the COMET Initiative. Additional contributions to the action plan were provided by core outcome set developers at a COMET meeting in Bristol in June 2014. The COMET public involvement vision is "to facilitate the optimal involvement of patients, parents, carers and members of the public as key stakeholders in the development of core outcome sets". The COMET public involvement objectives are:

1. To raise the awareness of the need to develop core outcome sets and the work of the COMET Initiative amongst public involvement organisations and patient organisations eg. patient charities / support groups
2. To be a central 'one-stop' information hub for guidance and resources to facilitate the involvement of patients in COS development
3. To produce resources for COS developers to assist them in planning for public involvement in both the design and conduct of core outcome set studies
4. To produce resources for patients interested in finding out more about core outcome sets and the COMET Initiative
5. To work with other groups to identify opportunities for developing core outcome sets with public involvement
6. To embed public involvement in the activities of the COMET Initiative
7. To collate examples of the impact of public involvement on core outcome sets
8. To work with others to further research into how to optimise patient involvement in COS development.

1.2 The aim of the PoPPIE working group is to work with the COMET Patient and Public Involvement (PPI) co-ordinator, in developing and implementing annual work plans based upon agreed areas of priority (informed

by the initial public involvement strategy and working towards the objectives outlined above) for the COMET Initiative and to monitor progress against the work plans. An initial task of the COMET PoPPIE working group each year will be to prioritise areas of work. The anticipated priorities for each year will be discussed by the COMET Management Group and key areas of work agreed. Minutes of the meetings will be sent to the COMET Management Group and any actions requiring specific guidance from the Management Group will be raised by the PPI co-ordinator with the Chair of the COMET Management Group in advance of their meetings.

2. Membership

- 2.1 The working group will be co-chaired by a public member and a professional member.
- 2.2 Membership will include the COMET PPI Coordinator, a core outcome set developer with experience of public involvement, two patients with experience of being involved in a core outcome set, a representative from a patient association, two representatives from two public involvement organisations and a researcher with an interest in methods for patient engagement'
- 2.3 The working group may invite other people to attend the group to address specific issues as required.
- 2.4 Membership will be for one year in the first instance.

3. Frequency of meetings

- 3.1 The meetings will be via teleconference with one face to face meeting. Meetings will be held three times / year.
- 3.2 Each meeting will last a maximum of 2 hours.
- 3.3 There is an expectation that most work will be undertaken by working group members between meetings by email or teleconference.

4. Attendance at meetings

- 4.1 Active attendance at, and between, meetings will be required from all group members

5. Reporting

- 5.1 The working group will report to the COMET Initiative Management Group.

6. Quorum

For a meeting to be quorate at least three members (including one public member) and the PPI co-ordinator must be present (in person or telephone / Skype). Meetings can go ahead if they are not quorate but major decisions cannot be made.

7. Responsibilities of members and recognition of contribution

- 7.1 To take an active role in the development and delivery of the COMET PoPPIE Strategy and work plan and deliver specific pieces of work to support and promote public participation involvement and engagement in the development of core outcome sets
- 7.2 To attend meetings three times / year
- 7.3 To read any background papers before meetings take place and comment / contribute to papers and reports between meetings
- 7.4 To actively contribute to specific task and finish projects agreed by the COMET Management Group
- 7.5 To listen to the views of other stakeholders within the working group and respect their views in line with the INVOLVE Standards for Involvement.
- 7.6 Members of the working group will be listed on the COMET website.
- 7.7 Outputs (such as articles, poster presentations, oral presentations and resources) developed by the group will acknowledge the contribution of PoPPIE members involved in producing the outputs.

8. Revising the terms of reference

Terms of reference will be subject to an annual review (or earlier as required).