

Crohn's and Colitis Canada's Promoting Access and Care Through Centres of Excellence (PACE) Terms of Reference

1. Purpose

The PACE Steering Committee's role and responsibility is to govern the operations of the PACE program, making recommendations and providing input on scientific and research-related matters relevant to the PACE program's goals of improving the quality of life of patients with IBD through integration of excellence in patient care and research.

The Oversight Committee will be responsible for the governance of the activities of the PACE program, guiding the overall strategy for PACE as a quality improvement initiative and providing budgetary oversight based on Crohn's and Colitis Canada's (CCC) mandate and the PACE program's goals of improving the quality of life of patients with IBD through integration of excellence in patient care and research. The Oversight Committee will be comprised of some members of the PACE Steering Committee and qualified external advisors.

2. Membership

PACE Steering Committee

The PACE Steering Committee will be comprised of the Lead Principal Investigator (PI), other Centres of Excellence PIs, CCC President & CEO, CCC VP, Research & Patient Programs and the CCC PACE Program Manager. If required, a policy maker with expertise in inflammatory bowel disease and or quality improvement in healthcare will be added to the PACE Steering Committee. The Lead PI, or a designate, will act as the Chair of the PACE Steering Committee.

Oversight Committee

The Oversight Committee will be comprised of CCC President & CEO, CCC VP, Research & Patient Programs, Chair of the CCC Scientific Medical Advisory Council (SMAC), or a SMAC designate, the Lead PI, two external advisors based on expertise with no conflict with the PACE program, one IBD Nurse, and one informed IBD patient. The CCC President & CEO, or a CCC designate, will act as the Chair of the Oversight Committee.

The Lead PI and the CCC PACE Program Manager will be the liaisons between the PACE Steering Committee and the Oversight Committee.

The PIs and CCC representatives will be asked to serve for the entirety of the PACE program. The external advisors will be asked to serve terms lasting up to three years.

3. Roles

PACE Steering Committee

The PACE Steering Committee will govern the progress of the PACE program, make recommendations and provide input on scientific and research-related matters relevant to the PACE program's goals. Members will guide decisions on:

- a. Research protocols and amendments with respect to the main project initiative
- b. Project planning for effective and measurable impact on improving the quality of life of patients in Canada
- c. Research proposals for new PACE initiatives
- d. Research outputs and quality of life impact reported by the PACE sites
- e. Qualified individuals to assist with PACE program activities (peer review, grant capture, etc.).
- f. The development of protocols measuring outcomes, deliverables and outputs
- g. Progress reports provided annually for each of the PACE projects

Oversight Committee

The Oversight Committee will govern the overall strategy for the PACE program and provide budgetary oversight. Members will guide decisions on:

- a. Budgets and financial reports
- b. Securing future funding sources and partnerships
- c. Review of progress reports and achievement of deliverables
- d. Research proposals for new or expanding PACE initiatives
- e. Research outputs and quality of life impact reported by the PACE sites

If either of the committees are making a decision regarding a specific PACE site's activities, milestones or budget, the Lead(s) for that site will be able to provide input but will not have decision-making authority. If the Oversight Committee believes they do not have the expertise to provide informed feedback, additional experts will be invited to participate in the peer review process.

4. Responsibilities

- a. Attend meetings on a regular basis and prepare in advance of meeting
- b. Share knowledge and experience
- c. Treat PACE program and the committee matters confidentially
- d. Notify the committee Chairs when conflicts of interest arise

5. Time Requirement and Meeting Procedures

- a. The PACE Steering Committee meetings will be held at least four times a year either in-person or via teleconference. Where possible, in-person meetings will be scheduled to coincide with national and international meetings.
- b. The Oversight Committee meetings will be held at least two times per year, coinciding with the payment schedule of the PACE program, either in-person or via teleconference; the PACE Steering Committee members should be present during at least one of these meetings. Where possible, in-person meetings will be scheduled to coincide with national and international meetings.
- c. Committee members may be consulted at other times throughout the duration of the project as needed to provide timely advice on research activities and outputs.
- d. Meetings will be led by the committee Chairs, or a designate, and supported by the Lead PI, VP, Research & Patient Programs, and the PACE Program Manager.
- e. Other guests will be in attendance at the meetings, as needed and appropriate.

6. Compensation

- a. All members will serve in a volunteer capacity.
- b. Travel and other eligible costs incurred specifically for activities related to the committees will be paid through PACE funding held at CCC, according to its expense reimbursement policy.

7. Revision

The terms of reference shall be reviewed at the end of the term served by the external advisors by the CCC President & CEO, CCC VP, Research & Patient Programs, and by the Lead PI.

The members of the Steering Committee and Oversight Committee will be invited to nominate external advisors. The Steering Committee will vote on the list of nominated external advisors and provide a ranked list. The Oversight Committee will review the proposed list and select the final nominees. The external advisors should have scientific and research expertise in gastroenterology and or quality improvement in the Canadian healthcare system.

8. Conflict of Interest

Crohn's and Colitis Canada must make every effort to ensure, not only that its decisions are fair and objective, but also that they are seen to be so. Therefore, individual committee members should avoid any actions that might give the appearance that a conflict of interest exists or could reasonably be viewed as affecting the committee member's objectivity. The following guidelines should be considered when selecting external advisors for the Oversight Committee: a) the individual should not be currently

affiliated with a designated PACE centre; b) the individual should not serve on a standing committee with any of the current PACE site leads; c) the individual should not have collaborated on a research project (i.e. research publication co-authorship) with a PACE site lead within the past 5 years.

Appendix A: Committee Members Jan 31, 2019

PACE Steering Committee Members

Ms. Mina Mawani, Dr. Kate Lee, Dr. Geoffrey Nguyen, Dr. Cynthia Seow, Dr. Remo Panaccione, Dr. Karen Kroeker, Dr. Alain Bitton, Dr. Waqqas Afif, Dr. Neeraj Narula, Dr. John Marshall, Ms. Katy Devitt

Oversight Committee Members

Ms. Mina Mawani, Dr. Kate Lee, Dr. Eric Benchimol, Dr. Geoffrey Nguyen, Ms. Barbara Currie, Dr. Naazish Bashir, Dr. Gil Melmed, Dr. Lawrence Hookey