

OCAP: Original Cohort Advisory Panel

Terms of reference

1. Aims & Objectives

1.1 Main aims:

- To represent the cohort of original study children
- To review study documentation and provide feedback to CO90s staff
- To represent and convey participants' opinions about planned research exercises

2. Membership

Members are recruited from the wider CO90s cohort of original study children.

2.1 Initial Membership

The first OCAP members were recruited in June 2006.

2.2 Future Membership

Since 2006, there have been three recruitment and re-enrolment exercises for OCAP, the most recent of which was September 2014.

2.3 Length of Membership

Membership is indefinite; re-enrolment occurs annually.

3. Procedures

3.1 Meetings

OCAP meet roughly six times a year to discuss items from a pre-arranged agenda. The panel and the CO90s participation team often need to communicate outside of meetings and members are consulted remotely via email, Facebook and Bristol Online Surveys (BOS). Involvement in OCAP is voluntary and members are not paid to sit on the panel. CO90s provides taxis or reimburses local travel expenses and provides refreshments at meetings.

3.2 Decision Making

Decisions are made after group consultation and discussion and every effort is made to include all OCAP members even if they are not physically present, e.g. they contribute via Skype or email.

3.3 Sub Committees/Focus Groups

There are occasional opportunities for OCAP members outside meetings e.g. to speak at a conference. Separate focus groups may take place for studies where only a subset of participants will be invited (eg. males only).

3.4 Reporting

The minute taker takes minutes during meetings and these are circulated to the Senior Management Team (SMT) and OCAP members. The participation team represents the voice of OCAP and the cohort at internal meetings. Where necessary, reports of OCAP decisions are made from the minutes and

presented to relevant parties eg. staff, researchers, funding bodies and ethics committees.

3.5 Feedback

At the start of each meeting, OCAP members receive updates on items discussed in the previous meeting so they know how their feedback has been actioned.

4. Roles

All OCAP members are eligible to be on the committee and it is anticipated that they will be in post for a minimum of one year, unless they request to stand down.

4.1 Chair(s)

(See OCAP Committee Role Description: Chair)

Two OCAP members currently share the role of chair. The chair(s) ensure that meetings progress according to the agenda and that all members have an opportunity to share their views.

4.2 Minute Taker

(See OCAP Committee Role Description: Note Taker)

The minute taker works closely with the chairs and participation worker accurately to record the discussions and outcomes of OCAP meetings. They are also responsible for ensuring that the participation worker has prompt access to meeting minutes, to be reviewed prior to distribution.

4.3 OCAP Member

(See OCAP Member Role Description)

OCAP members attend meetings and/or contribute remotely. All original study children are eligible to join OCAP as long as they feel they are able to commit to OCAP in line with the OCAP member role description.

4.4 Participation Worker

The participation worker is the PPI (Participant and Public Involvement) lead for CO90s and supports/facilitates OCAP. They collate the agenda and support the chair(s) and minute taker. The participation worker uses knowledge of PPI best practice to ensure meaningful involvement from OCAP. They are also responsible for ensuring the most salient points of OCAP meetings are minuted accurately and for representing the voice of OCAP and study participants in CO90s meetings.

5. Operations

5.1 OCAP meeting etiquette:

- Notify the participation worker/committee member if you are running late for a meeting.
- Make it know to all present in a meeting if you have to leave early, or temporarily during the meeting to take a call etc.
- Respect the views of others.

5.2 Agenda

The agenda is set by the participation worker and Chief Operating Officer. Agenda items are prioritised according to time sensitivity. The proposed meeting agenda is submitted to SMT for approval at least two weeks before the OCAP meeting.

5.3 Minutes

The minutes are taken by the minute taker and distributed promptly after being reviewed by the participation worker and chairs. All meetings are audio recorded and saved to the OCAP folder in the CO90s R: drive.

5.4 Contact list and Attendance log

A contacts list for all panel members is maintained along with an attendance log. It is the responsibility of all OCAP members to ensure that their contact details are kept up to date and that, where OCAP members are aware of other members' contact information, information is not misused or divulged.