

## The European Prospective Investigation of Cancer (EPIC-Norfolk)

### Participant Advisory Panel (EPAP)

#### Study Background: Appendix 1.

**Purpose and Role:** The EPIC-Norfolk Study actively promotes greater participant involvement in our research with the aim of developing and conducting research of the highest quality. The EPIC (Norfolk) Participant Advisory Panel (EPAP) was formed in March 2010 and acts as a consultative forum to provide a participant perspective on how research is prioritised, planned, conducted, communicated and used. EPAP is seen as a *PARTNERSHIP* between EPIC researchers and participants.

EPAP is consulted on a variety of research areas including (but not exclusive to):

- Designing research questionnaires
- Writing lay summaries and participant opinion statements
- Reviewing participant-facing information
- Initiating and reviewing website updates
- Reviewing methods of results dissemination
- Input into EPIC future phase development
- Review of potential future projects
- Review of potential collaborative projects

**Panel Membership:** The panel consists of EPIC-Norfolk participants and members of the EPIC-Norfolk research team

I. **Recruiting EPAP members:** EPIC-Norfolk participants put themselves forward as volunteers in response to information provided through various methods described in (II.)

II. **Methods of promoting EPAP**

- EPIC-Norfolk website
- Participant communication
- Newsletters
- Posters
- Public presentations
- EPAP presence at public events

III. **Membership structure**

- Core participant membership 14 - 16 (max) EPIC-Norfolk participants
- EPIC-Norfolk Research Manager (Norwich)
- EPIC-Norfolk Research Manager (Cambridge)
- EPIC-Norfolk Head of Bioinformatics (Cambridge)
- EPIC-Norfolk Researchers (max 2)

IV. **Membership guidelines**

- Membership length- unlimited
- Voluntary and non-binding
- No minimum attendance restrictions
- Non-attendance at 4 consecutive meetings without apologies- member is withdrawn

V. **Designated EPAP officers**

- Panel co-ordinator (research team member)
- Meeting chair (elected)
- Note taker (elected)
- Website summary writer (elected)

## **VI. Additional meeting attendees**

- Principal Investigator(s)
- Invited speakers- invited by panel co-ordinator
- Attendance of individuals with an interest- requested through panel co-ordinator

## **EPAP Meetings:**

- I. Venue- Assembly House, Norwich
  - II. Number of meetings- four per year (Jan, April, July (AGM), Oct)
  - III. Days, dates and times- arranged annually in advance
  - IV. Meeting length- Max. 2 hours
  - V. Morning coffee and light sandwich lunch provided
  - VI. Panel member expenses- reimbursable
- VII. **Agenda items-** an agenda will be assembled by the panel co-ordinator and circulated to members in advance of the meeting. Items will be collated from multiple sources:
- Panel requests
  - EPIC-Norfolk participant feedback
  - EPIC-Norfolk Management Committee
  - Wider research teams
  - Collaborating researchers
- VIII. **Meeting notes-** note taker will compile the meeting notes and pass to chairperson for review prior to distribution. The panel co-ordinator will disseminate completed minutes to all panel members and the EPIC-Norfolk Principal Investigators. Panel members will approve the previous minutes at the start of each meeting and any matters arising from these will be discussed as an agenda point.
- IX. **Website summaries-** website summary writer will summarise the agreed meeting minutes for publication on the open access EPIC-Norfolk website (details below).

**Panel Review:** An Annual General Meeting (AGM) will be held in July of each year. The following items will be fixed open discussion AGM agenda points:

- Election of designated EPAP officers
- Annual review of TOR
- Future meetings- venue, days, dates, times, length and details
- Distribution of annual EPAP feedback forms
- Renewal of photography permissions
- Future speaker / attendance requests
- Future agenda points

**Accountability:** The panel co-ordinator will act as the link between the panel and the wider research group. EPAP activity is reported as a regular agenda point at the EPIC-Norfolk Management Committee meetings and the study Principal Investigators also receive a copy of the meeting minutes. The work of EPAP is regularly reported to governance bodies and a summary is included on ethics applications and on research reports.

**Sharing of information and resources (including confidential materials):** Information is disseminated to panel members by the panel co-ordinator using appropriate methods e.g. email or letter.

Permission will be sought on an annual basis for the public use of photographs, named statements etc. Identifiable information will not be disclosed publically unless individual permission has been granted.

The EPIC-Norfolk website committee is responsible for maintaining the main EPIC-Norfolk website [www.epic-norfolk.org.uk](http://www.epic-norfolk.org.uk) where open public access can be gained to the **EPIC Participant Advisory Panel** page. This page contains the contact details of the panel co-ordinator, the EPIC vision statement for participant involvement, past meeting summaries and photographs of panel activities.