MASTERPLANS Committees – Information for Patient Collaborators

The purpose of this document is to provide information for patient collaborators, to assist in matching people to committees. The document summarises the main areas of responsibility of each committee; then further details are provided about what would be involved in each of the committees in turn. Finally, the 'person specification' for committee roles in general is provided.

Is being a committee member for you?

Being a committee member can be a very rewarding experience and it provides a great opportunity the views of patients to help shape the direction of MASTERPLANS. The project values the input of patient collaborators into MASTERPLANS committees very highly, and there will be patient collaborators on many of the MASTERPLANS committees.

The first thing to think about is whether being a committee member is for you. You may have many calls on your time and may find that your lupus symptoms are very demanding to live with, so feel uncertain about taking on a detailed commitment to MASTERPLANS which has a regular deadline and no flexibility on timing. We hope that some of you may feel confident enough that you could take responsibility as a committee member. There will be other opportunities in MASTERPLANS with more flexibility, and there will be more information about these in a following email.

As we have stressed in the past, the work of the project is very time sensitive and deadlines must be met before the Medical Research Council (MRC) releases funding for each period, so we must ask that those who want to volunteer as committee members are realistically able to fulfil this commitment. The other thing to think about is that it will be helpful for committee members to be involved in some of the other patient collaborator activities of MASTERPLANS.

Overview of areas of responsibility of each committee

There are two places for patient collaborators on each of the following committees:

- **Project Steering Group** – This is the senior operational committee and is responsible for the **day to day operational managemen**t of the project.
- **Longevity Committee** – This committee is responsible **for ensuring the long term value of the project**, i.e. ensuring that MASTERPLANS results become useful in clinic and as a basis for further research into lupus.
- **Access Committee** – This committee is responsible for ensuring fair and transparent access to MASTERPLANS data and samples by other researchers.

- **Commercialisation and Knowledge Transfer Committee** – This committee is responsible for managing how MASTERPLANS results are commercialised, e.g. by developing biomarker kits for use in clinic. An important part of its role will be to manage all aspects of intellectual property (IP) within the project.

Further information – Project Steering Group

- 2x patient collaborators, to include PPI Chair;
- Meetings (one hour) by teleconference **every 4 – 6 weeks**, plus 1 – 2 hours' reading time before the meeting;
- Two face to face meetings per year;
- Responsible for day to day operational management of the project:
    - Reviewing progress, risks and issues and making any necessary adjustments to project operations;
    - Reviewing on-going patient recruitment;
    - Helping MASTERPLANS respond to any major changes in project direction.

Further information – Longevity Committee

- 2x patient collaborators;
- Meetings (one hour): **twice a year**, normally by teleconference, plus 1 – 2 hours' reading time before the meeting. Meetings could become more frequent towards the end of the project;
- First meeting could be in person in London or Manchester;
- Responsible for:
    - Designing follow-on clinical trial(s) / studies, particularly concerning patient-facing aspects;
    - Identifying relevant funding calls and seeking additional international collaborators;
    - Any other matters related to achieving long term value for the project.

Further information – Access Committee

- 2x patient collaborators;
- Meetings (one hour): **twice a year**, normally by teleconference, plus 1 – 2 hours' reading time before the meeting. Meetings could become more frequent towards the end of the project;
- First meeting could be in person in Manchester;
- Responsible for:
    - Developing rules and processes for access to patient data and samples;
    - Reading applications for access to data / samples and deciding whether this should be granted, and on what terms;

- Note: will involve reading and commenting on long documents.

Further information – Commercialisation and Knowledge Transfer Committee

- 2x patient collaborators;
- Meetings (one hour) as required, depending on when commercialisation opportunities arise within MASTERPLANS. One 'kick-off' meeting in the first year of the project; meetings could become more frequent towards the end of the project if commercialisation proceeds as expected. Meetings will normally be by teleconference, plus 1 – 2 hours' reading time before the meeting;
- First meeting could be in person in Manchester;
- Responsible for:
    - Developing procedures for maximising the potential, including commercialisation of the project's findings;
    - Taking a balanced view on partners' shares of intellectual property (IP) rights, and managing how each partner should benefit financially from any commercialisation.

Necessary skills / abilities

Committee members will have many of the following attributes:

Experience:

- Experience of living with lupus or caring for someone who has lupus (should have had the condition for more than 2 years);
- Experience of contributing effectively to medium to large meetings.

Skills/aptitudes:

- An interest in, and a willingness to learn more about, the work of a particular committee;
- Good collaboration and communication skills in listening and talking with others and learning from their experiences, and confidence in reflecting these views so that they can be taken into account by other committee members;
- Understanding the big picture rather than just focusing on own thoughts, and using sound judgement in arriving at decisions;
- Able to read formal papers and extract information and ideas relevant to patients;
- Good at problem solving and negotiating;
- Reliable (particularly regarding attendance), good at managing own time and keeping to deadlines;
- Good understanding of, and respect for, the need for confidentiality;

- Have an awareness of and commitment to equality and diversity, and a desire to help to reflect the wide variety of people affected by lupus, particularly from different ethnic groups.

Reward and recognition

Please also see the related document 'Reward and recognition' for information on payments and expenses for committee members.