

Opportunities for MASTERPLANS Patient Collaborators

Patients can get involved in MASTERPLANS as

A Participants in the MASTERPLANS clinical studies and trials

Or B Collaborators in aspects of the research

Or in both ways

Participants:

Participants will be invited to enrol onto a clinical study or trial depending on their symptoms and medications. The studies and trials are looking at people with skin and/or kidney symptoms of Systemic Lupus. As the studies and trials are being conducted in a number of centres throughout the United Kingdom, most people will not need to travel a distance greater than their usual hospital. You would take part in the study/trial for one year.

If you are a MASTERPLANS patient collaborator, you will receive information when the MASTERPLANS studies/trials become open for recruitment.

Collaborators

Details of many opportunities for patient collaborators to contribute effectively to MASTERPLANS are listed below, with some idea of the level of intensity of work and skills/knowledge which would be helpful. Please read through the listing and consider where you feel your available time, skills and knowledge might be best used. Most of these activities will involve working collaboratively with others and require a willingness to listen, understand and communicate the experience of others with lupus.

WHAT OPPORTUNITIES ARE THERE?

We are looking for people to put across the perspective of the variety of lupus patients at the various **committees** involved in MASTERPLANS (see the list below). Committee members would need to prepare by reading the papers ahead of the meeting and then either attending in person or taking part by teleconference and speaking up where appropriate, with views of patients. We are also looking for **Team Members** and for **Team Leaders** to work on various aspects of the patient and public facing activities in this research project.

Some of you 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: others may feel more confident that they could take on a more demanding

role where they take responsibility as a **team leader (TL)** for a particular activity and can deliver to the agreed deadlines.

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) release funding, so we must ask that those who want to volunteer as team leaders are realistically able to fulfil this commitment.

WHAT'S INVOLVED IN THESE ROLES?

COMMITTEE MEMBERSHIP: *2 members for each committee*

See separate document inviting membership of MASTERPLANS committees.

NON-COMMITTEE activities

Communications projects team

Includes assisting with:

- Social media opportunities,
- MASTERPLANS website patient and public information area,
- Newsletters and posters,
- Information about the research results for patients and the public

Frequency – difficult to predict, but this would be fairly intense at some times, probably for several weeks on each project

Time commitment – we would like to have consistency of the team working on a particular project, so several hours per week per project could be expected

Venue – most work could be done from home, but we may want to explore team meetings either in a local venue or by teleconference

Necessary skills/abilities –

- Ability to grasp the key points of the research and their relevance to patients
- Clear writing style.
- Experience of working as a team,
- Computer skills,
- Design skills,
- Experience of communicating with a variety of audiences.

Outreach team

Help facilitate contact with people whose voices aren't easily heard within research.

Ideas about outreach to these groups and appropriate methods of contact:

- Look for opportunities to work with other agencies who may have better access to particular groups.
- Ensure that material is provided appropriately
- Plan for a good representation of lupus patients from the harder to reach groups to be involved as participants in the studies / trials.
- Willingness to organise events where necessary

Necessary skills/abilities –

- An understanding of equal opportunities,
- Good inter-personal skills,
- Ability to work innovatively

Time commitment – early involvement in the project is important to achieve this, probably 10 hours maximum.

Support/co-working - Contact with a number of organisations who have good relations with appropriate individuals and may offer advice to us and support where necessary.

Venue – preparation work on-line / at home, willingness to visit organisations and meet with people, good inter-personal skills.

Information resources for patient collaborators

Glossary – development and keeping up to date in consultation with others

Collect information from many sources which will help patient collaborators understand topics under consideration e.g. genetics, epigenetics, topical matters in research including ethics

Necessary skills/abilities –

- An interest in researching topics,
- Understanding of plain English
- An ability to write things in an appropriate style for patients and the public

Time commitment – responsibilities can be split to particular areas, important to work on this early in the project

Venue – can be done from home and via teleconference

Secretariat

Succinctly record discussions/ group meetings, facilitate patient and public newsletters if necessary to be circulated by post.

On occasions facilitate arrangements for patient group activities

Necessary skills/abilities –

- good computer skills,
- attention to detail,
- ability to summarise meetings and write well

Frequency – meetings would be two or three times a year

Venue – attendance at meetings is crucial, writing up and other work would be done at home

These plans may be adapted as appropriate to the project.

NB Some of these responsibilities could overlap, but will call upon *different* skills and qualities; hence team working will be crucial in all that we do.