

## Information for Members of Research Advisory Groups Supported by the McPin Foundation

Welcome! We are really pleased you've joined us. We use different terms to refer to the group you are a member of. These terms can include 'Lived Experience Advisory Panel (LEAP)' or 'Patient Advisory Group (PAG)'. In this document, we would like to provide you with some important information which you may find useful while you are a member of one of our groups.

We suggest that you keep this document safe in case you would like to refer to it at a later date.

### How McPin works with researchers and advisory groups

McPin aims to bring together people's experiences and apply these to the research studies that we work on. Often members of McPin staff are part of the research team for the studies we work with. We jointly hold conversations with people and researchers to mutually agree decisions on research studies. McPin continually advocates for the views of people with lived experience of mental health to be applied to research studies.



## Our responsibilities to people joining research advisory groups

After you choose to join an advisory group, a named McPin member of staff will:

- Let you know in advance where meetings will be held and at what time. We will always try to give you as much notice as possible. Meeting dates and times are usually arranged via email using an online meeting organising tool called Doodle.
- Provide you with copies of all the papers for each meeting by email. We can also provide you with paper copies if requested.
- Provide you with all the forms needed for claiming payment for attending meetings and any travel expenses. The staff member will also help you to fill out these forms if needed.
- Provide you with their details so you can contact them between meetings.
- Outline what activities you will be able to be involved in and examples of what you may be advising on as the research progresses.
- Listen to what activities you may like to be involved with and your suggestions.
- Keep your personal information and anything you discuss with us confidential. When providing group members with information about meetings or activities, we will always blind copy ('bcc') you into emails to protect your information, unless you have specifically consented to share your information with the rest of the group or the wider research team.
- Your named McPin contact will be able to discuss with you (in confidence) any reasonable adjustments or support you may need to be involved in research advisory group work.

McPin staff may also:

- Support you to take on any additional responsibilities available in groups.
- Discuss meeting agendas with you and other group members.
- Help to coordinate the production of study newsletters or news updates to keep members updated between meetings.
- Describe any potential opportunities to work on specific tasks outside of meetings, and help make arrangements for this, including offering you support.
- Provide you with the contact details of members of the research team.
- Discuss with you how the advisory group may like to communicate with one another outside of meetings, if appropriate.

Some of our other responsibilities to you are outlined throughout this information sheet.



## Responsibilities of all group members

We ask you to:

- Try to attend all group meetings. We understand that it is not always convenient (people take holidays, get ill, or have other commitments). If you cannot come, just let us know before the meeting. You are free to decide to withdraw from the group at any time. If you withdraw from a group, and wish to re-join the group later on, please do speak to the named McPin member of staff in confidence.
- Stay in contact with the McPin staff member who is leading the research advisory group. This is so that we can arrange meetings which work well for the group and share things like study documents with you.
- Claim your own travel expenses and meeting fee payments. We will give you support if needed but all claims must be signed by you, and receipts provided for the agreed expenses. We ask that claims be made within three months of meetings, but we encourage people to claim immediately after a session.
- Note that receiving payments often affects benefits. If you are in receipt of welfare benefits, you will need to declare any payments that you may receive to the Department of Work and Pensions (DWP) and your local council (if applicable). **If you have any concerns about how receiving payments for involvement work may affect your benefits, please do contact the named McPin member of staff in confidence. They can provide you with the contact details of organisations which can offer you further information and advice.**
- Be responsible for dealing with any tax issues that may arise from you receiving payments from The McPin Foundation.



## Payments and expenses

### Procedure for claiming payments and expenses from McPin

Where McPin offers payment for participating in a research advisory group, you will be paid via bank transfer following the completion of an invoice or hours claim form. We will provide you with a form so that you can claim payment after each meeting you attend.

Some group members may be offered or asked to do extra tasks between meetings. Where payment is offered for these tasks, a claim form will also be provided and the amount will be agreed in advance of you completing the task.

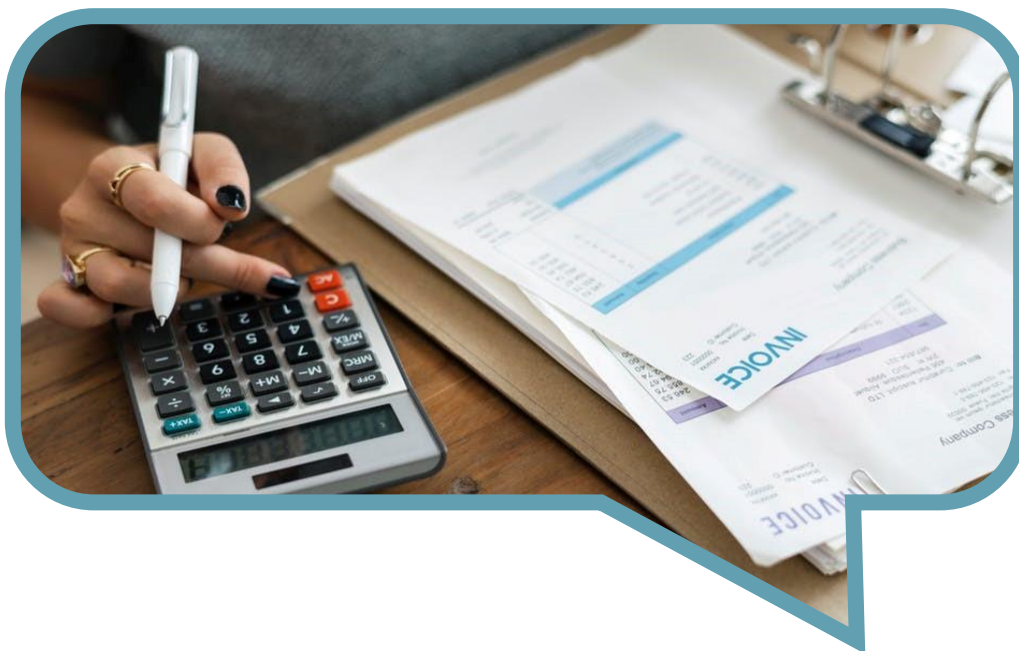
For some types of meetings and tasks, payments and/or expenses may not be offered. The McPin member of staff will always make this clear beforehand.

Agreed travel expenses can be claimed by filling out a McPin expenses claim form and attaching any receipts. Receipts are not required for mileage claims. As of June 2018, we reimburse mileage at a rate of 30p per mile. If receipts are not provided then payment is at the discretion of The McPin Foundation. We will make payment within 30 days of receiving a claim form.

*A copy of The McPin Foundation Expenses Policy is available on request.*

### Procedure for claiming expenses from another organisation

In some cases, payments and expenses are offered by another organisation which is funding the group, for example, a University or NHS Trust. In such cases, the McPin member of staff will provide you with the details of who to contact at the other organisation in order to claim payment and expenses.



## Conduct of meetings

When a group begins to meet, a McPin member of staff will be responsible for drawing up a set of 'ground rules' in collaboration with all group members and any other organisation staff who attend. These rules are intended to be helpful. They are intended to ensure that everyone is safe and able to contribute to meetings fully.

There are some rules that will be the same for people attending all groups, these are:

- Everybody should be respected.
- Nobody should use language that is likely to be offensive to others. Abusive language and verbal or non-verbal threats between members of groups at any time are not tolerated. This includes communications via email, phone, or social media with group members inside and outside of meetings.
- Everybody should have their say and everybody should be listened to. Please try not to interrupt or talk over others at meetings and help to facilitate the input of quieter members.
- Within a group, we offer each other support and challenge, but avoid judgements and personalising issues.
- If anyone reveals any personal information about themselves in meetings please keep this confidential.
- If you need to take a break at any time, please do so. If you are leaving a meeting and won't be returning, please let a member of McPin staff know.
- We welcome and encourage you to ask questions, no question is seen as a bad question.

These rules apply equally to everyone attending meetings, including members of staff. If anyone does not abide by these rules, and any others established for the specific group in which they are working, this may lead to them being asked to leave the group on a temporary or permanent basis.

We understand that for reasons such as illness, people may not be able to keep to the ground rules for each meeting. Such cases will be handled sensitively on a case by case basis by the McPin member of staff responsible for chairing or facilitating your group.



## Membership of groups

Most groups have members recruited at the beginning of the study and we attempt to keep membership constant throughout. However, at times it is important that new members can be recruited, or that people are able to leave the group if they wish. McPin welcomes members to discuss membership with us and suggest ideas to develop groups, including suggesting potential new members for recruitment. We really value the views of advisory group members.

Should rules not be followed that are set out in the Conduct of Meetings section, McPin reserves the right to ask members to leave the group on a temporary or permanent basis. This will always be a last resort and for a specific reason, that will have been discussed with the research project team including the Chief Investigator before a collective decision is made. Where this happens, a reason will always be discussed verbally first and then given in writing. We must stress this is a very rare occurrence and we do not expect to exclude anyone and will work hard to avoid this from happening. McPin will never ask members to leave groups based on their gender, sexuality, age or ethnic background.

Any decision to exclude a group member can be appealed by writing to the Research Director of McPin, Vanessa Pinfold, at the address below, setting out the grounds for your appeal. If you cannot put your appeal in writing you can contact the Research Director by phone (0207 922 7875). The Research Director will consider your appeal and carry out any further investigation which she deems necessary. Her decision on the matter will be final. The decision to exclude you will stand until your appeal has been decided or unless and until the Research Director decides otherwise.



## Suggestions

We welcome and value your suggestions and feedback on how we run and support groups. If you have any ideas or feedback, please do speak to the McPin member of staff supporting your group. You can also email: [contact@mcpin.org](mailto:contact@mcpin.org) or phone: **0207 922 7877**. We really value all your ideas and suggestions. We will always give a response to any suggestions that we receive.

## Complaints

McPin has a complaints procedure that can be accessed [here](#) or at [www.mcpin.org](http://www.mcpin.org). In the first instance, we encourage you to speak to a McPin member of staff to try and resolve the matter informally. If this is not possible, please contact a member of the research team (often a University employee) involved in the research advisory group.

## Keeping in contact with us

McPin produces an electronic newsletter and involvement bulletin. In these publications we include articles about our work, advertise jobs and involvement opportunities etc. To subscribe to these publications please visit: <http://mcpin.org/stay-in-touch-2/> or [www.mcpin.org](http://www.mcpin.org).

To contact McPin, you can either write, email, or phone us using the following details:



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