

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

Welcome!

Dear Advisory Group member,

You have been sent this information sheet because you are a member of a research advisory group with McPin. We are really pleased that you have joined us, and it is great that you want to get involved in our research.

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.

What are Research Advisory Groups

Research advisory groups are members of the public who are chosen to form panels or groups which use their lived experience to give opinions or advice on research studies. They provide a valuable mix of views that researchers alone may not have access to.

At McPin we use different terms to refer to the group you are a member of. These terms can include:

- Lived Experience Advisory Panel (LEAP)
- Service User Advisory Group (SUAG)
- Patient Advisory Group (PAG) or
- Young Person's Advisory Group (YPAG)

How McPin works with Researchers and Advisory Groups

McPin is a small mental health research charity which focuses on the most current and advanced issues in mental health research.

We encourage and involve people with lived experience of mental health conditions, by participation in our advisory groups and the assistance of our research. This research is conducted by McPin and qualified mental health researchers who are typically from institutions including government bodies, universities, charities, and other research organisations.

The McPin role is to link these institutions to advisory group members (like you), so that the views of people with lived experience of mental health can be used to inform research studies.

We facilitate, or offer a platform and environment, for conversations between advisory group members and researchers, to discuss, and ultimately agree on decisions made regarding research studies. These conversations can include meetings (face to face or online using Zoom), online feedback by email and telephone conversations.



Our Responsibilities to People Joining Research Advisory Groups

At McPin we are a team of people. After you choose to join an advisory group and throughout the study which you are involved with, you will usually have one or two main named contacts from our team.

The named McPin member of staff will:

Help with Schedules

- 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 schedule tool called [Doodle](#).

Provide You With all the Information You Need

- Provide you with copies of all the papers for each meeting by email. We will also provide you with paper copies of all the relevant documents in the meeting when they are held in person. For online meetings, you can request for paper copies to be sent to you in advance.
- Provide you with the forms you will need to complete, to claim payment for attending meetings and to claim back any travel expenses (See pages 4 to 5 for details about expenses). The staff member will help you to fill out these forms if needed.
- Provide you with contact details for the relevant McPin staff member so you can contact them between meetings.
- Outline what activities you may be involved in and examples of what you may be advising on as the research progresses.

Support Your Involvement in Groups

- Listen to what activities you may like to be involved with.
- Keep your personal information and anything you discuss with us confidential, and password protected. 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.
- The named McPin contact for the project 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 (see pages 6 to 7 regarding online meetings). For example, meeting you at the station before a meeting, accounting for dietary requirements, help with public speaking or participating in group discussions, help with using Zoom for online meetings.

McPin staff may also:

- Support you to take on any additional responsibilities available in groups. For example, writing the minutes for the meeting or leading an aspect of the meeting (if you wish).
- Discuss meeting agendas with you and other group members.
- Produce study newsletters or news updates to keep members informed about the research activities between meetings.
- Describe any potential opportunities to work on specific tasks relating to the project outside of meetings, and help make arrangements for this, including offering you support. *Please note that the selection of members for inclusion in specific activities, is at McPin's discretion; we try to make the selection of people to include as fair as possible, to make sure everyone has equal opportunities. This can, for example, mean drawing names out of a hat.*
- Provide you with the contact details of members of the research team.
- If appropriate, discuss with you how the advisory group may like to communicate with one another outside of meetings.

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.
- While you are a member of the research advisory group, 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.
- Take responsibility for claiming your meeting payments and travel expenses using invoices and claim forms provided by McPin. We will give you support if needed but all claims must be signed by you, and you also must provide receipts for the agreed expenses (see pages 4 to 5). We ask that claims be made within three months of meetings, but we encourage people to claim immediately after a session. Generally, we prefer people to book their own travel, unless it is a complicated, long distance or expensive journey or if you have a specific reason for us to book on your behalf.
- 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.
- Let us know if any of the information we have about you changes, such as your contact details.



Payments and Expenses

Procedure for claiming payment for meeting attendance 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. Please note that this form must be signed for us to process your payment. If you are submitting your form by email, please just type your name where a signature is required.

Claiming payment for extra tasks

Some group members may be offered extra tasks to do 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.

Claiming expenses for travel and food from McPin

For face-to-face meetings, agreed travel and meal expenses can be claimed by filling out a McPin expenses claim form and attaching any receipts.

Our expenses policy outlines the rules regarding claimable expenses and what evidence is required. You can request a copy of the full expenses policy if needed. Some key points from the expenses policy are:

- By car: Receipts are not required for mileage claims if travelling by car. As of June 2018, we reimburse mileage at a rate of 30p per mile.
- Bus travel outside London: please provide the ticket from your journey. If you require your ticket for the return journey, please ask a member of staff to take a picture or copy of the ticket before you leave.
- London bus/tube: For travel within London, we require details of your journey (the names of the stations that you travelled to/from and if it was peak/off-peak¹). If possible, we also request an oyster card/bank statement as proof of travel expense (ask a McPin member of staff if you require help with this).
- Taxis: Due to budgets, we do not typically allow expense claims for taxis. However, in certain circumstances (e.g. injury, planned travel disturbances) this may be allowed *with prior agreement from a McPin member of staff*.
- Trains: In the case of long-distance journeys and / or peak times, we prefer to book train travel in advance for you. This allows us to adhere to specific project budgets. We will contact you in advance of meetings to arrange this. If you do however wish to book your own travel, please let us know, and stick to off-peak, standard class tickets. If this is not possible, please discuss this with a member of McPin staff *before* you book your travel. If you require the ticket for the return journey, please ask a member of staff to take a picture or copy of the ticket before you leave.
- Food: When meetings are scheduled through lunch time (between 12:00pm and 2:00am), food will be provided. In special cases you can buy your own lunch and we will reimburse you, but please discuss this with us beforehand.

¹ Peak: Monday-Friday 6:30-9:30 and 16:00-19:00

Off-peak: all other times and if you travel from a station outside Zone 1 to a station in Zone 1 between 16:00 and 19:00, Monday to Friday

You may claim for meal expenses if you are required you to travel early in the morning or late in the evening. This is restricted to £5 before 7:00am and £15 after 8:00pm.

If receipts for food or any transport including taxis, are not provided, then payment is at the discretion of The McPin Foundation.

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.

We will make payment within **30 days** of receiving a claim form.

If you have any questions or need clarification on whether something may be claimed as an expense, please contact your named McPin member of staff. *A copy of The McPin Foundation Expenses Policy is also available on request.*

Procedure for claiming expenses from another organisation

In some cases, payments and expenses will be 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's 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.

Ground Rules and Tips for All Meetings

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

- Everyone in the room is equal.
- Respect one another.
- Avoid jargon, acronyms, or overly scientific language.
- When drawing from your own expertise and knowledge, whether that is talking academic research or lived experience, try to do so in a way that encourages constructive discussion without anyone being excluded from the conversation.
- Ask questions if you need to, no question is a silly question – if you are thinking it, someone else probably is too.
- Take as many breaks as you need to. If you are leaving, please let a member of staff know so that we're not worried.
- All sensitive information will remain confidential. No one is expected to disclose anything that they do not want to.

Ground Rules and Tips for Online Meetings

Due to the pandemic, Advisory Groups are in some cases being held online, using some online software called Zoom. Please have a look at the following [guidelines](#) for information about how to use Zoom.

We understand that there can be challenges with using Zoom online to hold our meetings. Some of our members may not have access to a computer, laptop or tablet. Some members may have a poor-quality or intermittent internet connection. Others may not feel comfortable working online in this way. If you do have any problems or concerns then please get in touch with your named McPin member of staff as soon as possible so that we can see what we can do to help.

You will need a working camera on your phone/tablet or computer in order to take part in online meetings. We have taken this approach to ensure that online meetings are a safe space for everybody

There are some specific ground rules for working online. In the meeting:

- Please accurately label yourself in the waiting room by your name (first name is fine).
- **Please keep your camera on.** We ask that you keep your camera on throughout the meeting, but we do understand that you may need to turn it off for short periods from time to time (for example, to answer your door, go to the toilet, etc).
- Be wary of background noise; please mute your microphone if not in use.
- Privacy: if you can, please either find a private space or wear headphones when in a call with us. This will help limit the chances of disturbance and distractions.

- Please do not record or take screenshots during the meeting. McPin staff may ask to record the meeting but this will always be optional, and any recording will be deleted after the notes have been written.
- Contribute in the way that you feel most comfortable. Use the 'chat' option to type responses if you would prefer. The chat will be saved so even if points don't get raised, they will still be accounted for.
- You can use the private chat function to message the chair of the meeting if you would like to raise a point to add to the notes or for them to bring into the discussion, or if you have any concerns.
- Please do not use the private chat feature to contact group members (other than staff). If you receive an unwanted private message from another group member, please contact the responsible McPin member of staff.
- You can use the raise your hand feature (or actually raise your hand) to speak/vote.

The McPin ground rules apply equally to everyone attending meetings, including members of staff. If anyone does not abide by these rules, or any other rules that have been established for the specific group in which they are working, we will talk to the individual and take action where necessary.

We understand that there may be reasons why people may not be able to keep to the ground rules all the time. 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.

If you need clarification on anything written in the ground rules, please contact your named McPin member of staff for help.



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 ground rules (see Conduct of Meeting section of this document) not be followed, 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, 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. We will work hard to avoid this from happening and do our upmost to protect group members. We will deal with everyone on a case-by-case basis, and you are protected under the Equality Act 2010 from any type of discrimination. 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.



Using your Lived Experience and Confidentiality

While you have applied for this position because you have specific lived experience that we would like you to reflect on, we recognise that this is sometimes a difficult thing to do. Your opinion, perspective and experience are valuable. However, we do not force you to directly discuss your personal experience if you do not wish to. You may prefer to discuss things from a broader perspective:

- “In my experience, people with mental health problems might...”
- “I think that people with mental health problems might prefer...”

Confidentiality is important for all members of the group – staff and group members included.

Discussions about personal experiences stay in the room. It is important not to assume that if something is disclosed in one circumstance that the individual is comfortable with that disclosure in another situation.

If we (as staff) use any information that has been discussed in a meeting when consulting with someone else (e.g. if we are asked about the feedback you have given on research) we will never personalise information or discuss anything identifiable. That means we will never use your name, age or any other information which could be used to identify you.

Please note that the only time when we would breach confidentiality is if any member of the group was thought to be at risk of harm to themselves or others. We maintain the right to look after both yours and others safety and in the first instance, we would take this to our safeguarding lead Clare Walsby.

We put your welfare and wishes first. We request an emergency contact person for each group member, and we would only contact them if there was ever a significant concern.



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 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. Please be aware that during the pandemic we are not always working in the office and there might be a delay in us responding to you.

Complaints

McPin has a complaints procedure that can be accessed [here](#) or at www.mcpin.org. In the first instance, we encourage you to speak to a McPin member of staff directly 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 once a month. 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.

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



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