

# MERC Patient Advisory Group Application Pack

Thank you for your interest in joining the Patient Advisory Group (PAG) to the UK ME Research Collaborative (MERC). Please read the role description, desirable skills and our Terms of Reference carefully before applying. We look forward to hearing from you.

Information about our online application form can be found at the end of this document in Appendix B.

## Role description

Membership is open to adults with ME/CFS and carers for people with ME/CFS, who share the PAG's values as laid out in its Terms of Reference (see Appendix A on page 3).

PAG are particularly interested in recruiting more members to represent the diverse patient voice as well as hearing from people with the skills and capacity to assist with the administrative activities of the group.

The PAG aims to support patient-centred biomedical research into ME/CFS and ancillary processes, by providing a direct patient voice, a voice that is as diverse and inclusive as possible, to advise the MERC and associated bodies and platforms. Recently the PAG has been involved in a wider range of initiatives and hence are looking to expand our number. The PAG's current main focus is on supporting the Department of Health and Social Care's Delivery Plan for ME/CFS. The PAG are Co-Chair and member of the Delivery Plan's Research Working Group and are a member of the Attitudes and Education Working Group. As Co-Chairs of the Research Working Group they sit on the Task and Finish Group.

In the past PAG has heavily involved in:

- UK Priority Setting Partnership for ME as a steering group member <https://www.psp-me.co.uk/>
- Securing funding for Decode ME with the CMRC (now MERC) <https://www.decodeme.org.uk/>
- Various CMRC (now MERC) working groups
- As a stakeholder in the NICE ME/CFS guideline review

The PAG is a flexible organisation and will evolve to support the needs of the research community.

Up to two representatives of the PAG sit on the MERC Board at any given time, and two representatives attend each MERC Board meeting.

Not being well enough to physically attend meetings is not a barrier to joining the PAG – all meetings PAG currently attend are virtual or hybrid.

We recognise the impact of the illness may affect ability to participate at times. However, we ask that at the time of application, you anticipate that you will be able to engage as fully as possible.

Although PAG aims to be inclusive, we recognise that people with severe ME/CFS are unlikely to be able to participate, so we welcome applications from people who have had direct experience of severe ME/CFS previously or as a primary carer.

We seek to have a balance of those who have recovered from ME/CFS, those who are mildly or moderately affected, those who are severely affected and carers. We also seek gender and age balance, bearing in mind the demographics of the disease. We aim to be as representative of the ME/CFS population as possible

Except for the severely affected, members should be prepared to devote several hours per week on PAG work during intensive periods of its activity each year, and in particular, in due course undertake their turn as Convenor or Assistant Convenor.

Members with at least six months' service will be expected to volunteer for monthly slots on the Convenor Team rota, subject to adequate health. All PAG members are welcome to sign up to the rota, throughout the year.

PAG members can choose to be anonymous and not have their name shared (in part or in full) on meeting minutes or other open-access documents. Any decision made regarding anonymity will be fully respected.

Full details regarding the PAG, including Purpose and Working Methods, plus more information about the commitment expected from members, can be found in the Terms of Reference in Appendix A. Please read these fully before deciding whether or not to apply.

PAG membership is a voluntary role and no reimbursement will be made for time and participation unless physical attendance at meetings is required where limited funding for expenses may be available although this cannot be guaranteed. PAG membership will not be higher than 20 members.

Applicants will be assessed on their ability to fulfil the person specification outlined below.

## Desirable skills

### Experience, knowledge, and interests

- Be aged 18 or over and based in the UK.
- Knowledge and understanding of concerns of ME/CFS patients and carers
- Have a keen interest in critical evaluation and being able to look at a situation as objectively as possible, respecting the rights of others to hold alternative viewpoints
- Have a keen interest in keeping broadly up to date with ongoing research into ME/CFS, in the UK and internationally.
- Hold experience in one or more of the following areas (preferred but not essential):
  - research
  - health care
  - science communication
  - sciences
  - statistics
  - education
  - ethics
  - charitable funding
  - work in voluntary committees
  - organizational or management skills
  - networking skills (whether with patient groups or researchers).

### Skills and behaviours, as health allows

- Able to devote time and energy to PAG discussions and statements
- Able to check email and our private online discussion platform on a regular basis
- Able to use basic software, e.g. email, online discussion platforms and video conferencing
- Able to participate in Zoom and Teams meetings (with camera off or by phone if necessary)
- Able to listen to, read and assimilate information and analyse evidence that is sometimes complex
- Ability to participate in discussions without having a pre-set agenda
- Able to demonstrate tact and discretion
- Able to uphold confidentiality by not sharing details of PAG discussions or PAG discussions with other bodies outside the PAG
- Willing to take a proactive approach to working with the MERC and other bodies
- Willing to answer questions put to the PAG by the MERC and other bodies
- Willing to seize opportunities to educate researchers and others about the lived experience(s) of those with ME/CFS. (This includes involvement with the Task and Finish group and Working Groups of the ME/CFS Delivery Plan announced by the Secretary of State for Health and Social Care in May 2022 and may extend to identifying potential practical issues for study participants, questions, gaps, or concerns about studies.)
- Willing to challenge and be challenged

Some of the PAG vacancies will, out of necessity, be reserved for those able to commit to assisting with the administrative running of the PAG.

# Appendix A: Patient Advisory Group (PAG) to the UK ME Research Collaborative (MERC)

Terms of Reference

Version 4 November 2022

## Purpose of the PAG

The PAG aims to support patient-centred biomedical research into ME/CFS and ancillary processes, by providing a direct patient voice, a voice that is as diverse and inclusive as possible, to advise the MERC and associated bodies and platforms (e.g. as co-chair of the UKCRC ME/CFS Research Working Group). The PAG is a flexible organisation and will evolve to support the needs of the research community.

Up to two representatives of the Patient Advisory Group sit on the MERC Board at any given time.

Our responsibility is to do our best for the greater good of all people with ME/CFS, by:

- educating ourselves about ongoing research into ME/CFS, in the UK and internationally;
- being as aware as possible of the concerns of ME/CFS patients and carers;
- devoting time and energy to PAG discussions and statements;
- answering questions put to us by and being proactive in working with the MERC;
- sending up to two representatives to each MERC Board meeting; and
- seizing opportunities to educate researchers and others generally about the lived experience(s) of those with ME/CFS. (This includes involvement with the Task and Finish group and Working Groups of the ME/CFS Delivery Plan announced by the Secretary of State for Health and Social Care in May 2022 and may extend to identifying potential practical issues for study participants, questions, gaps or concerns about studies.)

## Membership

Membership is open to adults with ME/CFS and carers for people with ME/CFS, who share the PAG's values. Members who hold office in other ME/CFS groups or bodies should declare this for the sake of transparency.

There is a maximum of 20 PAG members.

The PAG may from time to time invite new members to apply. We seek to have a balance of those who have recovered from ME/CFS, those who are mildly or moderately affected, those who are severely affected and carers. We also seek gender and age balance, bearing in mind the demographics of the disease. We aim to be as representative of the ME/CFS population as possible.

Except for the severely affected, members should be prepared to devote several hours per week on PAG work during intensive periods of its activity each year, and in particular, in due course undertaking their turn as Convenor or Assistant Convenor (see Offices). During their time of membership, we wish all

members to remain regularly involved (active): to check email and Slack on a regular basis, to participate, and if they cannot, to communicate this to other members as soon as possible. PAG members may, with the agreement of PAG, pause their membership and become inactive for short periods if circumstances require. PAG members who cease to engage with the group for a prolonged period without informing other members that they need to pause membership may be removed from the group at the discretion of the active PAG members (see PAG Decisions).

Members wishing to resign may do so by letter to the Chair of MERC and the rest of the PAG; Members who are unable to adhere to the Terms of Reference may be asked to resign.

PAG members have a term of office of 5 years after which they may reapply for membership under an agreed selection process.

## Offices

Members with at least six months' service will be expected to volunteer for monthly slots on the Convenor Team rota, subject to adequate health. All PAG members are welcome to sign up to the rota, throughout the year.

The Convenor and Convenor Team will seek to identify substantive and procedural matters requiring PAG decision or participation. The team will consult PAG members, organise the collation of individual views, and seek to facilitate consensus on these matters as appropriate (see PAG Decisions)

Each Convenor will normally hold office for one calendar month. The Convenor will be assisted in office by two Assistants and a reserve, together the "Convenor Team". The Convenor Team supports one another and operates as flexibly as possible. The Convenor role may need to shift to Assistants for periods of time during any given month, and it is up to the team to organise this. Ideally, to maintain continuity, an Assistant should serve in the month preceding and the month following his/her Convenorship, health permitting (or, failing this, at least one member of the existing Team should normally overlap with the incoming Team).

The Convenor will be the primary facilitator of PAG consensus decision-making and collating individual responses. The Convenor is also the primary facilitator of communications between PAG, the MERC and others. PAG members are welcome to join in the work of the PAG at all times, and the Convenor Team will invite contributions as well as consulting on views. The Convenor Team will, after consultation, propose decisions and draft substantive communications (normally emails) from the PAG to MERC and others, and other documents as necessary for discussion and approval by the wider PAG. The Convenor Team will organise PAG videoconferences to aid discussion and decision-making as required. Final document approval, and any other substantial decisions, will be open to the PAG as a whole (see [Decisions](#) for the procedure to be followed).

Two PAG reps will attend MERC Board meetings, with a third acting as note-taker. The Convenor Team is responsible for organising attendance at MERC Board and other meetings, ensuring the best possible representation of PAG, and also ensuring all those fully engaged in the PAG have equal opportunity to attend meetings over time. Each member representing PAG at a MERC or other meeting must be well-prepared and must have engaged with PAG preparations for that meeting. Severely ill members who cannot engage in PAG discussions and preparations prior to MERC and other meetings are welcome to give their views via the Convenor Team.

In addition, the severely-affected or housebound members may be able to listen in to MERC Board meetings (or parts of meetings) on mute via telephone/Zoom from their home.

PAG members will not routinely be invited to represent PAG at meetings until they have completed a sufficient period of induction, usually six months.

## Data Protection

All PAG members and any agreed proxies must agree and adhere to the MERC PAG GDPR Policy.

<https://drive.google.com/file/d/1zUdIR5oOZHPdu7Nvt1oxvGZtzSFqg3f/view>

## Convenor Team Proxy

The Convenor Team may be assisted by volunteer proxies (non-PAG members) as agreed by the PAG. It is recognised that the administrative functions associated with the effective running of PAG are demanding for those living with ME/CFS. Protecting the health of individuals by reducing this burden is a priority

## Accountability

While the PAG as a whole seeks to understand and communicate the often-diverse views and concerns of those with ME/CFS, there is no expectation that the PAG represents all people with ME/CFS. PAG members primarily represent their own lived experience of ME/CFS, informed by their understanding of current research and debate.

Where there are different individual opinions, it may be appropriate to collate these and convey all views to the MERC and others. When a decision is required, the PAG will endeavour to reach this by consensus (the absence of expressed fundamental objection) or, where this is not possible, by majority vote of active members, whereupon minority views should be expressed, and will be shared with the MERC or others. (See [Decisions](#))

## Values

We uphold the values of the MERC as outlined in its Charter:

- We are an intellectually generous community sharing data, best practice and technologies.
- We are a creative community harnessing new ideas, new technologies and new ways of working.
- We are a collaborative community inviting all stakeholders to join our programmes and shape our activity.
- We are an enabling community, facilitating the leverage of further resources for CFS and M.E. research.
- We support and expect the highest quality research.
- We encourage insightful questions and open and informed debate; we applaud and listen to those who have questions about research.
- We never accept harassment of any person or group by any other person or group, or the branding of any group due to the actions of a few.

As a PAG, we are an honest and transparent community creating trust and mutual respect.

Other values that the PAG seeks to uphold and embody are: equality, diversity, generosity, flexibility, kindness, democracy, integrity, inclusivity and high ethical standards.

We also expect that Members:

- consider any research requirements and implications for all study participants, without having a pre-set agenda;
- have a keen interest in critical evaluation and be able to look at a situation as objectively as possible, respecting the rights of others to hold alternative viewpoints;
- be willing to challenge and be challenged;
- be able to listen to, read and assimilate information and analyse evidence that is sometimes complex
- demonstrate tact and discretion, and uphold confidentiality

## Review

These Terms of Reference will be reviewed as and when the group feels it is appropriate, and at the latest within 5 years.

## Working Methods

### Within the PAG

As a group we operate online. Tuition will be provided for new members who require it.

We communicate and 'meet' via emails, Slack online discussion platform (<https://slack.com/is>), and by Zoom (Members should check any costs associated with access either via WiFi, data or their own phone company). We understand that severely affected members may find some methods of communication easier than others and we will endeavour to make adjustments to ensure that their views are heard. We strive to maintain a culture of mutual respect and support. (See [Values](#) and [Accountability](#)).

As we work proactively, as well as in response to developments and opportunities in the world of ME/CFS research, there is no set number of PAG 'meetings' per year. We endeavour to find a day and time for meetings when the most members can attend. Regular weekly meeting slots are scheduled to be utilised as and when required. We sometimes take indicative votes on Slack or via Doodle poll to arrange meeting times.

Because ME/CFS limits our time and energy, we are flexible in our working methods and rely on group members coming to the fore when others are unwell or unable to engage fully. We also understand that severely affected members may not be well enough to take on certain responsibilities.

We have a monthly rota for the Convenor Team (Convenor and two Assistants, plus a reserve). (See [Offices](#), above.) The Convenor Team facilitates communication between the PAG, the MERC and others, as well as organising PAG work. For example, the Team will invite all PAG members to take part in preparations for MERC Board and other meetings, responses to questions, reports or statements, video conference or online discussion. The Convenor Team takes responsibility for collating views or facilitating consensus, as appropriate.

The Convenor and Convenor Team monitor our group email address. The Convenor will forward any substantial emails received to all PAG members and copy all PAG members into substantial emails sent out. The content of substantial replies will be circulated and discussed within PAG before being sent on behalf of the group. All PAG members can ask to view the group email account at any time.

When we are asked by the MERC or others for our opinions, for a group view on a particular topic, or to make a presentation, we share resources to understand the topic and discuss it by videoconference, email or Slack - occasionally on the basis of a draft document prepared by a subgroup.

Shared Google documents may be set up by the Convenors and used to collate opinions and edit documents.

Members may contribute to the ongoing tracking of research developments and ME/CFS patient opinion, posting screenshots or links on Slack.

### Subgroups

Subgroups of PAG members may be set up to support the working groups of the MERC and other projects that PAG are involved with. PAG representation on the MERC working groups is determined by the individual Terms of Reference for each group. In addition to subgroup members all other PAG members are free to contribute to these subgroups at any time. Any subgroup member may represent the PAG at the MERC working group and other meetings. Whilst these PAG subgroups do not have a leader one PAG member plus a reserve are nominated to be the named contacts with the MERC working group leader. Subgroup communications with the working group should be via these named contacts. The agenda and minutes of PAG subgroup and MERC working group meetings will be shared on Slack and by email.

### PAG Interaction with Non MERC Initiatives

The PAG may from time to time have input to, or involvement in, ME/CFS related but non MERC initiatives. The nature of the PAG's relationship with any given initiative to be agreed by the PAG. Communications should generally take place through the PAG email account in the usual way unless agreed otherwise. Past/current involvement includes:

- Stakeholder to NICE ME/CFS guideline review
- Stakeholder to NICE Long Covid guideline review
- Steering group member of James Lind Alliance Priority Setting Partnership on ME/CFS (Prioritise ME PSP)
- Member of the ME/CFS Delivery Plan Task and Finish Group
- Co-Chair and member of the UKCRC ME/CFS Research Working Group as part of the Secretary of State's ME/CFS Delivery Plan
- Member of the Attitudes and Education Working Group for the above Delivery Plan

### PAG Decisions

Videoconferences may take place regardless of how many members are present. For decisions to be made a minimum number (see below) of active PAG members must be engaged either by email, on Slack or verbally. Members are encouraged to make written contributions in advance of meetings if they are unable to attend.



### Substantial action points

The Convenor Team will facilitate consultation, to the extent possible, with all other active Members on each PAG substantial action point requiring a decision, to take the sense of the membership. An emerging basis for action will be presented to the Members for consensus adoption. This proposed action will be adopted unless at least one Member objects to it on fundamental grounds, whereupon the Convenor will move a vote. Action will then be decided by a simple majority vote, dissenters being encouraged to express any fundamental dissent which will be shared by the Convenor with the relevant body as appropriate. Substantial decisions made by a consensus and/or vote process as outlined above require participation of at least 50% of active Members.

### Minor action points

Decisions which are of a minor nature may be made following similar processes to above, with at least 30% of active Members partaking in the decision-making process (verbal, written or both). This includes decisions of a minor nature on action points that arise during video conferences if this is necessary to ensure the effective functioning of the PAG.

### Resolution of disagreements

The PAG endeavours to work harmoniously. As an evolving group we will reflect on our working processes to ensure they are in line with our values. When there are disputes, the PAG member(s) should articulate their disagreement clearly in writing (1000 words or less). The matter will then be discussed by the PAG as a whole, if appropriate, or by a smaller number of members. They will ask whether PAG values as stated in this Terms of Reference have been adhered to. If not, the group will seek to answer why this has happened and what needs to change as a result.

## Communications between PAG and MERC

These may be written, or by videoconference, or in person/virtually at a MERC Board meeting. The Convenor, or members of the convenor team, act as the primary communicator with the MERC and others unless otherwise delegated.

We desire that as many PAG members as possible attend MERC Board meetings at some point. There may be limited funding to go towards travel costs.

## Confidentiality

PAG members agree to keep PAG, and PAG/MERC/other external body, discussions and communication strictly confidential within the group, except to the extent that it is agreed to canvass the opinion of others outside the PAG.

The need for confidentiality can be paramount, particularly when dealing with government bodies and as regards the intellectual property of researchers. Confidentiality is also necessary because of the sensitive nature of some members' experiences (in relation to their and their family members' ME/CFS) which they may choose to share during the course of PAG discussions.

A list of PAG members is not published. The chair of the MERC is made aware of the names of all PAG members.

## Definition of Terms

We recognise that there is controversy surrounding the terms 'Chronic Fatigue Syndrome' and 'ME', alone and in various combinations. We use the term 'ME/CFS' in this document, as this is the term adopted in the 2021 NICE guideline.

# Appendix B: Application to join MERC Patient Advisory Group

To apply to join the MERC PAG please complete this online form:

<https://docs.google.com/forms/d/e/1FAIpQLSdMA7gDMnUt5WeD16evwbEoAX5hDtdsJsLU-gtUBApXSPagYw/viewform?usp=sharing>

This is a Google form.

If you have a Google account and are logged in your application will save as you complete it. You will be able to leave the form and return to it at a later date to complete it in stages. The application will not complete and be sent to us until you click submit at the end.

If you do not have a Google account, you can still complete the form but it will not save as you go. The application must be completed and submitted in one go.

The questions contained on the form are repeated below. You may find it helpful to prepare your answers in advance of completing the form and copy and paste them into the form.

If you are unable to access the form in this format please email [mercpagpublic@gmail.com](mailto:mercpagpublic@gmail.com) to explain your access needs.

Please be aware that recruitment is on an ongoing basis currently from November 2022 - February 2023 (inc). We will be in contact as soon as possible, but within the limits of our capacity, so do not be concerned if it takes a few weeks.

- Email
- Name (first and last name)
- Contact number
- Would you agree to abide by our Terms of Reference (Appendix A of application pack)?
- Would you agree to abide by our Data Protection Policy (see Terms of Reference, Appendix A of application pack)?

The PAG seeks to have a balance of those who have recovered from ME/CFS, those who are mildly or moderately affected, those who are severely affected and carers. We also seek gender and age balance, bearing in mind the demographics of the disease. We aim to be as representative of the ME/CFS population as possible.

- Gender
- What is your experience of ME/CFS - are you a patient or carer of someone with ME/CFS?
- Age group
- If a carer, age group of person with ME/CFS that you are caring for[10]
- First half of postcode

Please note we do not request full address details from applicants at this stage in the recruitment process but, if your application is successful, you will be expected to provide your full address for admin purposes

- Ethnicity.
- What severity and duration of illness are you familiar with?
  
- Please can you tell us why you are interested in joining the MERC Patient Advisory Group

Please note that this and following answer boxes in the form have a single line showing but expand as you add more text.

- Please provide a short summary (no more than 700 words, but fewer words may be sufficient) of the experience, knowledge, interests, skills and behaviours that you would bring to the role.

We will be considering applications based on how individuals meet the stated person specification criteria so please consider this fully and include this in your summary.

- What do you hope to get out of being a MERC Patient Advisory Group member?
- Is there anything specific that you would like or need from us?

#### Administrative support

Some of the PAG vacancies will, out of necessity, be reserved for those able to commit to assisting with the administrative running of the PAG.

- Please indicate if you are able to assist in this way, what experience you have and what time you could commit. Please indicate if you could monitor and respond to external emails on a daily basis.

#### Access requirements

- Do you have any access needs or requirements that we need to be aware of?

## Declaration

I declare that all the information I have given on this application form is true to the best of my knowledge and belief. I understand that my application may be rejected and/or that I may be dismissed if I have given information which is found to be false.

Application forms will be deleted after the completion of our recruitment process. Successful candidates will be asked to introduce themselves to the group via our Slack system.