**Patient Advisory Group application pack**

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

**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).

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 CMRC and associated bodies and platforms (eg. as a NICE stakeholder in the current ME/CFS guidelines 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 Group sit on the CMRC Board at any given time, and two representatives attend each CMRC Board meeting. Not being well enough to physically attend meetings is not a barrier to joining the PAG.

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 are particularly interested in hearing 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.

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.

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 is available. PAG membership will not be higher than 15 members.

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

**Person specification**

**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.

**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, eg. email and online discussion platforms
* Able to listen to, read and assimilate information and analyse evidence that is sometimes complex
* Able 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 outside the PAG
* Willing to take a proactive approach to working with the CMRC
* Willing to answer questions put to the PAG by the CMRC
* Willing to seize opportunities to educate researchers and others about the lived experience(s) of those with ME/CFS (This may extend to identifying potential practical issues for study participants, questions, gaps or concerns about studies.)
* Willing to challenge and be challenged

**Appendix A: Patient Advisory Group (PAG) to the UK CFS/ME Research Collaborative (CMRC) Terms of Reference**

*Version 2 adopted September 2018*

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 CMRC and associated bodies and platforms (e.g. as a NICE stakeholder in the current ME/CFS guidelines review). 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 CMRC 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 CMRC;
* sending up to two representatives to each CMRC Board meeting; and
* seizing opportunities to educate researchers and others generally about the lived experience(s) of those with ME/CFS.  (This 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 15 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. 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: 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 have a term of office of 5 years after which they may reapply for membership under an agreed selection process.

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

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.

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 and the CMRC.  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 CMRC and other documents as necessary for discussion and approval by the wider PAG.  The Convenor Team will organise PAG teleconferences 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, including in time limited conditions).

Two PAG reps will attend CMRC Board meetings, with a third acting as telephonic note-taker. The Convenor Team is responsible for organising attendance at CMRC Board 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 CMRC 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 CMRC 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 CMRC Board meetings (or parts of meetings) on mute via telephone from their home.

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 CMRC. 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, whereupon minority views should be expressed, and will be shared with the CMRC. (See Decisions)

Values

We uphold the values of the CMRC 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.

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

1. Within the PAG

We communicate and ‘meet’ via emails, Slack online discussion platform (<https://slack.com/is>), and by teleconference (freeconferencecall.com 0330 number – members should check that this is free for 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.

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 and the CMRC, as well as organising PAG work. For example, the Team will invite all PAG members to take part in preparations for CMRC Board meetings, responses to questions, reports or statements, teleconference 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 view the group email account at any time.

When we are asked by the CMRC 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 teleconference, email or Slack - occasionally on the basis of a draft document prepared by a subgroup.

Members are helped to create free teleconference accounts and may participate in or volunteer to host teleconferences.  We endeavour to find a day and time when the most members can attend. We sometimes also take indicative votes on Slack to arrange meeting times.

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

1.2  PAG Decisions

Teleconferences may take place regardless of how many members are present, but for decisions to be made a minimum number (see below) of PAG members must be engaged either by email, on Slack or verbally.

Substantial action points, not urgent

The Convenor Team will facilitate consultation, to the extent possible, with all other Members on each PAG substantial action point requiring a decision, to take the sense of the membership. The Convenor Team will seek volunteers and then delegate interim tasks to subgroups or individuals for action as appropriate, and then present an emerging basis for action 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 online vote, dissenters being encouraged to express any fundamental dissent which will be shared by the Convenor with the relevant body as appropriate (CMRC, PAG, NICE…) Substantial decisions made by a consensus and/or vote process as outlined above require active participation of at least 50% of Members.

Substantial action points, urgent

Where substantial decisions are to be taken, efforts will be made to consult with all PAG members, as above, to the extent possible. Where this is not possible because of time limitations and a teleconference is held for the purpose of urgent decision making, the following procedure will be used.

Members are encouraged to make written contributions in advance of discussions regarding decisions if they are unable to attend discussion teleconferences. As above, the proposed action will be adopted unless at least one Member present 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 (CMRC, PAG, NICE…)

Substantial, urgent, decisions made by a consensus and/or vote process during a teleconference as outlined above require participation of 50% of Members, including written views or votes submitted in advance.

Minor action points

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

1.3 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.

2. Communications between PAG and CMRC

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

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

Confidentiality

PAG members agree to keep PAG and PAG/CMRC 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 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) which they may choose to share during the course of PAG discussions.

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 to be adopted in the new NICE guidelines. The alternative term ‘CFS/ME’ is used by the CMRC in its name and charter (including as cited in this document).

**Application to join CMRC Patient Advisory Group**

**This form (ie. pages 9 and 10 of this application pack) must be completed in full and returned to anna@actionforme.org.uk by 5pm Wednesday 7 November 2018. Thank you.**

|  |  |  |  |
| --- | --- | --- | --- |
| Last name | First name(s) | | Title |
| Address | | | |
| Email address | | | |
| Home telephone number | | Mobile number | |
| Please can you tell us why you are interested in joining the CMRC Patient Advisory Group. | | | |
| What is your experience of M.E./CFS – are you a patient or carer of someone with M.E./CFS? What severity and duration of illness are you familiar with? | | | |
| Please provide a short summary (no more than 700 words) 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 CMRC Patient Advisory Group member? Is there anything specific that you would like or need from us? | | | |

**Access requirements**

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.

|  |
| --- |
| Do you have any access needs or requirements that we need to be aware of? Would you be able to attend CMRC meetings (usually in London) to represent PAG (not essential for all PAG members)? If not in person, could you attend by phone? |

**Please tick the boxes that apply to you:**

|  |  |
| --- | --- |
| **Age group** | |
| 18 to 30 years |  |
| 31 to 40 years |  |
| 41 to 50 years |  |
| 51 to 65 years |  |
| 65+ years |  |
| Do not wish to answer |  |

|  |  |
| --- | --- |
| **Gender** |  |
| Male |  |
| Female |  |
| Do not wish to answer |  |

**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.

Signed…………………………………………………………..

Date……………………………………………………………...

**Data Protection Act 2018**

Information provided on this application form will be treated as confidential and held in secure conditions. Access will be restricted to those involved in the recruitment and selection process. Data you provide may be copied for use in the recruitment process and once this is completed, the information will be stored for a maximum of 12 months and then destroyed. If you are the successful candidate, relevant information will be taken from your application and transferred to your personal file. We are unable to process your application unless we can use your personal data. By signing and submitting this form, you are giving your consent to the processing of your data in the ways described.