



Guidance for recruiting and involving people with fibromyalgia and their carers in research opportunities

Fibromyalgia Action UK is frequently contacted by researchers who are looking to recruit and involve people living with fibromyalgia in research opportunities.

Fibromyalgia Action UK intends to accommodate all research-related requests whenever possible, providing that Fibromyalgia Action UK judges that such requests are of interest to people living with fibromyalgia. Research should also align to the charity's vision, 'Fighting for freedom from fibromyalgia'. The following guidelines specify our standards and the information we require. These guidelines also detail the responsibilities you have as a researcher to people living with fibromyalgia who are involved in your work.

Your point of contact with Fibromyalgia Action UK will be Trustee, Simon Stones, who is also the charity's Research Liaison.

Recruiting people living with fibromyalgia to your research opportunity

There are several ways in which Fibromyalgia Action UK can help make people living with fibromyalgia and their carers aware of opportunities that they may like to participate in. We currently circulate opportunities via our website, social media platforms (Facebook and Twitter), HealthUnlocked and by email to our Regional Co-ordinators and local support groups.

Due to issues of data protection, we are unable to release the contact details of Fibromyalgia Action UK's contacts directly to researchers and other third parties. This means that Fibromyalgia Action UK would circulate, on the researcher's behalf, details of the opportunity.

Researchers should also be aware that all research carries risk, and therefore, Fibromyalgia Action UK asks all researchers to demonstrate that they have received or are seeking to receive ethical approval. Research participation opportunities will only be published once ethical approval has been granted. This does not apply involvement opportunities during the development of research proposals, since ethical approval is unlikely to have been granted.

Should you wish us to help facilitate recruitment to your study, you will need to complete an application form which can be downloaded from our website, or sent to you by our Research Liaison. This allows us to assess all opportunities against a set of established criteria that ensures the opportunity is appropriate and of relevance to people living with fibromyalgia. When you return your application form, this will be assessed by Simon Stones, Trustee and Research Liaison at Fibromyalgia Action UK. It may also be passed onto other Trustees at the charity in strictest confidence for their comments.



Eligibility for recruitment

Fibromyalgia Action UK welcomes applications from researchers in the United Kingdom (UK) wishing to recruit participants living in the UK into their research study. In your application, you will need to show:

- ✓ The benefit of your research to people living with fibromyalgia;
- ✓ Where the research will be conducted;
- ✓ Who will conduct the research;
- ✓ How you will communicate with your participants;
- ✓ The evidence of your eligibility to conduct research in the UK.

Applications from researchers outside of the UK are welcomed, but will be reviewed on a case-by-case basis for their applicability.

Dissemination of research findings

Fibromyalgia Action UK expects to be given advance notice of any press releases or publications arising from research studies that have approached Fibromyalgia Action UK for support. Where possible, researchers are encouraged to publicise research study findings that are readily accessible to members of the public. Fibromyalgia Action UK expects researchers to make every attempt to publish the findings of their research, regardless of a positive or negative outcome. Fibromyalgia Action UK also requests that researchers share findings with the charity upon completion of the research, so that it can be published on the charity's website and social media platforms.,

What we look for when reviewing research opportunities

- ✓ Is this a relevant and appropriate opportunity for an individual living with fibromyalgia or caring for someone with fibromyalgia to contribute to fibromyalgia research and/or the improvement of fibromyalgia services?
- ✓ How is this study novel, and what evidence gap is it likely to address?
- ✓ Has this study received (or are the plans to seek) approval from a relevant research ethics committee?
- ✓ Have you summarised the study in plain English without unnecessary jargon?
- ✓ Have you discussed confidentiality and anonymity in your participant information sheets, and what will happen to the data collected?
- ✓ Are participants reminded that their participation in this study is voluntary, and that they are able to withdraw from the study at any time?
- ✓ If participating in the opportunity involves costs (for example, travelling to a venue or staying away from home overnight), have you included details of which expenses will be reimbursed and how?
- ✓ Is the consent and/or assent process appropriate for the target audience of the study?
- ✓ Is this a market research study? Fibromyalgia Action UK does not currently assist with recruitment to market research studies. However, we will consider these requests on a case-by-case basis. If the research is sponsored by a pharmaceutical company, they should be members of the Association of the British Pharmaceutical Industry (ABPI).
- ✓ Have you considered how you will share feedback and study results to those who will participate in your study?



- ✓ Could participating in the research raise distressing issues or memories for people living with fibromyalgia? If so, is this clear from your summary of the opportunity and what support will be made available?

We ask that researchers submit applications to recruit people with fibromyalgia in their study well in advance of planned recruitment deadlines. We aim for a turnaround time of between one and two weeks maximum to make a decision, and once approval has been granted, the opportunity will be circulated via our network within five working days. Please note that after you have submitted an application, we may come back to you with further questions to help us assess the opportunity and this can lead to a longer turnaround time.

Fibromyalgia Action UK's affiliation with research opportunities

It should be clear that advertisement of your research opportunity is not a recommendation for participation in the research opportunity. Fibromyalgia Action UK does not take any responsibility for external opportunities advertised and is therefore not liable for any claims concerning negligence, harm or oversight that may arise during the course of the research opportunity. It should be emphasised that participation in research is voluntary, and that participants can withdraw from the research opportunity at any time without giving reason.

Further information and summary

The research organisation and any individuals or organisations working on their behalf must adhere to all relevant guidelines relating to participant consent/assent, confidentiality and data protection. Applications must also clearly state any commercial support/links to research studies.

Participants should be provided with the following information:

Before the study begins:

- ✓ A lay summary of the research study must be given in clear, jargon-free language that is appropriate to the needs of the participants. This should include information about research aims and proposed timescales.
- ✓ A brief summary of the potential benefits of participating in the research study for the individual and more broadly for people living with fibromyalgia.
- ✓ Clear information about the potential risks of participating in the research study.
- ✓ Clear information about reimbursement of expenses.
- ✓ The name and contact details of the researcher should be given to participants in case they have comments or concerns while participating in the study.

After the study has taken place:

- ✓ A summary of the outcomes in easy-to-read, jargon-free language, appropriate to the needs of the participants. For research studies, this should be given once the results of the research are publicly available.
- ✓ If the research study is a trial of medicines, participants should be informed of which medicine they have been taking for the research study and at what dosage. They should also be given clear information about whether or not they



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are likely to be able to access this medicine after the research study has been completed, and once the results of the research are publicly available.

Research involvement opportunities

Aside from recruiting people with fibromyalgia and/or their carers into research studies, Fibromyalgia Action UK welcomes researchers to request support to share involvement opportunities to people with fibromyalgia and their carers, so that they can work with researchers in a collaborative manner to shape research.

The types of opportunities that people could become involved in can range from participating in focus groups about their experience of fibromyalgia care, to commenting on the design of a research study, reviewing a project application from the lay perspective, and commenting on participant information sheets and consent forms.

It is expected that people who get involved as lay research partners are never out of pocket with expenses, and it is the responsibility of the researcher to ensure that this is i) costed into research applications; and ii) discussed at the earliest opportunity with the lay research partner. In addition, lay research partners who contribute to the study should be acknowledged in an appropriate way. For example, as a co-applicant on a grant, or as a co-author on a research publication.

Confidentiality and anonymity

The Fibromyalgia Action UK confidentiality agreement at present does not apply to this situation, as it is for people “working with” Fibromyalgia Action UK, and in particular, with Fibromyalgia Action UK data or resources. Individuals taking part in external research opportunities should ensure that researchers are going to respect their data and maintain confidentiality and/or anonymity. The responsibility of maintaining confidentiality and/or anonymity in any research remains the responsibility of the researcher and their institution.

Contact us

If you have questions about any of the information above, or wish to discuss recruitment support and involving people with fibromyalgia in your research, please contact Simon Stones, the Research Liaison at Fibromyalgia Action UK:

Email: research@fmauk.org