

Guidelines for involving people affected by asthma in research opportunities



Asthma UK is regularly contacted by researchers and organisations that are looking to involve people affected by asthma in research and policy related opportunities.

It is the intention of the charity to support these requests whenever possible, providing they are of interest to people affected by asthma, they meet Asthma UK's vision to 'stop asthma attacks and cure asthma' and that they will not compromise the charity in any way. The following guidelines detail our criteria and the information we require; they also detail the obligations you have to people affected by asthma who are involved in your work.

Who are the Research and Policy volunteers?

Research and Policy volunteers are people affected by asthma who choose to work with Asthma UK to use their experience of living with the condition to shape asthma research and influence Asthma UK's campaigning work. The term 'affected by asthma' means either someone who has asthma themselves or is a family member, partner, friend or carer of someone who has asthma.

Research and Policy volunteers do not necessarily represent the views of Asthma UK but instead reflect some of the diverse range of views and experiences of people who know what it is like to live with the condition.

The types of opportunities that Research and Policy volunteers get involved in can range from participating in focus groups about their asthma care to commenting on the design of a research study or reviewing a project application from the lay perspective.

Recruiting people affected by asthma to your opportunity

There are various ways in which Asthma UK can help make Research and Policy volunteers and others affected by asthma aware of opportunities that they may like to participate in:

- We currently circulate opportunities to our Research and Policy volunteers via our monthly Research and Policy volunteer email bulletin (circulated on the third Wednesday of each month) or through targeted emails to volunteers.
- Involvement opportunities in research funded by Asthma UK may additionally be eligible to be included on our [Opportunities to get involved in our research](#) webpage or social media channels.

Due to issues of data protection, we are unable to release the contact details of Research and Policy volunteers or Asthma UK's contacts directly to a third party. This means that Asthma UK would circulate, on the researcher's behalf, details of the opportunity via email or the other channels detailed above. Please be aware that there may be a charge for this service. Applicants should also be aware that all research carries risk and therefore may require ethical approval. Asthma UK asks applicants to demonstrate that they have received or are seeking to receive such approval.

Should you wish us to help facilitate recruitment to your study, you will need to complete and submit the online application form from our [Involving people with asthma in your research](#) webpage. This allows us to assess all opportunities against a set of established criteria that ensures the opportunity is appropriate and

of relevance to people affected by asthma. When you submit your application form, this will be assessed by members of the Research Team at Asthma UK.

Eligibility for recruitment

Asthma UK welcomes applications from UK-based researchers wishing to recruit UK-based participants into their research study. In your application you will need to show:

- the benefit of your research to people living with asthma in the UK
- 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

Dissemination of research findings

Asthma UK expects to be given advance notice of any media releases or publications arising from the research study, and Asthma UK reserves the right to use the findings for its own publication and research purposes. Where appropriate, researchers are encouraged to post research study findings on their institution's website or in printed or electronic media that is readily accessible to the UK public. Asthma UK expects researchers to make every attempt to publish the findings of the research regardless of a positive or negative outcome.

What we look for when reviewing involvement opportunities

- Is this a genuine opportunity for a person affected by asthma to contribute to asthma research, the improvement of asthma services and/or to raise awareness of the diverse realities of living with asthma?
- Is it an appropriate opportunity for people affected by asthma to have a say and make a difference (i.e. will it be an empowering and productive experience for the person affected by asthma who is taking part)?
- Does the study replicate previous work, and if so why?
- Is the opportunity aimed at children and young people? Asthma UK currently facilitates recruitment to research and policy opportunities for under 18s on a case-by-case basis.
- Is it a market research study? Asthma UK does not currently assist with recruitment to market research studies, however we will consider these on a case-by-case basis. Please note, Asthma UK will seek to identify the third party and the purpose of the research. Pharmaceutical companies should be members of the ABPI.
- Does the opportunity involve or relate to endorsing a particular treatment or product? It is Asthma UK's policy not to endorse any treatments or products.
- Have you summarised the requirements in plain English without unnecessary jargon? Would participating effectively in the opportunity require specific skills, knowledge or experience? Have you given information about any training or induction available?
- Have you considered how feedback will be given to people affected by asthma regarding the impact their involvement has achieved once their involvement ends?
- What arrangements are in place to let Research and Policy volunteers know whether or not they have been successful in being selected for the opportunity?
- Could participating in the opportunity stimulate painful memories or raise distressing issues for people affected by asthma? If so, is this clear from your summary of the opportunity and what emotional support will be made available?
- If the opportunity is to participate in a piece of research, have you obtained any research ethics approval which may be required? Is information available for participants about confidentiality and what will happen to the data collected?

- If participating in the opportunity involves costs (e.g. travelling to a venue, eating meals away from home, staying away from home overnight), have you included details of which expenses will be reimbursed and how?
- Is insurance cover necessary and is it clearly explained?
- Is the opportunity relevant to Asthma UK's current [Research Strategy](#)?

When we review an opportunity (especially if it has been posted by an organisation we are not familiar with) we might arrange to speak to the individual or organisation concerned in order to clarify any information we are unsure of or to request further information we feel is necessary. It is also a way of providing a more 'personal service' whilst building a rapport with the various individuals and organisations involved in asthma research and policy activities. However if we contact you and you do not respond to us within one month, we will consider your request to post an opportunity to be withdrawn.

We ask that researchers submit applications to involve people with asthma in their study well in advance of recruitment deadlines. We aim for a turnaround time of between one and two weeks to make a decision and once approval has been granted, the opportunity will be circulated to our volunteers. 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. In addition, **please note that the Research and Policy email bulletin is circulated on the third Wednesday of each month, and we are unable to include any opportunities received less than a week prior to this.**

Fees

Asthma UK reserves the right to charge a fee for facilitating recruitment to opportunities, based on the costs of fulfilment, plus an administration fee. However, as Asthma UK recognises that valuable research may be jeopardised or lost should full financial compensation be sought from those with a limited ability to pay, support may be available to those who are unable to meet these fees. Please contact the Research Operations Officer for further details.

Asthma UK's affiliation with the opportunity

It should be clear that advertisement of your opportunity is not a recommendation for participation in the opportunity. Asthma UK does not take any responsibility for external opportunities advertised and is therefore not liable for any claims concerning negligence, harm or oversight that might arise during the course of the opportunity. It should be agreed that volunteers can withdraw from the opportunity at any time without giving reason and any information provided by the volunteer will be destroyed. Liability for the opportunity lies with the person signing the application form and their organisation.

Further information

For researchers looking to recruit participants to their clinical trial, the study must have been peer-reviewed and be funded by a recognised organisation (for example, Asthma UK, other charities or not-for-profit organisations with independent peer-review systems, Research Councils, Department of Health and Social Care).

If the research study relates to equipment, the research must have been independently reviewed and approved by the MHRA for its use and trial in the UK. As is required by law, if the research study is a clinical trial, this must have approval from the MHRA, and follow-up appointments must be provided for participants following the completion of the trial.

The research organisation and any individuals or organisations working on their behalf must adhere to all relevant guidelines relating to participant consent, confidentiality and data protection.

Applications must clearly state any commercial support/links to research studies. Asthma UK will not accept applications from researchers who have funding support from the tobacco industry.

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 asthma.
- Clear information about the potential risks of participating in the research study.
- Clear information about reimbursement of expenses and any remuneration.
- Insurance cover for taking part in the study must be disclosed.
- The name and contact details for a research representative 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 drug trial, participants should be informed of which drug they have been taking for the research study and at what dosage. They should also be given clear information about whether or not they are likely to be able to access this drug after the research study has been completed and once the results of the research are publicly available.

Contact the Research Team

If you have questions about any of the information above, or wish to discuss involving people with asthma in your research, please contact the Research Team at Asthma UK:

E: research@asthma.org.uk

T: 0207 786 4946