

# Research and Policy volunteers

## Information sheet

Signing up as a Research and Policy volunteer provides you with the chance to take part in a vast array of activities. Here are just some examples of the opportunities available to our Research and Policy volunteers.

### **Represent the views of people with asthma**

#### **Acting as an asthma representative**

As a Research and Policy volunteer you can share your experiences as a person living with asthma to influence researchers and politicians, as well as take part in research activities and policy work yourself.

Activities include:

- providing a case study of your experiences of asthma to help develop policies and strengthen our campaigns - this might involve responding to occasional emails asking about your experiences
- taking part in research studies, from interviews and questionnaires to clinical trials for new asthma treatments
- taking part in working groups looking at a broad range of issues
- helping to educate people about the realities of living with asthma
- speaking publicly about your experiences of asthma

This is your opportunity to represent people affected by asthma in all areas of our research and policy work, from helping researchers to understand more about asthma through their work to speaking at parliamentary events with leading politicians. The opportunities are endless!

Types of audiences that you may be working with include:

- other people with asthma
- Asthma UK
- scientists
- researchers
- healthcare professionals
- policy makers
- pharmaceutical companies which develop asthma treatments
- pressure groups
- health authorities

#### **Taking part in focus groups**

By taking part in focus groups, you can help Asthma UK to obtain the viewpoints of people living with asthma on specific topics that are important and relevant to them.

Focus groups are one of the ways that Asthma UK engages with people with asthma in order to obtain their viewpoints on specific topics. They are made up of a small group of people (typically 8-10) from a wide cross-section of society to help ensure that the responses received are representative of all

people with asthma. They involve a roundtable discussion of selected topics of interest in an informal setting and are directed by moderators who guide the discussion and chair the proceedings. They are used to help inform the work of research, services, policy and information at Asthma UK, and can be extremely effective.

Previous focus groups include:

- establishing what choices people with asthma want from the NHS in terms of access to healthcare
- a series of regional focus groups to discuss our basic asthma research strategy and the priorities outlined in it for research into the causes and mechanisms of asthma
- 'Your Health, Your Care, Your Say' - a focus group on the future of community health and care services

## **Taking part in surveys**

Surveys are another great way for Asthma UK and other research organisations to gather information from people affected by asthma to inform their work to help improve the lives of the 5.4 million people with asthma living in the UK.

Surveys are one of the main research methods used to obtain information. They could include questionnaires, web polls or interviews. Often these surveys are not particularly time-consuming so could be a great way to feed into the research, policy, services and information activities of Asthma UK if you are busy. There are a number of surveys that Asthma UK and others have undertaken to obtain the views and experiences of people affected by asthma.

For example, Asthma UK is currently undertaking a project to examine the use of corticosteroids in the treatment of asthma. We sent out a questionnaire to our members to find out the concerns that people with asthma have regarding their use and the effect that these concerns have on how they take their medicine.

## **Influencing Asthma UK's research**

Based on your experiences as a person living with asthma, you can help influence Asthma UK's research in the following ways.

### **Assessing research funding applications**

Asthma UK has, to date, spent over £50 million on vital research projects based in the UK to investigate the causes and treatments of asthma, as well as trying to prevent it developing in the first place. In addition to Asthma UK's research grant programme, this funding also currently supports two professorships, Fellowships and a number of studentships.

Asthma UK invites proposals for research grants in an annual call. We involve people affected by asthma in this annual research funding process by providing Research and Policy volunteers with the opportunity to act as lay reviewers. They are asked to give their opinions on which asthma research applications we should support from the perspective of someone who understands what it is like to live with the condition. Research and Policy volunteers involved in Asthma UK's grant round attend a compulsory one-day training session to help them prepare for the role.

## **Representing people with asthma on our Research Review Panel**

Along with our panel of lay reviewers, Asthma UK also provides Research and Policy volunteers with the opportunity to act as a lay representative on our Research Review Panel (this is a 30-member panel that also includes scientists and clinicians who help identify and recommend the applications they feel are suitable for funding by Asthma UK).

Applications for funding are currently assessed in a two-stage review process. During stage one, all funding applications are assessed for scientific quality and relevance to asthma by our lay reviewers (see above) and Research Review Panel, along with external national and international reviewers that are researchers themselves and have a significant level of scientific expertise in the subject area. During stage two, the highest scoring research proposals are selected to be discussed by the Panel at the grant review meeting. Those proposals that are considered to be the best science and most relevant to people affected by asthma are then recommended for funding. Lay representatives on the Research Review Panel are responsible for acting as 'the voice' of people with asthma on the Panel and are also provided with a compulsory one-day training session to help prepare for the role.

## **Monitoring funded research**

In addition to involving people affected by asthma in our annual research funding process, we want to get people involved in the research that we are funding in terms of seeing the results of specific projects as they happen.

Helping us to communicate the outcomes of research we have supported and how they will benefit people affected by asthma

We communicate about our research in a variety of ways, but we would like your help to do this in the most effective way for people with asthma and support the work we do in this area. We would also like you to help us ensure that all of the research we fund leads to relevant outcomes for people with asthma.

## **External research opportunities**

From time to time, Asthma UK is approached by researchers from external research institutions looking for people with asthma to take part in their research studies.

We consulted with people with asthma and found that they would like to hear about opportunities like these even if they were not led or endorsed by Asthma UK. Asthma UK has since developed a set of guiding principles and documents which will enable us to ensure that we only assist with recruitment for volunteers to research studies that meet our criteria. These include checking that the research is funded by a reputable organisation, that people affected by asthma will be well-informed of progress throughout the research study and of the results obtained after it has finished, and also that the correct ethical approval has been obtained. We will also provide information for participants and researchers to ensure that as much benefit is gained from the involvement of people affected by asthma as possible. Please note that we only assist with recruitment to research studies for adults, not children, however there is often the opportunity for parents to get involved in research on their child's behalf.

## **What Asthma UK is looking for in its Research and Policy volunteers**

Anybody aged 18 upwards who is affected by asthma and has an interest in asthma research or campaigning for Asthma UK can become a Research and Policy volunteer.

You do not need to have a scientific or research background, nor do you need experience in campaigning in order to take part.

If you are particularly interested in our research work, you will feel the greatest benefit from the experience if you are willing to familiarise yourself with medical and research language and have a genuine interest in research to help us understand more about asthma, how to treat it and ultimately how to prevent it developing in the first place.

There will be the opportunity to work independently, for example reviewing research grant applications and submitting feedback, however for some of the opportunities, eg being a member of our Research Committee and assisting with the development of our research strategy, you will need be confident in communicating in a mixed group of researchers, healthcare professionals and people with asthma. You should also have the ability to listen to others and express your own views about the concerns of people affected by asthma in discussions.

If you are particularly interested in our policy and parliamentary campaigns work, all you need to have is an interest in improving the lives of people with asthma and to be willing to share your experiences with Asthma UK in order to help us develop policies and carry out effective campaigns. If you are interested in campaigning or sharing your experiences with other audiences, you should have the ability to express your own thoughts and feelings and be confident enough to do so. It may be helpful to have some experience of talking in group situations with different audiences.

Overall you should be willing to learn new skills, share your experiences and have a genuine interest in research and policy. The staff at Asthma UK will be on hand to provide you with relevant support and advice at all times. Training and inductions may also be provided, depending on the specific projects and initiatives involved.