Frequently Asked Questions about MRF/Asthma UK Research Grants and lay involvement in the grant process

Q1. Why are we being asked to write a lay summary?
A1. In 2009 Asthma UK introduced greater involvement of lay people in their research funding programme. Each application that is submitted to one of their funding rounds (including the 2015 Research Grants jointly funded by the Medical Research Foundation (MRF) and Asthma UK) is reviewed and scored by up to six scientific reviewers and four to five lay reviewers, one of whom will also sit on the Research Review Panel.

The lay reviewer’s role is not to comment on the science of the application, but to ensure that the research proposed is of relevance and importance to people affected by asthma. They provide the unique and important perspective of someone affected by asthma. To help them review your application, the lay summary needs to contain enough information for the lay reviewers to assess the relevance and importance. It should also be written in such a way that a non-scientist can understand the project plans – this may be the only section of the form to which a lay reviewer will refer. Without a clear, detailed and thoughtful lay summary, the lay reviewers will have difficulty assessing your application against our review criteria and providing constructive feedback for the Research Review Panel and the applicants.

Q2. Who are the lay reviewers?
A2. The lay reviewers and lay panel members are selected from Asthma UK’s Research and Policy volunteer group. They are people affected by asthma (either they have asthma themselves or are carers of people with asthma) who are not health care professionals or asthma researchers. The criteria for becoming a lay reviewer are to:

- know what it is like to live with asthma, usually either having asthma themselves or through caring for someone with asthma
- be enthusiastic about research and be willing to familiarise themselves with medical and research language, although a lay reviewer does not need to know about current asthma research or be able to understand complex scientific terminology
- be able to listen to others and express their own views in discussion
- be comfortable discussing research involving animals and with Asthma UK’s position on animal research
- have a reasonable level of literacy.

Asthma UK’s lay review group come from a diverse range of backgrounds and reflect the different perspectives of people with asthma in our grant round process. The role of the lay reviewers is to reflect the diverse perspectives of people affected by asthma, as opposed to representing the views of all people.

Q3. Does the Medical Research Foundation (MRF) have any lay representatives in the 2015 MRF/Asthma UK Research Grants round?
A3. The review processes normally used by the MRF and Asthma UK are different in some aspects. Given Asthma UK’s experience in supporting asthma research, applications for the 2015 MRF/Asthma UK Research Grant round will undergo Asthma UK’s normal review process, which complies with the Association of Medical Research Charities’ best practice guidelines.
Asthma UK has well-established and highly respected processes for involving people with asthma in their research funding programme. Given that the MRF funds medical research across a broad spectrum of disease areas, Asthma UK will coordinate the lay involvement aspects for the 2015 MRF/Asthma UK Research Grant round and involve Asthma UK’s existing group of lay reviewers. Although Asthma UK works closely with the lay reviewers to facilitate their involvement, they remain impartial in the review process and each lay reviewer assesses applications independently and based on the defined review criteria.

The Research Review Panel for the 2015 MRF/Asthma UK Research Grants round will be an ad-hoc panel, formed of scientific members nominated by each research charity, as well as up to six lay members nominated by Asthma UK.

Q4. What value can lay reviewers have?
A4. Lay reviewers can:
- ensure that the research funded is of importance and relevance to people affected by asthma
- comment on the practical aspects of recruiting and involving people with asthma in research studies
- offer a different perspective to that of scientific reviewers
- help to ensure that the research doesn’t just measure outcomes that are identified and considered important by researchers.

Q5. I would assume that lay reviewers have gained considerable knowledge about their condition and therefore agree to review or sit on a review panel. Surely they are therefore not to be regarded as ‘real’ lay people?
A5. Lay reviewers are there to complement the role of the scientific reviewers. It would not be possible for a small group of people to represent the voices of all people with asthma in a similar way that it would not be possible for a scientific expert to comment from all perspectives in their research area.

In order to avoid the group becoming ‘professionalised’, lay reviewers and lay Panel members sit in their role for three to four years before retiring, similar to scientific members of the Research Review Panel.

Whilst training is given to lay reviewers to support them in their role, this is not to increase their scientific knowledge, but focuses on what is expected from a lay review. It is therefore imperative that the lay summary is written in plain English.

Q6. Isn’t there an issue as lay reviewers won’t be able to understand the science?
A6. Asthma UK’s lay reviewers have successfully reviewed applications on complex basic research applications in previous grant rounds. The most important thing is that the lay summary was written in plain English and includes enough information for the reviewer to understand what the project aims and methods are, what will be expected of participants, and what the impacts may be for people with asthma. Complex ideas in research can be readily learned if they are explained without jargon.
Q7. I'm still not convinced that the time spent writing a lay summary is worthwhile. Are there any other reasons for doing this?
A7. Yes. Your proposal will not only be reviewed by scientific peer reviewers but also discussed by our Research Review Panel members. The scientific Panel members represent a broad spectrum of basic and clinical researchers, so not all Panel members will be specialists in your particular field of research. The lay summary can therefore also serve the purpose of clarifying unfamiliar/specialist terms or methodologies used in the application.

In addition, if you are able to clearly communicate the purpose of your research in your application, whether basic or clinical, the chances are that you will also be able to successfully report and disseminate the outcomes of your project. An increased awareness of your research can equal additional funding, enhance career development and help to build new partnerships to propel your work. So, quite simply, learning how to translate your work into plain English is a skill that can benefit your research in numerous ways.

Finally, your lay summary will be used for publicity and fundraising purposes should your application for funding be successful. It must therefore be clear enough to describe to members of the public what your research plans are and what the potential impacts may be for people with asthma.

Q8. Won’t lay reviewers be biased against basic research applications?
A8. In reality research funders often find that the opposite is true. In Asthma UK’s 2014 Innovation Grants round, the top 15 highest scoring grant applications for lay reviewers comprised 13 basic research proposals and two clinical, and in the 2013 Project Grants round the top 20 highest scoring grant applications for lay reviewers comprised 13 basic research proposals and four clinical.

Q9. What criteria are the lay reviewers using to assess our applications?
A9. Lay reviewers who are members of the Research Review Panel will be scoring your application against relevance to Asthma UK’s Research Strategy (found here) and also against relevance and importance to people with asthma. Further lay reviewers will then be assessing your application for importance to people with asthma only. We provide thorough guidance and support for our lay reviewers and ask them to consider the following aspects:
   - Is the research important to people affected by asthma?
   - If the research involves people affected by asthma as participants, does it seem feasible and realistic on a practical level?
   - What is the likely impact of the project and how could this help someone affected by asthma?
   - Is the project a good use of charitable funds?

Q10. Will the lay reviewers be scoring our applications?
A10. Lay reviewers will give a score for your application which will then be used as a guide for the Research Review Panel when deciding which applications to fund. When lay review was introduced to the review process in 2009 there were long discussions around how best to weight scores such that lay reviews carried an appropriate weighting but would also remain meaningful. Since then, we have used the scoring ratio of 3:1 in terms of scientific review:lay review, and a weighted score is calculated as such for each application.

Feedback from applicants, scientific reviewers and lay reviewers involved in previous grant rounds has almost unanimously indicated that this scoring ratio should remain the same.
Q11. Do you have any tips for writing a lay summary?
A11. Over the years we have compiled the following top tips for writing a lay summary based on feedback from lay and scientific reviewers and applicants involved in our grant rounds.

- Write your lay summary as if it's for a major broadsheet newspaper or a journal such as the Economist.
- The first sentence is crucial - you need to engage the reader and invite them to read on. Try to explain your research in 25 words and then use this as your first sentence.
- Set the scene carefully and explain how your work fits into the bigger picture. Do not, however, use the summary to explain what asthma is – the summary will be reviewed by people with personal knowledge of the condition.
- Give the reader a reason to care about what you do - explain how your work will help people affected by asthma, even if this is a long way off.
- Find a balance between accuracy and information overload - avoid using too much jargon, technical and scientific terms and acronyms. If you can’t avoid some technical terms, make sure you explain them clearly. This doesn’t mean you should shy away from explaining complex ideas or methodology – just make sure you explain them in plain English.
- Your primary aim is to be easily understood - avoid overly complicated English and uncommon, overly academic words.
- Be wary of using complex, logical arguments - short sentences and brief arguments will make your research much easier to digest.
- Think about the order and structure of information - use headings and bulleted lists to break up the text, for example using headings such as: Background, aims and objectives, methods (including implications for participants and details of planned procedures), timelines, impact and dissemination plans.
- As alluded to above, explain carefully the methods of your proposed project, particularly if people with asthma will be taking part in your research. For example, lay reviewers regularly ask for more details over planned bronchoscopies and other invasive procedures as they may have concerns around feasibility and justification of such methods. By giving them sufficient information and a clear justification, you allow them to make a balanced assessment of your plans and to provide constructive feedback.
- Check spelling and grammar closely - any mistakes will undermine your message.
- Finally, to help you view your work from an entirely different perspective, ask at least one non-scientist (this could be a patient, friend or member of the family) to review your lay summary and point out phrases or concepts they don't understand.

For more information on writing a lay summary, please visit the following pages of Asthma UK’s website.

Q12. Do you have any examples of ‘good’ lay summaries?
A12. Yes. One of Asthma UK’s researchers, Dr Ian Sayers, has kindly agreed to share the lay summary he submitted as part of his application to Asthma UK’s 2013 Project Grants round. This summary (copied below) received very positive feedback from our lay reviewers and we have highlighted several key aspects which help to make it an effective summary.
**Lead Applicant:** Dr Ian Sayers, University of Nottingham

**Lay Title:** How do altered forms of newly identified patient’s genes (called IL33 and ST2) cause asthma and can we learn from this to design new treatments?

**Lay Summary:**
It has long been known that asthma runs in families and that genetic abnormality in peoples’ DNA are important when we talk about risk of developing asthma. We aim to take recent genetic information forward and try to understand what is altered in the lungs of people with asthma that carry these genetic abnormalities, the first step to targeting changes for clinical benefit. This is important as there is a need for new more effective treatments in asthma, particularly for those patients that do not respond well to existing drugs.

The opening paragraph sets the scene – what is the issue, what has previous research shown, and why does it matter to people with asthma.

**What we have done so far:**
We have important new information about genetic abnormalities in asthma, i.e. that altered forms of two genes [IL33 and binding partner ST2] are strongly associated with asthma. These previously unrecognised abnormalities reveal potential mechanisms where the lungs might become affected by asthma. Importantly, our data has been confirmed by other international groups.

We have preliminary data extending this association with asthma and have found that the same abnormalities are also associated with lower lung function in asthma patients, an important finding suggesting these abnormalities may also be important in how asthma presents in patients.

Interestingly, elevated levels of IL33 has been identified in the cells lining the airways (epithelium) in asthma patients suggesting IL33/ST2 function may be altered in these cells, thus contributing to asthma. These cells are important in forming a barrier between the outside environment and the lung and respond to stimulations such as bacteria. We have confirmed that these cells have IL33 and ST2.

**What are the key questions?**
The main questions to be addressed in this proposal are; i) what asthma features are the gene abnormalities particularly important in and ii) how do these abnormalities change how the cells of the airway lining function leading to asthma.

Use of headings helps the reader to navigate the summary, and piece together the rationale for the project

When technical terms can’t be avoided, they are clearly explained

Highlighting the key questions provides focus and helps the reader to assess the main elements of the study
What we propose to do to answer these questions:
To investigate which clinical features of asthma these gene abnormalities are particularly important for we will use large numbers of asthma patient and non-asthma control DNA samples with clinical information. Through collaboration (six UK Centres including Nottingham, Manchester, Southampton, Belfast, Glasgow, Birmingham) we have access to >4,500 samples. More specifically, we will determine the effect of genetic abnormalities spanning the IL33 and ST2 genes to specific aspects of asthma including: lung function and allergic inflammation. This component of the research will link specific aspects of asthma with the presence or absence of specific gene abnormalities and may be useful in informing which abnormalities to focus on in the cell work (see below).

To investigate the effect of carrying a specific gene abnormality on cell function we will predominantly use cells previously isolated from the airway lining (via bronchoscope technique) of asthma patients and stored during other projects. Dr Shaw (Nottingham) and Professor Brightling (Leicester) are clinical co-investigators on the current proposal and have isolated these cells. We have large cell banks in Nottingham and Leicester that will be screened for IL33 and ST2 gene abnormalities. This is an important consideration as the bronchoscope technique to isolate cells is invasive and every patient cell (a precious resource) is used for as many experiments as possible so that there is no wastage. We will also use cells isolated in the same manner from people without asthma for comparison. Cells with or without the key abnormalities (10-15 per group) will be grown in Dr Sayers’s laboratory. Dr Sayer’s group has all the necessary expertise, equipment and techniques for the experiments.

The cells will be characterised for changes in the level and function of both IL33 and ST2 including how these cells respond to stimulations that are important in asthma e.g. bacteria, viruses and allergens such as house dust mite. This component of the research will identify how the gene abnormalities have affected normal cell function the first step to potentially reversing this change in asthma patients.

People involved
This study brings together a formidable team of researchers from the field of asthma research and involves six UK centres, a unique opportunity. The study includes both basic and clinical scientists with distinct but complementary skills. Dr Ian Sayers (Principle Applicant) has a long term interest in molecular mechanisms underlying asthma, particularly identifying susceptibility genes and the role of these genes in asthma biology. Professor Ian Hall (Co-Applicant) is a clinical scientist and world leader in the field of respiratory genetics and cell biology. Professor Brightling (Co-Applicant) is a clinical scientist running research programmes spanning both clinical and basic research in asthma. Dr Dominick Shaw (Co-Applicant) is a clinical scientist with a research interest in airway epithelium. All applicants have worked together previously and represent a productive research team. The current proposal
builds on established collaborations as part of the Asthma UK genetics of severe asthma (AUGOSA) initiative (IS/IPH/CB/AS/RC/LH/AM/JH/NT) and collaborations between Nottingham-Glasgow (IS/IPH/CM/NT/RC) to examine the role of IL33/ST2 in peripheral cell function.

**Relevance to asthma and associated allergies**
The first step to developing new treatments that potentially target abnormalities in asthma patients is furthering our understanding of the nature of these changes at the patient, tissue and cell level. This proposal aims to bridge this gap in knowledge for two genes IL33 and ST2 that are beyond doubt altered in asthma. The outcomes of this proposal will be essential for focussing approaches to target IL33/ST2 for clinical benefit in asthma.

**Likely timescales to impact and reason why**
This proposal sets out to identify altered biology of the airways in asthma that at least in part may lead to an increased risk of developing asthma. This will represent a significant level of new understanding. However, in reality more research will be needed including the development of new drugs to target these changes prior to potential impact on asthma patients, i.e. we anticipate at least 5-10 years prior to a clinical impact with new compounds. However, one immediate outcome will include the identification of patients were these gene abnormalities are particularly relevant. This is important as these asthma patients may respond better to drugs that target IL33/ST2.

**Relevance to Asthma UK’s research strategy**
This proposal directly addresses Asthma UK priority areas “Biology of Asthma” and “Preventing & Curing Asthma” as we aim to further our understanding of molecules and cells involved in asthma and importantly understand the role of these molecules in the increased risk of developing asthma. The identification and translation of genetic influences in asthma and the role of the airway lining have been highlighted as major gaps in our knowledge by Asthma UK (The State of Play in Asthma Research 2011). Two areas addressed in the current proposal.

**Dissemination of results**
We endeavour to feed back the results of our research to the patients involved; we also hold open days within the respiratory biomedical research unit in Nottingham to help patients and volunteers understand how their efforts have taken respiratory research forward. The outcomes of the research will also be disseminated via talks and seminars within Nottingham and via national and international conferences. Finally, the research will also be published in peer reviewed journals with accompanying press releases on the Asthma UK and University of Nottingham websites as we have done previously.