



Asthma treatment concerns: patients and clinicians working together to prioritise future research

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James Lind Alliance (JLA) partnership

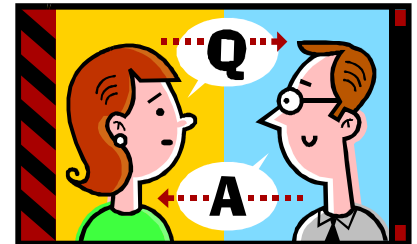


- The JLA is founded on the principle that research frequently fails to address questions that matter to patients
- Their objective is to identify and prioritise treatment uncertainties that are shared by patients and clinicians
- Asthma UK and the British Thoracic Society formed the first partnership in February 2005

Identifying patient concerns



- Asthma UK developed a postal questionnaire and a web survey to reach as diverse a group as possible
- The questionnaire was refined by the asthma working group to ensure it was easy to understand and relevant information would be obtained



- The question we asked was:

If you had the chance to ask an asthma scientist, doctor or nurse about the most important unanswered question you have about your asthma treatment or your child's asthma treatment ... what would you ask them?

Identifying patient concerns



- **Mailed out 1,200 questionnaires**
 - Response rate was approximately 14%
 - Each response generated approximately 3 treatment uncertainties
- **Website survey ran for two weeks**
 - Generated over 200 responses
- **Working group comprising patients, clinicians and Asthma UK staff set out to categorise the responses**



Identifying patient concerns



- **Examples of treatment uncertainty responses:**
 - *‘How will inhalers and tablets affect my children after 20 years or more of daily use?’*
 - *‘I would like to know more about injections and breathing type exercises to help my condition. You are only told about prescription medication, never about complementary medicines’*
 - *‘Do the asthma steroid based inhalers inhibit natural growth of the child e.g. height, weight?’*
 - *‘What is the best way of dealing with allergies to cats & dogs?’*

Identifying clinicians concerns



- The British Thoracic Society used the British Guideline on the Management of Asthma to identify treatment uncertainties
- This guideline is based on the most up to date medical evidence
- It provides treatment recommendations based on the level of evidence
- From this guideline clinicians were able to identify treatment uncertainties based on lack of evidence

Categorising treatment uncertainties



- The working team teased out the treatment uncertainty from each response
- Identified a series of key words
- Linked key words to broad categories
 - Adverse affects
 - Asthma management
 - Co-morbidities
- Developed a taxonomy to classify responses
 - 12 categories
 - 2 further sub-categories for each
 - Adverse effects - drug - steroid



Prioritising treatment uncertainties

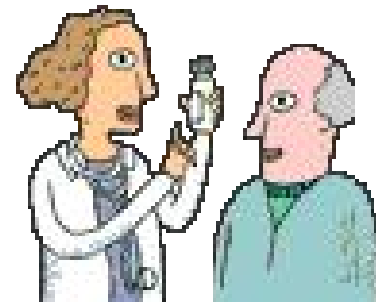


- The frequencies of each category and associated sub categories were calculated
- These were ranked and the top 21 patient and clinician treatment uncertainties went forward to a prioritisation exercise
- At the prioritisation meeting smaller groups comprising people with asthma, researchers and clinicians initially ranked the 21 priorities
- This was followed by further discussion and a final rank order was established. Ten priorities will be written up in a format that can be taken to funders in the hope of obtaining funding for research in these areas

Top ranking patient concerns



- Across all ages and genders one of the largest concerns for people with asthma is the potential side effects of asthma medication
- People with asthma want better information that will help them to control their asthma more effectively. This includes general management information eg potential triggers, value of flu vaccine



- Many people have more than one condition and this often means that they are seen by more than one specialist. People with asthma want to know the most effective way of managing asthma in such cases

Prioritising treatment uncertainties



- People with asthma want to know more about the benefits of using non pharmacological interventions eg vitamins, breathing exercises and role of diet



What worked and what didn't?



- It was difficult to explain to people with asthma what was meant by a treatment uncertainty



- Patients value opportunities to engage in research
- Patient input can really focus research and ensure that the outcomes are more relevant