Identifying and overcoming challenges in asthma care and self-care

<u>Cochrane Airways</u> ran a workshop with 15 people with asthma and parents of teenagers with asthma, and 5 healthcare professionals. A full report of the <u>workshop is available here</u>. Participants identified and voted for the following research questions:

What is the most effective way of organising local asthma services to ensure all people with asthma can access information & support? (e.g. specialist nurses)

Education about living with asthma (reducing social stigma) AND training to help children having asthma attacks for teachers. A) Managing attacks/worsening symptoms; B) general awareness - "normalising"

What is the best way to ensure access to up-to-date, relevant information about regular treatments & how they work & ensuring appropriate understanding? (i.e. taking it when well) - For different populations

What is the effect of understanding your asthma attack & having a personalised asthma plan (based on what has worked before?)

What do we know about the short-term and long-term effects of regular medication (e.g. steroids), how much is safe, when to 'step up' or 'step down'?

What is the best way to achieve shared understanding between doctors + patients with acute asthma?

Reasons for not taking medications (e.g. oral steroids) for patients are different to what doctors are thinking (oral steroids make me crazy; I can't sleep on steroids versus bone density)

How do we work in partnership with patients & empower them to treat asthma alongside other conditions & consider how drugs & symptoms overlap & interact?

Asthma acute attack and anxiety: do the following help? Using a pulse oximeter at home to measure oxygen; fast-track asthma service; phone application for monitoring asthma; being told nothing works

For teenagers + adults - does learning how to stay calm (breathing/yoga) help you to manage asthma attack?

What evidence-based self-help (e.g. diet, vitamin D, exercise) measures are useful in controlling long-term symptoms/asthma?

Drs/consultants/nurses/other healthcare professionals talking to each other. More joined-up thinking (e.g. consultant advises treatment which GP prescribes)

After the workshop, the editorial team met to decide which of these research questions could be turned into Cochrane review questions. We incorporated the workshop discussions with mapping of existing Cochrane Reviews, clinical experience and knowledge of the research base available to answer each question. The research questions outlined in bold above are being taken forward as new Cochrane Reviews.



What next?

Using the research priorities from the workshop, and through a process of discussion, we decided to commission the following reviews. We plan to work on these reviews from December 2014 to May 2017.

- Educating school staff about how to respond to an asthma attack and awareness of asthma
- Lay-led and peer support interventions for teenagers and adults with asthma
- Personalised asthma plans for people with asthma
- Stepping down courses of inhaled steroids for people with asthma
- Shared decision-making for people with asthma
- High dose versus low dose oral steroids for asthma attacks
- Pulse oximeters at home for people with asthma
- Fast-track asthma services for people with asthma
- Cognitive behavioural therapy (CBT) for teenagers and adults with asthma
- Relaxation therapy & other coping strategies for use during an asthma attack

What else did we learn?

This was a fantastic opportunity to hear what people said about living with asthma. We asked "What does 'control' mean to you?" and someone said "choosing life". People are interested in finding out how they can live with asthma. Goals were planning holidays, stopping exacerbations, reducing oral steroids, using reliever inhaler as little as possible, knowing what to do when you have symptoms, being symptom free, managing everyday routine and avoiding hospitals. Each personal goal may not be possible to capture in a clinical trial, but we should be mindful of them when we are working.

In many ways, these markers of asthma control are remarkably similar to the 'research outcomes' used in trials and Cochrane reviews, but they are framed in a more aspirational and positive way.

"To do what I want – everything I want to do"

We heard that quality of life is not a concept discussed at the doctors. It would be great if people could speak with their doctor about what quality of life means for them and set meaningful goals for symptom control from this discussion.

We need to be mindful of framing research outcomes in a more patient-focused way. For example, we usually measure the number of hospital admissions which is often reported in clinical trials, but length of stay may be just as important.

Many people discussed side-effects they experience on oral steroids such as mood swings and insomnia, but they said these are not frequently discussed with GPs. Long term side effects like osteoporosis do not feel relevant at the time, when you have to live with side-effects which impact you and those around you.

Asthma can be disempowering – "doctors and nurses can become anxious and you end up feeling like a patient rather than a person managing a long-term condition". Seeing David Beckham use his inhaler was empowering, so people wanted to see more celebrities using inhalers in public.



"We need to know what works for us and not just what the professional says might work."

People with asthma need help and support from friends, family, teachers and colleagues, but they also need support from healthcare professionals when things go wrong. In the UK, consultants in hospitals can recommend treatments which then the GP has to prescribe – sometimes resulting in long delays in getting treatments. People with asthma are human; sometimes they lose their inhaler and need a new one right away, but struggle to make an appointment.

A teenager spoke of the vicious cycle of putting on weight due to taking oral steroids, but the weight makes it harder to exercise and self-esteem goes down.

It was good for us to simply talk with people with asthma and remember what the work we do is really all about.

Further information

Cochrane Airways have already published a number of other reviews on interventions for asthma including lifestyle interventions which people can do alongside taking their medications. The following selected reviews are relevant to issues raised in the workshop about managing asthma alongside medications, however more Cochrane reviews can be found by searching www.summaries.cochrane.org.

Breathing exercises improve asthma symptoms and boosted quality of life according to a review by Freitas and colleagues. Most breathing exercises are designed to be used in an asthma attack to calm people, so although this was not examined in the review, people at the workshop and in the survey said that breathing exercises were helpful. They are unlikely to be harmful, unless they prevent people from going to hospital when they need to.

Exercise was shown to be well-tolerated, with no adverse events <u>in a review by Carson and colleagues</u>. Fitness was improved and exercise appeared to increase quality of life in accordance with the advice from Asthma UK "<u>Exercising regularly makes you feel good and is great for your body in lots of ways</u>". <u>Swimming may be a good form of exercise for people with asthma.</u>

Based on evidence (including a Cochrane review), methods to reduce house dust mite allergen levels in the home are not recommended in UK guidelines. Reducing exposure to a number of different allergens in the home and in food may reduce the likelihood of children being diagnosed with asthma. But reports of reduction in asthma from lowering exposure to a single allergen are inconclusive.

You can get more information about living with asthma from Asthma UK or the NHS website. <u>UK asthma guidelines</u> are published by the BTS/SIGN.

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