

"Identifying and overcoming challenges in asthma care and self-care"

**A workshop supported by the National Institute for Health Research, UK
Cochrane Centre and the Cochrane Airways Group.**

Thursday 2nd October 2014

Workshop report

1. Background to Cochrane Airways Group and the workshop

Cochrane Airways is a group of authors and editors that forms part of the Cochrane Collaboration, which is a not-for-profit, independent, global network of over 28,000 people working together to provide the best evidence for healthcare decisions. There are over 5,400 Cochrane Systematic reviews published on clinical questions ranging from pregnancy through to falls in the elderly; chemotherapy to yoga and many more.

The Cochrane Airways Group works with authors (typically health professionals and researchers) to produce over 280 systematic reviews on asthma, chronic obstructive pulmonary disease (COPD), bronchiectasis and other lung diseases.

Systematic reviews are important tools for making decisions in health care. They help organisations that purchase healthcare services fund the right treatments and care packages, they help general and specialist health professionals, and the public keep up-to-date with evidence of what works and what doesn't, and they help guideline producers develop clinical guidance (advice to health professionals based on the most up to date evidence) that is appropriate, helpful and consistent wherever people access health care services and treatment. A typical systematic review question might be "Is giving reliever drugs through a spacer as effective as delivering them through a nebuliser for people having an asthma attack?". All the evidence for that question is gathered, quality assessed and where possible the results are combined to give an overall answer to the question.

Getting the right question is crucial to the process, the Cochrane Airways Group is interested in what people with asthma and specialist health professionals think are useful questions that will have an impact on people with asthma and the services they use.

As well as getting the right questions the Cochrane Airways Group was very interested in knowing what research outcomes (results) are most important to people making decisions about the management of asthma, and those living with asthma or caring for a person with asthma. These two factors were the backbone of the workshop discussions.

2. Workshop participants

Eighteen people participated in the workshop (5 had to pull out at the last minute). Participants ranged from health professionals (GP with interest in respiratory medicine, practice nurse, asthma clinic nurse, respiratory physiologist, children's respiratory specialist), adults and teenagers with asthma (severe asthma, longstanding asthma) and two parents of teenagers with asthma. The team felt that people with mild asthma were not represented at the workshop.

There were three small group facilitators, three support people for the small groups which included members of the Cochrane Airways Group, and a medical librarian (who was also observing for the day).

Background papers sent before the workshop outlined the purpose of the day, how it was going to run and some information about the Airways Group, Systematic Reviews and Research Outcomes.

3. Workshop objectives

- ▶ Discuss living with asthma and asthma treatments, in three key areas. **Agree the issues** that the Cochrane Airways Group need to consider for their systematic reviews
- ▶ To agree which of these **issues matter most** in terms of developing research questions for reviews of research
- ▶ Discuss research outcomes (results) in asthma research reviews, talk about the **most important** for reviews of asthma research

4. Workshop outline

The workshop programme is available in Appendix 1

Following some introductions of the team and the participants, the scene was set for the day, with focus on maximum participation.

In the morning the group discussed three topics in large, and small groups;

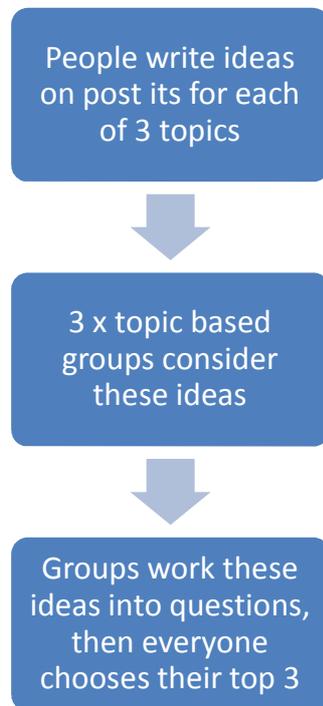
Group 1. What do you do when you have an asthma attack?

Group 2. What are the problems/issues you face in taking your regular inhaler?

Group 3. What helps you (or not) to control your asthma?

Following clarification of the topics (*on Topic 2 mainly, it was reworded to taking any regular medication including inhalers*) people made note of their ideas on numbered post its. All three topics were populated with plenty of ideas and questions and the relevant post its were taken through to the small group as a starting point for discussion. As concrete research ideas and questions emerged from the small groups these were agreed and then written up on A2 paper. Each group was aiming for about five fully discussed questions.

The questions were ranked in the small groups with each participant identifying their personal number 1, 2, and 3 questions.



Following lunch all participants were encouraged to read each of the questions from all three groups and make comments on these using post its. A process of large group voting followed, enabling the team to identify 10 important research questions across these topic areas.

The group then considered research outcomes (results) from an individual, and group perspective. Emma Welsh from the Cochrane Airways Group, outlined what a research outcome (result) looked like and gave examples of those used in systematic reviews, and how often they are used in reviews. Discussion and comments from participants included clarifying what some outcomes meant, e.g. withdrawal, and functional status.

One participant pointed out that for each of the research outcomes, confounding factors (things that might be affecting the research outcome unrelated to the intervention being considered) and need consideration. An example of this discussion was the outcome of 'hospital admission' where an elderly patient living alone with no downstairs toilet/bathroom may be likely to be admitted to hospital.

We then focussed on research outcomes that participants felt were important to either people with asthma or health professionals that treat and look after them. The health professionals worked together in a group with three small groups of people with asthma. To help this discussion people were asked to address the following questions:

1. What are the **five most important** areas of your life at present in relation to your asthma treatments and self-care?
OR
2. What are the **five most important** things you would like your asthma treatment and self-care to achieve?
OR
3. What are the **five most important** research outcomes that would help your clinical/professional asthma practice?

Some participants found naming five too much, others not enough and had to decide which ones to include in their top five. Once participants had settled on their 5 outcomes they distributed them on pre labelled posters around the room that had existing outcome themes according the category that they felt best fitted their important outcomes. For these labels we used outcomes currently used by the Cochrane Airways Group, and suggested via a Face Book survey with Asthma UK members, plus an 'other' category for those that didn't fit anywhere.



5. Results

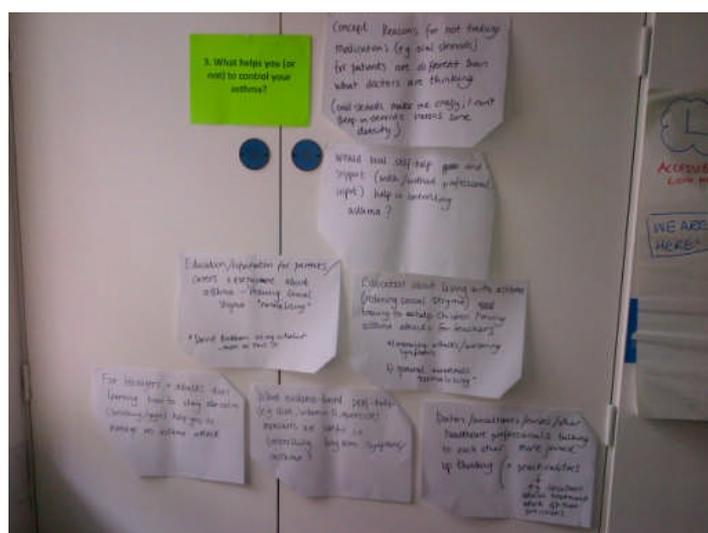
5.1 Results from morning discussion: most important research questions for reviews of asthma research

All participants were given 10 stickers to use on the 23 questions generated by the three small groups. They were advised that they could use 2 stickers for questions that they thought were particularly important - but no more than that.

The 12 most voted for questions, and the group that they came from are described below.

Group	Research question	Votes	Rank
Grp 2	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)	20	1=
Grp 3	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"	20	1=

Grp 2	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	18	3
Grp 1	What is the effect of understanding your asthma attack & having a personalised asthma plan (based on what has worked before?)	13	4
Grp 2	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'?	10	5
Grp 1	What is the best way to achieve shared understanding between doctors + patients with acute asthma?	9	6
Grp 3	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)	8	7=
Grp 2	How do we work in partnership with patients & empower them to treat asthma alongside other conditions & consider how drugs & symptoms might overlap & interact?	8	7=
Grp 1	Asthma acute attack and anxiety: do the following help? Using a pulse oximeter (measure oxygen); a fast-track asthma service; phone application for monitoring asthma; being told nothing works	8	7=
Grp 3	For teenagers + adults - does learning how to stay calm (breathing/yoga) help you to manage an asthma attack?	8	7=
Grp 3	What evidence-based self-help (e.g. diet, vitamin D, exercise) measures are useful in controlling long-term symptoms/asthma?	8	7=
Grp 3	Drs/consultants/nurses/other healthcare professionals talking to each other. More joined-up thinking (+ practicalities - e.g. consultant advises treatment which GP then prescribes)	8	7=



5.2 Results from afternoon discussion: most important research outcomes (results) for reviews of asthma research

All participants discussed and chose their five most important research outcomes, and then assigned them to the categories where they fitted best.

Outcome heading In order of most number of people that identified outcome	Outcomes as described by participants	Number of post its
Quality of life	<ul style="list-style-type: none"> • Quality of life (x 3 post its) • Keeping my current level of health and mobility • Being able to go out in the cold weather without wheezing • Doing everyday activities; play sport, walk, run etc • Not to think about asthma! • To be able to travel (prohibitive drug regime and travel insurance) (x2 post its) • Better air quality in towns and cities, as this restricts me from doing stuff • Not going into hospital • Being there for my grandchildren • Eliminate or reduce constant cough - it restricts what I do and irritates friends and family 	12
Asthma Control	<ul style="list-style-type: none"> • To be able to run every day even if I choose not to • To have better exercise tolerance • Having symptom free days and avoiding further drugs • Reducing daily symptoms, x 2 • We need an overall 'measure' of asthma control • Having a written action plan - including clear steps for medication changes and when needed (based on previous best personal and predicted values) • Not waking up at night • A good nights sleep • Not waking up at night with symptoms • To be able to maintain my attendance at work through good control of asthma 	11
Relationships with care/treatment providers/health	<ul style="list-style-type: none"> • An open, honest and ongoing relationship with my GP/asthma nurse enabling my drug and care choices to be assessed and discussed 	6

professionals	<ul style="list-style-type: none"> • As above so that I can appraise new products and thinking about asthma • Developing a sense of trust and involvement in my care (considering co morbidities) • A discussed and written plan with health professionals that takes into account my co-morbidities • Avoiding drug changes by health professionals without consultation • How to ask some patients difficult questions such as sex 	
Use of rescue medication	<ul style="list-style-type: none"> • Do I need blue inhaler? • How to reduce the amount i.e. take as little as possible • Overuse? • To be able to go out cycling without a rescue inhaler • Access to prednisolone 'out of hours' so that I can start rescue meds when I need them most 	5
Flare ups - leading to oral steroids, hospital admission, trip to A & E etc	<ul style="list-style-type: none"> • Avoiding hospital • Reduce frequency of attacks • Exacerbations requiring steroids • Not to need prednisolone again • Chemical Air Pollution 	4
Access to health professionals and hospitals	<ul style="list-style-type: none"> • Ease of access to health care professionals and specialist services • Access to consultations • Access as attacks can come severely and quickly • Raising individual's awareness of an acute attack - what works for which people? 	4
Lung function tests (e.g. peak flow meter)	<ul style="list-style-type: none"> • Objective measures in children • Stabilising my lung function • Excellent lung function - never to struggle for breath again • Predicting those at most risk in early years of asthma 	4
Side Effects of treatments	<ul style="list-style-type: none"> • Long term and side effects of steroids • Side effects of inhaled treatments • Side effects of oral steroids (taken for exacerbations) 	3
Biological markers	<ul style="list-style-type: none"> • Children's height • Testing reversibility is important in diagnosis • Defining different asthma phenotypes 	3
Confidence about ability to self manage (or care for)	<ul style="list-style-type: none"> • Predicted measurements, personalised measurements 	3

	<ul style="list-style-type: none"> • Independence in my home environment • Managing my own care (avoiding professionals) 	
Education about asthma	<ul style="list-style-type: none"> • Knowing what patients want and need to know • Understanding pro and cons of different treatments so that I can make good choices (with professional advice) 	2
Cost effectiveness (new category)	<ul style="list-style-type: none"> • Cost effectiveness • Being able to easily and cost effectively take treatments (financial implications of easy to use devices) 	2
Adherence/compliance (new category)	<ul style="list-style-type: none"> • Medical adherence • Increasing patient compliance 	2
Anxiety about asthma	<ul style="list-style-type: none"> • Give me the confidence that I can live a full life without fear of my asthma limiting me/getting worse 	1
Serious adverse events	<ul style="list-style-type: none"> • Mortality (death) 	1
Other	<ul style="list-style-type: none"> • Recognition of learning from mistakes • Validity of diagnosis % who actually have asthma! • Hospital advisor • Focussing on symptoms is important 	4
Social Stigma		0
Adverse events		0

6. Discussion on some of the more popular outcomes

Quality of Life (QoL)

QoL generated the most top five post its and the discussion ranged from measuring QoL using different scales, difficulty creating a QoL questionnaire, validation, practical difficulties with usage, QoL varying from day to day and week to week etc, healthcare professionals using of QoL questionnaires.

A participant suggested using coloured dots to distinguish patients and healthcare professionals so Sally Crowe requested a show of hands for those who had added post-it notes to this research outcome; a mix of patients and healthcare professionals had prioritised QoL research outcomes. However it was recognised that commissioners of services might have different priorities for outcomes, especially in the cost of asthma services and treatments.

There was further discussion around adherence (compliance or sticking to) to medication, fertility, co-morbidities (other medical conditions alongside asthma), importance of reporting mortality (death) in research, primary (most important and main) outcomes, patient reported outcome measures (PROMs - where the patient records aspects of their health), patient experience, need for patient involvement in developing outcomes, and partnership working between patient and clinicians.

Asthma Control

In the Group 3 discussion in the morning, before research questions were generated, they described what they saw as Asthma Control, see below. This was shared with the whole group and an overriding message of this discussion was the need for a more positive spin in how asthma control is perceived as an outcome for asthma research. Too often outcomes (in reviews and clinical trials) may be negative in tone and not reflect the aspirations of people with asthma to choose life. Another interesting discussion point was the aspiration of being 'drug free' (or reducing drugs), and the health professionals focus on compliance/adherence to treatments.

What does “control” mean to you?

- Action plan
- Routine
- Plan holidays
- Managing, for day to day living
- Symptom free
- Stop hospital admissions
- Stopping exacerbations and so reducing oral steroids
- To do what I want – everything I want to do
- Knowing what to do when I have symptoms (use of inhalers)
- Using blue inhaler as little as possible (using preventer)
- Education of others to help e.g. teachers
- Help from others – e.g. GP when need to replace inhaler when mislaid (quickly! Not in 48 hours)... support (perceptions)

7. What will happen to this information? Next steps

Emma and Chris will work together with other members of the Cochrane Airways Group and use the 12 most voted for questions to create ten Cochrane Reviews questions. This might involve splitting some of them up into more than one smaller review topics. It may be that we already have Cochrane Reviews that answer a question, or the question is not really suitable for a Cochrane review. This process will be quite involved, though we will try and remain true to the themes and topics and concerns that were discussed in the workshop. We will send participants the list of review topics and everyone will have a chance to comment on the questions before the end of 2014.

We will then commission the protocols (plan) for the reviews to be written. We will invite workshop participants to comment on the protocols.

We will let participants know when each review is published. When all the reviews are published, we will prepare a leaflet/newsletter to explain the results from all the reviews.

8. Workshop evaluation

12 forms completed a mix of people with asthma and healthcare professionals (using named forms as an indicator, 18 participated - 5 left early before completing evaluation = 12 of 13 returned).

What did you enjoy and/or find most useful about the workshop?

Comments about participants

- Discussion between HP's and people with asthma/parents, hearing other views and experiences
- People participating - great
- Hearing patients' and parents points of view

Discussion

- Thinking and talking about asthma from so many different viewpoints
- I felt listened to and taken seriously (person with asthma)
- Hearing what people with asthma want from health professionals
- Diverse range of opinions
- What a complex subject we picked (topics from morning)
- Everybody contributed and variation of views confirmed
- Particularly enjoyed the reactions to the outcomes discussion and the small group work

Other

- Looking forward to hearing about priorities and project outcomes
- Enjoyable and useful
- I learned a lot
- Stimulated by experiences of others
- People facilitating - brilliant
- It has empowered me to improve my relationship with my GP/Nurse and the basis of the ideas discussed today

Any changes or improvements that would you recommend? (E.g. the venue, workshop materials, facilitators, workshop content etc.)

- Is "what is important to me?" the right question to ask about outcomes for people with asthma? This may bias them not to talk about more functional outcomes.
- More health professionals participating
- More people with mild/moderate asthma participating
- The style of working was very 'active' and may not have been reflective enough for some
- Challenge of keeping the discussion in the context of systematic reviews
- Can this approach be replicated?



Did the workshop meet its aims?	1	2	3	4	5 (4)	6 (11)
How useful has the workshop been to you, and/or your organisation?	1	2	3 (1)	4 (1)	5 (7)	6 (7)
How would you rate the workshop overall?	1	2	3	4 (2)	5 (4)	6 (10)

Venue feedback:

- Too much noise and too hot (x3)
- It was "so hot and noisy" with the drilling etc
- Toilets not flushing

Acknowledgements

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Workshop team;

Facilitators: Sally Crowe, Sandra Regan Crowe Associates Ltd
Leanne Metcalf - Independent Facilitator

Support roles and observer;

Ann Daly - Crowe Associates Ltd
Chris Cates and Emma Welsh (Cochrane Airways Group)

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Appendix 1 - workshop programme

10.00	Registration, tea and coffee	
10.30	Welcome and setting the scene for the workshop <ul style="list-style-type: none"> • What we want to achieve in the workshop, getting to know each other and working together • What is the Cochrane Airways Group? • What is a systematic review and why are they important? 	Sally Crowe Chris Cates Emma Welsh
11.00	Introduction to the 3 topics for discussion What do you think about these topics?	Chris Cates Sally Crowe
11.30	Small group discussion: 1. What do you do when you have an asthma attack? (Main Room) 2. What are the problems/issues you face in taking your regular inhaler? (Drayton Room 2) 3 What helps you (or not) to control your asthma? (Drayton Room 1)	Facilitators: Sally Crowe (1) Leanne Metcalf (2) Sandra Regan (3) Supported by: Chris Cates (1) Ann Daley (2) Emma Welsh (3)
12.45	Lunch	
13.30	Large group exercise <ul style="list-style-type: none"> • Commenting on the research questions from each of the small groups • What are the most important? 	Sally Crowe

14.00	Research outcomes (results) in asthma research <ul style="list-style-type: none"> • What do we mean by research outcomes (results)? • Working in pairs on outcomes (results) that matter to you 	Emma Welsh Sally Crowe
15.00	Refreshment break	
15.20	Large group discussion reviewing the research outcomes <ul style="list-style-type: none"> • How similar, how different? • How important? 	Whole group
15.50	<ul style="list-style-type: none"> • Summing up and reflections on the workshop • What happens next? 	Sally and Emma Chris Cates
16.00	Workshop finishes, goodbyes and thanks	