



A survey and stakeholder group prioritised key systematic review questions in airways disease

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ABSTRACT

Objective: Priority setting is important for healthcare research. The Cochrane Airways Group wanted to prioritise topics for systematic reviews across all chronic respiratory diseases with limited resources and according to latest Cochrane policy.

The objective was to prioritise 10 reviews of importance to the public (patients, carers, healthcare professionals and researchers) from a patient survey.

Study design and setting: We convened a stakeholder group of patients, carers, healthcare professionals and representatives from charities. We conducted an online survey to collect uncertainties about the treatment and management of respiratory disease from the public. Uncertainties were ranked by the stakeholder group, and scoping searches refined the uncertainties into systematic review questions.

Results: We received 147 survey responses. We removed duplicates and blank responses and asked the stakeholder group to rank 100 uncertainties. The first round of voting produced a list of 29 topics and the second round resulted in 12 uncertainties. These uncertainties were scoped with literature searches and teased out further into systematic review topics. We identified 3 Cochrane reviews to update, 8 new review topics, and 3 evidence gaps.

Conclusion: We successfully convened a stakeholder group and prioritised a list of uncertainties in the treatment and management of airways diseases that had been identified by patients and the public.

1. Introduction

Priority-setting has become an important part of the healthcare research process, with influential bodies such as the WHO and the NIHR (National Institute for Health Research) advising researchers to factor it into their work [1]. In 2019 Cochrane introduced a requirement for Cochrane Review Groups (CRG) to set priorities for new or updated reviews every three to five years [2]. Since 2012, Cochrane Airways, a CRG, has conducted priority-setting projects on specific clinical areas, for example in asthma [3]. Prioritising each clinical area from our large scope (including asthma, COPD, bronchiectasis, obstructive sleep apnoea, chronic and sub-acute cough, interstitial lung diseases, sarcoidosis, pulmonary hypertension and alpha-1 anti-trypsin deficiency) in turn, would be unsustainable in that time-frame. We had previously avoided doing whole-of-scope priority-setting because it felt too difficult to hold such a diverse patient population in mind and weigh such different topics against each other. However, to meet Cochrane's new requirement and to find out what is possible, it seemed developing a 'whole of scope' priority-setting method was essential.

Asthma and COPD affect an estimated 262 million [4] and 384 million [5] people around the world, respectively. In the UK COPD costs the health

service £1.9 billion annually, while asthma costs £3 billion each year [6]. These diseases dominate our review output. While there has been less research and fewer Cochrane Reviews on the less common respiratory diseases such as interstitial lung diseases, they are burdensome for the people living with them [7]. With this project, we wanted to shift the decision-making power away from the editorial team towards stakeholders.

There have been many priority-setting processes to date, many of which are based on the James Lind Alliance (JLA) process [8], including our own asthma priority-setting project [9] which began by considering uncertainties from an existing JLA process, the Asthma Priority-setting partnership [10]. Recent examples include anaesthesia and perioperative pain [11], young people with cancer [12], and type 2 diabetes [13]. The JLA process is the gold standard, but we wanted to test a simpler process that would be applicable to other Cochrane or evidence synthesis groups.

Prioritised research questions may result in the update of an existing review, reveal a gap in our scope that requires a new Cochrane Review, or they may be a true uncertainty – a question with no research evidence to answer it. Throughout this paper, we use the word uncertainties for questions identified by patients and public and Cochrane Review questions to refer to the final prioritised topics.

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2. Objectives

- Primary objective:
 - Identify up to 10 priority reviews of importance to the public (patients, carers, healthcare professionals and researchers) from a patient survey.
- Secondary objectives:
 - Engage stakeholders with expertise and lived experience across our scope in our priority setting processes
 - Identify potential new stakeholders, contributors, and funding streams.

3. Methods and materials

We developed a plan for the priority-setting exercise and published it on our website in advance [14]. The work involved four main elements:

1. Convening a stakeholder group
2. Conducting a survey of patients and the public to identify ‘uncertainties’ in the treatment and prevention of lung diseases
3. Prioritising the survey results
4. Developing PICO for Cochrane Reviews

3.1. Cochrane Airways priority-setting group (CAPSG)

We placed an advert on our website and on Cochrane’s Task Exchange platform [15] to recruit members for a stakeholder group (CAPSG). Members of the CAPSG could include people living with a respiratory condition or carers of someone with a respiratory condition, Cochrane or external stakeholders such as healthcare professionals, including doctors and nurses, people linked to organisations that are involved with healthcare research, providing patient information, developing guidelines, or research funders. Members of the CAPSG could not be employed or have received money from a drug company or device manufacturer within the last three years.

3.2. Survey - “your lungs, your questions”

We created an online survey on Google forms with three questions: 1) what lung disease the respondent (or the person they cared for) was living with, 2) what role they most identified with e.g. patient, carer, or researcher, and 3) what they wanted to know about preventing and treating lung diseases. The survey was based on a survey run by the Cochrane Heart Group [16]. We promoted the survey on social media channels and by email. The British Lung Foundation (BLF) and the European Lung Foundation (ELF) promoted the survey on social media. The survey ran from 23 July to the 9 September 2019. It was initially available in English, and we asked the Cochrane community for volunteers to translate it into other languages to increase the number of people who would be able to respond.

The results of the survey were collated in Excel and reviewed by one researcher (EJD). Blank responses were discarded, duplicate uncertainties were removed or merged, responses with multiple submitted questions were separated into individual uncertainties, and questions were edited for clarity. Questions were grouped into themes that emerged from the data to help the CAPSG with their decisions. The collated uncertainties were reviewed by a clinician (RF) and a member of the CAPSG to check whether the editing was fair, retained the original meaning and whether the list was manageable for the CAPSG.

3.3. Prioritising survey results

We held three online Zoom meetings to prioritise the survey findings. In the first meeting we introduced members of the CAPSG to Cochrane Airways and the purpose of the project. We aimed to create a safe space for

members to speak by emphasising that members could contribute thoughts about the topics or report inappropriate behaviour by email or telephone at any time. We explained the survey and the results, and asked members how they would like to rank the priorities. We allowed time to discuss the survey results and ask for clarifications. The ranking method agreed on by the CAPSG was for members to each chose their top ten uncertainties. We used weighted ranking, where each members’ top choice was given 10 points; the second choice was given 9 points and so on to give a “weighted score”. CAPSG members ranked the survey results following the first meeting. Because of the high number of topics, we were unable to provide background information for each one. We therefore asked the members of the CAPSG if they could rank the uncertainties without this information, which they agreed to do.

We brought forward all the topics that received two or more votes, or a score of ten or more points to the second meeting. We reviewed the results of this first round of ranking and discussed how to conduct the second round. We initially suggested that members vote for their top 5 topics, but members preference was to vote for their top 10. At each stage, we reviewed the full list to ensure that topics highlighted as priorities for low-and middle-income countries (LMIC) and by patients had been retained.

We reviewed the second round of ranking at our third meeting and confirmed that all members could ‘live with’ the final ranking. We discussed review questions that could be developed from the uncertainties and suggested how we would develop PICO for review questions.

At all stages, we held a space for CAPSG members to suggest ways to modify the process, agree (or not) to the process, be heard, and feel heard, and to live with the overall result even if there was disagreement about individual items. At the end of the project, we conducted an evaluation.

3.4. Developing PICO

Cochrane intervention reviews typically use the PICO format for setting a research question. PICO stands for: P = participants I = intervention, C = control, O = outcomes. Questions submitted by patients & public are not all suitable for Cochrane Reviews in their raw form, for example they are may be too broad, or open to interpretation. To help refine the questions, we conducted preliminary scoping searches for each uncertainty and presented the results of these searches in a short report that was inspired by the format used by Canada’s Drug and Health Technology Agency [17]. We also developed a series of ‘overview’ tables based on the format that was used in an overview of interventions for bronchiectasis [18]. The overview tables collated any existing Cochrane Reviews that addressed a particular uncertainty together with information on any new trials found through preliminary searches that may be suitable for inclusion in an update to the Cochrane Review. The necessity for this scoping work arose from the meetings and was not anticipated or included as part of the original project plan.

4. Results

4.1. Cochrane Airways priority-setting group

We received 19 applications to join the CAPSG. We rejected seven applications received through Cochrane’s crowd-sourcing platform TaskExchange because the applications did not provide enough information about the applicants’ motivations and experience. EJD and RF invited 12 people to join the group, and they all accepted. The final group comprised of six health care professionals (HCPs) including a respiratory nurse specialist, a GP trainee, an ED doctor, and a specialist respiratory doctor. Three members identified as living with an airways disease and one identified as a carer. Two of these members were also researchers and one was a former healthcare commissioner. One member was a current review author with Cochrane Airways. There were two representatives from UK lung organisations; Asthma UK and the British Lung Foundation (BLF) (these organisations merged during the process). One member was from Egypt, living

in Oman and one member was from the USA. The rest of the members lived in the UK.

4.2. Results of the survey

The survey was translated into Spanish and Russian by volunteers in Cochrane and promoted on the Spanish language and Russian Cochrane twitter accounts. We received 147 survey responses in English, 14 responses in Russian and none in Spanish. Forty-six people (31%) had asthma, 35 (24%) had COPD and 20 (14%) had bronchiectasis. We received seven survey responses from people with other airways diseases. Of the 147 respondents, 100 (69%) identified as a patient, 31 (21%) identified as a healthcare professional and 16 (10%) identified as carers or researchers.

Blank responses were discarded, and after removal or merging of duplicates, separation of multiple uncertainties, and editing for clarity we were left with a total of 100 uncertainties for prioritisation. While the question we asked focused on prevention and treatment, some of the answers we received were broader. Because there were so many questions, we decided to group them so that they were easier for the CAPSG to manage. Uncertainties were therefore grouped into 10 themes: triggers; evidence mapping; treatments (drugs); treatments (non-drug); treatments (mixed); prognosis; diagnosis; prevention and cure; service provision; and other. See data repository for the full list of uncertainties [19]. Both the clinician and CAPSG member who reviewed this list agreed that the interpretation of the survey results was reasonable.

4.3. Prioritisation of survey results

The CAPSG completed two rounds of ranking (Fig. 1). Eleven out of 12 (92%) members of the CAPSG voted in the first ranking exercise and 29 uncertainties were taken forward to the next round.

All 12 members of the CAPSG voted in the second-round ranking exercise. We planned to identify 10 research questions, but because refinement was needed to create systematic review questions, we decided to take forward the top 12 uncertainties (Table 1). None were identified as especially relevant for people in LMICs (low- and middle-income countries).

4.4. Developing PICO's for Cochrane Reviews

We produced 11 scoping search reports and collated four overview tables [20]. We looked at the National Review of Asthma Deaths report

Table 1
Final uncertainties. These were based on a weighted rank.

Rank	Uncertainty	Weighted score
1	Interventions to prevent asthma deaths (e.g. how to identify an at-risk patient)	66
2	New evidence mapping exercise for COPD (Chronic Obstructive Pulmonary Disease)	55
3	Interventions to improve engagement/adherence to routine care for parents of children with long term respiratory conditions	50
4	Interventions to improve engagement with self-management and education for people with IPF (Idiopathic Pulmonary Fibrosis)	42
5	Personalized/targeted therapies for ILD (Interstitial Lung Disease) guided by genotype or phenotype	39
6	New evidence mapping exercise for interventions to prevent asthma (e.g. vitamin D, allergen exposure, childhood exposure to air pollution etc.)	36
7	Care pathways to improve access to specialist respiratory services	35
8 =	Interventions for difficult to treat non-atopic asthma	34
8 =	Interventions to prevent/cure IPF (Idiopathic Pulmonary Fibrosis)	34
10 =	Improving access to routine reviews for respiratory conditions for adults and children with mental health problems and learning disability	32
10 =	Interventions to help health care professionals identify at-risk patients with asthma/other long-term respiratory conditions	32
10 =	Interventions to improve awareness and knowledge of bronchiectasis for healthcare professionals	32

[21] to help us generate ideas around interventions for preventing asthma deaths, which was the top-ranking uncertainty. We ran five scoping searches and produced one overview table related to preventing asthma deaths. We did not run scoping searches for every uncertainty; “Improving access to routine reviews for respiratory conditions for adults and children with mental health problems and learning disability” fell outside the scope of our group, and we knew that there are relatively few available interventions for ILD, therefore scoping work around “Personalized/targeted therapies for ILD” was premature.

Following the scoping work, we produced a final list of recommendations for Cochrane Review questions to address the uncertainties (Table 2). We identified three existing Cochrane Reviews to update and eight new review topics. For three of the uncertainties, we found there was insufficient evidence to warrant a Cochrane review. We labelled these as an ‘evidence gap’ and planned to revisit them in three to five years. The final list was circulated by email and approved by the CAPSG.

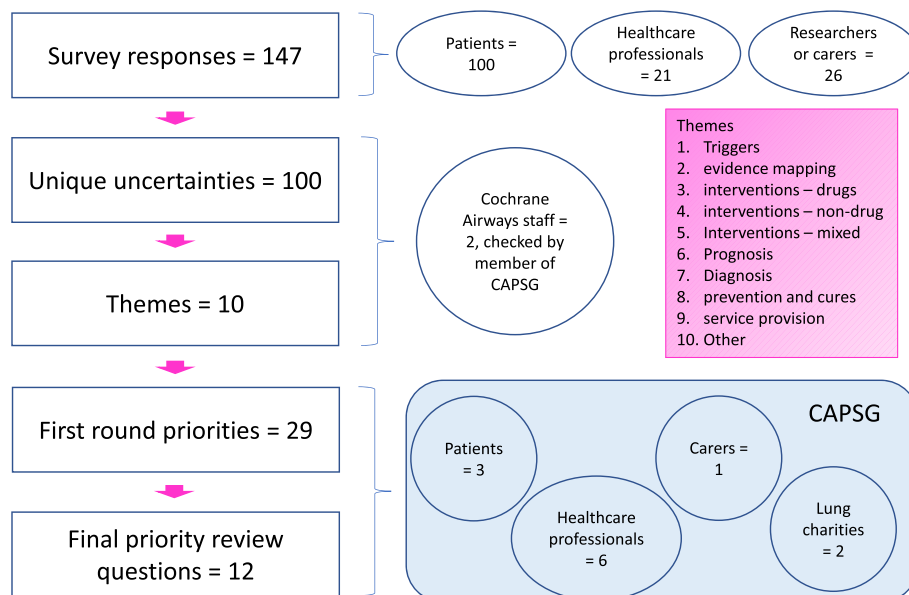


Fig. 1. Flow diagram.

Table 2
Review topics.

Rank	Uncertainty	Review topics
1	Interventions to prevent asthma deaths (e.g. how to identify an at-risk patient)	<ul style="list-style-type: none"> Increased versus stable doses of inhaled corticosteroids for exacerbations of chronic asthma in adults and children (update existing review)
2	New evidence mapping exercise for COPD	<ul style="list-style-type: none"> Evidence map of interventions for COPD (new review)
3	Interventions to improve engagement/adherence to routine care for parents of children with long term respiratory conditions	<ul style="list-style-type: none"> Interventions to improve engagement/adherence to routine care for parents of children with long term respiratory conditions (new review)
4	Interventions to improve engagement with self-management and education for people with IPF	<ul style="list-style-type: none"> Evidence gap (revisit in 5 years)
5	Personalized/targeted therapies for ILD guided by genotype or phenotype	<ul style="list-style-type: none"> Evidence gap (revisit in 5 years)
6	New evidence mapping exercise for interventions to prevent asthma (e.g. vitamin D, allergen exposure, childhood exposure to air pollution etc.)*	<ul style="list-style-type: none"> Vitamin D supplementation in pregnant or breastfeeding women or young children for preventing asthma (new review)
7	Care pathways to improve access to specialist respiratory services	<ul style="list-style-type: none"> Care pathways to improve access to specialist respiratory services (new review)
8=	Interventions for difficult to treat non-atopic asthma	<ul style="list-style-type: none"> Anti-IL5 therapies for asthma (update) Omalizumab for asthma in adults and children (update) Anti-interleukin-13 and anti-interleukin-4 agents versus placebo, anti-interleukin-5, or anti-immunoglobulin-E agents, for children and adults with asthma (new review) Biologics for chronic severe asthma: a network meta-analysis (new review) Antifibrotic therapies for idiopathic pulmonary fibrosis (new review)
8=	Interventions to prevent/cure IPF	<ul style="list-style-type: none"> No review title proposed (outside of scope)
10=	Improving access to routine reviews for respiratory conditions for adults and children with mental health problems and learning disability	
10=	Interventions to help health care professionals identify at-risk patients with asthma/other long-term respiratory conditions	<ul style="list-style-type: none"> Interventions to help health care professionals identify at-risk patients with asthma/other long-term respiratory conditions (new review)
10=	Interventions to improve awareness and knowledge of bronchiectasis for healthcare professionals	<ul style="list-style-type: none"> Evidence gap (revisit in 5 years)

* We interpreted this question as primary prevention of asthma.

4.5. Evaluation by the CAPSG members

Eight (67%) members of the CAPSG completed the evaluation. A detailed description of the evaluation is available in our project report [22]. Most people reported a positive experience, and we received some constructive suggestions for running future CAPSG meetings.

The main tension highlighted was that the process is complicated, and a lot of background information is needed to make informed decisions. Some CAPSG members would have preferred formal scoping of the questions earlier in the process.

5. Discussion

This successful project achieved our aims by identifying 12 research uncertainties which were refined into 12 topics for Cochrane Reviews. We also engaged stakeholders with lived experiences of respiratory diseases and partners from professional bodies. There has been considerable interest in developing Cochrane Reviews and some of these are underway and have made good use of the scoping work we did. Some members of the CAPSG are involved in conducting and drafting these Cochrane Reviews.

Due to limited resources, the survey was based on an existing survey and not piloted, and it was available in three languages only as we relied on volunteer translators. The survey was distributed through social media and the responses were limited to followers. We did not formally analyse demographics of the CAPSG members as part of our evaluation which was an oversight, however the majority were White people from the UK. This lack of diversity may have led to a biased set of uncertainties. One option would be to target other groups such as non-USA and non-UK residents, as suggested by Lindson et al. [23], but there may be other ways such as using reports from international organisations that would allow us to hear their voices without requiring unpaid work from them.

The patient members of the CAPSG had direct experience of living with asthma, bronchiectasis, or COPD (or a combination of these), but not the rarer diseases. The group acknowledged this and asked for information about the burden of living with other respiratory diseases so that they could take these into account when ranking. However, the healthcare professionals had treated people with respiratory diseases other than asthma

and COPD, and most of the patients were also researchers or had been involved in commissioning, so we did not feel this was a huge threat to the exercise. Furthermore, there was a mixture of diseases represented in the final 12 uncertainties.

We conducted all the CAPSG meetings online over Zoom. This meant we did not need to pay travel expenses and enabled us to convene an international group. However, some problems with the online format of the meetings were highlighted – namely that it was hard to get to know people, and some members were inhibited to speak. We aimed to make the meetings safe spaces where people could talk freely, and any concerns would be heard. The chair stressed that any concerns could be raised with her at any time during the meeting or in writing or telephone and that she welcomed feedback on herself. Lessons learned were to set ground rules and to ask for feedback early in the process. A The chair was mindful of the importance of allowing all voices to be heard to minimise the risk of disengagement by less vocal members, and so worked hard to ensure the conversation remained focussed. We were clear throughout that the results were the work of the CAPSG and owned by them, so the work really was co-produced.

Many of the uncertainties submitted through the survey were unsuitable for a Cochrane Review, but we retained them to remain true to the concerns of the respondents. To accommodate this, we expanded our final priority topics from 10 to 12 and refined the questions later in the process through scoping searches. We have dealt with the tensions of high-level versus disease-specific prioritisation for the past 25 years, however this project has allowed this to be brought into the open and for stakeholder perspectives to be heard and documented.

Other Cochrane Groups have conducted a prioritisation exercises and while there is some variation in methods, like us they all aimed to prioritise a set of Cochrane Reviews involving stakeholders on more limited resources than a full JLA process requires. The Cochrane Consumers and Communication Group ran a workshop with 26 participants (consumers, HCPs, decision-makers) to “revise and select 12 priority topics from a list of 21 previously identified topics.” This workshop was held face-to-face, travel costs were reimbursed, and a \$50 voucher was given to participants. The initial topics were identified by the review group rather than stakeholders [24]. The Tobacco Addiction group ran a process consisting of two surveys and a workshop – the first survey asked participants for

uncertainties, and the same participants were invited to rank the results. The workshop had 43 participants, and was transcribed and themes drawn out, and reasons for and against each topic were retained [23]. This study involved more analysis than ours. In addition, independent facilitators were employed, and the project team left the room during the workshop so as not to influence proceedings.

The Public health group also used a stakeholder survey, but it was more involved than our survey. Respondents were asked to identify up to 10 questions and to give a suggested PICO, along with any reviews they were aware of answering this question. They were also asked if they would like to contribute to a review. The Cochrane Acute Respiratory Infections Group conducted a two-phase project. The first phase evaluated gaps between published RCTs and Cochrane Reviews. Sixty-eight such review questions had 4 or more RCTs and were taken through to phase 2. These topics were prioritised, and further uncertainties suggested. After a second round of voting, 25 topics were identified. Their process did not include a workshop, either online or in-person [25]. The Cochrane Eyes and Vision Group have recently published a protocol for a priority setting exercise [26]. They plan to identify 10 to 15 priority-research questions based on existing information in Eyes and Vision Research and seek input from stakeholders.

Despite the differences we have highlighted, all these processes have used (or plan to use) external stakeholder input, either in person, online, through surveys, or a combination, with the aim of agreeing a list of priority reviews to take forward.

6. Conclusions

Cochrane Airways convened a stakeholder group to prioritise research uncertainties for systematic reviews based on a survey of patients and the public. We prioritised 12 topics to take forward as potential Cochrane Reviews or review updates. Cochrane Review Groups and other evidence synthesis groups should allow sufficient time and funding for priority-setting. Using our method required scoping literature searches to help inform decisions.

What is new

- We prioritised 12 systematic reviews using a method compliant with Cochrane policy
- With appropriate support, stakeholders can prioritise work across multiple diseases
- Evidence synthesis groups can use this method to shape workplans for little resource

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Declaration of interests

EJD, ES and RF: were employed by St George's, University of London to work on Cochrane Airways interests. RF is the Coordinating Editor for the Cochrane Airways Group, otherwise, none known.

CRediT authorship contribution statement

Emma J. Dennett: Conceptualization, Methodology, Investigation, Data curation, Writing – original draft, Project administration. **Elizabeth M. Stovold:** Conceptualization, Methodology, Investigation, Writing – review & editing. **Rebecca Fortescue:** Conceptualization, Methodology, Supervision, Writing – review & editing.

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