

Identifying the most important outcomes for systematic reviews of rhinosinusitis research

A pilot project supported by the National Institute for Health Research, UK
Cochrane Centre, Cochrane ENT Disorders Group and evidENT.

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Prepared by Crowe Associates Ltd

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Acronyms

- Outcomes Most Important for Patients, Public and Practitioners (OMIPPP)
- Ear Nose and Throat (ENT)
- Sino Nasal Outcome Test (SNOT 22)

Plain Language Summary

This project aimed to identify the most important outcomes (results) for reviews of research into rhinosinusitis. Outcomes are what we expect to see change, improve or get worse during or after clinical trials of treatments for rhinosinusitis. Examples could include changes in symptoms, changes in the need for type of further treatments required, side effects of treatments and/or general quality of life. What outcomes researchers choose to use may depend on a variety of issues such as how measurable they are, and how important they are either to health professionals and/or people living with rhinosinusitis.

Reviews of research compare and combine the results of previous clinical trials to enable researchers to get the best possible understanding of how well treatments and care for rhinosinusitis work. Those results can be used by patients, carers, health professionals, and health providers to make treatment decisions based on the best available information and evidence

Identifying the most important treatment outcomes and then using them in reviews of research will help to ensure that future reviews are more useful to patients with rhinosinusitis and those involved in their care.

To find out what the important outcomes are for people we used an online survey which had been tested beforehand with a variety of people. We used existing contacts (email addresses) and social media (Face book, Twitter) to publicise the survey. 235 people completed the survey; 155 healthcare professionals and 80 people with rhinosinusitis. Healthcare professionals included mostly Ear Nose and Throat specialists but also GP, and specialists in allergies. Over half of the people (with CRS) who completed the survey were currently experiencing problems with their condition.

The people who completed the survey provided 653 suggestions of important outcomes. Of these 169 were from people who have rhinosinusitis, and 380 were from healthcare professionals. We removed 104 because they didn't fit the description of an outcome, e.g. suggestions for treatments (taking a steamy shower), 56 of these were from professionals and 48 from patients.

The majority of the suggested outcomes (70%) concerned how well the symptoms of rhinosinusitis were improved and managed. These came from both patients and health professionals showing that there is shared opinion from respondents that reviews of research into rhinosinitis should use outcomes that measure symptoms (and improvements), but the relative importance of the symptoms was different between the two groups. Individual symptoms listed as important outcomes included (in order of importance) nasal discharge or drip, nasal blockage, facial pain, headache (as distinct from facial pain) impaired sense of smell, congestion and breathing difficulties. Less frequently suggested symptoms were sleep disturbance and tiredness, no less important though for those that experience them.

We were also interested in the effectiveness of using social media for sharing the online survey. There is no specific patient group or charity for rhinosinusitis, so we had to rely on a

'blanket' approach using a variety of methods. This proved somewhat successful with 64 survey participants (mostly patients) finding their way to the survey via social media.

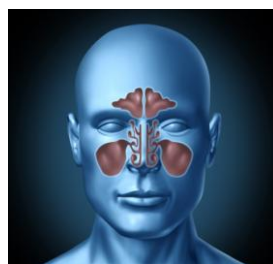
From this part of the work we gained useful learning about how we could do it better next time, for example the value of making personal connections wherever possible (to discuss the importance of the survey for example) and allowing more time for survey messages to roll out.

We would like to thank everyone that completed the survey; their views were very important. This project has contributed to the current debate and decision making about what to measure in reviews of research in rhinosinusitis.

1. Background to the project

The Cochrane ENT Disorders Group consists of authors and editors from the UK and internationally, and forms part of Cochrane www.cochrane.org. Cochrane is an independent, global network of people working together to provide the best evidence for healthcare decisions. There are over 5,400 Cochrane Systematic Reviews of research published on clinical questions ranging from pregnancy through to falls in the elderly; chemotherapy to yoga. All the evidence for each question is gathered, quality assessed and where possible the results are combined to give an overall answer to the question. The Cochrane ENT Group produces systematic reviews on all aspects of Ear Nose and Throat diseases.

The Cochrane ENT Disorders Group were interested in knowing what research outcomes (results) are most important to people making clinical decisions about the management of rhinosinusitis, and to those living with it, who make important personal health decisions. The results from this pilot project will help identify important outcomes from patient and clinician perspectives and will inform future discussions and plans for reviews of interventions for rhinosinusitis.

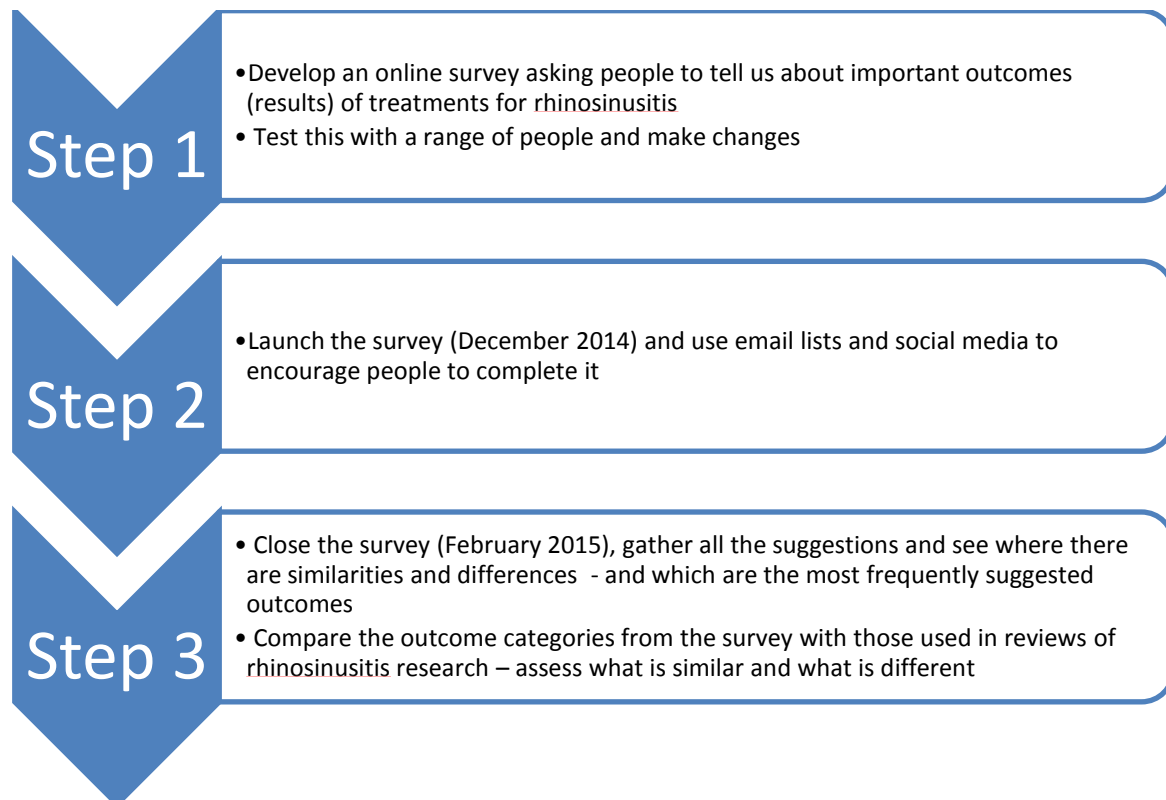


The group chose rhinosinusitis because: it is very common (estimates at 10% of the UK adult population¹); can be very debilitating; and there has been limited research to assess what outcomes should be measured for this condition, especially from the patients' perspective. This project is funded by the UK Cochrane Centre www.ukcc.cochrane.org and is part of a larger project called Outcomes Most Important for Patients, Public and Practitioners (OMIPPP). The project is evaluating three different ways to engage with patients, public and practitioners (such as doctors, nurses, physiotherapists etc) across three different health conditions. A separate report on this will be available on this later in 2015.

The team working on this include members of Crowe Associates Ltd www.crowe-associates.co.uk, ENT surgeons with a specialist interest in rhinosinusitis and members of the EvidENT team at University College London.

2. Overview of process and methods

2.1 Flow diagram of process



2.2 Choice of method

We chose to use an online survey to gather and prioritise important outcomes for rhinosinusitis; this was a relatively simple survey with open questions and opportunities for participants to include free text answers. We also wanted to use Social Media (Face book, Twitter etc) as well as existing email networks to get the message out about the survey to both health professionals working in the area and to people with the condition. Online surveys have proved popular and effective in other related initiatives such as the James Lind Alliance www.lindalliance.org and they are a low cost approach.

The Cochrane ENT Group has excellent links with relevant professional organisations and was confident that the views of these organisations could be sought on this question. We were less confident about accessing the views of the general public and recipients of rhinosinusitis treatment and care, due to the lack of patient advocacy groups. An exception is Fifth Sense (a group concerned with loss of smell, related to rhinosinusitis in a sub set of their membership). We therefore decided to ask survey respondents where they heard about the survey to assess the success of these routes to survey.

2.3 Developing the survey

Following a review of outcomes research literature, and building on the team's experience with developing similar surveys for James Lind Alliance prioritisation projects and ENT data gathering exercises, the survey was developed using Survey Monkey software. It was designed to achieve two main goals: to gather outcomes of interest in CRS to both health professionals and people with the condition, and get a sense of the most important of these.

Survey participants were asked to suggest or describe their three most important outcomes for treatments of rhinosinusitis (see below).

***For people with rhinosinusitis:** What results from treatments are most important to you?*

***For health professionals:** What are the most important outcomes that you want from treatments for people with rhinosinusitis?*

Other outcomes development processes often use two - four steps in refining responses and agreeing consensus (Delphi and James Lind Alliance prioritization processes) whereas we were interested in getting results from one 'hit'. The option of allowing respondents to only suggest 3 key outcomes ensured that people focussed on the most important issues for them and very few survey responders tried to fit in more than 3.

We also wanted to design a survey that was easy to complete, and easy to analyse. The project team had several versions of the survey before a final product was ready for piloting.

2.4 Piloting and launching the survey

The survey was piloted by 17 people and modifications made. It was then run from 19th December 2014 until 10th February 2015. There was an incentive for people to complete the survey (£25 online vouchers) and on reflection this may have encouraged some spamming of the survey. Offending submissions were deleted from the data.

We developed a 'route to survey' which outlined all of the potential people and groups that might be interested in participating; this included the ENT and OMIPPP team's networks and contacts. An invitation to participate in the survey was developed by the project team and this was used as the core material for all publicity. In addition a flyer was developed and circulated to interested parties and smaller card versions of the flyer produced, as an alternative way of advertising the survey. Wherever possible emails were personalised.

The route to survey document was updated regularly, email reminders sent (and logged) and suggestions made for additional contacts from the ENT team and other survey participants. Where organisations declined to participate in advertising the survey a reason was sought and recorded.

2.5 Analysing the survey data

All free text data was downloaded from Survey Monkey in an excel spreadsheet, and a unique ID was allocated to each responder and outcome, in accordance with the data analysis protocol developed earlier with the ENT team. We kept the responses within their professional and individual categories to allow for comparison between the two data sets.

Two team members analysed the data in two stages, applying an approach to thematic analysis that allowed for developing themes from the data itself. Firstly they read through all the submissions and identified themes - using post it notes to mark these themes and start grouping them. Secondly they read through the submissions again and allocated each submission to one or more themes.

In total 8 outcome themes were identified, and several of these required sub themes for example in symptom management and improvement we decided to allocate specific symptoms suggested in the survey respondents to sub categories as we thought this would interest the team and prove more useful. Following consultation with the ENT team we made the distinction between sino nasal symptoms and more general symptoms.

Photo: Initial mapping of outcomes into themes



2.6 Checking the data analysis

Submissions that didn't fit with the project objectives (for example submissions that described treatments rather than outcomes) were sent to the ENT group for checking along with requests for clarification and meaning (e.g. where technical terms were used). Fifty six of these were from professionals, and 48 from patients. We contacted one respondent where we needed further clarification.

A random selection of submissions (50) were put into a separate excel spreadsheet with their allocated themes and sent to the ENT group for comments and feedback. A teleconference was held with 4 of the team, changes were made to the themes and allocations in light of this feedback, and out of scope items removed from the data set. At a final meeting of the ENT group (5 participated) we discussed the themes again and some changes were made, mainly to the wording and allocation of sub themes to main themes. This reflected the specialist ENT input and was welcomed by the OMIPPP team.

3. Results

3.1 Overview of responses

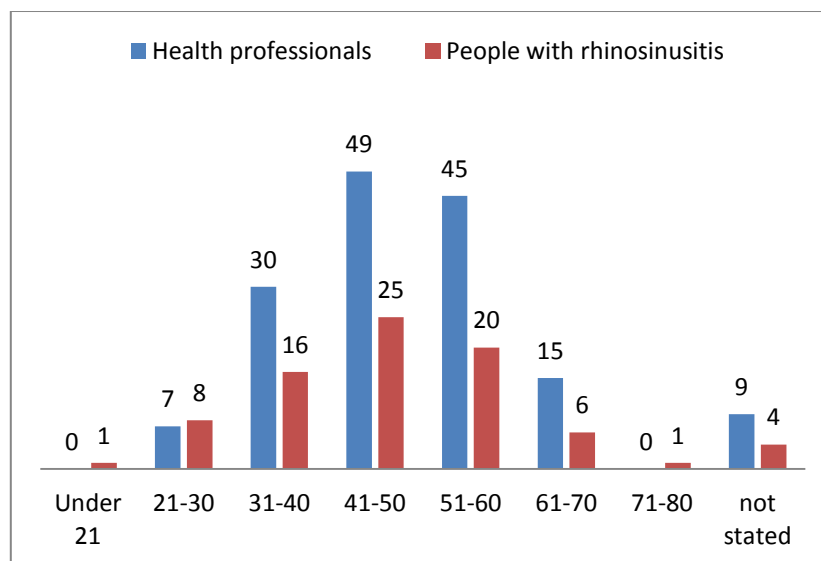
There were over 900 responses to the survey (approx 600 of these were spam). We extracted 235 usable responses, from 155 healthcare professionals and 80 people with rhinosinusitis.

From the 235 usable responses there were 653 suggestions of important outcomes. Of these 549 (169 from people with rhinosinusitis, and 380 from healthcare professionals) fitted our description of an outcome. 104 were removed from the data as they didn't fit our understanding of an outcome - these included suggestions for treatments, comments on the properites of tools (e.g. scales) to measure patient reported outcomes, and items that we were unable to understand.

More male healthcare professionals responded to the survey than female (109 and 18 respectively). The team felt that this reflected the predominance of male ENT specialists. In people with rhinosinusitis more women than men responded (59 and 39 respectively). The gender of respondents across both groups was as the evidENT team would expect - whilst there are more men with the condition, in their experience women are more likely to participate in ENT survey activity.

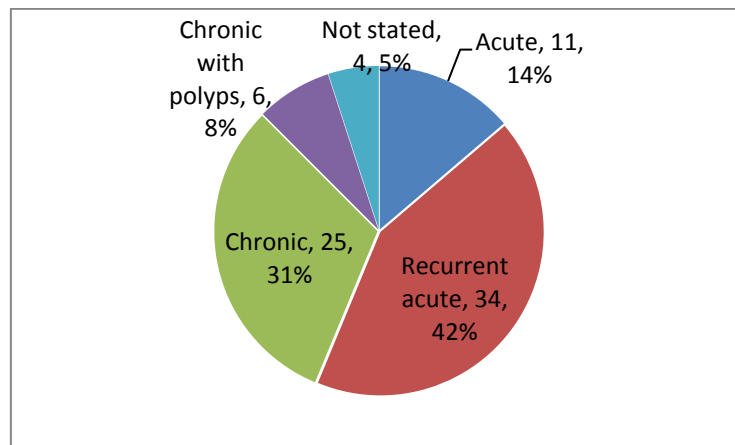
There was a good spread of ages responding in both groups, with a few more people under 30 with the condition responding than we had imagined might. Some people did not state their age or gender: in order to make the survey as easy and quick to use as possible, we allowed people to keep moving through even if they didn't give responses, rather than requiring that they answer every question before moving on. This meant that for some of our data we were unable to allocate to a demographic and is a limitation of this approach.

Graph 1: Age of respondents



Of the Health Professionals who responded, the majority were ENT Consultants (116), with a few others such as nurses (3), respiratory and allergy specialists (11) and GPs (8) some with a special interest in respiratory medicine.

We asked the people with rhinosinusitis to self-classify according to their understanding of their condition (see the pie chart below). There are some problems with this approach, and the team felt that there were probably more people with chronic rhinosinusitis than our data would suggest. This was primarily because when respondents were asked if they still had problems 52% said that they do, suggesting they probably had chronic rhinosinusitis.



We asked people to tell us the first half of their postcode, and this allowed us to see that respondents in both groups came from across the country, with a few coming from overseas.

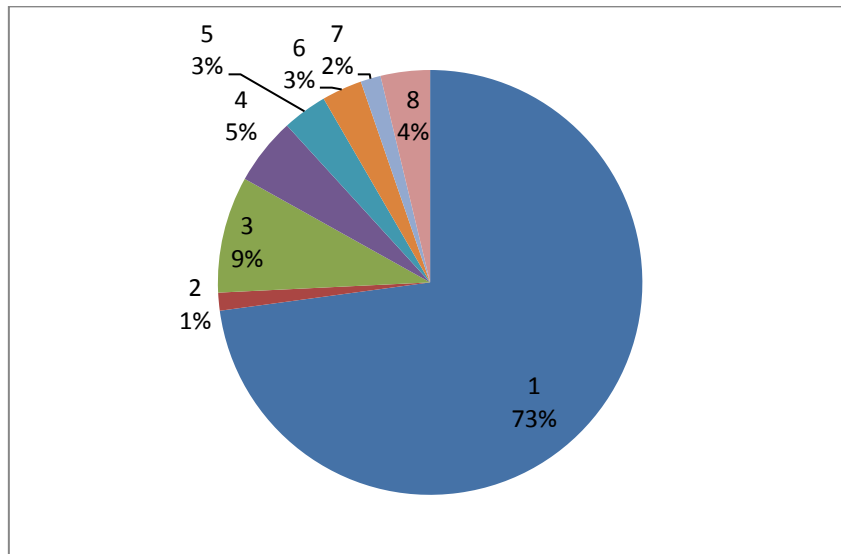
We also collected data on ethnicity, where people were happy to share this. The majority of respondents in both groups classified themselves as White: English / Welsh / Scottish / Northern Irish / British. This is not necessarily representative of the people with the condition and rhinosinusitis is not more common in black and ethnic minorities. From our experience, this is more likely to be a limitation of doing a short, online survey. In discussion with the evidENT team it was felt that doing the survey face-to-face in clinics, and over a longer period would probably result in a wider ethnic mix.

3.2 Themes in the survey data

The first analysis of the data resulted in 11 themes, with a number of sub-categories. In consultation with the evidENT team this was reduced to eight themes:

1. Improvement and management of symptoms
2. Reducing need for surgery
3. Quality of Life (not related to symptoms)
4. Medication rescue and duration
5. Adverse (harmful) and side effects of treatments
6. Objective outcome measures
7. Other respiratory conditions (e.g. rhinosinusitis and living with Asthma)
8. Reducing acute exacerbations, and resulting consultations?

The chart below shows the spread of responses across themes. It can be seen that Theme 1, improvement and management of symptoms, was by far the most frequent outcome.



We have focussed on reporting the detail of theme 1 as this was the overwhelming result of the survey. This theme contained several sub-categories divided into two areas (sinonasal and other) according to guidance from the evidENT team.

Some respondents chose to put either "improve, reduce, resolve" symptoms as one of their choices (mostly professionals) and as these aren't specific about symptoms we have put these into the 'other' category:

Sino nasal

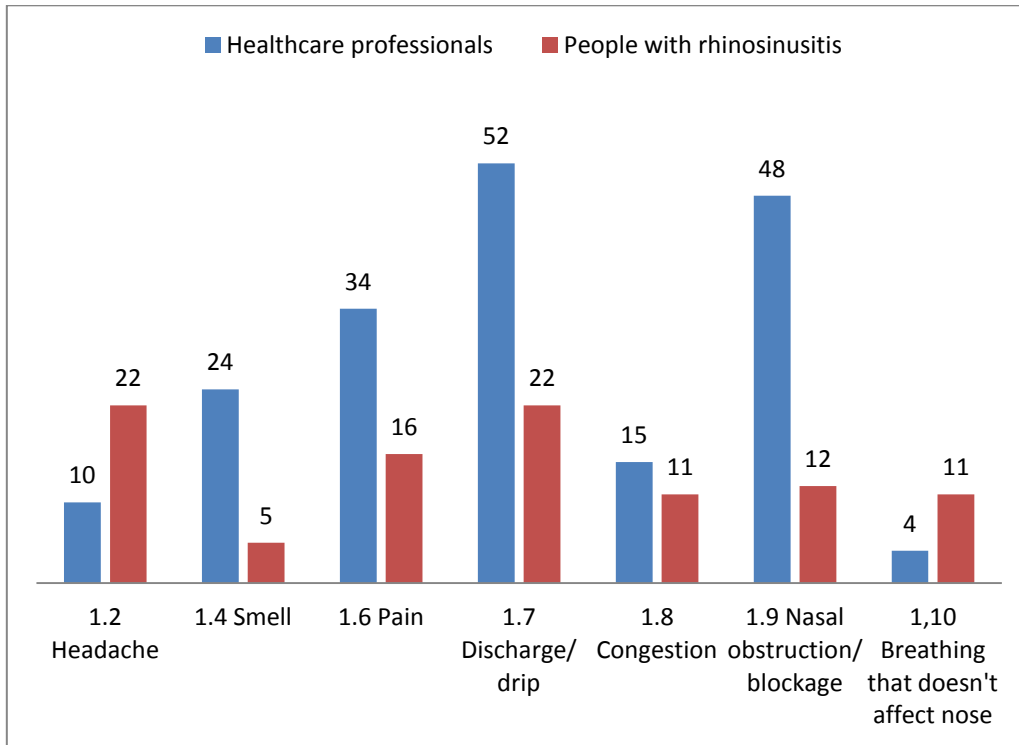
- 1.2 Headache
- 1.4 Smell
- 1.6 Pain
- 1.7 Nasal discharge/ drip
- 1.8 Congestion
- 1.9 Nasal obstruction/ blockage
- 1.10 Breathing that doesn't affect nose

Other

- 1.1 "improve, reduce, resolve" symptoms
- 1.3 Sleep
- 1.5 Fatigue
- 1.11 Specific Patient Reported Outcome Measures (PROMs) such as SNOT 22

We have showed the breakdown in sinonasal symptoms, with nasal discharge (drip) and nasal obstruction and blockage showing the strongest representation in the data. Whilst more healthcare professionals completed the survey we can still see that these themes were important to both people living with rhinosinusitis and healthcare professionals. 80% of patients prioritized outcomes that were symptom related, whilst 69% of the health professional responses described symptom improvement or management.

Graph 2: Theme 1 Breakdown of outcomes and scores for sinonasal symptom improvement and management

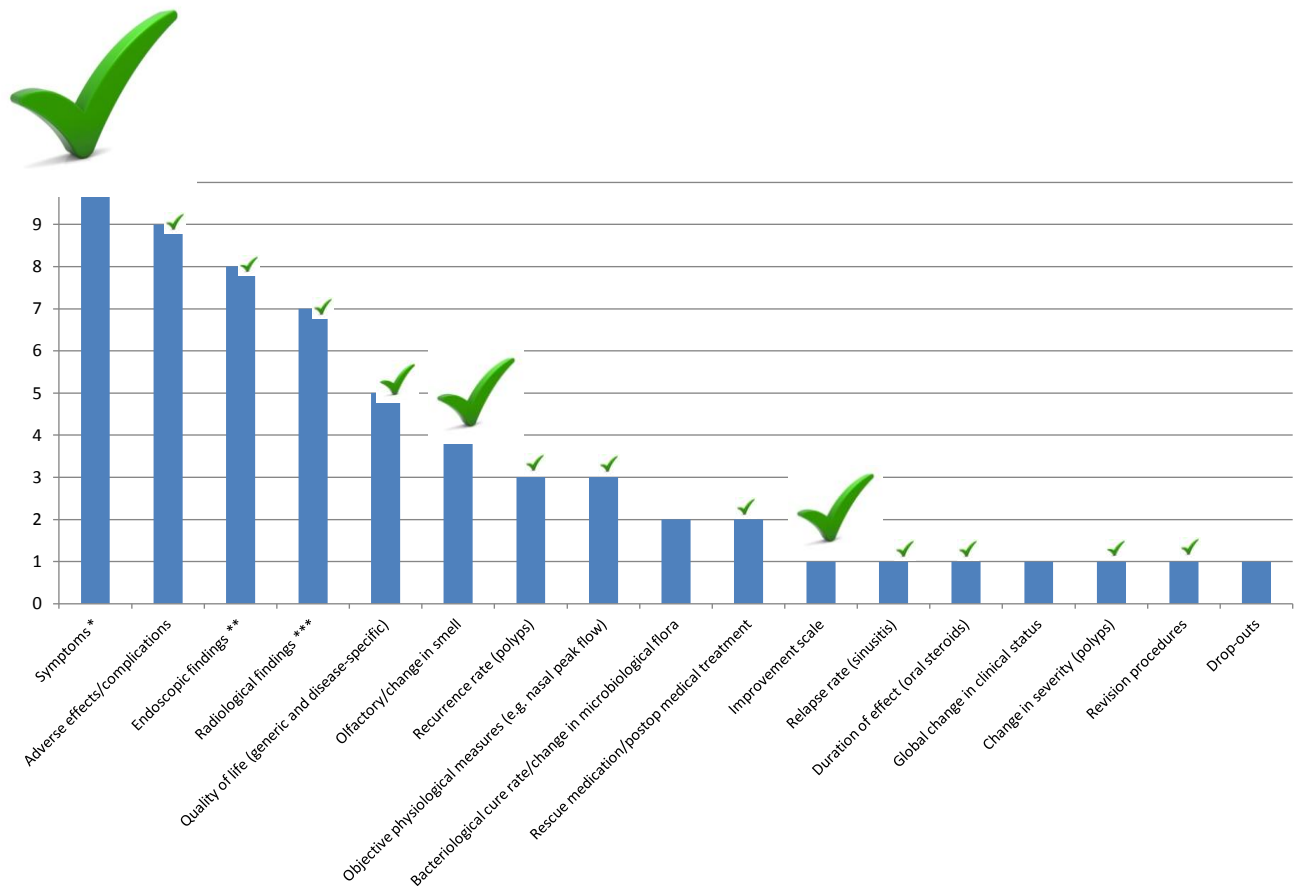


3.3 Comparing survey outcomes with those used in Cochrane reviews of rhinosinusitis research.

The Cochrane Review Group provided us with a list of the primary and secondary outcomes that they use in their systematic reviews for interventions for Chronic Rhinosinusitis. We have mapped our (OMIPPP) survey themes to that list, showing where the size of response was by the size of the tick. **Figure 1.**

More detail is contained in Table 1 where we have noted the prevalence of the responses from the survey with the review outcomes currently used. We also compared the responses of people with rhinosinusitis and health professionals, as we thought this interesting. The different colours show where there is an approximate match between the nature of outcomes used in reviews and those suggested in the survey.

Figure 1: OMIPPP ENT Survey Outcomes mapped to those used in Cochrane Rhinosinusitis Reviews



* “Sinonasal symptoms (improvement in)”/“Symptom scores (VAS or Likert scores)”/“Clinical cure rate post-treatment (no clinical symptoms or substantially improved)”/“Symptom improvement (Likert/VAS/QoL questionnaires)”/“Reduction in validated nasal symptoms scores/Changes in the visual analogue score/rhinosinusitis disability index”/“change in symptom scores (overall or nasal obstruction) and polyp size (grade) and participants with reduction in these measures ('responders')”/“Disease severity, as measured by patient-reported disease-specific symptom scores. This includes rating of nasal obstruction and other sinonasal symptoms (using visual analogue scales or other methods)”.

** Endoscopic findings/scores/view/appearances.

*** Radiological findings/scores/response rate/CT appearance.

In Figure 1 the size of the green tick shows the approximate degree of overlap between the survey responses and the outcomes currently used in systematic reviews of rhinosinusitis interventions.

Table 1 Detail of survey outcomes and those used by the ENT Disorders Review Group

| Cochrane CRS Reviews | OMIPPP theme | % of total outcomes | % outcomes expressed by patients | % outcomes expressed by professionals |
|--|--|---------------------|----------------------------------|---------------------------------------|
| Adverse effects/ complications | 5. Harmful (adverse) & side effects including: - Unintended harmful events | 3% | 2% | 4% |
| Endoscopic findings | 6. Objective outcome measures including: - Radiological - Endoscopic/ Examination | 3% | 0% | 4% |
| Change in severity (polyps) | | | | |
| Radiological findings | | | | |
| Objective physiological measures (e.g. nasal peak flow) | | | | |
| Quality of life (general & disease specific) | 3. Quality of Life including - Return to normal activity - Psychological | 9% | 5% | 11% |
| Symptoms | 1. Improvement & management of symptoms including - <i>Sinonasal</i> : Headache; Smell; Pain; Nasal discharge/ drip; Congestion; Nasal obstruction/ blockage; breathing that doesn't affect nose - <i>Other</i> : "improve, reduce, resolve" symptoms; Sleep; Fatigue - <i>Patient Reported Outcome Measures</i> e.g. Visual Analogue Scale, SNOT22 | 73% | 80% | 69% |
| Olfactory/ change in smell | | | | |
| Improvement scale | | | | |
| Recurrence rate (polyps) | 8. Reducing acute exacerbations, and resulting consultations | 4% | 4% | 4% |
| Relapse rate (sinusitis) | | | | |
| Revision procedures | 2. Reducing need for surgery | 1% | 0% | 2% |
| Rescue medication/ postop medical treatment | 4. Medication, rescue, duration | 5% | 6% | 5% |
| Duration of effect (oral steroid) | | | | |
| Bacteriological cure rate/ change in microbiological flora | | | | |
| Global change in clinical status | | | | |
| Drop-outs | | | | |
| | 7. Other Respiratory conditions (including Asthma) | 2% | 3% | 1% |

Table 1 shows the degree of alignment between the survey results and current use of outcome measures for systematic reviews. The degree of dominance of symptoms outcomes being important for both patients and ENT practitioners is interesting and suggests that other non symptom related outcomes used in rhinosinusitis reviews should be considered carefully in relation to the review question. What is not reflected in the graph or table is the specific symptoms that people described in the survey. For example whilst the review group identify smell specifically, items such as headache and pain (mostly facial) are not highlighted for systematic review outcomes.

There are a number of instruments that capture the impact of rhinosinusitis across a number of symptoms and domains, and some were specifically named by ENT Specialists, highlighting awareness of these tools. These may capture some of the important specific symptom outcomes highlighted in the survey.

These results also suggest some investment in patient reported outcome measure (PROM) tools that are able to capture these symptoms accurately and reliably. A starting point for this could be to compare these findings with SNOT22 a current Patient Reported Outcome Measure for rhinosinusitis research.

The working group were pleased with these results which support an earlier editorial decision within the Cochrane ENT Disorders Group to use symptom improvement and management outcomes in all reviews of interventions for rhinosinusitis. This is also reflected in plans this summer (2015) to develop set of core outcomes for clinical trials that assess treatments for rhinosinusitis. It will be interesting to see how much convergence there is in this work and that of core outcomes development for rhinosinusitis.

3.4 What were the most effective ways of publicising the survey?

We asked survey respondents to tell us how they came to the survey, 217 people answered this question giving us an indication of what worked and what didn't in terms of advertising the survey.

Excluding ENT specialists we estimate that the twitter activity was most effective in recruiting patients to the survey. This medium also recruited non ENT health professionals (some with rhinosinusitis), alternative therapy practitioners and 'other'.

Twitter also enabled the team to identify patient and public involvement opinion formers and influencers to share the survey. In total 44 people completing the survey came via twitter. We had 7 people find the survey via the Twitter and Face book accounts of the Cochrane Consumer Network and another 7 who found the survey via INVOLVE People in Research website (which matches the publics' interest in research to projects) which we had targeted with Twitter.

The most effective routes to encourage ENT specialists to contribute were much more likely to be peer to peer contact and personal endorsement from the clinicians in the working group (24), and the email lists that exist for ENT professional organisations (74). Fifty two people described their route to the survey via 'email', we cannot allocate these to any

particular category but it is likely that some of these might have been from the peer to peer, or mailing list activity.

The team designed and printed Postcards for the survey and offered these to healthcare professionals to give to patients. Only 1 respondent cited this as their route to the survey.

Using social media was a relatively new development for evidENT and the review group (both are active on social media, but more for the alert to new research reviews and updates).

The team used the INVOLVE SoMe guidance <http://www.invo.org.uk/wp-content/uploads/2014/11/9982-Social-Media-Guide-WEB.pdf> as a starting point for this part of the project. The learning for the team in using social media included;

- The value of a 'Tweet Sheet' whereby example twitter messages, hash tags and the survey link were assembled together with a list of Twitter handles (identification) that may be interested in promoting the survey
- Experimenting with tweeting at different times of the day - it was easy to measure the impact of this by the number of retweets and favourites that were attached to each tweet - the best times to tweet for this project were later in the day, (3pm onwards) and Friday evening was especially popular
- Keeping the momentum up and getting the balance right - it is important to schedule tweets across time periods and not having large gaps in information flow but also not sending out repetitive messages
- Experimenting with different types of tweets, we found that certain tweets "What on earth should we measure in rhinosinusitis research?" were very popular - as were tweets that were slightly mischievous such as "Drip Drip - living with sinusitis - tell us what matters to you"
- It seemed important to have a conversation with people on Twitter and SC had many exchanges with people both public and professionals. Common conversations were along the lines of "the role of outcomes reflecting what happens in consulting rooms" "great to see you asking what people see as important" or "sinusitis sucks!" Having a conversation enabled us to encourage sharing of the message and that there were real people behind the project.
- It is possible that using Twitter and Facebook in might have triggered the spam responses, although this has not been the experience of numerous James Lind Alliance Surveys the team have done via Twitter and Facebook. The team suspect it was the introduction of an incentive to complete the survey that triggered spam. This was not a particular drain on project resources, but was irritating.
- Installing software to deal with SPAM.

5. Conclusions and Implications of the project

The main finding of this project, that most people with rhinosinusitis and specialist health professionals preference outcomes in systematic reviews that address improvement in symptoms. These results suggest that a strong focus on symptom improvement outcomes should be present in all rhinosinusitis related reviews. The prevalence scores from each of the specific symptoms mentioned could guide the ENT review group to consider which specific symptom outcomes reviews should include as primary or secondary outcomes.

The ENT review group have indicated that they will be starting a process of developing a core outcome set for rhinosinusitis in 2015 - 2016. This will set out the key outcomes to measure in all future clinical trials and will help the Cochrane ENT Disorders Group combine studies which are using the same or similar outcomes. This project has delivered helpful information about the likely outcomes that will be considered, from a variety of relevant perspectives for this process.

The use of purely online techniques that are relatively cheap to administer, together with a light touch analysis and checking back with the working group suggests that outcomes that are important for patients and practitioners can be identified and explored to inform future outcomes development work for the ENT review group.

The project has helped to introduce new people with rhinosinusitis to the team who in turn can explore future ways of working together. With a dedicated member of staff for patient and public involvement this means that this work will be co-ordinated and patients participating in future research activity will be supported.

The work on social media has been helpful. The ENT review group do not have a large presence on social media so the learning from this project will help to develop this area of communication between the review group and others interested in what they are doing.

5. Acknowledgements

We are especially grateful to the working group who helped the project team at every stage of the process. They include; Anne Shilder, Iliatha Papachristou, Aneeka Degun, Martin Burton (eviDENT) and Cochrane ENT Group, Carl Philpott, Claire Hopkins (ENT Specialists).

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1. Hastan D, Fokkens WJ, Bachert C, Newson RB, Bislimovska J, Bockelbrink A, et al. Chronic rhinosinusitis in Europe - an underestimated disease. A GA(2) LEN study. *Allergy* 2011;66(9):1216-23.

6. Appendix

Full copy of the ENT survey

1. Introduction

What is Rhinosinusitis?

Rhinosinusitis is a common problem affecting UK adults, caused by inflammation of the nasal passages and sinus cavities. It can cause nasal blockage, a runny nose (including dripping at the back of the nose), loss of sense of smell, facial pain/pressure and sleep disturbance, and has been shown to significantly reduce quality of life.

Rhinosinusitis is divided into 2 main (acute or chronic) categories depending on how long the illness lasts. Treatment for rhinosinusitis varies, and can involve medical treatments, surgery and alternative therapies.

Why are we conducting this survey?

The information you are giving us will help us to ensure that future research best meets the needs of people with rhinosinusitis, whilst also being important to the healthcare professionals who work with them.

Who are we?

We are authors and editors working on this for the Cochrane Ear, Nose and Throat (ENT) Disorders group. For more information about the Cochrane Collaboration and the ENT Disorders Group see www.ent.cochrane.org

How long will it take to complete?

The survey will take less than 10 minutes of your time-

Who should complete this survey?

Please complete this survey if you have, or have had, Rhinosinusitis; or are a healthcare professional working with people who have it.

Please note that, by taking part in this survey, you are agreeing to the information you provide being used to inform future research, which may include publication of results. However, any personal data you provide will not be used to identify you in any way.

Free draw for Amazon vouchers

You can also win an Amazon Voucher worth £25 - we have 5 to give away. If you would like to be entered into the free draw, you can give us your contact details at the end of the survey.

Contact for further information

If you would like further information about the survey please contact sally@crowe-associates.co.uk

2. About you and your important outcomes (results)

Please tick the ONE that applies:

- I am someone with rhinosinusitis [**now go to section 2.1**]
- I am a health or social care professional [**now go to section 2.2**]

If you could tick both please decide which one you are going to answer as; or, if you wish, you can take the survey twice.

2.1 For people with rhinosinusitis:

Please tick the ONE that applies to you:

Please don't worry if you don't know the answer to this question – you can still complete the survey

- Acute (short term)
- Recurrent acute (repeated short term)
- Chronic (long term)
- Chronic with polyps

Do you still have problems at the moment?

Before completing the boxes, please take a minute to first think about what improvements you would like from your treatment for rhinosinusitis. You might consider symptoms that really bother you, how the condition impacts on your quality of life, taking time off work for doctor visits or having to take medication

For example, when asked about what was important about controlling their condition, a group of people with asthma said things like: avoiding asthma flare ups, not going into hospital, and avoiding side effects of asthma treatments like weight gain.

Please tell us the top 3 improvements that you most want from treatments, or after seeing your doctor or healthcare professional.

Please write a maximum of **THREE** improvements (1 per box). **Remember that we are interested in the improvements that are most important to you, and there is no right or wrong answer.**

2.2 For health professionals:

What are the most important outcomes that you want to see reported in research into the effects of treatments for people with rhinosinusitis?

Please write a maximum of **THREE** outcomes (1 per box). **Remember that we are interested in the outcomes that are most important to you, and there is no right or wrong answer.**

Outcome 1:

Outcome 2:

Outcome 3:

Health professionals, please also tell us what your role is:

- ENT Consultant
- ENT Junior Doctor
- GP
- GP with special interest in ENT or respiratory medicine
- Nurse
- Respiratory /Allergy physician
- Other (please state):

3. More about you

We ask for this information in order to understand how the importance of results (outcomes) may be different between different groups of people. We do not need your name and contact details (unless you ask to be kept informed about the results of the survey) and none of the information we collect will be made publicly available in a way that would identify you.

i) Which category includes your age?

- 18-20
- 21-30
- 31-40
- 41-50
- 51-60
- 61-70
- 71-80
- 81-90
- 90 or older
- Rather not say

ii) What is your gender?

- Male

- Female

iii) What is the first half of your postcode (e.g. OX11)

iv) What is your ethnic group? (choose one option that best describes your ethnic group or background)

White

- English / Welsh / Scottish / Northern Irish / British
- Irish
- Any other White background

Black / African / Caribbean / Black British

- African
- Caribbean
- Any other Black / African / Caribbean background

Other ethnic group

- Arab
- Any other ethnic group, please describe

Asian / Asian British

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background

Mixed / Multiple ethnic groups

- White and Black Caribbean
- White and Black African
- White and Asian
- Any other Mixed / Multiple ethnic background

4. And finally....

(i) Where did you hear about this survey?

(ii) Do you want to be kept informed about the results of this survey?

Please delete the answer that does not apply:

Yes / no

If Yes, please tell us your email address:

This will be kept securely in keeping with the Data Protection Act 1998.

(iii) Do you want to be entered into the draw for one of FIVE £25 Amazon vouchers?

Please delete the answer that does not apply:

Yes / no

If Yes, please tell us your email address:

This will be kept securely in keeping with the Data Protection Act 1998.

More about the Cochrane Collaboration

The Cochrane ENT Disorders Group is a group of authors and editors that forms part of [The Cochrane Collaboration](#). Cochrane is a not-for-profit, independent, global network of over 28,000 people working together to provide the best evidence for healthcare decisions. They do this by making available systematic reviews.

A systematic review is a review of all research focused around a particular question. Review authors find, check the quality, select and combine all high quality research evidence relevant to that question. They will provide a summary answer to the question, and indicate where more research is needed. There are thousands of Cochrane Systematic reviews published ranging from pregnancy through to falls in the elderly, sinus surgery and many more.

Decisions need to be made about which outcomes to focus on in systematic reviews of research. However outcomes that are important to research designers, research funders and health policy makers may not be so important to patients and health professionals.

The ENT group is keen that reviews address outcomes that are important for both people with rhinosinusitis and the health professionals that treat them, as well as the wider health and research community. The results of this survey will help to make those decisions.

The ENT Disorders Group produces systematic reviews of evidence for the prevention, treatment and rehabilitation of ear, nose and throat and hearing and balance disorders and head and neck cancers. They are interested in all therapies and treatments, including those that might be considered alternative or complementary.

You can read more about the work of the ENT Disorder Group at www.ent.cochrane.org. This project is in collaboration with the United Kingdom Cochrane Centre.

Thank you for taking part in this survey.