

[Participant Information Sheet](#)

Study Title: An International e-Delphi exercise to define the components of a clinical review of people using CPAP therapy

18-04-17 - Research team: Phyllis Murphie, Dr Stuart Little, Professor Brian McKinstry, Professor Hilary Pinnock.

Invitation

We would like to invite you to participate as a member of an expert panel in our research study in order to reach consensus on the content and frequency of a review of those using CPAP therapy.

Before you decide whether to participate you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Ask questions if anything you read is not clear or if you would like more information. Take time to decide whether or not to take part.

What is the purpose of the study?

Published guidelines on the management and review of people with Obstructive Sleep Apnoea Hypopnoea Syndrome (OSAHS) recommend regular review of people using Continuous Positive Airway Pressure (CPAP) therapy. However, they do not collectively provide a clear consensus or clarity regarding the appropriate content and frequency of such a clinical review.

We wish to address this by conducting an international e-Delphi study. This is a research technique for reaching consensus in a systematic manner using email. The aim is for the participants to contribute ideas, and then rank suggestions in successive rounds until consensus is achieved regarding the content of a clinical review. Page 4 provides a summary of the e-delphi process in a table format, and the rounds are described in more detail below.

Why have I been invited?

Potential participants have been identified by their publications, prominent role in conferences, professional bodies or guideline committees. We have also approached patient groups (e.g. the European Lung Foundation – European Patient Ambassador Participation group) to identify lay advisors for the expert group.

We have identified your e-mail from relevant publications or University/professional websites as clinicians who are involved in clinical review of people using CPAP therapy. We aim to recruit an expert panel of up to 50 healthcare professionals and academics working in sleep medicine and up to five expert patients.

Do I have to take part?

Participation is voluntary and if you decide to take part we will ask you to return an electronic consent form. You are free to withdraw at any time without giving a reason.

What will happen if I agree to take part and what will I have to do?

The e-Delphi usually has three rounds in which we will ask you to complete and return an excel data collection sheet by e-mail to Phyllis Murphie at: s1470044@ed.ac.uk

Round 1. This is an open round with the aim of generating a list of possible components of a CPAP clinical review. We will start with some suggestions that we have identified from the literature and guidelines and ask you to add any additional components and /or comments in a simple excel spreadsheet that you think are important. We will also ask you to comment on how often a CPAP review should take place.

Round 2. We will collate the responses from the first round to create a list of possible components of a CPAP clinical review. In round 2 we will ask you to rate the importance of these components on a scale of 1-5 (0 = unimportant - 5=very important).

Round 3. We will collate all the scores from round 2 and ask you to re-score the components in the light of the median scores from the second round using the same scoring criteria 1-5 (0 = unimportant - 5=very important).

Usually three rounds are enough for a group of people to reach a consensus. If not we may request a fourth round.

Do I have to complete all the rounds?

You are free to withdraw at any time from the study, however, the aim of a Delphi exercise is to reach consensus amongst a group of people and the success of this process depends on participants completing all the rounds of the study. There will be at least four weeks between each round in order to provide time to respond, but long periods during the Spring/early summer without e-mail access might make it difficult for you to contribute fully.

Expenses and payments?

There are no expenses or payments associated with the research study.

How long will it take to complete each round and how often will I be contacted by email?

We estimate it will take approximately 15 minutes per round. Our proposed timetable is to commence the e-Delphi study in April- May 2017 and to complete by July 2017.

You will receive an e-mail with the details for each of the three (possibly four) rounds. Phyllis Murphie will send an e-mail reminder (if necessary) as each deadline approaches.

What are the possible disadvantages and risks of taking part?

There are no perceived disadvantages or risks associated with participating in the study.

What are the benefits of taking part?

The information we get from the study will help to increase our understanding regarding the important components of a clinical review of people with OSAHS who are using CPAP therapy and ultimately improve care for all such patients.

The benefits of participating in the study are that your input will contribute to research that is part of ongoing work by a PhD candidate and it may also inform future guidelines.

You may voluntarily waive anonymity regarding participation if you would like your name acknowledged in publications as having contributed to the Delphi process.

What if there is a problem?

Phyllis Murphie's principal supervisor is Professor Hilary Pinnock (hilary.pinnock @ed.ac.uk)

If you have any concerns or complaints about this research, please contact Professor Sarah Cunningham Burley, Dean of Molecular, Genetic and Population Health Sciences [sarah.c.burley@ed.ac.uk 0131 650 3217]

Will my taking part in the study be kept confidential?

What will happen to the results?

All study participants' comments, suggestions and data will be used anonymously. No responses or comments will be attributed to named members of the panel.

This e-Delphi study is a crucial component of Phyllis Murphie's PhD, in which she is developing a telehealth intervention to deliver routine reviews for people using CPAP for OSAHS. In the absence of clear guideline recommendations for what should be included in a review, the e-Delphi will provide the required consensus to inform a telehealth review.

We will present abstracts, publish the results in a peer reviewed journal. The findings will be of interest to guidelines which currently do not make clear recommendations about CPAP/OSAHS reviews.

A copy of the peer reviewed publication will be emailed to the participants, with a lay summary.

Who is organising the research?

The research team consists of: Phyllis Murphie, Dr Stuart Little, Professor Brian McKinstry, and Professor Hilary Pinnock. Usher Institute of Population Health Sciences and Informatics, University of Edinburgh.

Further information and contact details:

If you have any questions or if you would like to participate in this e-Delphi consensus process, please e-mail Phyllis Murphie at s1470044@ed.ac.uk who will be pleased to provide any further information that you need.

Summary of the e-Delphi process

Round	What information will I be given?	What will I have to do?	How long will it take?	When will this round happen?
1	Some components of a CPAP review will be listed will be listed on a simple Excel spreadsheet from Phyllis Murphie. There will be a free text space to add additional suggestions.	<ul style="list-style-type: none"> You will be asked to add any additional components that you think are important in a clinical review of someone using CPAP therapy You can comment on, or suggest changes to the listed components 	15 mins	April – May 2017
2	The suggested suggestions from the first round will be collated and candidate components listed on the Excel spreadsheet.	<p>Score the candidate components of the clinical review in order of importance.</p> <ul style="list-style-type: none"> Criteria: 1-5 (Unimportant - 5 most important) How important is this component of a clinical review from your perspective as a clinician and/or researcher / patient? 	15 mins	May -June 2017
3	All the components from the second round will be listed on the Excel spreadsheet. The median scores from the second round will be displayed along with your second round score.	<p>Again score the research questions in order of importance.</p> <ul style="list-style-type: none"> Criteria: 1-5 (Unimportant - 5 most important) How important is this component of a clinical review from your perspective as a clinician and/or researcher / patient? You may (or may not) wish to change your score in the light of the expert panel's median score from round 2. 	15 mins	June –July 2017
	Usually three rounds are enough for a group of people to reach a consensus. If not we may request a fourth round in early June which will be exactly the same as the third round			
Presentation of results at: National/International Respiratory Conference 2017				