

eSURVEY AND INVITATION

Dear <<name>>,

We are pleased to invite you to participate in a Delphi survey to see if we can produce an agreed name and definition of a new clinical syndrome of chronic breathlessness caused by medical conditions.

The survey should take 5 minutes to complete.

A clinical syndrome is a constellation of clinical findings caused by an underlying disease(s). The clinical findings may constitute a range of symptoms and physical findings, or describe one symptom in a particular context(s) and may include response to interventions targeted at the syndrome itself. The syndrome should be recognisable in the clinical and research settings. Examples of clinical syndromes include heart failure, delirium, sepsis, parkinsonism and chronic pain.

During July and August 2015, experts from the following disciplines: respiratory medicine, cardiovascular medicine, primary care, medical, nursing, respiratory physiology, neuroimaging, intensive care, oncology and palliative care were consulted.

There was agreement that the symptom of breathlessness could be raised to a clinical syndrome of *chronic refractory breathlessness* if the breathlessness:

- due to a causative medical condition(s) *persists* despite treatment for that condition;
- leads to negative consequences for the patient; and
- responds to interventions aimed at the breathlessness.

There was also consensus that recognition of a clinical syndrome would influence clinical practice, service provision and policy, researchers and research funding.

However, although suggestions for the name and definition were generated, it was agreed that wider consultation through Delphi survey rounds would be important.

If you could take a few minutes of your time to complete the following survey questions (by clicking on the link below). Please also indicate if you would be willing to take part in subsequent rounds.

SURVEY

NAME OF SYNDROME

A1. The following relates to the **name**. Show the **name** you feel would best identify the syndrome to both lay and professional audiences.

Do you want to describe it as: (**indicate one response from each of the two columns**)

Chronic	intractable	breathlessness	syndrome
Persistent	refractory		
Refractory	persistent		

intractable chronic
Descriptor not needed Descriptor not needed
Other..... Other

Please add any comments:

A2. With regard to the **timescale of the breathlessness**, please indicate the **one descriptor** that should be used.

- a. If using 'chronic' or 'persistent', this should be individually assessed and not further defined
- b. If 'chronic', should this refer to breathlessness which:
 - a. Will be chronic from this point forward
 - b. Has been present for 1 month
 - c. Has been present for 3 months
 - d. Has been present for 6 months
 - e. Has been present for 12 months
- c. If persistent, should this refer to breathlessness which:
 - a. Will be persistent from this point forward
 - b. Has been present for 1 month
 - c. Has been present for 3 months
 - d. Has been present for 6 months
 - e. Has been present for 12 months

Please add any comments:

DEFINITION OF SYNDROME

The following relate to the **definition**.

During consultation, it was agreed that the symptom of breathlessness could be raised to a clinical syndrome if the breathlessness remained a problem despite treatment for that condition and resulted in negative consequences for the patient.

Please underline the statement which best describes the treatment of the underlying disease.

- a. Treatment of underlying medical disease(s) is optimised
- b. The underlying medical disease(s) is receiving best possible treatment
- c. No preference

Please add any comments:

B3. With regard to negative consequences of the breathlessness, please indicate any which should be explicitly included in the definition:

- a. Significant physical limitations
- b. Deconditioning
- c. Social isolation

- d. Depression
- e. Anxiety
- f. Financial concerns
- g. Spiritual distress
- h. Health service utilisation
- i. *Unscheduled* health service utilisation
- j. None of the above are needed for the definition

Please add any comments:

Thank you very much for your help. Please indicate here if you would be happy to receive the next Delphi survey round.

Table S1. Summary of freetext comments circulated with survey 3

1. **Name.** The main area of disagreement related to whether a descriptive word e.g. “refractory” should be part of the NAME, or only used in the DEFINITION.
 - The term “refractory” carries the implication that there's no point in doing anything about it as it won't respond to therapy – which is not what we are trying to convey with the name of this syndrome. It risks being misunderstood by clinicians, patients and the lay public.
 - The word refractory is particularly misleading for German speakers.
 - A change of "chronic breathlessness" to "refractory breathlessness" would need education through under and post graduate training for nurses and doctors.
 - Keep the name simple. Chronic Breathlessness Syndrome *implies* that breathlessness persists despite treatment of the underlying cause. We don't say "Chronic Persistent Bronchitis," or "Chronic Intractable Pain Syndrome"
 - Chronic has the same acceptable meaning as persistent or "always there" and therefore you don't need two words in the definition that commonly mean the same thing.
 - You don't need refractory in the title of the syndrome, but it does need to be defined in the detail.
2. **Treatment.**
 - The definition refers to breathlessness which persists despite treatment directed at the *underlying disease pathophysiology*, rather than its effects or symptoms. That is – “despite disease treatments” – rather than “despite breathlessness treatments” . Other comments are included below:
 - optimal suggests that it is evidence based without the need for this qualification.
 - optimal "evidence-based" is important to state, otherwise the treatment utilized could be suboptimal
 - This 'syndrome' would help identify patients with COPD/CHF/ etc who despite pharmacological therapy are still breathless (where the mechanisms: deconditioning, anxiety and depression, dysfunctional breathing are similar). This would help identify patients that would benefit from a generic 'breathlessness' approach.
 - ... pulmonary rehabilitation can, for example, be included as an option as treatment for Chronic Breathlessness Syndrome caused by a chronic lung disease
3. **Consequences.**
 - There are so many, that listing becomes too complicated, could just have a “catch all” of “negative consequences regarding the physical, psychological, social and spiritual dimension”.
 - Consequences are individual to the person, but given the characteristics defined by your original panel of experts, some acknowledgement of consequences in the definition should be included.
 - These are "correlates" or "covariates" - they vary or change because of the phenomenon (symptom) of chronic breathlessness -...they are conceptually outside the phenomenon- not the phenomenon itself. If included in the definition it will be conceptually incorrect.
 - In order to be a syndrome, I think that it needs to have any negative abnormal consequence. Breathlessness is normal during certain levels of exertion. Some could say that "chronic" would separate normal from abnormal breathlessness but that word can be understood in many ways.
 - Description of negative consequences helps to de-medicalise the definition and identifies the illness experience. Both are important to include.
 - Think these are helpful for people who are not specialist yet
 - Not all limitations are physical, but they can be just as devastating!