Supplementary Item 1 - Search Strategy

The search strategy was derived from a Cochrane review protocol on the topic of interest (Howell et al., 2012) and included terms as follows:

**Medline**
1. Exp Dyspnea/ or Dyspn*.mp
2. breathless*.mp
3. (breath*adj5 (difficult* or labor* or labour* or discomfort or uncomfortabl* or distress*)).mp
4. (short*adj5 breath*).mp
5. 1 or 2 or 3 or 4
6. exp Self Care/
7. (self-manag* or selfmanag* or self-car* or selfcar* or self-monitor* or selfmonitor* or self-administrat* or selfadministrat* or self-medicat* or selfmedicat*).mp
8. exp Patient Education as Topic/
9. Pulmonary rehabilitation*.mp
10. 6 or 7 or 8 or 9
11. 5 and 10
12 exp Pediatrics/
13 exp Child/
14. 12 or 13
15. 11 not 14
16. limit 15 to (English language and humans)

**CINAHL**
S1 (MH “Dyspnea+”) OR “Dyspn*”
S2 (MH “Self Care+”) OR “Self Care”
S3 (MH “Symptom Distress”)
S4 (MH “Self Administration+“)
S5 (MH “Patient Education+”)
S6 (MH “Rehabilitation, Pulmonary+”)
S7 S2 OR S3 OR S4 OR S5 OR S6
S8 S1 and S7
S9 S8 Not Child Not Pediatric Limiters – Publication date 19610101-20180331; English language
## Supplementary Item 2 - Outcomes of Interest

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Description</th>
<th>Reference</th>
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<tbody>
<tr>
<td>Adapted BORG Scale</td>
<td>Measures subjective breathlessness during physical activity.</td>
<td>1</td>
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<tr>
<td>Inhalation Technique</td>
<td>An ad hoc assessment using videotape scored by trained observers using a device-specific inhalation checklist.</td>
<td>2</td>
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<tr>
<td>Self-Efficacy Scale</td>
<td>Measured perceived Self-efficacy which reflects patient’s ability to manage condition.</td>
<td>3</td>
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<tr>
<td>Chronic Respiratory Questionnaire Self-Administered-Survey (CRQ-SAS)</td>
<td>assesses health-related quality of life in respiratory conditions.</td>
<td>4</td>
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<tr>
<td>Clinical COPD Questionnaire (CCQ)</td>
<td>Consists of 10 items (each scored between 0 &amp; 6), divided into three domains (symptom, functional, mental).</td>
<td>5</td>
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<tr>
<td>COPD Self-Management Interview (COPD-SMI)</td>
<td>Descriptions read to subjects based on three stages of an exacerbation (feeling well, early exacerbation &amp; severe exacerbation). In each scenario, three self-management domains are assessed: medication use, healthcare seeking decisions and self-care.</td>
<td>6</td>
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<tr>
<td>Diary for respiratory symptoms</td>
<td>Patients rated their respiratory status on a four-point scale, using the categories: usual, mild, moderate or severe. The diary card recorded: prednisone &amp; antibiotic use; contact with doctors, nurses, specialist, pharmacist &amp; other comments.</td>
<td>7</td>
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<tr>
<td>Exacerbation</td>
<td>An ad hoc questionnaire designed to collect patient’s exacerbation event as judged by medical officer to require a prescription for oral steroids.</td>
<td>8</td>
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<tr>
<td>Hospital Anxiety and Depression Scale (HADS)</td>
<td>Measures anxiety &amp; depression in the medical setting.</td>
<td>9</td>
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<tr>
<td>Medical Research Council Scale (MRC) Dyspnoea Scale</td>
<td>Assesses breathlessness severity with regard to the level of disability caused.</td>
<td>10</td>
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<tr>
<td>Number of Stops</td>
<td>An ad hoc measure that counts the number of stops required by patients to avoid breathlessness during physical activity.</td>
<td>11</td>
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<tr>
<td>Numeric Rating Scale (NRS)</td>
<td>used to measures patient-reported intensity of the worst &amp; average breathlessness over the past 24 hours ('breathlessness severity'), 'distress' &amp; 'coping' with breathlessness.</td>
<td>1, 12</td>
</tr>
<tr>
<td>Self-administered Knowledge Questionnaire</td>
<td>An ad hoc questionnaire designed by the study team with 18 items formulated by respiratory physicians &amp; nurses.</td>
<td>2</td>
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<tr>
<td>Self-management Questionnaire</td>
<td>Uses two rapid onset &amp; two slow onset scenarios of exacerbations adapted from a validated qualitative questionnaire.</td>
<td>13</td>
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<tr>
<td>St George Respiratory Questionnaire (SGRQ)</td>
<td>A disease-specific quality of life, measuring- ‘Symptom’ (distress due to respiratory symptoms), ‘Activity’ (effect on mobility &amp; physical activity), &amp; ‘Impact’ (assesses impact of disease).</td>
<td>14</td>
</tr>
<tr>
<td>Visual Numeric Scales (VNS)</td>
<td>adapted from the Visual Analogue Scale (VAS), was used to measure 7 HRQoL health indicators.</td>
<td>15</td>
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</tbody>
</table>
Supplementary item 2 describes the breathlessness-related outcomes utilised in the systematic review and narrative synthesis entitled “Low-intensity educational interventions supporting self-management to improve outcomes related to chronic breathlessness a systematic review”. Whilst some outcomes are not directly measuring breathlessness, they do have breathlessness-related dimensions as identified in our introduction – i.e. sensory-perceptive, affective or impact. These domains are featured in HRQoL measures such as the St George Respiratory Questionnaire (SGRQ). Some other symptoms – most notably anxiety, fatigue, insomnia and pain – commonly present with breathlessness as a cluster. Indeed, while the HADS ostensibly measures anxiety and depression in a generalised way, measurement of these constructs in people with chronic breathlessness is likely to at least in part be assessing the affective dimension of breathlessness.

References: