VANGUARD

A project to develop and feasibility test Respiratory Nurse Sensitive Outcome Indicators for Chronic Obstructive Pulmonary Disease

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VANGUARD: Value Added Nursing Gains Advantage in Respiratory Disease

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Executive summary

There is currently a lack of evidence for the effectiveness of Respiratory Nurse Specialists (RNS). This has provided an opportunity to examine what respiratory nurse specialists do, their impact on patient health outcomes and experiences and ways of capturing and monitoring any impact.

Nurse-sensitive outcome indictors (NSOI) measure changes in patient condition or experiences of care that are strongly influenced by nursing care input. NSOI's do not provide definitive answers but indicate the quality of care. A NSOI needs to demonstrate that a significant variation in the indicator is attributable to nursing such as i) a recognised contribution of nursing; ii) evidence to support sensitivity to nursing; and iii) nurses must 'own' responsibility (in terms of legitimate authority, self-perception and sphere of practice).

This report outlines the process undertaken to develop a Respiratory Nurse Specialist Outcome Indicator (RNSOI) for patients with chronic obstructive pulmonary disease.

The project has involved three studies:

Study 1: A scoping exercise to identify a potential set of key specialist respiratory NSOI, which involved identifying potential items for inclusion and a consensus exercise to determine the relevance and priority of the potential indicators identified
Study 2: Pilot testing of the NSOI set to establish, feasibility, reliability, validity and sensitivity to change.
Study 3: Assessment of the current evidence-base for the developed respiratory NSOI.

Although, further testing of the RNSOI will be required, the preliminary testing of the RNSOI has demonstrated good psychometric properties (reliability, internal consistency and validity) and is acceptable to patients with COPD and Respiratory Nurses Specialists and clinical management.

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1. Background

Measuring the impact of variation in the quality of nursing care has become an imperative driven by several issues during the past several years. Heightened public attention to patient safety and adverse outcomes has prompted national organizations, such as the Department of Health and NHS (1,2,), and the Royal College of Nursing (3), to consider and implement recommendations for monitoring nursing quality indicators. The rhetoric of the specialist nursing's impact on patient outcomes is not currently matched by the strength of the evidence base. There is a lack of evidence for the effectiveness of respiratory nurse specialists and whether or not such roles provide value for money (4). These issues highlight the importance of exploring the respiratory nurse specialist role, its impact on patient health outcomes and experience, and of developing ways of capturing and monitoring any impact. The development and implementation of a set of respiratory nurse specialist outcome indicators is the first step in addressing these issues.

The role of the RNS has been to provide support for patients with respiratory disease following recommendations from the Royal College of Physicians in the 1980's (5, 6). The number of RNS across the UK has grown over the last three decades, as a result of changes to medical training, expansion of nursing roles, and the need to meet the demands for high quality cost effective cares for patients with respiratory conditions. The role of the RNS is varied, including the provision of nurse led services in primary and secondary care. The National Outcomes Strategy to Transform Respiratory Care (7) signifies the role of the RNS is to deliver high quality care, particularly community-based care.

Nurse sensitive outcome indicators are described as an outcome that can be arrived at, from a nursing intervention, which is sensitive to nursing care and represent the consequence of a nursing intervention (8). It is important that the 'intervention' must being within the scope of nursing practice and integral to the processes of nursing care (9) and should reflect the quality of care (10). Furthermore, if nurses are to be held accountable for an outcome, with the quality of nursing services measured against it, the evidence base for the link between nursing and the outcomes should be clear (11). Specific indicators for quality respiratory nursing care are yet to be identified.

2. Aim and Objectives

The aim of the project was to develop a set of Respiratory Nurse Sensitive Outcome Indicators (RSNOI) to be used in clinical practice to measure the quality of nursing care for patients with COPD. Three stages were employed to meet the following objectives:

- Stage 1 A scoping exercise to identify an item set of potential RNSOI
- Stage 2 Pilot testing of the NSOI set to establish feasibility, reliability, validity and sensitivity to change
- Stage 3 Assessing the evidence-base for RNSOI

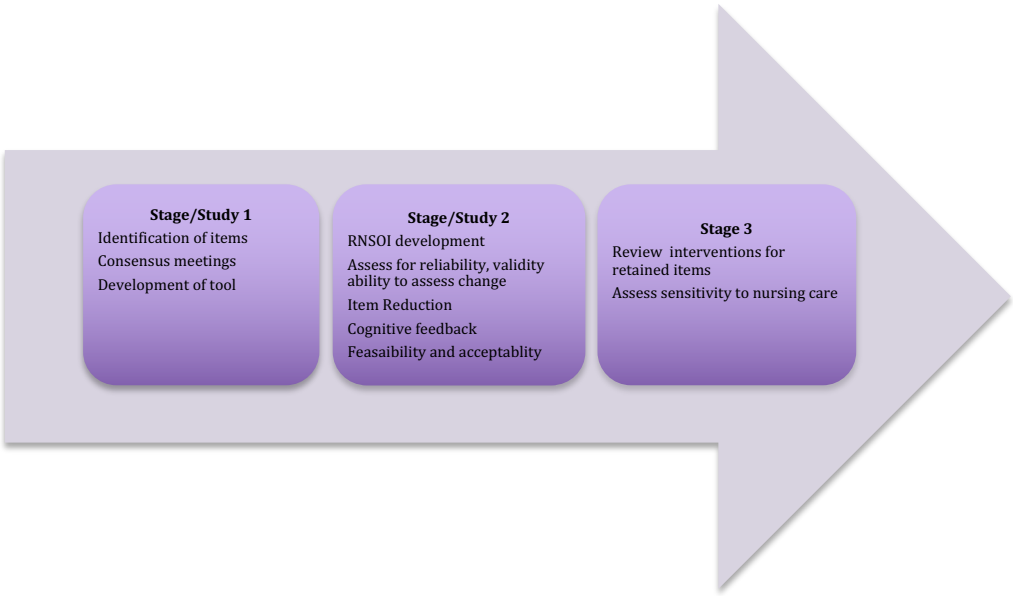
3. Methods

A mixed methods design was employed to develop the RNSOI, following a recommended process outlined in the Food and Drug Administration (FDA) guidance (12) for the development of patient reported outcome measures (PROM) instrument (Figure 1).

This has involved 3 stages, which are described below

Stage/ Study 1: identification and prioritisation of symptoms and experiences of people living with COPD.
Stage/ Study 2: cross-section study employing quantitative and qualitative methods to establish feasibility, reliability, and content validity of the tool.
Stage 3: reviewing the evidence base to support nursing interventions relevant to the symptoms and experiences included in the RNSOI.

Figure 1. The process of developing RNSOI (adapted from FDA 2009)



4. Study 1. Item generation - Identification and prioritisation of items for inclusion in the RNSOI

4.1. Methods

The first stage of this study involved a review of the current literature to explore patient reported symptoms of COPD and their experiences of living with COPD. The second stage of study 1 adopted qualitative methods to gain consensus on identified symptoms and experiences of living with COPD. This provided items for inclusion in the draft RNSOI.

4.2. Literature review – stage 1

The aim of the literature review was to answer the following research questions:

1. What symptoms do patients with COPD suffer with?
2. What are experiences of patients living with COPD?

A scoping exercise was used to identify the most suitable terms used to describe COPD and their symptoms and experiences. A systematic search of qualitative literature was conducted in May 2014 using following databases:

- **Medline**: Produced by US National Library of Medicine (1946-May 2014)
- **CINAHL**: Cumulative Index to Nursing and Allied Health Literature (1937- May 2014)
- **Embase**: Reed-Elsevier Excerpta medica Database (1980-May2014)
- **BNI**; British Nursing Index (1994- May 2014)
- **PsychINFO**: Pyschology database (1806-May 2014)

Searches for unpublished 'grey' literature were undertaken through the 'Open Grey' database. Hand searches were undertaken from the references in the identified papers and where necessary, attempts to contact the authors to clarify/ justify points highlighted within the paper were made.

The following search terms were identified through the thesaurus:- Medical Subject Heading (MeSH); "patient/people/person"; "COPD/ Emphysema"; "experience/living"; and "symptoms", as outlined in Table 1

Studies were limited to qualitative methodology, but otherwise kept broad to capture the range of symptoms and experiences described.

The review of the literature was an iterative process, using thematic analysis (13). This involved reading and re-reading the papers, identifying the symptoms and experiences reported, including authors' interpretation, and documenting quotes from participants within the studies. The experiences described were synthesised and collated into themes.

Table 1: Search terms - Patient reported symptoms and experiences of COPD

#1	COPD
#2	Emphysema
#3	#1 OR #2
#4	Symptom* adj
#5	#3 AND #4
#6	Patient *adj
#7	Person*adj
#8	people*adj
#9	#6 OR #7 OR #8
#10	Experience (explode –adult)
#11	Living (explode –activities of daily living)
#12	#10 OR #11
#13	#9 AND 12
#14	#5 and #13
#15	#14 limit to qualitative

4.3 Literature review results

In total, 26 papers were included in the review. Seventeen symptoms were identified, and four main experience themes were identified, with 11 sub-themes (Table 2). The majority of participants included in the studies were diagnosed with moderate to very severe COPD.

Many of the studies concentrated on individual symptoms experienced by people with COPD and not the overall impact of living with COPD. Breathlessness was the most troublesome symptom for patients with COPD and some evidence that several symptoms are related

Table 2. Symptoms and experiences of COPD

Symptom	
Breathlessness	Panic
Fatigue/tiredness	Anorexia
Functional activity/ ability	Constipation
Anxiety and Fear	Confusion
Cough with sputum or without sputum	Dysphagia
Nocturnal symptoms	Restlessness
Pain	Incontinence
Depression	Sickness
Wheeze	
Experience Themes	**Sub themes**
Anxiety and fear of living with COPD	• Anxiety about exacerbations • Fear of breathlessness • Fear of disease progression and dying
Understanding COPD	• Lack of knowledge and education about COPD • Impact of limitations • Management of exacerbations
A sense of loss	• Loneliness • Isolation
Impact on carers	• Being dependent on others • Burden for carers • Carers concerns about COPD

4.4 Prioritising symptoms and experiences of living with COPD – Stage 2

4.4.1 Methods

Nominal Group Technique (NGT) is a qualitative research approach, which can be utilised to gain in depth information on a given topic and consensus. NGT was adopted to gain consensus on the most important symptoms and experiences of living with COPD. The technique was developed for use in healthcare (14), allowing the generation of information and ideas in response to an issue, which can be prioritised through group discussion, achieving a consensus.

Two of the items listed in table 2, i.e. cough with or without sputum and anxiety and fear, could be misunderstood and could cause confusion. These were therefore listed as separate symptoms: cough with sputum; cough without sputum; anxiety; fear. This resulted in a list of nineteen symptoms, which were presented to the participants of the consensus meeting

With the advice from an expert patient advisor, eleven statements were developed, from the four themes described in table 2. These are listed below:

- I am fearful of a flare up/ attack
- I am fearful of disabling symptoms
- I am confident in managing my symptoms
- I am not confident in managing my symptoms
- I feel isolated and/ or lonely
- I find it difficult to identify the symptoms of a flare up or attack
- I am anxious about my symptoms
- I am concerned about the future
- I am concerned regarding the impact on my carers
- I am acceptant of living with my condition
- Having COPD limits what I can do

4.4.2. Recruitment

People with COPD and carers

The British Lung Foundation, The European Lung Foundation and The British Thoracic Society were approached to identify potential participants. People with a self-confirmed diagnosis of COPD, were invited to participate in the consensus meeting. Carers of people with COPD were also invited to participate. It was anticipated that it might be difficult for them to attend a separate meeting and therefore the meetings involving people with COPD and carers, were combined. The inclusion and exclusion criteria for participants are displayed in table 3.

Respiratory Nurse Specialists

Three national respiratory organisations - The British Thoracic Society, The Association of Respiratory Nurse Specialists and The Primary Care Respiratory Society–UK, were contacted and requested to nominate potential respiratory nurse specialists, from their membership.

4.4.3 Data Collection

All participants were requested to provide for general demographics. The participants with COPD were requested to identify their Medical Research Council (MRC) breathlessness score (15) and to complete the COPD Assessment Tool (CAT) (16) prior to commencing the NGT. The MRC breathlessness score (15) is a validated tool to measure disability associated with breathlessness and exercise limitation. The CAT (16) is a validated tool to measure health related quality of life and the impact of COPD on an individual.

Discussions during the consensus meeting were captured through transcription onto flip charts and enabled participants to review salient points made during the discussions.

Table 3 Inclusion/ Exclusion Criteria for Participants (study 1)

Participants	Inclusion Criteria	Exclusion Criteria
People with a self confirmed diagnosis of COPD	• >35 years • Self confirmed diagnosis of COPD • Able to give informed consent	• Multiple co-morbidities • Cognitive impairment • Unable to speak English • Unable to travel to the meeting venue (i.e. housebound)
Carers of people with COPD	• 18 years • Carer of someone with a self confirmed COPD • Able to give informed consent	• Unable to speak English • Cognitive impairment • Unable to travel to the meeting venue
Respiratory Nurse Specialists	• >21 years old, RGN, employed as a respiratory nurse specialist • 3 years' experience within respiratory speciality • Currently involved in the care for patients with COPD • Clinically based for > 50% of the role. • Able to give informed consent	• < 50% of role is clinically based • generic nurses (e.g. district nurses, ward based nurses)

4.4.4 Data Analysis

Data from NGT can be analysed using both quantitative and qualitative approaches. The final stage involves voting and ranking of the items generated in the earlier stages. Participants were given score cards on which to rank the 10 most important issues identified in the list created from the earlier stages of NGT, with 10 being of the greatest importance (and 1 being the least important). The scores from the participants for each item were collated, giving an overall score, with the highest score being the item of greatest importance to the group, providing an over-arching consensus

4.4.5 Ethical Approval

The University of Manchester Ethics Committee granted a favourable ethical opinion (UREC 14284 August 2014)

4.5 Results

Five consensus meetings using the NGT were conducted between October 2014 and February 2015. Four meetings involved people with COPD and their carers. The meetings were held in London, Nottingham, Oldham and Tameside. One meeting involving RNS was held in London. The RNS group was run separately to reduce the risk of individuals being inhibited, resulting in potential information being withheld and loss of rich of data.

4.5.1 Participants demographics

Patients and carer: A total of 19 people with COPD and 13 carers attended the consensus meetings. Due to illness within the participants, Group 1 and Group 2 were below the ideal number for nominal group technique, but the meetings were still conducted, as the participants attending were keen to continue with the exercise and it was felt that relevant data would be collected. The demographics of the 42 patients and carer participants attended the meetings held for people with COPD and their careers are displayed in Table 5. In several cases the person with COPD and their carer worked through the consensus exercise together

Participants were representative of patients with moderate to severe COPD based on their MRC and CAT scores, and represented the population cared for by respiratory nurse specialists (table 4).

Table 4 Demographics of Participants (People with COPD and Carers)

People with COPD	Group 1	Group 2	Group 3	Group 4	Total
No with COPD	3	2	10	4	19
Gender	2 males	2 females	7 males	3 males	12 males 7 females
Median Age Age Range	68 (64-73)	76 (70-83)	72 (58-77)	71 (65-77)	71 (58-83 years)
Mean MRC score	2-4	4-5	4	4	3-4
Median COPD Assessment Test	26	28	27	24	27
Median Years with COPD (Range)	22(16-19)	10(10-11)	6(1-29)	10(4-16)	1-29 years
Carers					
No of carers	2	1	5	5	13
Gender	1 male	1 female	5 females	4 females	11 females
Total	**5**	**3**	**15**	**9**	**42**

Nurses: Eight RNS volunteered to participate in the consensus meeting, but due to work commitments two withdrew the day prior to the meeting, resulting in six nurses participated in the meeting. The demographics of the participating nurses are displayed in Table 5.

The demographics of the RNS suggest that they are experienced nurses with significant experience in caring for patients with COPD. They are representative of the RNS workforce, covering the acute and community settings. However, it is noted that they were all female.

Table 5 Demographics of RNS

Respiratory Nurse Specialists	Number
Gender	6 females
Median age	43 (Range 35-48 years)
Median time in current position	9 years (Range 5 months –18 years)
Community based	3
Hospital based	1
Community and hospital based	2
Median number of COPD patients seen/week	13 (Range 10-20)

4.5.2. Consensus for Symptoms of COPD

The results of the consensus exercises for COPD symptoms for the people with COPD, carers and the respiratory nurse specialist group are displayed in Table 6.

Table 6. Combined Ranking of Symptoms

Symptoms	Over all	COPD/Carer Rank	RNS Rank
Breathlessness	**1**	**1**	**1**
Functional ability	**2**	**2**	**2**
Fatigue	**3**	**3**	**6**
Cough with phlegm	**4**	**5**	**3**
Fear	**5**	**4**	**7**
Panic	**6**	**6**	**4**
Anxiety	**7**	**8**	**5**
Wheeze	**8**	**7**	**12**
Depression	**9**	**10**	**9**
Pain	**10**	**9**	**15**
Cough without phlegm	**11**	**12**	**11**
Restlessness	**12**	**11**	**-**
Nocturnal symptoms	**13**	**13**	**8**
Dysphagia	**14**	**14**	**-**
Incontinence	**15**	**15 =**	**13**
Confusion	**16**	**15 =**	**-**
Sickness	**18**	**17**	**10**
Anorexia	**17**	**18 =**	**14**
Constipation	**18**	**18 =**	**-**

4.5.3. Consensus of the experiences of living with COPD

The combined results of the consensus exercises for COPD experiences for the people with COPD, carers and the RNS group are displayed in Table 7.

Table 7 Combined Ranking of Experiences

Experiences	Overall	COPD/ Carer Rank	RNS Rank
Having COPD limits what I can do	**1**	**3**	**1**
I am fearful of a flare up or attack	**2**	**2**	**3**
I find it difficult to identify the symptoms of a flare up or attack	**3**	**1**	**5**
I am anxious about my symptoms	**4**	**6 =**	**2**
I am not confident in managing my symptoms	**5**	**8**	**4**
I am concerned about the future	**6**	**4**	**9**
I am fearful of disabling symptoms	**7**	**5**	**6**
I accept my life living with COPD	**8**	**9**	**10**
I am concerned regarding the impact on my carers	**9**	**6 =**	**11**
I am confident in managing my symptoms	**10**	**10**	**8**
I feel isolated and/ or lonely	**11**	**11**	**7**

4.6. Discussion

4.6.1 Symptoms

In comparing the ranking of symptoms between groups, the importance of different symptoms were ranked similarly among COPD participants. There were differences in the ranking of symptoms between COPD and nurse participants. Fatigue and fear were rated higher by COPD participants, and cough, anxiety and panic being rated higher by RNS.

The number of symptoms that appeared in the list for prioritisation was higher than anticipated by the COPD and carer participants. However, they did acknowledge that COPD could affect people differently and at different stages of the disease. Breathlessness, lack of ability to do the things they wanted (functional ability), feeling fatigued, fear, cough with phlegm and panic were ranked the most important symptoms by people with COPD and their carers.

The RNS ranked breathlessness, impact of functional ability, cough, panic, and anxiety highly. The importance of understanding the patient and recognising that they could have multiple symptoms and potential co- morbidities, was highlighted within the discussions.

4.6.2 Experiences of living with COPD

It was apparent that the people who participated in the nominal group discussions received support from attending the Breathe Easy group or being involved with the European Lung Foundation. Participants discussed how they had learnt from the groups and pulmonary rehabilitation, and about living with the symptoms of COPD. There was a sense of being part of a 'family' and being aware of helping each other and others. Therefore, it was not surprising that they did not rank feeling lonely or isolated highly.

The participants with COPD also expressed the view that some healthcare professionals did not understand the impact of having COPD had on them, and what it is like to live with COPD.

The RNS group highlighted the importance of continuity of care and providing clear consistent information and guidance. Frustration with the current challenges in the provision of healthcare, linking social and health care needs together, was clearly articulated within the nurse group. This resulted in the inability to provide the quality of care and interventions that they felt would be most appropriate.

The impact of the disease and potential 'attacks' or 'flare ups' play a big part in living with COPD. It was clear that being able to identify the signs of an exacerbation could be difficult for both individuals and their carers. The participants expressed fear of going into hospital, frequently stating poor previous experiences, with poor organisation of care as a problem; for example, having to repeat medical history and medications and being moved from ward to ward.

Carers indicated that they felt unprepared and unsupported at times in providing the care and making decisions about escalating treatment and accessing emergency care. However, when a RNS had been involved in their care and ongoing management, their expertise and experience was valued and respected.

Surprisingly, the impact on carers and acceptance of living with COPD was ranked significantly lower in the RNS group, than in the people with COPD and carer group. This may be related to the wording of the statements and the emphasis the RNS placed on the individual with COPD.

The nurses also felt that anxiety about symptoms was an important issue, but people with COPD did not rank it as highly.

4.7 Conclusion

Initially all identified symptoms and experiences were included as items in the draft RNSOI. Whilst both groups ranked the major symptoms and experiences of living with COPD similarly there were some disparities in the ranking between the two groups. The results suggest that a RNSOI will be of benefit to enable focus on symptoms and experiences, which are of greatest importance to an individual patient.

5. Study 2. RNSOI development, including item reduction, assessment for reliability, validity, ability to assess change, feasibility and acceptability

5.1. RNSOI design

RNSOI consisted of five sections. The first four sections included the items retained from study 1 and related to symptoms and experiences of living with COPD:

- *Question 1* related to the symptoms that the individual is currently experiencing
- *Question 2* related to the level of fear and anxiety the individual experiences due to the symptoms identified
- *Question 3* reflected on how confident the individual felt in managing the symptoms they were experiencing
- *Question 4* related to the impact COPD has on the individual and their family and/ or carers. The literature review did not include the impact on carers, but following expert panel review, they were added for inclusion in the final list.

For each question, a scaling range of 0 – 5 was used.

Question 5 focused on service evaluation and participant perceptions of the effectiveness of the RNS, with a positive, negative or non-applicable responses option being given.

The wording and layout of the RSNOI was reviewed and approved by expert patient advisors, identified by the British Lung Foundation, European Lung Foundation and the British Thoracic Society.

5.2. Methods

A mixed methods approach was adopted. Quantitative methods were used to identify items for inclusion or deletion, and to test the instruments psychometric properties. A qualitative approach was used to assess feasibility and acceptability of the RNSOI for use in practice.

A cross sectional psychometric testing method was used with a sub-group of patients who competed the RNSOI at a second time point (approx. 2 weeks later) to test its repeatability (17). Hierarchical item reduction methods (18) and psychometric testing were applied to identify items with the best measurement properties to be retained in the final item-set.

Semi-structured face to face or telephone interviews with the RNS involved in the data collection, and their managers, were conducted assess the feasibility and acceptability of using RNSOI in clinical practice.

5.3 Recruitment

Patients: Patients with a diagnosis of COPD under the care of an RNS across four NHS sites in England were recruited to participate in the study.

RNS and Clinical Managers: RNS and their managers at the participating sites were invited to participate in a semi-structured interview conducted either face to face or via the telephone.

5.4 Data Collection

5.4.1 Patients with COPD

Participant demographics and clinical information was collected:

- Confirmation of COPD diagnosis and severity of disease
- Age
- Gender
- Previous 12 month exacerbation history
- Previous 12 month hospital admission history
- Current medications

The first questionnaire set, issued on recruitment, consisted of the Draft RNSOI and several validated questionnaires used to assess content and construct validity of the Draft RSNOI:

- Draft RNSOI
- St Georges Respiratory Questionnaire-C (SGRQ-C) (19)
- Dyspnoea-12 (D12) (20).
- Hospital Anxiety and Depression Scale (HADS) (21)
- FACIT-Fatigue: Functional Assessment of Chronic Illness Therapy-Fatigue Scale (FACIT-F) (22)
- Bristol COPD Knowledge Questionnaire (BCKQ) (23)
- PREM COPD-9 (24)

The second question set, completed 10-14 days later consisted of

- Global rating of change
- Draft RNSOI
- Participant feedback on RNSOI

5.4.2 RNS and Clinical Managers

The semi structured interviews were undertaken with questions being based on the following topics:

- Gaining information about how the impact of the RNS is currently measured within their service
- Perceived benefits of the Draft RNSOI for the service and for the RNS
- Perceived problems with using the Draft RNSOI in practice
- Opinions on the usefulness of the Draft RNSOI
- Opinions on who should issue the Draft RNSOI
- Perceived issues with implementation, including barriers

- Frequency of use
- Opinions on dissemination of results
- Opinions on usefulness of the results

The interviews were audio recorded and the recordings transcribed verbatim. The analysis was iterative allowing themes to emerge.

5.5 Data Analysis

Data was analysed using IBM SPSS Statistics Version 22 (IBM Corp., 2013). Clinical and demographic data was analysed using descriptive analysis.

Item reduction, using hierarchical reduction methods (18), informed decisions regarding item removal. Descriptive statistics were adopted to identify items for potential removal including: i) items with more than 25% missing responses; ii) items that demonstrate significant sex or age bias ($p<0.05$); iii) items that demonstrate floor or ceiling effects (> 50% endorsement at either end of the item measurement scale); iv) Items with high item–item correlations ($r>0.8$), v) low item-total correlations ($r<0.3$) (26). Non-parametric tests (Spearman Correlation and Mann-Witney U test) were employed to determine item association with age and gender ($p >0.05$).

In addition, the reports of item relevance in the literature (High = 10 or more; Medium = 5 or more; Low reports = less than 5) and consensus meetings (High = 1-10; Low = 10 or higher) were taken into consideration. Items that were highly reported in the literature, or highly ranked in the consensus meetings, were discussed within the Expert Advisory Group and agreement as to whether items were retained was sought.

Reliability, through intra-item correlations, was tested using data from patients who stated on completed the second questionnaire, that their global health was ‘about the same’ since completing baseline questionnaires. Test-retest was assessed using the Kappa statistic for categorical variables (levels >0.75 acceptable) and intra-class correlation coefficient (ICC) (levels >0.7 acceptable). (16).

Internal consistency was measured using Cronbach’s *a* statistic. This statistic uses inter-item correlations to determine whether items are measuring the same domains. If the items show good internal consistency, Cronbach’s *a* should exceed .70 (16)

Pearson’s coefficient was used to measure content and construct validity (whether the RNSOI’s correlate in the expected direction with other relevant outcomes, SGRQ-C, D-12, HADS, FACIT-F Scale, BCKQ and PREM COPD-9). Values greater than 0.7 represent excellent correlations (17).

5.6 Ethical Approval A favourable ethical opinion was obtained (NRES Committee London South East -15/LO/1563 September 2015) and NHS R&D approval was granted from the participating sites.

5.7 Results

5.7.1 Participant demographics

90 participants were recruited from RNS caseload, either following a clinic appointment or a home visit, from three sites participating in the study. The participant demographics are displayed in table 8. Participants reported having co existing comorbidities as presented in Table 9.

Table 8 Demographics of participants (study 2)

	No = 90
Gender	57% (51) female
Age	74 years ±9.44
FEV_1 predicted	47.7% ±15.98
FEV_1 severity –Mild (<80% predicted)	1%
FEV_1 severity –Moderate (50-79% predicted))	44.3%
FEV_1 severity -Severe (30-49% predicted)	40.9%
FEV_1 severity -Very severe (<30% predicted)	13.6%
SGRQ –C Total	63.52 ±18.05
SGRQ –C symptoms	71.11±16.28
SGRQ –C Activities	86.87 ±20.38
SGRQ –C Impacts	47.05 ±23.84
D12 Total	15.37 ±9.94
D12 Physical	10.16 ± 5.84
D12 Affective	5.2 ± 4.85
HADS Total	11.97 ± 7.84
HADS Anxiety	5.37 ± 4.52
HADS Depression	6.59 ± 3.87
FACIT-F	32.29 ± 12.26
PREM COPD 9	11.6 ± 9.9
BCKQ	27.1 ± 10
Current Smoker	25%(22)
Pack year History	51± 31.69
Recruited from: **Inpatient** **Outpatient** **Community**	 1%(1) 7%(6) 92%(83)
Patient reported exacerbations in previous year	3.1 ± 2.97 (range 0-14)
Patient reported COPD related hospital admissions in previous year	1.02 +1.28 (range 0-8)
COPD action plan issued	89% (76)
Lives alone	48% (43)
Review in last year from GP	88% (79)
Reviewed by Community matron	7.8% (7)
Reviewed by District nurse	13% (12)

Table 9 Participants' Co morbidities

Comorbidity	No = 90
Diabetes	14.4% (13)
Cardiovascular disease	40% (36)
Hypertension	46.7% (42)
Osteoporosis	24.4%(22)
Depression	17.8% (16)

5.7.2 Hierarchical item reduction

Following hierarchical reduction methods and discussions with the Expert Advisory Group, the following items were retained in Question 1:

- Breathless
- Fatigue
- Wheeziness
- Dry Cough
- Productive cough
- Symptoms on waking
- Symptoms during the night
- Symptoms affecting day today activities

Question 2 was felt to be redundant due to repetitiveness.

The following items were retained within the item set for Question 3:

- Breathlessness
- Fatigue
- Wheeziness
- Dry Cough
- Productive cough
- Symptoms on Waking
- Identifying symptoms of an exacerbation
- Knowing what medication to take for an exacerbation
- Knowing how to help recovery

The following items were retained within the item set for Question 4:

- Concerned about the future
- Concerned about the impact on family
- COPD limits what I can do
- I have difficulties in accepting COPD
- Family worry about my future
- Family concerned about how COPD limits me

Tables 10, 11 and 12 demonstrate the justification for the deletion items from the draft RNSOI.

Following the hierarchical item reduction, fifty items were removed, with thirty items being retained for psychometric testing.

5.7.3 Psychometric Testing

Psychometric testing for preliminary reliability, internal consistency and validity of the 30 retained items is reported in this section.

The total RNSOI and its three separate sections demonstrated excellent internal reliability (Cronbach Alpha .87, .85, .72 and .87 respectively). The RNSOI demonstrated good stability over time (ICC = 0.80).
The RNSOI items correlated with the PROMs as described in table 13.

Table 10 Justification for deletion of items for Question 1

Item	Justification					
	Report in literature	**Ranked by patients**	**Ranked by RNS**	**Floor/ ceiling effect**	**Correlation with age/ gender**	**Expert Panel Advice**
Restlessness	Low report	Low ranking (11)	Low ranking (0)	Floor (60%/ 64%)	No	
Afraid	Medium report	High ranking (4)	High ranking (7)	Floor (72%).	No	Remove
Fear	High report	High ranking (4)	High ranking (7)	Floor (70%65%)	No	Remove
Nausea	Low report	Low ranking (17)	Low ranking (0)	Floor (74%/ 76%).	Correlation with age	
Vomiting	Low report	Low ranking (17)	Low ranking (0)	Floor (87%/90%).	No	
Pain	High report	High ranking (9)	Low ranking (15)	Floor (70%/72%)	No	Remove
Poor appetite	Low report	Low ranking (18)	Low ranking (10)	Floor (62%/ 66%)	No	
Confusion	Low report	Low ranking (15)	Low ranking (0)	Floor (75%/ 74%)	No	
Urinary Incontinence	Low report	Low ranking (15)	Low ranking (0)	Floor (70%/ 76%).	No	
Constipation	Low report	Low ranking (18)	Low ranking (14)	Floor (67%/72%).	No	
Swallowing	Low report i	Low ranking (14)	Low ranking (13)	Floor (78%/ 82%)	No	

Table 11 Justification of deletion of items for Question 3

Item	Justification					
	Report in literature	**Ranked by patients**	**Ranked by RNS**	**Floor/ ceiling effect**	**Correlation with age/ gender**	**Expert Panel Advice**
Restlessness	Low report	Low ranking (11)	Low ranking (0)	Floor (63%)	No	
Afraid	Medium report	High ranking (4)	High ranking (7)	Floor (72%).	No	Remove
Fear	High report	High ranking (4)	High ranking (7)	Floor (67%)	No	Remove
Nausea	Low report	Low ranking (17)	Low ranking (0)	Floor (78%).	Correlation with age	
Vomiting	Low report	Low ranking (17)	Low ranking (0)	Floor (90%).	No	
Pain	High report	High ranking (9)	Low ranking (15)	Floor (70%)	No	Remove
Poor appetite	Low report	Low ranking (18)	Low ranking (10)	Floor (66%)	No	
Confusion	Low report	Low ranking (15)	Low ranking (0)	Floor (78%)	No	
Urinary Incontinence	Low report	Low ranking (15)	Low ranking (0)	Floor (73%).	No	
Constipation	Low report	Low ranking (18)	Low ranking (14)	Floor (78%)	Correlation with age	
Swallowing	Low report	Low ranking (14)	Low ranking (13)	Floor (82%)	No	

Table 12. Justification for deletion of items in Question 4

Item	Justification					
	Report in literature	**Ranked by patients**	**Ranked by RNS**	**Floor/ ceiling effect**	**Correlation with age/ gender**	**Expert Panel Advice**
I feel lonely	Low report	Low ranking (11)	High ranking (7)	Floor (65%)	Correlation with age	Remove
I feel isolated	Low report	Low ranking (1)	High ranking (7)	Floor (67%)	No	Remove
Family worried about their future	n/a	n/a	n/a	Floor 56%	No	Remove
Family feel burdened	n/a	n/a	n/a	Floor (64%)	No	Remove
Family worry that they do not know how to help me	n/a	n/a	n/a	Floor (54%)	No	Remove
Family have difficulties in accepting my COPD	n/a	n/a	n/a	Floor (66%)	No	Remove

Table 13 Correlation with PROMS

PROM	Question 1	Question 2 (reversed scoring	Question 3	RNSOI Total
SGRQ-C Total	*r* .615**	*r*.188	*r .560***	*r* .491**
SGRQ-C Symptom	*r* .296**	*r*.098	*r* .166	*r* .424*
SGRQ-C Activities	*r* .284**	*r*.046	*r* .206	*r* .217**
SGRQ-C Impacts+	*r .690***	*r*.126	*r .598***	*r .554***
D12 Total	*r .603***	*r*.098	*r* .580**	*r .491***
D12 Physical	*r .941***	*r*.111	*r* .420**	*r .401***
D12 Affective	*r .913***	*r*.081	*r* .683**	*r .528***
HADS Total	*r .774***	*r*.183	*r .667***	*r .642***
HADS Anxiety	*r .768***	*r*.237*	*r -.648***	*r .661***
HADS Depression	*r . 671***	*r* .093	*r .595***	*r . 527***
FACIT-F	*r* -.754**	*r* -.238*	*r* -.630**	*r* -.636**
PREM 9	*r* .325**	*r* -.105	*r* .278**	*r. 174*
BCKQ	*r* 0.15	*r* .140	*r* .130	*r* 0.93
** Correlation significant at 0.01 *Correlation significant at 0.05				

5.7.4 Patients' experiences of RNS care

Question 5 focused on service evaluation and effectiveness of the RNS

93% of the participants were reviewed by a RNS within the previous month, with 77% being seen at home, 13% in the outpatient setting and 10% through a telephone consultation. The various aspects of the RNS review are described in Table 14. The participants indicated that the RNS listened to carers concerns (59%), provided practical support (51%) and emotional support (54%) to carers. However, there were 8%, 11% and 10% respectively, of data missing in this section. 49% participants lived alone and the RNS may not have had contact with their care.

Table 14 Summary of RNS review

RNS assessment	Yes
RNS asked about main COPD symptoms	96%
RNS asked about other symptoms	87%
RNS aware of impact of symptoms	81%
RNS asked about overall health	89%
RNS provided useful information	97%
RNS provided practical information	94%
RNS provided written information	85%
RNS provided an action plan	90%
RNS provides advice on recognising an exacerbation	89%
RNS provides advice on managing symptom exacerbations	90%
RNS provides advice on when to seek help	91%
RNS provides advice on where to seek help	92%
RNS checked inhaler technique	97%
RNS check other medications	93%
RNS listened to concerns	93%
RNS provided with emotional support	88%
RNS listened to carers concerns	59%
RNS provided emotional support to carers	51%
RNS provided practical support to carers	54%

5.7.5. Feasibility and Acceptability of RNSOI

The format and wording of the RNSOI tested was reviewed by the Expert Reference Group and expert respiratory patients identified by the British Lung Foundation and the European Lung Foundation, during the developmental phase.

Participant Acceptability of RNSOI

The Patient Feedback questionnaire was completed by 84 (90%) participants returning the second set of questionnaires.
Participants were asked to rate how easy it was to complete the RNSOI, with a visual analogue scale of 0 - 10 (0=not easy, 10=extremely easy). Three participants did not complete this part of the questionnaire, giving a 96% completion rate. The median score for ease of completion was 8.0.

They were asked to respond to eight questions related to the content and layout of the question, which required a positive or negative response. The results are outlined in Table 15.

Table 15. Content and layout of RNSOI

Question	Yes	No
I did not understand some of the questions	37%	63%
Some of the questions do not related to me	66%	34%
There were too many questions	67%	33%
I did not like the layout of the questionnaire	14%	86%
The writing was too small	10%	90%
The questionnaire was too detailed	50%	50%
The questionnaire was not detailed enough	4.5%	95.5%
The questionnaire did not ask about some things that I think are important	15%	85%

Participants were invited comment and offer suggestions about the design of the RNSOI. The following issues were highlighted;

- The length of the questionnaire was too long, with some questions being repetitive leading to some confusion over answering the questions
- Help may be required due to poor eyesight, difficulties in reading and understanding the questions. This was reinforced with one participant stating that they would have found it difficult to complete without guidance from their nurse

Respiratory Nurse Specialists' and Clinical Nurse Managers' Feedback

Five semi-structured interviews were conducted with 3 RNS and 2 clinical nurse managers (CNM) employed by 3 of the participating sites, to gain insight to the feasibility and utility of the RNSOI in clinical practice.
Both managers were nurses and been qualified for 19.5 years, working in their current roles between 2-5 years.
The RNS were all female (32 – 42 years old) and had been qualified between 7 and 16 years. They had been employed in their current role between 2 and 12 years. They had relevant post basic training, which included asthma, COPD and spirometry modules and smoking cessation training. One RNS was a non-medical prescriber. On average, they reviewed 36 patients (range 20-55) either face to face contact or via telephone.

Four themes emerged from the qualitative analysis:

- The design of the RNSOI;
- Usefulness of RNSOI,
- Implementation of RNSOI
- RNSOI as an evaluation tool.

Summary of Feasibility and Acceptability of RNSOI

The layout and format of the questionnaire appears to be acceptable to patients with COPD. However, some of the questions were not understood, and some items were felt not to be relevant, by a significant proportion of the population studied. This has

been through addressed hierarchical reduction methods, where redundant items have been removed, resulting in a reduction in the length and repetitiveness of the questionnaire. Some patients may need guidance in completing the questionnaire due to sight and literacy related issues.

The RNS and CNM interviewed provided positive feedback on the design and clinical utility of the RNSOI and felt that it would be a useful tool to use to demonstrate effectiveness of the RNS and to identify gaps in services, and for potential areas for service development. The only major concerns identified, related to the length of the tool which has been addressed with the item reduction process, and implementation issues regarding to change in current practice.

In addition, the feasibility of the RNSOI had been discussed at the British Thoracic Society Nurse Advisory group open meeting at the BTS Winter Meeting 2016, which was attended by approximately 40 people. There was positive interest expressed in using the RNSOI in clinical practice to demonstrate the impact and value of RNS in, which no concerns highlighted regarding the content or design of it.

5. 8 Conclusion

Following the hierarchical item reduction and psychometric testing, the RNSOI has been modified (Appendix 1).

Part 1, contains three sections with a total of 30 items. Each question is scored separately:

- Section 1 relates to current symptoms experienced (11 items), with a total score range of 0-55: a low score reflects a low symptom burden
- Section 2 relates to how confident the patient is in managing their symptoms and exacerbations (13 items), with a total score range of 0-65: a low score reflects greater confidence in managing their symptoms
- Section 3 relates to the impact of having COPD on the individual and their family and carers (6 items) with a total score range of 0-30: a low score reflects low impact

Part 2 ‘How are we doing”, contains 5 sections with a total of 21 items. Sections 1 and 2 are not scored, but sections 3- 5 are scored separately, with 1 point being given to a positive response:

- Section 1 related to when and where they last had contact with their RNS.
- Section 2 asks the participant to list their main COPD symptoms
- Section 3 relates to whether the RNS asks about the COPD symptoms and is aware of the impact the symptoms may have on the participant (2 items), with a total score ranging from 0-2, with higher score suggesting high quality nursing care.
- Section 4 relates to whether the participant has received support and help from the RNS in the identification and management of an exacerbation (5 items) with a total score ranging from 0-5, with higher score suggesting high quality nursing care.

- Section 5 related to the support and help received from the RNS to the participant and their family or carers (11 items) with a total score ranging from 0-11, with higher score suggesting high quality nursing care.

6. Stage 3. Identifying Nurse Sensitive Interventions

6.1.1 Methods

A systematic review of the literature for evidence based interventions that target the items retained in the RSNOI was undertaken.
The items retained include the following symptoms and the impact of living with COPD, highlighting the importance of self management:

- Breathlessness
- Productive cough
- Dry cough
- Wheeziness
- Fatigue
- Anxiety
- Panic
- Depression
- Self management

Expert opinion and agreement was sought and from experienced senior RNS on the interventions identified in the literature review.

6.1.2 Search Strategy

Medline, CINAHL, PyschInfo, ASSIA databases and the Cochrane library, were searched for interventions for the management of the items retained in the RNSOI. The search was iterative but based around key words/ index terms for the symptoms and skills identified, COPD, treatment/management and nurse.
An example for breathlessness is displayed in Table 16. National and international guidelines for the management of COPD and individual symptoms were also reviewed. Google scholar, hand searches were also undertaken.

Table 16. Example of literature search for breathlessness

1	Dyspnea/ dyspnoea/ Breathless/ness
2	COPD
3	1 AND 2 (COPD and breathlessness)
4	Treat*
5	1 AND 4 (Breathlessness and treatment)
6	3 AND 4 (Breathlessness in COPD and treatment)
7	Manage*
8	1 AND 7 (Breathlessness and management)
9	3 AND 7 (Breathlessness in COPD and management)
10	Nurse/ Nurs*
11	MeSH descriptor Nurses explode all trees
12	10 OR 11 (Nurse)
13	5 AND 6 AND 8 AND 9 Treatment/ management COPD Breathlessness)
14	13 AND12 (Nurse and treatment and management)

Primary research evidence from controlled trials (both randomised and non-randomised), observational studies systematic reviews and guidelines evaluating the treatment of COPD were included. In addition, the treatment of symptoms where there were no COPD specific evidence, were reviewed and assessed if applicable for patients with COPD. Qualitative studies, non-controlled trials and non-English language published studies were excluded.

6.3 Results

Limited studies demonstrating the contribution of nursing alone in the management of the symptoms experienced by patients with COPD were found. Therefore, evidence for interventions recommended within guidelines has been reviewed and the nursing contribution has been considered and agreed with an expert panel of experienced RNS (n =7).

6.3.1 Breathlessness

Six non pharmacological and two pharmacological interventions were identified to ease breathlessness (table 17). There is a strong evidence base for inhaled bronchodilators for the management of breathlessness. Inhaler technique is discussed in the self management as ensuring inhaler technique is optimised is essential to ensure optimal drug deposition in the lungs. All of the interventions identified are sensitive to nursing care as displayed in table 18.

Table 17. Interventions for breathlessness

Symptom - Breathlessness	Systematic review	RCT	Strength of evidence for intervention
Positioning		Yes	2C
Pulmonary Rehabilitation	Yes		1A
Hand held fan		Yes	2A
Integrated breathlessness services		Yes	1A
Pursed lip breathing		Yes	2A
Walking aids	Yes		1A
Inhaled technique	No	No	N/A
Auditory Stimuli with Music	Yes		2B
Opioids (oral morphine)	Yes		1A
Oxygen therapy	Yes		1B

Table 18 Nurse Sensitive Interventions for Breathlessness

Breathlessness
Pulmonary Rehabilitation. RNS would assess and refer patients with COPD for pulmonary rehabilitation. In addition, RNS are actively involved in the delivery of pulmonary rehabilitation
Pursed lipped breathing techniques*.* Physiotherapists have, traditionally delivered many of the interventions used in the management of breathlessness in COPD. However, with multidisciplinary working, it is reasonable to assume that RNS will be able to educate patients in the techniques described, or identify a need to refer to respiratory physiotherapist, for their expertise.
Positioning, walking aids, hand held fans. It would be appropriate for a RNS to be able to assess and educate patients for these interventions.
Integrated breathlessness services. It would be appropriate for a RNS to assess and refer to a breathlessness service and provide on going support to patients. Equally a RNS could be involved in the delivery of the service***.***
Auditory Stimuli with music RNS could advise patients to exercise with music.
Inhaled medication It would be appropriate to expect a RNS to assess for the appropriateness of the introduction of inhaled bronchodilators and inhaled corticosteroids (including assessing and selection of inhaler device), and to evaluate the effectiveness of them.
Oral morphine*.* It would be appropriate to expect a RNS to assess for the appropriateness of the introduction of morphine, and to evaluate the effectiveness of it. It would be necessary for the RNS to provide education to the patient of the potential drug interactions and side effects.
Oxygen therapy - It would be appropriate to expect a RNS to identify the need and the appropriateness of commencing oxygen therapy and to monitor usage and blood gases. It would be necessary for the RNS to provide education to the patient and to ensure safely assessments are made e.g. fire risk, trip/ fall assessment. RNS could provide an oxygen assessment and review service.

6.3.2 Cough

The management of dry and productive cough have been reviewed together, with the evidence of sputum clearance being included in this section. There is limited evidence for management for cough in COPD only. Two non pharmacological and one pharmacological interventions were identified to relieve cough and aid sputum clearance (table 19). The interventions identified are sensitive to nursing care as displayed in table 20.

Table 19 Interventions for cough and sputum clearance

Symptom - Cough	Systematic review	RCT	Strength of evidence for intervention
Active cycle of breathing, forced expiration technique and positive expiratory pressure +/- oscillating devices	Yes		2C
Cough Suppression Therapy		Yes	1B
Mucolytics	Yes		2C

Table 20 Nurse Sensitive Interventions for Cough and Sputum clearance

Cough
Active cycle of breathing, forced expiration techniques and Positive expiratory pressure +/- oscillating devices. RNS should be able to identify the need for referral to physiotherapy / be able to teach the techniques to assist with sputum clearance and would be able to educate and support patients with techniques.
Cough Suppression Therapy has traditionally been delivered by Speech and Language Therapists or Physiotherapists, with an interest in respiratory care. However, a RNS could be taught the techniques involved in cough suppression therapy. RNS should be able to identify the need and refer for intervention. In addition, they could support patients to ensure adherence with cough suppression therapy.
Mucolytics RNS should recognise the need and be able to recommend/ prescribe a mucolytic.

6.3.3 Wheeze

There is little evidence for the management of wheeze in adults. National and international guidelines (25, 26) rarely mention wheeze, in relationship to presenting symptoms and with dyspnoea. Given the limited evidence, it is difficult to determine nursing interventions that may improve wheeze.

However, it is acknowledged that wheeze has good face validity from the Expert RNS advisors and is recognised a cardinal symptom when diagnosing COPD and COPD exacerbations (25, 26). In addition, the preliminary validity testing of the RSNOI demonstrated that wheeze had good psychometric properties and therefore, it has been retained as an item.

6.3.4. Fatigue

Fatigue is common in patients with COPD and is associated with dyspnoea and depression (27). There is limited evidence for the management of fatigue in COPD alone, although management of co-existing symptoms may improve fatigue e.g. breathlessness. Three interventions were identified to improve fatigue in COPD (table 21), with the interventions sensitive to nursing care as displayed in table 22.

Table 21. Interventions for Fatigue

Symptom - Fatigue	Systematic review	RCT	Strength of evidence for intervention
Pulmonary Rehabilitation	Yes		1A
Self Management	Yes		1A
Auditory Stimuli with Music	Yes		2B

Table 22. Nurse Sensitive Interventions for the management of fatigue

Fatigue
Pulmonary Rehabilitation RNS would assess and refer patients with COPD for pulmonary rehabilitation. In addition, RNS are actively involved in the delivery of pulmonary rehabilitation.
Self Management Providing education to patients with COPD is an integral part of the RNS role.
Auditory Stimuli with Music RNS could advise patients to exercise with music.

6.3.5 Anxiety and Panic

Anxiety and panic have been combined as it is recognised that panic is a subtype of anxiety, and thereby defined as panic disorder. Anxiety is a common co morbidity in patients with COPD, with an estimated prevalence of 36%, which does not appear to be associated with the severity of airflow obstruction (28). In addition, people with COPD are 85% more likely to experience anxiety disorders than case controls (29)

Four interventions, which improve anxiety and panic in COPD, were identified (table 23) with the interventions sensitive to nursing care as displayed in table 24.

Table 23 Interventions for anxiety and panic

Symptom – Anxiety and panic	Systematic review	RCT	Strength of evidence for intervention
Cognitive Behavioural Therapy	Yes	Yes	1A
Patient Education		Yes	1A
Pulmonary Rehabilitation	Yes		1A
Mind –body interventions	Yes		2C

Table 24 Nurse Sensitive Interventions for anxiety and panic

Anxiety and Panic
Cognitive Behavioural Therapy RNS would assess and refer patients for psychological support e.g. CBT with specific training, RNS can incorporate CBT into their day to day practice.
Patient Education Providing education to patients with COPD is an integral part of the RNS role and RNS should be actively involved in patient education.
Pulmonary Rehabilitation RNS would assess and refer patients with COPD for pulmonary rehabilitation. In addition, RNS are actively involved in the delivery of pulmonary rehabilitation.
Mind-body interventions RNS would assess and refer patients for psychological support.

6.3.6 Depression

Depression is common co morbidity in patients with COPD with an estimated prevalence of 40%, which do not appear to be associated with the severity of airflow obstruction (30). It is suggested that depression is both a cause and a consequence of COPD (30).
Five non pharmacological and one pharmacological interventions for the management of depression in COPD, were identified (table 25) with the interventions sensitive to nursing care as displayed in table 26.

Table 25. Interventions the management of depression

Symptom– Depression	Systematic review	RCT	Strength of evidence for intervention
Pulmonary Rehabilitation		Yes	1A
Patient Education		Yes	1A
Cognitive Behavioural Therapy	Yes	Yes	1A
Mind body interventions	Yes		2C
Selective Serotonin Re-uptake inhibitors		Yes	2B

Table 26. Nurse Sensitive Interventions for the management of Depression

Depression
Cognitive Behavioural Therapy RNS would assess and refer patients for psychological support e.g. CBT. With specific training, RNS could incorporate CBT into their day to day practice.
Patient Education Providing education to patients with COPD is an integral part of the RNS role. and RNS should be actively involved in patient education.
Pulmonary Rehabilitation RNS would assess and refer patients with COPD for pulmonary rehabilitation. In addition, RNS are actively involved in the delivery of pulmonary rehabilitation.
Mind-body interventions RNS would assess and refer patients for psychological support and may be involved in the delivery of services after specific training.
Selective Serotonin Re-uptake inhibitors RNS should recognise the need and be able to refer to an alternative AHP for assessment. They should be able to assess effectiveness of treatment.

6.3.7. Self management

In chronic disease management patient involvement in decisions about their health and self management strategies is crucial to enable individuals to address both symptoms and exacerbations in a timely manner. Self management involves formalised education programmes, which provide skills and support for health promoting behaviour (31) Different components of care are delivered by a multidisciplinary team and can be delivered by integrated disease management, in which different health care professionals work collaboratively to provide efficient and quality care (32). A definition of a COPD intervention has recently been agreed through an international expert group consensus (33). It is defined as:

'A COPD self management intervention is structured but personalised and often multi component, with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease.' (33 pg 50)

Three interventions were identified to aid self management in COPD (table 27)
The interventions sensitive to nursing care as displayed in table 28.

Table 27 Evidence for self management in COPD

Self management	Systematic review	RCT	Strength of evidence for intervention
Pulmonary rehabilitation	Yes		1A
Self management interventions	Yes		1A
Action plans	Yes		1B
Inhaler technique	No	No	N/A

Table 28 Nurse Sensitive Interventions for self management

Self management
Pulmonary Rehabilitation RNS would assess and refer patients with COPD for pulmonary rehabilitation. In addition, RNS are actively involved in the delivery of pulmonary rehabilitation.
Inhaler technique Given the importance of adequate drug deposition, it would be appropriate to expect an RNS to be able to assess and correct inhaler techniques for all of the different inhaler devices. They should be an expert in the different devices and be able to advise on the most appropriate inhaler device, and medication for the individual patient.
Self management interventions Providing education, which includes self management to patients with COPD is an integral part of the RNS role.
Action Plans Providing education, which includes management of exacerbations of COPD to patients with COPD is an integral part of the RNS role. RNS should be able to identify patients who would be able to effectively commence emergency treatment (antibiotics and oral corticosteroids).

In addition, inhaler technique has been included, as the majority of medication prescribed for the management of symptoms, are delivered by an inhaled route. Therefore, RNS's should have the knowledge and expertise to support patients in receiving optimum drug delivery. This would include knowledge of inhaled preparations, devices and technique. They should be able to assess and correct inhaler technique, recommending change in device and molecule if required.

6.4 Summary

Following the review of the literature for the management of the items retained in the RNSOI, the interventions identified, with the exception of wheeze, are sensitive to nursing care. Wheeze has been included as it has good face validity, and preliminary validity testing of the RSNOI demonstrated that it had good psychometric properties.

7. Project summary and next steps

The three stages of the project have developed and undertaken preliminary validity and psychometric testing of a tool that could be used to measure the impact and quality of the care delivered by RNS to patients with COPD.

The final version of the RNSOI is available in Appendix 1.

Additional funding will be sought to undertake further validity testing of the RSNOI, with a different cohort of patients. There is interest from the RNS community with the UK to be involved in assisting with this.

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Appendix 1

Respiratory Nurse Sensitive Outcome Indicator for COPD. Part 1

Section 1. Please indicate if you are **currently** experiencing any of the symptoms and how they affect you. Please tick one box in each row

	I am not currently experiencing this symptom	This symptom affects me mildly vey severely				
		1	2	3	4	5
I am breathless						
I am wheezy						
I have a productive cough						
I have a dry cough						
I feel fatigued (tired)						
I feel anxious						
I feel depressed						
I feel that I panic						
My symptoms trouble me when I wake up in the morning						
My symptoms trouble me throughout the night						
My symptoms affect my day to day activities						
	Total Score for Section 1					

Please turn the page over

Section 2. Please indicate how **confident** you are with managing your COPD symptoms and identifying and managing a flare up or attack of COPD. Please tick one box in each row only

	I am not currently experiencing this symptom	I am very confident				I am not very confident at all
		1	2	3	4	5
Breathless						
Wheeziness						
Productive cough						
Dry cough						
Fatigued (tired)						
Anxiety						
Depression						
Panic						
Identifying the symptoms of a flare up/ attack						
Knowing what extra medications I can take						
Knowing when to seek help						
Knowing where to seek help						
Knowing what I need to do to help my recovery						
	Total Score for Section 2					

Section 3. Please indicate how having COPD affects you. Please tick one box in each row

	Does not affect me at all	Affects me A little				Very much
		1	2	3	4	5
Having COPD limits what I can do						
My family/ carers are concerned that my COPD limits what I can do						
I have difficulties in accepting my life with COPD						
I am concerned about the impact my COPD has on my family/ carers						
I am concerned about my future						
My family/ carers worry about my future						
	Total Score for Section 3					

Thank you for completing this questionnaire

Respiratory Nurse Sensitive Outcome Indicator for COPD. Part 2
'How are we doing?'

You have received care from a Respiratory Nurse Specialist and we are interested to know how you feel their input has affected your experience of living with COPD. Your answers will remain anonymous so please answer honestly.

Section 1. Please indicate when and where you last had contact with your Respiratory Nurse Specialist

When did you last see or have contact with your Respiratory Nurse Specialist				
Today	Within the last week	Within the last month	More than a month ago	I can not recall
Was the last contact you had with your Respiratory Nurse Specialist				
A home visit	An outpatient appointment	An admission to hospital	A telephone call	I can not recall

Section 2. Please list your main COPD symptoms

My main COPD Symptoms are:

1.

2.

3.

Section 3. Please indicate if your Respiratory Nurse Specialist asks about your symptoms and the impact they have, on your day to day life

My Respiratory Nurse Specialist:	**Yes**	**No**	**I do not know**
Is aware of the impact of my main COPD symptoms, listed in question 2, on my day to day life			
Is aware of the impact of my other COPD symptoms on my day to day life			

Section 4. Please tell us about the support and help you have received from your Respiratory Nurse Specialist, when you suspect a flare up or attack of your COPD

My Respiratory Nurse Specialist has given me advice on:	Yes	No	I can not recall
What to do when your symptoms become more troublesome than usual?			
Recognising the signs of a flare up or attack?			
How to manage a flare up or attack?			
Where to seek appropriate help?			
When to seek help if I am not getting better			

Section 5. Please tell us about the support and help you and your family/carers have received from your Respiratory Nurse Specialist, in managing your symptoms and living with COPD

My Respiratory Nurse Specialist:	Yes	No	I can not recall
Has provided me with usual information to help me manage my symptoms			
Has provided me with practical advice to help me manage my symptoms			
Has provided me with written information to management my symptoms			
Has provided me with an action plan			
Has checked that I am using my inhalers correctly			
Checks that I know how to use all of my medications			
Listens to my concerns			
Provides emotional support to me			

My Respiratory Nurse Specialist	Yes	No	N/A
Listens to my family/ carers concerns			
Provides practical support to my family/ carers			
Provides emotional support to my family/ carers			

If you would like to provide any additional information about the care you have received from your Respiratory Nurse Specialist, please use the space below

Thank you for completing this questionnaire