



Common Drug Review *Patient Group Input Submissions*

Spiriva (tiotropium) for Chronic Obstructive Pulmonary Disease (COPD)

Patient group input submissions were received from the following patient groups. Those with permission to post are included in this document.

British Columbia Lung Association & Lung Groups – permission granted to post

Lung Association of Saskatchewan — permission granted to post

Ontario Lung Association — permission granted to post

The Lung Association AB&NWT– permission not granted to post

CADTH received patient group input for this review on or before January 23, 2015.

CADTH posts all patient input submissions to the Common Drug Review received on or after February 1, 2014 for which permission has been given by the submitter.

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CADTH does use reasonable care to prevent disclosure of personal information in posted material; however, it is ultimately the submitter's responsibility to ensure no personal information is included in the submission. The name of the submitting patient group and all conflict of interest information are included in the posted patient group submission; however, the name of the author, including the name of an individual patient or caregiver submitting the patient input, are not posted.

British Columbia Lung Association & Lung Groups

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Spiriva(tiotropium) Respimat
Name of the patient group	British Columbia Lung Association & Lung Groups
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Permission is granted to post this submission	Yes

1.1 Submitting Organization

The Mission of the British Columbia Lung Association (BCLA) is to improve lung health and to lead lung health initiatives. Our vision is healthy lungs for everyone. Our role is to improve respiratory health and overall quality of life through programs, education, research, training, treatment, advocacy and prevention of lung disease.

The BCLA is a major Canadian charitable organization with more than a century of experience and leadership in lung disease prevention, treatment and management. Today our areas of interest and expertise include the entire scope of respiratory diseases including COPD (chronic bronchitis and emphysema), asthma, idiopathic pulmonary fibrosis, lung cancer, sleep apnea and tuberculosis. We work together with the Canadian Lung Association and other partners to help the one in five Canadian who have breathing problems.

Our staff and volunteers include health professionals and interested individuals and patients with a broad range of training and experience in lung disease and lung health that enables our organization to develop and lead programs of education and health promotion at the highest standard. The British Columbia Lung Association provides approximately \$1.2 million each year to internationally recognized physicians and scientist doing research in BC on lung diseases. All funding proposals go through rigorous national peer review system so that the most promising research can be explored. This world class research is discovering the causes of lung disease, finding new treatments, and giving hope for a future free of lung disease.

1.2 Conflict of Interest Declarations

The British Columbia Lung Association has several sources of funding for programs and operations and is supported by individual and corporate donations, and through service contracts with government organizations. Funding sources include direct mail campaigns such as the Christmas Seals campaign, memorial giving, bequests, Special events such as Climb the Wall: Stair Climb for the fight against lung disease!, Bicycle Trek *for* life and breath and our RUSH event. The Lung Association, does, from time to time receive program grants from health industry/pharmaceutical companies. Our relations and interactions with pharmaceutical companies remain transparent and positions of the Lung Association are developed without industry influence.

The BCLA has received health educators program grants from the following pharmaceutical companies: Grifols, GlaxoSmithKline, InterMune, AstraZeneca, Boehringer Ingelheim, Pfizer, Novartis and Merck Frosst.

Neither the principal author, nor the BCLA, has conflicts to declare in respect to the compiling of this submission.

Section 2 — Condition and Current Therapy Information

2.1 Information Gathering

The BCLA is significantly invested and involved in both COPD research and provision of patient services *and* programs. We have Certified Respiratory Educators on staff who provide expert educational consultations to respiratory patients, their family members and caregivers dealing with COPD and other lung disease. The vast knowledge and experience garnered through research, best practice guidelines and direct involvement with patients is the basis of the information provided.

2.2 Impact of Condition on Patients

COPD is a debilitating and degenerative lung disease characterized by progressive airflow limitation in the lungs. It is used to describe two specific lung diseases: chronic bronchitis and emphysema. Among the symptoms of chronic bronchitis are cough and long-term, continuous mucus production.

Emphysema is characterized by the destruction of the walls of the air sacs (alveoli) in the lungs, leading to the loss of elasticity and disrupting the normal exchange of oxygen and carbon dioxide.

COPD is the fifth leading cause of death and morbidity, the prevalence is increasing as the population is aging. Over the last 20 years COPD in females has doubled due to cigarette smoking.

COPD sufferers will often require assistance and become increasingly dependent on others to the most basic human task of daily living activities. Depression and feelings of hopelessness are common among patients with COPD.

Lung attacks or flare-ups drive disease progression. As the disease progresses frequency of flare-ups increase and overall lung function and lung health typically decline and risk of hospital admission increases. COPD is the most common cause of hospital admission.

2.3 Patients' Experiences With Current Therapy

The therapies used and recommended by the Canadian Thoracic Society include: Quit smoking, education of both the patient and their family is invaluable, improve exercise tolerance and daily activity, reduce lung attacks or flare-ups, exercise and pulmonary rehabilitation, reduce frequency of complications of the disease, improve health status and to reduce mortality.

COPD medication use to prevent and lessen symptoms and treat lung attacks.

Therapy as the disease progresses, usually see medications added on to one another in a stepwise fashion, seeing patients taking multiple medications. These medications that are available typically help open airways, and prevent lung attacks. Oxygen is used in severe cases. Please check our websites for the description of the COPD medications: www.lung.ca or www.bc.lung.ca

Unmet Needs: Of critical importance to the treatment of COPD are medicines that will help reduce or stop the progression of the disease and subsequent hospitalization. Additional therapies are needed that go beyond symptomatic relief. New treatments are urgently needed that will work to improve overall lung function. New treatment options are required as the disease progresses

The BCLA believes that access to COPD medications will serve to reduce cost on admissions to hospital and improve the overall lung health of patients with COPD. It is projected that by 2020 COPD will be third most common cause of death. The BCLA support the quick access to respiratory medications such as that for COPD patients and recommended by the Canadian Thoracic Society

We recognize that not all patients or individuals respond the same to various types of formulations of medications and BCLA support having access to the medications to which a particular patient responds better.

We also recognize that not all patients are able to use inhalation devices effectively and we also support having access to the inhalation devices which the patient are able to use correctly. Delivery of the medication effectively is important in the treatment of COPD.

Unmet Needs: Medications are of critical importance in the treatment and management of COPD. It improves lung function and breathing, reduce lung attacks and prevent patients with repeat admission to hospital there by improving the lives of COPD patients

2.4 Impact on Caregivers

Our health care system places a lot of demands on both the patient and caregivers. Caregivers are often the spouse, the children and other relations. Financial challenges are the obvious ones, depending on the level of reimbursement for medicine.

Another major impact identified by patients and care givers is physical activity. The impact is most noticeable on patients' progressive inability to perform day to day tasks as they begin to notice that they had previously taken for granted (e.g. negotiating a staircase that they climb every day)

As the patient's condition deteriorates, they tend to stay at home more which means that their fitness levels further deteriorate and their body's ability to use oxygen efficiently is further compromised_ As the condition progresses, further compromises are made in patient's independence with huge implications for caregivers. Patients with COPD and their caregivers experience anxiety and depression. This disease has a progressive debilitating course.

Section 3 — Information about the Drug Being Reviewed

3.1 Information Gathering

The BCLA is significantly invested and involved in both COPD research and provision of patient's services and programs. We have Certified Respiratory Educators on staff who provide educational expert consultations to respiratory patients with COPD, their family members and caregivers. The vast knowledge and experience garnered through research, best practice guidelines and direct involvement with patients is the basis of the information.

3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

The active ingredient in Spiriva Respimat (tiotropium) is identical to that in the Spiriva Handihaler; only the delivery device is changed. Tiotropium is included in the class of long-term muscarinic antagonist (LAMA) which is recommended in the comprehensive management of COPD as written in the CTS, Canadian Thoracic Society COPD guidelines. We support access to those medications recommended by the CTS.

The new delivery device Respimat delivers Spiriva in a soft mist delivery system for better deposition in the lungs with a reduced dose of tiotropium to achieve the same effect

The patient's choice of delivery device must be individualized to what is best suited for the individual patient. We support having access to inhalation devices which the patient is able to correctly use with ease and which improve the effective delivery of the medication to the lungs.

Lung Association of Saskatchewan

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Spiriva (tiotropium) RESPIMAT
Name of the patient group	Lung Association of Saskatchewan
Name of the primary contact for this submission:	[REDACTED]
Position or title with patient group	[REDACTED]
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Website	www.sk.lung.ca
Permission is granted to post this submission	Yes

1.1 Submitting Organization

The Mission of the Lung Association of Saskatchewan is to improve lung health one breath at a time. Our Vision is Healthy lungs for everyone. Our Role is to improve respiratory health and the overall quality of life through programs, education, research, training, treatment, advocacy and prevention of lung disease.

COPD remains one of the Lung Association of Saskatchewan's priorities. The Lung Association provides support to people living with lung disease and their caregivers through a number of initiatives: A Helpline is staffed by licensed health care professionals who are Certified Respiratory Educators (CREs). CREs provide educational consultations to COPD patients and their family members on all aspects of COPD prevention, diagnosis and management. Regular public telehealth and Webinars are conducted on topics related to improving quality of life and current treatments available for COPD. Awareness campaigns on COPD are implemented and educational support for Pulmonary Rehabilitation programs in Saskatchewan are provided. Collaboration with health regions on special projects such as identifying and meeting the needs of COPD patients in the emergency department and the Health Quality Council of Saskatchewan's COPD Collaborative to improve the quality of care for COPD patients in Saskatchewan are fostered. The development of written and on-line COPD resources including a series of delivery device teaching videos is ongoing. A COPD Toolkit was developed to facilitate the establishment and enhancement of COPD rehab programs. The Lung Association is also contracted by the Saskatchewan Ministry of Health to provide training and services for the SAIL home oxygen program to improve the management of COPD.

The Lung Association has provided significant funding support of a Professorship to the University of Saskatchewan. This professorship has permitted Saskatchewan to retain one of the top COPD experts in Canada.

The Lung Association of Saskatchewan has developed and administers RESPTREC™ (the Respiratory Training and Educator Courses) for health care professionals across the country including courses on COPD management and Foundations of Education.

The Lung Association of Saskatchewan is a member of the Canadian Lung Association partnership. The Lung Association through its medical society, the Canadian Thoracic Society (CTS), produces the Canadian clinical guidelines for the diagnosis and management of COPD. All educational initiatives of the Lung Association of Saskatchewan are based upon evidence-based, best practice guidelines published by the CTS.

1.2 Conflict of Interest Declarations

a) *We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements:*

The Lung Association of Saskatchewan has multiple sources of funding for programs and operations and is supported by individual and corporate donations, and through service contracts with government organizations. Funding sources include: direct mail campaigns such as the Christmas Seals campaign, raffles, such as Share the Air, door-to-door fundraising, memorial giving, bequests, and service contracts with government organizations. The Lung Association, does, from time-to-time receive program grants from health industry/pharmaceutical companies. Our relations and interactions with pharmaceutical companies remain transparent, and policy positions of the Lung Association are developed without industry influence.

The Lung Association of Saskatchewan has received unrestricted grants from the following pharmaceutical companies: AstraZeneca, Boehringer Ingelheim, GlaxoSmithKline, Grifols, InterMune, Merck Frosst, Novartis, Nycomed, Pfizer, Roche and Takeda.

b) *We have the following declaration(s) of conflict of interest in respect of those playing a significant role in compiling this submission:*

Neither the principal author, nor the Lung Association of Saskatchewan, has conflicts to declare in respect to the compiling of this submission.

Section 2 — Condition and Current Therapy Information

2.1 Information Gathering

The Lung Association of Saskatchewan is significantly invested and involved in both COPD research and the provision of patient services and programs. We have Certified Respiratory Educators on staff who provide expert educational consultations to COPD patients, their family members and caregivers. The vast knowledge and experience garnered through research, best practice guidelines and direct involvement with patients is the basis of the information provided.

2.2 Impact of Condition on Patients

COPD is a debilitating and degenerative lung disease where lung function can progressively deteriorate.

COPD slowly damages airways, the breathing tubes that carry air in and out of the lungs. COPD makes airways swollen and partly blocked by mucus. It also damages the tiny air sacs at the tips of the airways. This makes it hard to move air in and out of the lungs. In COPD sufferers, the air tubes narrow, airflow becomes limited and lung function is reduced, leading to disability and premature death.¹

The two cardinal symptoms of COPD are shortness of breath and limitation of activity. Shortness of breath and limitation of activity has an impact on all parts of life: daily activities, hobbies, travel, and relationships. As the disease progresses, it has an intense impact on the quality of patients' lives. Sufferers feel old before their time, finding normal daily routines and even leisure activities an uphill struggle.² Regular daily functions become exceptionally hard to perform. COPD sufferers will often require assistance and become increasingly dependent on others to do the most basic human tasks of daily living, including dressing, hygiene care, preparing meals, cleaning, etc. Depression and feelings of hopelessness are very common among COPD sufferers as the disease gradually dominates their lives.

Exacerbations (flare-ups or lung attacks) drive disease progression. As the disease progresses frequency of exacerbations increase, overall health and lung function typically decline, and risk of hospitalization increases. The average patient experiences two to three lung attacks per year.³

COPD lung attack outcomes can range from the need for further medical intervention to death.^{4,5} Co-morbidities in COPD are common. Other associated health problems, include frequent chest infections, including pneumonia and the flu, pulmonary hypertension, heart problems, osteopenia or osteoporosis, eye problems like glaucoma and cataracts, cachexia: losing body mass, loss of appetite, feeling nauseated and weak, malnutrition, weak muscles and lung cancer.⁶

^{1,2}The Human and Economic Burden of COPD. Canadian Thoracic Society 2010.

^{3,4}O'Donnell DE, Chair, SA et al. State of the art compendium : Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease. Can Respir J 2004; 11(Suppl B).

^{5,6}O'Donnell DE et al. 2008 Update CTS Guideline - Highlights for Primary Care - Recommendations for Management of COPD. Vol 15 Supplement A January/February 2008.

2.3 Patients' Experiences With Current Therapy

The therapies used and recommended by the CTS include:

- COPD can't be cured, but it can be treated. Proper COPD treatment includes these steps:
 - Quit smoking to slow down COPD progression
 - Exercise
 - Education regarding patient self-management
 - Pulmonary rehabilitation
 - COPD medications to prevent and lessen symptoms and treat COPD flare-ups
- Therapy, as the disease progresses, will usually see medications added on to one another in a step-wise manner, ultimately seeing patients taking multiple medications. The treatments that are available are typically used to open airways, and to prevent and treat flare-ups. Supplemental oxygen is used in more severe COPD, where low oxygen levels can cause shortness of breath and fatigue. People who take supplemental oxygen must continue taking their other medications.
- For a more thorough understanding of the medicines used in the treatment of COPD the Lung Association of Saskatchewan urges the reviewer(s) of this submission to visit: <http://sk.lung.ca/lung-diseases/medications/prescription-drugs-lung-disease>

Adverse Effects/Side Effects of COPD Medications

- The frequency and severity of the following side effects are dependent on many factors including dose, duration of therapy and individual response.
- Bronchodilators (medicines to treat shortness of breath) can have side effects such as dry mouth, and in men who have trouble with their prostate gland, possible difficulty in urinating, shaky hands (tremor), and fast heartbeat. Slow-onset bronchodilator pills can have side effects such as nausea, heartburn, restlessness and fast heartbeat. Combination medicines: (inhalers that combine a bronchodilator and a corticosteroid to prevent and treat COPD flare-ups) can have side effects such as shaky hands (tremor), fast heartbeat, thrush, a sore throat or a hoarse voice. Corticosteroid pills have potentially more severe side effects than the inhaled corticosteroids including thinning and bruising of the skin, fluid retention, weight gain, emotional changes, problems with blood sugar control and blood pressure control, risk of weakening of bones, cataracts and glaucoma.
- For a more thorough understanding of the side effects of medicines used in the treatment of COPD the Lung Association of Saskatchewan urges the reviewer(s) of this submission to visit: <http://sk.lung.ca/lung-diseases/medications/prescription-drugs-lung-disease>

Accessing Therapy

- The Lung Association of Saskatchewan believes that access to COPD medications will serve to improve overall COPD management, and reduce overall health care costs. COPD is a major cause of death, disability, and hospitalisations, and is a major driver of health care costs. It is one of the most common reasons for hospitalisations, and is projected to be the third most common cause of death by the year 2020.
- The Lung Association supports the access to medications recommended by the Canadian Thoracic Society COPD guidelines.
- We recognise that not all patients respond the same to various types of formulations of medications and we support having access to medications to which a particular patient responds better.
- We recognise that not all patients are able to use inhalation devices effectively, and we support having access to inhalation devices which the patients are able to use correctly and which improves the effectiveness of the drug.

Unmet Needs

- Of critical importance to the treatment of COPD are medicines that will improve lung function and breathing, and help to reduce exacerbations and subsequent hospitalizations.

2.4 Impact on Caregivers

Our health care system places a lot of demands on both patients and caregivers to manage the patient's illness. Recognizing the severe limitations the disease imposes on patients, and the level of care required by many COPD patients, there is a dramatic impact on the caregiver's lifestyle and routine. Caregivers are often the spouse of the COPD patient. Recognizing that COPD is more prevalent in older Canadians, caregivers themselves are often older Canadians.

The following challenges are often faced by caregivers of patients with COPD:

Financial Challenges for Family Caregivers

- depending on the level of reimbursement for medicines in any province, and recognizing that many older Canadians are often on fixed incomes, COPD can put financial strains on both the patient and the caregiver

- because of the mobility impairments caused by COPD, there are often added expenditures incurred by the caregiver and patient for assistive devices and home modifications to accommodate mobility impairments
- caregivers often become very reliant on social supports

Physical and Mental Wellbeing

- because of the level of care required by many COPD patients, and the limitations on mobility, frequently caregivers will experience feelings of isolation and depression
- recognizing that caring for a patient is frequently a full-time commitment, many caregivers find their ability to manage their own physical health and mental wellbeing is very limited
- exhaustion is a common experience with caregivers of COPD patients

Section 3 — Information about the Drug Being Reviewed

3.1 Information Gathering

The Lung Association of Saskatchewan is significantly invested and involved in both COPD research and the provision of patient services and programs. We have Certified Respiratory Educators on staff who provide expert educational consultations to COPD patients, their family members and caregivers. The vast knowledge and experience garnered through research, best practice guidelines and direct involvement with patients is the basis of the information provided in Section 3.

3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

The active ingredient in Spiriva Respimat (tiotropium) is identical to that in the Spiriva Handihaler; only the delivery device is changed. Tiotropium is included in the class of long-acting muscarinic antagonists (LAMA) which is recommended in the comprehensive management of COPD as per the Canadian Thoracic Society guidelines. We support drug access to those drugs recommended by the CTS.

The new delivery device Respimat delivers Spiriva in a soft mist delivery system for better deposition in the lungs with a reduced dose of tiotropium to achieve the same effect.

The choice of a delivery device should be individualized to what is best suited for the patient. We support having access to inhalation devices which the patient is able to use correctly and which improves the effectiveness of the drug.

Ontario Lung Association

Section 1 — General Information

Name of the drug CADTH is reviewing and indication(s) of interest	Spiriva Respimat / Tiotropium bromide Chronic Obstructive Pulmonary Disease (COPD)
Name of the patient group	Ontario Lung Association
Name of the primary contact for this submission:	[REDACTED]
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Name of author (if different)	
Patient group's contact information: Email	info@on.lung.ca
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Website	www.on.lung.ca
Permission is granted to post this submission	Yes

1.1 Submitting Organization

The Ontario Lung Association is a registered charity that assists and empowers people living with or caring for others with lung disease. It is a recognized leader, voice and primary resource in the prevention and control of respiratory illness, tobacco cessation and prevention, and air quality and its effects on lung health. The Association provides programs and services to patients and health-care providers, invests in lung research and advocates for improved policies on lung health. It is run by a board of directors and has approximately 70 employees, supported by thousands of dedicated volunteers and works out of a provincial office in Toronto and nine community offices throughout Ontario.

1.2 Conflict of Interest Declarations

a) *We have the following declaration(s) of conflict of interest in respect of corporate members and joint working, sponsorship, or funding arrangements:*

The Ontario Lung Association receives sponsorship and grants from a number of pharmaceutical companies which support educational and research initiatives. Companies who provide funding to the Ontario Lung Association include: Pfizer, GlaxoSmithKline, Boehringer Ingelheim, AstraZeneca, Merck, Novartis, Takeda, InterMune, Grifols, Actelion, Astellas, Bayer, J&J, OHRSA, Roche, RX&D, Valent Pharmaceuticals, and Eli Lilly. This year we also received program funding from the Ontario Home Respiratory Services Association (OHRSA). None of these organizations participated in any way in this submission.

b) *We have the following declaration(s) of conflict of interest in respect of those playing a significant role in compiling this submission:*

(Nothing to declare)

Section 2 — Condition and Current Therapy Information

2.1 Information Gathering

The information provided in section two was obtained from ten completed on-line surveys sent to patients living with COPD, their caregivers, as well as several one-to-one phone conversations with patients and input from a certified respiratory educator.

2.2 Impact of Condition on Patients

The symptoms and challenges that patients experience as a result of COPD are many, but at the top of the list were fatigue and shortness of breath. These were followed closely by mucus, wheezing, difficulty fighting infection and coughing. Patients also identified loss of muscle and bone density, depression, anxiety and loss of self-worth. One patient identified weight gain as a result of the condition. Tasks like walking up stairs, opening doors or getting the mail causes shortness of breath and fatigue. Carrying groceries into the house must be done in several trips with resting periods in between. All day to day tasks take much longer. Increased risk of infections was noted as an ongoing issue as was their mood /emotional well-being. The need for oxygen and medications are constant and the inability to do daily activities like housework, cooking or shopping leave some people feeling depressed, frustrated and without hope. COPD impacts almost all aspects of day-to-day life for people living with it. It affects: the ability to participate in physical and leisure activities (as noted by every respondent in the survey), the ability to work, travel and socialize. It also affects relationships with families and friends, independence, and for many their financial situation. Having to retire/leave the work force was mentioned several times. COPD slowly robs people of their independence. One patient said: “it’s a constant fight to remain upbeat, to remain independent”, and another person wrote: “it is a constant fight to maintain independence and reduce depression. Each plateau you reach means adjustments, and the inability to earn an income means having to “make do” all the time.”

2.3 Patients’ Experiences With Current Therapy

Treatments tried by those interviewed included: Spiriva, Advair, Symbicort, Daxas, Prednisone, Ventolin, Atrovent, Serevent, Seebri, Onbrez, and a few had recently tried Breo Ellipta.

Current treatments do provide some relief for: fatigue, shortness of breath, cough, appetite loss, low energy, and the inability to fight infection, but the side effects such as: palpitations, dry mouth, mouth sores, vision and urinary problems and impact on mood need to be better managed.

The desire for fewer medical appointments was mentioned several times, as was a wish for less cost burden. Current therapies do not reduce mucus production enough or hold oxygen levels high enough. Overall, patients would like their treatments to provide enough help that they will experience improved independence and require less assistance from others. The desire for more / increased energy was noted many times throughout the survey.

2.4 Impact on Caregivers

Caregivers of those living with COPD experience many of the same negative impacts on their lives. They too indicate that caring for people with COPD has affected their work, their relationships with family and friends, and their physical and leisure activities. As well, their independence and the ability to travel and socialize were impacted. Having to take time off work to drive those they are caring for to get groceries, run errands or make medical appointments was cited as problematic for caregivers.

Section 3 — Information about the Drug Being Reviewed

In this section, guidance or examples are provided to help identify the type of information that CDR, CDEC, and participating drug plans will find most helpful in understanding the needs and preferences of the majority of patients. Objective, experiential information that is representative of most in the patient group is preferred. There is no need for patient groups to submit published information, as CDR and CDEC have access to current scientific literature through the manufacturer's submission and a rigorous, independent literature search. However, relevant unpublished studies may be submitted in addition to the completed template.

3.1 Information Gathering

The information provided in section three was obtained from ten completed on-line surveys sent to patients living with COPD, their caregivers, as well as several one-to-one phone conversations with patients and input from a certified respiratory educator.

3.2 What Are the Expectations for the New Drug or What Experiences Have Patients Had With the New Drug?

Key treatment outcomes of COPD that patients and their caregivers would most like addressed are: to reduce shortness of breath, reduce coughing, reduce fatigue and improve appetite. They would like an increased ability to fight infection and have a higher energy level. Ideally, patients would experience an improved quality of life, improved lung function and reduced hospital admissions.

Patients indicated that they would be able to live with some side effects, but nothing worse than they are already experiencing and nothing that was irreversible. One patient said: "most side effects would be bearable if I could just breathe a bit better and could wake up with enough energy to get through the day."

Patients do not want to travel to a health-care setting to receive new treatments. They do not want to have to make additional changes to daily routines for themselves or their caregivers and do not want anyone to have to take time off work to accommodate treatments. Patients want to improve enough so that they will be less of a burden to their family.

Finally, patients would like there to be less or no cost burden associated with new treatments.

All patients within this evidence group submission have used the drug Spivira Respimat. They rated it as "equal" or "the same as" when comparing it to other available treatments in terms of: administration of the drug, time required to accommodate the treatment, cost burden and side effects. In terms of treatment of the condition, one patient rated it as "better than" other available treatments and the other patients rated it as "the same." Swelling of hands, feet and joints was noted more than once as the "least bearable" side effect of this treatment.

Section 4 — Additional Information

All patients indicated that shortness of breath and fatigue were the symptoms they would most like to improve. Patients would like to be less dependent on oxygen. Patients also indicated that they would like to know more about new treatments for their condition – when they become available / how to be a part of trials or experimental groups. Many patients also expressed interest in accessing information on new therapies.