

Appendix Table 3. Other quantitative results

Study ID	Values and preferences category	Instrument	Study design	Description of health states	Age: Mean (SD) or other format	Country or countries of Origin	Setting	Gender (Male/Female)	Sample size	Sampling Strategy	Quote for sampling strategy (or Other, Please specify)	Response rate	Funding Sources	Reported format	Result
Borge 2014	Uncategorized survey	Illness perception scale	Cross-sectional survey	Booklet/card	64.6 (10.2); in 36, max 87	Norway	outpatient	male 79 (51.3) Female 75 (48.7)	154	Other	person fulfilling inclusion criteria were invited by mail to participate in this study	40%	Unclear	Mean (SD)	"How much does your illness affect your life?": 5.9 (2.6) "How much control do you feel you have over your illness?" 5.6 (2.5) "How much do you think your treatment can help your illness?" 4.5 (2.6) "How concerned are you about your illness?" 5.6 (2.9) "How much does your illness affect you emotionally? (e.g., does it make you angry, scared, upset or depressed?": 4.8 (2.8)
Bratas 2010	Direct choice	Forced choice: treatment	Cross-sectional survey	Narrative explained by interviewer, Booklet/card	rehab 65.0 (9.1)/outpatients 67.2 (10.2)	Norway	secondary	male 110/female 95	205	Consecutive	Participants in the rehabilitation group were recruited from 3 rehabilitation centres in mid and eastern Norway, comprising consecutive cases of COPD patients; Participants in the outpatient group were recruited by 3 pneumologists at 2 hospitals and 1 private practice centre in mid-Norway comprising consecutive cases of outpatients with COPD	57%	Unclear	Choice or proportion of choice	A total of 161 patients chose inpatient rehabilitation and 44 chose outpatient clinics. The decision to choose rehabilitation may be determined by impaired health-related quality of life, psychological distress and lack of psychological support from a significant other.
Brophy 2008	Direct choice	forced choice: inhaler	Randomized controlled trial	No description	68 (SD 7)	UK	secondary	male 13/female 12	25	Unclear	Following an initial screening to assess eligibility, patients entered a two-week run in period. [...] Afterwards, patients were randomized to receive either 3 weeks of intermediate or high-dose bronchodilator therapy in a crossover manner	89% completed	Unclear	Choice or proportion of choice	Preference for bronchodilator treatment nebulizer vs MDI and spacer : 15 patients vs 10 patients
Bulcun 2014	Direct choice	Conjoint analysis/Discrete choice analysis	Cross-sectional survey	Booklet/card	60.8 (SD 8.6)	Turkey	secondary	male 45/female 3	49	Consecutive	Consecutive patients diagnosed with COPD who were admitted to the polyclinic at the Department of Chest Disease, Faculty of Medicine, Kirikkale University, Kirikkale, Turkey, were included in this study	Unclear	Unclear	Influence or contribution or weight of certain aspects/attributes	Extent to which the doctor gives sufficient time to listen to the patient RARELY: -1.5 SOMETIMES: -0.5 ALWAYS: 2.0 Difference between highest and lowest utility levels: 14.4 Extent to which treatment seems to relieve symptoms RARELY: -6.3 SOMETIMES: -3.2 ALWAYS: 2.8 COMPLETELY: 6.7 Difference between highest and lowest utility levels: 53.4 Possibility of experiencing adverse effects from treatment 20%: -0.9 10%: -0.06 4%: 1.0 Difference between highest and lowest utility levels: 8.2 Extent to which the patient sees the same doctor for each of his/her visits NEVER: -0.8 SOMETIMES: 0.2 ALWAYS: 0.5 Difference between highest and lowest utility levels: 6.0 Extent to which the doctor treats the patient as an entire person DOES NOT: -0.5 DOES: 0.5 Difference between highest and lowest utility levels: 4.5 Costs of treatment 60 TL (30 USD): -1.8 40 TL (20 USD): -0.06 20 TL (10 USD): 0.5 No cost: 1.4 Difference between highest and lowest utility levels: 13.2

Chakrabarti 2009	Direct choice	forced choice: treatment	Cross-sectional survey	Narrative explained by interviewer, Decision aid	Median 69, IQR: 14 years	UK	Hospitalized patients	34/16 68%/32%	50	Consecutive	Sixty-one consecutive patients meeting the inclusion criteria were contacted over a 5-month period. Of these, 50 agreed to participate in the study.	82.0% (50/61)	Unclear	Choice or proportion of choice	Willingness to accept a IMV during an exacerbation after stage 4: 60% (30/50) willing, 30% (15/50) unwilling, 10% (5=50) unsure; after stage 5: 70% (35/50) willing , 24% (12/50) unwilling, 6% (3/50) unsure.
Chapman 1993	Direct choice	forced choice: inhaler	Cross-sectional survey	Narrative explained by interviewer	70.8 (SD 5.4); range 63-85	Canada	outpatients	men 41; women 39	80	Other	word of mouth and advertisement in the hospital and senior facilities	Unclear	Asthma Society of Canada and by educational grants from Claxo Canada and 3M Pharmaceuticals, United States. Manuscript received December 3, 1992;	Choice or proportion of choice	preference for breath actuated device vs conventional MDI: 71.3% vs 18.8% vs 10% no preference MDI familiar group: 72.5% vs 15% vs 12.5% no preference MDI unfamiliar group: 70% vs 22.5% vs 7.5% no difference
Chapman 2011	Direct choice	forced choice: inhaler	Randomized controlled trial	Narrative explained by interviewer, Booklet/card	63.9 (SD 9.21)	Canada, USA	UNCLEAR	male 60%, female 40%	82	Unclear	Unclear	Unclear	Industry - Novartis	Choice or proportion of choice	overall preference for Breezehaler vs Handihaler vs no preference: 60.5% vs 30.9% vs 8.6% Remove/open cap: 58.0% vs 19.8% vs 22.2% Open mouthpiece: 64.2% vs 9.9% vs 25.9% Insert capsule: 24.7% vs 44.4% vs 30.9% Close mouthpiece: 38.3% vs 14.8% vs 46.9% Hold while inhaling: 59.3% vs 21.0% vs 19.8% Remove capsule: 30.9% vs 46.9% vs 22.2% Close after use : 35.8% vs 23.5%vs 40.7%
Claessens 2000	Direct choice	Forced choice: treatment	Cohort study	no description	median 70	USA	Hospitalization	517/491 (51.3%/48.7%)	1008	Other	SUPPORT was conducted in two phases at five sites. From June 1989 to June 1991 (Phase I) and from January 1992 to January 1994 (Phase II), patients were enrolled who met study criteria at five hospitals: Beth Israel Hospital, Boston; MetroHealth Medical Center, Cleveland; Duke University Hospital, Durham, North Carolina; St. Joseph's Hospital, Marshfield, Wisconsin; and the University of California at Los Angeles, Los Angeles.	Unclear, for both lung cancer and COPD/ Response rates for patient interviews were 87% for Week 1 and 72% for Week 2 interview s for the 56% and 67% of patients, respectively, who were not comatose, intubated, or otherwise incapable of response.	SUPPORT was made possible by grants from the Robert Wood Johnson Foundation . Dr. Claessens was supported by a Veterans Administration Ambulatory Care Fellowship, White River Junction, Vermont, and a Fellowship in Palliative Medicine, Ottawa, Ontario.	Choice or proportion of choice	Preference for treatment focusing on relieving pain and discomfort rather than extending life : 58% Preference for Do Not Resuscitate order : 37% "Very unwilling" or "Would rather die" than be attached to a ventilator "all the time" : 78%
Dales 1999	Direct choice	Probability trade off	Repeated surveys	Narrative explained by interviewer, Decision aid, Audiobooklet	66 years (range, 42 to 84 years; quartile 57-74)	Canada	outpatient (pulmonary function laboratory, as well as ambulatory respiratory and general medicine clinics of the Ottawa General Hospital, affiliated with the University of Ottawa, Canada)	10men/10 women	20	Consecutive	A convenience sample of consecutive pts	90%	Ontario Thoracic Society	Choice or proportion of choice	Baseline Choice ventilation Choice After Decision Aid-yes: 5 (71%), strength of preference for MV (mean): 0.89 Choice After Decision Aid-no: 2 (29%), strength of preference for MV (mean): 0.01 Baseline Choice no ventilation Choice After Decision Aid-yes: 1 (10), strength of preference for MV (mean): 0.6 Choice After Decision Aid-no: 9 (90), strength of preference for MV (mean): 0.08 Baseline Choice uncertain Choice After Decision Aid-yes: 2 (67), strength of preference for MV (mean): 0.9 Choice After Decision Aid-no: 1 (33), strength of preference for MV (mean): 0.4
Downey 2009	Uncategorized survey	End of life Priority Score	Cross-sectional survey (9-interview with quantitative survey)	No description	(mean (SD)) 1. Total COPD sample (n=156): 62.4 (13.4) 2. COPD patient sample (n=96): 66.7 (9.2) 3. COPD nonpatient sample (family member or friend from subset of the COPD	United States	Outpatient/hospitalized (not specified) for COPD patients; community for nonpatients	(% - female) 1. Total COPD sample (n=156) 2. COPD patient sample (n=96): 45.5% 2. COPD patient sample (n=96): 28.1% 3. COPD nonpatient sample (family member or friend from subset of	1. Total COPD sample (n=156) 2. COPD patient sample (n=96) 3. COPD nonpatient sample (family member or friend from subset of the COPD patients)	Unclear	"This study involved three Seattle-area samples of patients with advanced life-limiting or terminal illness: (1) a sample of	Unclear	National Institutes of Health, National Cancer Institute grant #5 R01 CA106204; an American Lung Association Career Investigator Award; the Robert Wood Johnson	Mean (SD)	End-of-life priority score measured by rank order (out of 5) (based on priority scores ranging from 0 (not one of top five priorities) to 5 (the highest priority aspect of the end-of-life period)) Time with family and friends: 2.21 (2.00) Pain under control: 2.24 (2.20) Breathing comfort: 1.27 (1.83) Dignity and self-respect: 1.07 (1.65) At peace with dying: 0.97 (1.67) Human touch: 0.75 (1.45) Avoid strain on loved ones: 0.76 (1.46) Avoid life support: 0.70 (1.51) Goodbyes said: 0.53 (1.24) Bladder and bowel control: 0.44 (1.16) Unafraid of dying: 0.40 (1.09) Laughter and smiles: 0.39 (1.03) Health care costs covered: 0.33 (0.99) Control over situation: 0.36 (1.11) Means available to hasten death: 0.37 (1.08)

					patients) (n=60): 55.5 (16.0)			the COPD patients) (n=60): 73.3%	(n=60)		patients with end- stage chronic obstructi ve pulmonar y dis- ease (COPD) (n 1/4 96) and a family member or friend for a subset of these patients (n 1/4 60), interview ed between 1999 and 2002		Foundation ; and the Lotte & John Hecht Memorial Foundation		Visit from spiritual advisor: 0.40 (1.09) Funeral arrangements in order: 0.26 (0.82) Wishes discussed with doctor: 0.13 (0.62) Time with pets: 0.20 (0.76) Sufficient energy: 0.18 (0.69) Able to feed self: 0.25 (0.86) Meaning and purpose in life: 0.01 (0.08) Bad interpersonal feelings resolved: 0.06 (0.35) Spiritual ceremony after death: 0.10 (0.59) Time alone: 0.09 (0.55) Attend important events: 0.00 (0.00)
Downey 2013	Uncategorized survey	Preference Rating (from 1 definitely no to 4 definitely yes)	Cross- sectional survey	Booklet/card	68.6 (9.6)	USA	primary	male 100%	196	Unclear	Unclear	93%	Unclear	Mean (SD); Choice or proportion of choice	Mechanical Ventilation with Current Health Patient's Actual Preference Preference Rating (from 1 definitely no to 4 definitely yes) mean (SD): 2.7 (1.2) Probably or Definitely Wants Treatment, n (%): 111 (61) Cardiopulmonary Resuscitation with Current Health Patient's Actual Preference Preference Rating (from 1 definitely no to 4 definitely yes) mean (SD): 3.0 (1.1) Probably or Definitely Wants Treatment, n (%): 142 (76) Importance of Avoiding Ventilation/Dialysis in Last Week of Life, mean (SD) (range: 0 (not important) to 10 (extremely important)): 7.8 (3.2)
Dowson 2004	Direct choice	ranking: treatment	Cross- sectional survey	Narrative explained by interviewer	Mean (SD): 71.3 (7.2)	New Zealand	inpatient s	16/23	39	Consecuti ve	Participa nts were recruited from a nonacute , 12-bed, cardio- respirato ry ward located at Burwood Hospital, Christchu rch, New Zealand. Typically, patients admitted to this ward are transferr ed from acute wards in a 660- bed general hospital when they were consider ed medically stable, respondi ng to treatmen t and able to mobilize with one assistant. ..Patients who meet the above criteria are referred on the basis of bed availabilit y and hence not all potentiall y suitable patients are admitted to this ward.	83.0% 39/47	Unclear	Choice or proportion of choice	Maintenance when well scenario 1. Phone GP or after hours practice 2.6% 2. Take (extra) prednisone 0% 3. Continue regular medications 69.2% 4. Take extra reliever 5.1% 5. Go to hospital 0% 6. Maintain COPD exercises 12.8% 7. Start an antibiotic 0% 8. Do sputum sample and send to GP 0% 9. Call the hospital services 0% 10. See my GP 0% 11. Use breathing control methods 7.7% 12. Use huff and puff to clear phlegm 0% 13. Use a nebuliser 2.6% Early exacerbation scenario 1. Phone GP or after hours practice 28.2% 2. Take (extra) prednisone 2.6% 3. Continue regular medications 15.4% 4. Take extra reliever 2.6% 5. Go to hospital 2.6% 6. Maintain COPD exercises 5.1% 7. Start an antibiotic 17.9% 8. Do sputum sample and send to GP 0% 9. Call the hospital services 0% 10. See my GP 12.8% 11. Use breathing control methods 0% 12. Use huff and puff to clear phlegm 0% 13. Use a nebuliser 10.3% Severe exacerbation scenario 1. Phone GP or after hours practice 25.6% 2. Take (extra) prednisone 0% 3. Continue regular medications 2.6% 4. Take extra reliever 0% 5. Go to hospital 51.3% 6. Maintain COPD exercises 0% 7. Start an antibiotic 0% 8. Do sputum sample and send to GP 0% 9. Call the hospital services 5.1% 10. See my GP 12.8% 11. Use breathing control methods 2.6% 12. Use huff and puff to clear phlegm 0% 13. Use a nebuliser 0%
Eakin 1997	Uncategorized survey	The perceived importance of COPD self-care on a 5-point scale	Cross- sectional survey	Narrative explained by interviewer Other: perceived importance of COPD self- care (1 = not important, 5 = extremely important)	66.3 (10.6)	USA	research institute	female 43.0%	65	Other	Participa nts were recruited from ads in a local newspap er (N 5 40), a local Better Breather s Club (a chronic lung- disease support and informati on group sponsore d by the American Lung Associati	70%	Unclear	Mean (SD)	Perceived importance of COPD self-care activities mean (SD) Stopping smoking: 4.8 (0.63) Taking lung medications: 4.6 (1.10) Engaging in physical activity: 4.2 (0.70) Practicing relaxation: 3.7 (1.20) Using breathing techniques: 3.6 (1.50) Following an eating plan: 3.3 (1.30) Using bronchial drainage or controlled coughing: 2.6 (1.70)

											on; N 5 15), a local group-pulmonologist practice (N 5 8), and other sources (N 5 2). The newspaper ad and flyers used to recruit				
Fox 1999	Direct choice	Forced choice: treatment	Cross-sectional survey	Narrative explained by interviewer	Unclear	USA	hospitalized	Unclear	1016	Consecutive	consecutive sample	89% (11% died)	Robert Wood Johnson Foundation	Choice or proportion of choice	preference for palliative care: 33.6%
Fried 2002	Direct choice	Probability trade off	Cross-sectional survey	Narrative explained by interviewer, Pictorial descriptions of risk (pictogram)	72.2±7.0	USA	inpatient s and outpatients	male 49%	81	Consecutive	consecutive pts with certain diagnoses identified and then screened for inclusion criteria	82% participation rate	Unclear	Choice or proportion of choice	treatment preferences (proportion of wanting the treatment under certain circumstance) SCENARIO 1 —LOW BURDEN, RESTORATION OF CURRENT HEALTH: 97.5% SCENARIO 2 —HIGH BURDEN, RESTORATION OF CURRENT HEALTH: 86.4% SCENARIO 3 —LOW BURDEN, functional impairment: 25.9% SCENARIO 4 —low BURDEN, cognitive impairment: 13.6%
Fried 2007	Direct choice	Probability trade off	Repeated surveys	Narrative explained by interviewer, Pictorial descriptions of risk (pictogram)	UNCLEAR for COPD	USA	hospitalized	UNCLEAR for COPD	64	Consecutive	Sequential charts of persons aged 60 and older with a primary diagnosis of cancer, heart failure (HF), or chronic obstructive pulmonary disease (COPD) were screened for the primary eligibility requirement	81% completed three or more interviews, and 65% completed four or more	grants from the Department of Veterans Affairs Health Services Research and Development Service, from the National Institute on Aging (NIA), from the Claude D. Pepper Older Americans Independence Center at Yale and a Paul Beeson Physician Faculty Scholars Award, from the National Institute of Arthritis and Musculoskeletal and Skin Diseases.	Choice or proportion of choice	Willingness to Undergo High-Burden Therapy to Avoid Death: 32 (50%) Willingness to Risk Physical Disability to Avoid Death: 41 (64%) Willingness to Risk Cognitive Disability to Avoid Death: 44 (69%)
Gaber 2004	Direct choice	Forced choice: treatment	Repeated surveys	Narrative explained by interviewer	Mean (range) 74.1 (48-92)	UK	outpatients	41/59	100	Unclear		Unclear	Unclear	Choice or proportion of choice	Number of patients: Patient's views towards "yes" CPR, IV and NIV: 48 Patient's views towards "yes" IV and NIV: 19 Patient's views towards "yes" IV: 10 Patient's views towards "no" CPR, IV and NIV: 12
Goossens 2014	Direct choice	Willingness to pay, Conjoint analysis/Discrete choice analysis	Cross-sectional survey	Other: Discrete choice experiment questionnaire	Mean 68.1	Netherlands	inpatient (hospitalization as usual vs early discharge)	66/41 62%/38%	107	Other	all patients with COPD and their informal caregivers who participated in the GO AHEAD trial	77.0% 107 of 139	Governmental/ Netherland s Organisation for Health Research and Development	Choice or proportion of choice	always usual hospital care: 29 (25%) always early assisted discharge: 5 (46%) Both: 33 (29%) Willingness to pay Pulmonary instead of generally trained nurse: 46.67 € One/two nurses instead of more: 36.64 € Additional nurse visit per day: -4.67 € Lower readmission risk, per %-point: 3.97 € Hospital instead of general practitioner as contact: 54.88 € Early assisted discharge (Class 1): -505.12 € Early assisted discharge (Class 2): -71.94 € Early assisted discharge (Class 3): 185.95 € Early assisted discharge (Class 4): 565.62 € Burden on caregiver, per hour(Class 1): -3.32 € Burden on caregiver, per hour(Class 2): -47.53 € Burden on caregiver, per hour(Class 3): -25.82 € Burden on caregiver, per hour(Class 4): -10.45 €
Hanada 2015	Direct choice	Forced choice: treatment	Repeated surveys	no description	First survey: 73.6 (7.1) range: 53-87 Second survey: 73.1 (7.3)	Japan	Department of Respiratory Medicine and Allergology at Nara Hospital, Kinki University Faculty of Medicine, Ikoma, Japan between August 2010 and May 2011	First survey: 52/5, 91.2%/8.8 % Second survey: 37/2, 94.9%/5.1 %	First survey: 57 Second survey: 39	Unclear	The first survey enrolled 57 patients with COPD examined at the Department of Respiratory Medicine and Allergology at Nara Hospital, Kinki University Faculty of Medicine, Ikoma, Japan between August 2010 and May 2011.	Unclear	Private/ Department of Respiratory Medicine and Allergology, Nara Hospital, Kinki University Faculty of Medicine	Choice or proportion of choice	First survey Preference of Resimat or HandiHaler Preferring Resimat: 45.6% (Resimat is much better 3.5%; Resimat is better: 42.1%); Second survey Preference of Resimat or HandiHaler the percentage of patients who preferred the Resimat significantly increased from 38.5% to 79.5% during the 2- to 3-year follow-up 13 patients reported preferring the Resimat due to the "experience", and eight patients attributed their satisfaction to the "easy handling without the need to replace the inhalation capsule". Conversely, some dissatisfied patients reportedly disliked having to hold their breath after inhalation (n=2). One patient reported failing to press the button and inhale at the appropriate moment on a few occasions, and another reported that having to inhale twice was troublesome.
Hansen 1990	Direct choice	Forced choice: treatment	Randomized controlled trial	no description	Mean (range) 66 (45-83)	Denmark	outpatients	24/24	48	Random		Unclear	Unclear	Choice or proportion of choice	Number of patients Patients preferred turbutaline: 23 Patients preferred placebo: 9 Patients indicated not difference between treatments: 16
Hansen 1994	Utility, Direct choice	VAS, Forced choice: inhaler	Trial, non-randomized or non-controlled	no description	Mean (range) 66 (54-81)	Denmark	outpatients		25	Random		Unclear	Unclear	Median (Range)	VAS 2 weeks after treatment: 67 (1-100) for turbuhaler and 48 (7-99) for pari inhalerbooy
Haughney 2005	Direct choice	Conjoint analysis/Discrete choice analysis	Cross-sectional survey (A fractional design)	Booklet/card	66	France, Germany, Spain, Sweden and the UK	outpatients	82/43	125	Consecutive		Unclear	Unclear	Mean	Impact on everyday life Little impact on activities, able to go for a short walk: 7.6; Able to wash and dress and move around the house: 4.4; Able to wash and dress, walking almost impossible : 3 Medical care No need to see the doctor: 5.7;

															<p>Needed to see a doctor: .6</p> <p>Number of attacks Fewer attacks in the future: 4.2; No change in the number of attacks in the future: 2.8</p> <p>Breathlessness No worse than usual: 3.9; Worse than usual: 1.7</p> <p>Speed of recovery <1 week: 3.1; 2 weeks: 0.7</p> <p>Cough and phlegm/spit No worse than usual: 3.7; Worse than usual: 2.4</p> <p>Social impact No worse than usual: 1.2; Worse than usual: 0.6</p> <p>Sleep disturbance No worse than usual: 2.6; Worse than usual: 0.6</p> <p>Impact on mood No worse than usual: 1.8; Worse than usual: 0.8</p>
Hernández 2013	Uncategorized survey	Impact of shortness of breath	Cross-sectional survey	Narrative explained by interviewer, Booklet/card	Mean 68,7	Canada	outpatients	491/440	931	Consecutive		Unclear	Unclear	Choice or proportion of choice	<p>Shortness of breath: impact on activities of daily living EXTREME: 6% VERY MUCH: 29% MODERATE: 28% A LITTLE: 24% NOT AT ALL: 13%</p>
Hwang 2011	Direct choice	Forced choice: treatment	Cross-sectional survey	no description	Age group: Percentage 40-49: 2.3% 50-59: 13.3% 60-69: 35.3% 70-79: 40.0% ≥80: 9.0%	Korean	university-affiliated hospital	256/44 85.3%/14.7%	300	Unclear	This study was based on the nationwide survey including urban and rural areas in Korea. Eligible subjects were the patients who visited university-affiliated hospitals after having been diagnosed with COPD according to the GOLD guideline. The distributions of participating centers were as follows; 33% in Seoul, Gyeonggi-do, and Gangwon-do, 9% in Daegu and Gyeongsangbuk-do, 9% in Busan and Gyeongsangnam-do, 9% in Jeolla province and 6% in Chungcheong province.	unclear	Unclear	Choice or proportion of choice	<p>Overall, the most common treatment prescription for the condition of the respondents was a fixed combination of inhaled corticosteroids and long-acting β2 agonists (48.0%), followed by long-acting anticholinergics (38.0%). As expected, the treatment rate was low in the mild group compared to other groups. Forty-one percent of the respondents didn't know the exact name of at least one of their prescriptions</p>
Janssen 2011b	Direct choice	Probability trade off	Cross-sectional survey	Other: questionnaire with description of scenarios						Unclear		62.9%	Unclear	Choice or proportion of choice	<p>COPD patients preferring CPR: 70.50% COPD patients preferring MV: 70.50%</p> <p>Low-burden likelihood of death 0%: 95.2% likelihood of death 1%: 95.2% likelihood of death 10%: 94.3% likelihood of death 50%: 88.6% likelihood of death 90%: 48.6% likelihood of death 99%: 34.3% likelihood of death 100%:</p> <p>High-burden likelihood of death 0%: 82.9% likelihood of death 1%: 82.9% likelihood of death 10%: 82.9% likelihood of death 50%: 75.2% likelihood of death 90%: 38.1% likelihood of death 99%: 27.6%</p> <p>Low-burden likelihood of functional impairment 0%: ... likelihood of functional impairment 1%: 94.3% likelihood of functional impairment 10%: 92.4% likelihood of functional impairment 50%: 67.6% likelihood of functional impairment 90%: 35.2% likelihood of functional impairment 99%: 34.3% likelihood of functional impairment 100%: 28.6%</p> <p>Low-burden likelihood of cognitive impairment 0%: ... likelihood of cognitive impairment 1%: 91.4% likelihood of cognitive impairment 10%: 86.7% likelihood of cognitive impairment 50%: 40.0% likelihood of cognitive impairment 90%: 19.0% likelihood of cognitive impairment 99%: 11.4% likelihood of cognitive impairment 100%: 6.7%</p>
Janssen 2011c	Direct choice	Forced choice: treatment	Cross-sectional survey	no description	Dutch patients: 66.7 (9.3) US patients: 68.7 (10.0)	Dutch, US	outpatient	Dutch patients: 75/47, 61.5%/38.5% US patients: 360/31 92.1%/7.9%	Dutch patients: 122 US patients: 391	Consecutive and other	The Dutch dataset consisted of 124 outpatients with moderate to very severe COPD. Patients	Unclear	This project was part of an international research fellowship supported by CIRO+ (Centre of Expertise for Chronic Organ	Choice or proportion of choice	<p>Patients' preferences in their current health state for MV: 70.5% of Dutch population and 58.2% of US patients reported they would accept Patients' preferences in their current health state for CPR: 69.7% of Dutch and 70.2% of US patients</p>

											<p>were recruited by their clinical specialist at one university and two general hospitals, and data were collected in 2008 and 2009. The first US dataset consisted of 376 patients with COPD from the Veterans Affairs (VA) Puget Sound Health Care System (Seattle, WA, USA), recruited between 2004 and 2007. The second US dataset consisted of 115 patients with severe COPD. These patients were identified through ambulatory pulmonary clinics in three hospitals (one university hospital, one university-affiliated hospital and one VA Medical Center) and through an oxygen delivery company between 1999 and 2002 in Seattle. The final sample included 122 Dutch and 391 US patients with COPD who had valid responses for the primary outcome measure (Quality of Communication (QOC) questionnaire) and the covariates included in the regression models at study enrollment (83.4% of the original datasets).</p>	<p>Failure, Horn, the Netherlands). The original Dutch study was supported by: Proteion Thuis (Horn, the Netherlands); CRO+; grant 3.4.06.082 from the Netherlands Asthma Foundation (Leusden, the Netherlands); and Stichting Wetenschappelijke Verpleeghuiszorg (Utrecht, the Netherlands). The original US studies were supported by the Health Services Research and Development, Dept of Veterans Affairs (grant IIR 02-292) and the American Lung Association. J.R. Curtis was funded by a K24 Award from the National Heart, Lung, and Blood Institute (grant K24 HL068593).</p>			
Jarvis 2007	Direct choice	Forced choice: inhaler	Cross-sectional survey	Narrative explained by interviewer	Mean (range) 73,5 (65-89)	UK	outpatients	36/17	53	Random		Unclear	Unclear	Choice or proportion of choice	<p>Patients pMDI device difficult to use: 46% Patients DPI use device difficult to use: 17% Patients using a pMDI alone felt able to identify a "clinical benefit": 58% Patients using a DPI alone felt able to identify a "clinical benefit": 33% DPI users had rated their inhaler as easy to use: 83% (10/12 patients) DPI users were "unsure" as to whether they received any benefit: 50%</p>
Jordan 2014	Direct choice	Preferences of information	Cross-sectional survey	Other: questionnaires on patient preference regarding information desired from their doctors	Mean (SD) 60 (1.16)	Argentina	outpatient	19/25 43.2%/56.8%	44	Random	Patients were randomly approached by one of the investigators (UNCLEAR), who in no instance was a	unclear	Unclear	Choice or proportion of choice	<p>Preference of information What are all possible side effects of treatment: absolutely want 80 (80.8%); would like 16 (16.2%); do not want 3 (3%) What effect can I expect from this treatment: absolutely want 85 (85.9%); would like 9 (9.1%); do not want 4 (4%) Is my disease cancer or not: absolutely want 85 (85.9%); would like 9 (9.1%); do not want 3 (3%) Is there any chance for cure: absolutely want 86 (86.9%); would like 12 (12.1%); do not want 1 (1%) What will the treatment exactly do: absolutely want 78 (78.8%); would like 14 (14.1%); do not want 6 (6.1%) What is the medical name of my disease: absolutely want 79 (79.8%); would like 11 (11.1%); do not want 8</p>

rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$36.02 (26.67-45.38)
Mild side effects (no side effects as reference) \$19.41 (14.45-24.38)
Moderate to severe side effects (no side effects as reference) \$61.03 (56.07-66.00)

Willingness to pay for moderate patients
Little or no relief (complete relief as reference) \$65.54 (57.52-73.56)
some relief (complete relief as reference) \$29.36 (21.34-37.38)
Feel medicine start to work within 20 min (within 5 min as reference) \$10.42 (7.17-13.68)
Feel medicine start to work within 30 min or more (within 5 min as reference) \$10.04 (6.79-13.29)
Requires some practice and care (quick and easy as reference) \$6.08 (2.52-9.63)
More difficult and time-consuming (quick and easy as reference) \$19.20 (15.65-22.76)
3-5 times of rescue medicine use per week (rarely, 1-2 times per week or less as reference) \$19.98 (12.88-27.07)
rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$33.68 (26.58-40.78)
Mild side effects (no side effects as reference) \$13.46 (9.57-16.95)
Moderate to severe side effects (no side effects as reference) \$57.77 (54.28-61.26)

Willingness to pay for severe/very severe patients
Little or no relief (complete relief as reference) \$67.51 (56.31-78.71)
some relief (complete relief as reference) \$26.64 (15.44-37.83)
Feel medicine start to work within 20 min (within 5 min as reference) \$13.41 (8.72-18.10)
Feel medicine start to work within 30 min or more (within 5 min as reference) \$18.33 (13.64-23.02)
Requires some practice and care (quick and easy as reference) -\$0.19 (-5.40-5.02)
More difficult and time-consuming (quick and easy as reference) \$12.81 (7.60-18.01)
3-5 times of rescue medicine use per week (rarely, 1-2 times per week or less as reference) \$18.13 (8.10-28.16)
rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$24.54 (14.51-34.56)
Mild side effects (no side effects as reference) \$13.46 (8.57-18.35)
Moderate to severe side effects (no side effects as reference) \$60.35 (55.46-65.24)

WTP for 40-62 years old patients
Little or no relief (complete relief as reference) \$51.59 (44.41-58.77)
some relief (complete relief as reference) \$20.49 (13.31-27.67)
Feel medicine start to work within 20 min (within 5 min as reference) \$8.28 (5.28-11.28)
Feel medicine start to work within 30 min or more (within 5 min as reference) \$10.51 (7.51-13.51)
Requires some practice and care (quick and easy as reference) \$4.46 (1.15-7.76)
More difficult and time-consuming (quick and easy as reference) \$13.48 (10.17-16.78)
3-5 times of rescue medicine use per week (rarely, 1-2 times per week or less as reference) \$19.71 (13.27-26.14)
rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$28.41 (21.98-34.84)
Mild side effects (no side effects as reference) \$13.23 (10.11-16.35)
Moderate to severe side effects (no side effects as reference) \$48.29 (45.17-51.41)

WTP for 63-88 years old patients
Little or no relief (complete relief as reference) \$77.88 (69.51-86.24)
some relief (complete relief as reference) \$36.41 (28.05-44.78)
Feel medicine start to work within 20 min (within 5 min as reference) \$11.97 (8.53-15.41)
Feel medicine start to work within 30 min or more (within 5 min as reference) \$15.95 (12.51-19.39)
Requires some practice and care (quick and easy as reference) \$5.27 (1.46-9.07)
More difficult and time-consuming (quick and easy as reference) \$18.07 (14.27-21.88)
3-5 times of rescue medicine use per week (rarely, 1-2 times per week or less as reference) \$19.53 (12.21-26.85)
rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$35.16 (27.84-42.48)
Mild side effects (no side effects as reference) \$17.00 (13.25-20.75)
Moderate to severe side effects (no side effects as reference) \$71.01 (67.26-74.76)

WTP for male
Little or no relief (complete relief as reference) \$69.71 (60.62-78.80)
some relief (complete relief as reference) \$27.30 (18.21-36.38)
Feel medicine start to work within 20 min (within 5 min as reference) \$10.36 (6.63-14.09)
Feel medicine start to work within 30 min or more (within 5 min as reference) \$11.45 (7.72-15.18)
Requires some practice and care (quick and easy as reference) \$8.00 (3.78-12.22)
More difficult and time-consuming (quick and easy as reference) \$18.57 (14.35-22.79)
3-5 times of rescue medicine use per week (rarely, 1-2 times per week or less as reference) \$23.29 (15.23-31.34)
rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$35.23 (27.18-43.29)
Mild side effects (no side effects as reference) \$12.99 (8.97-17.01)
Moderate to severe side effects (no side effects as reference) \$67.57 (63.55-71.59)

WTP for female
Little or no relief (complete relief as reference) \$59.10 (52.34-65.86)
some relief (complete relief as reference) \$27.58 (20.83-34.34)
Feel medicine start to work within 20 min (within 5 min as reference) \$9.72 (6.89-12.54)
Feel medicine start to work within 30 min or more (within 5 min as reference) \$14.12 (11.29-16.94)
Requires some practice and care (quick and easy as reference) \$2.58 (-0.48-5.64)
More difficult and time-consuming (quick and easy as reference) \$13.32 (10.25-16.38)
3-5 times of rescue medicine use per week (rarely, 1-2 times per week or less as reference) \$17.86 (11.87-23.85)

															rescue medicine use every day (rarely, 1-2 times per week or less as reference) \$29.29 (23.30–35.27) Mild side effects (no side effects as reference) \$15.92 (12.95–18.90) Moderate to severe side effects (no side effects as reference) \$52.44 (49.47–55.42)
Kessler 2006	Uncategorized survey	Impact of exacerbation	Cross-sectional survey	Narrative explained by interviewer	Mean (SD) 664, (8,5)	France, Germany, Spain, Sweden and UK (Europe)	outpatients	82/43	125	Consecutive		Unclear	Unclear	Choice or proportion of choice	Impact of exacerbations on activities of daily living: 86% (n=108) Impact of exacerbations on stop all activities: 47% (n=59) Impact of exacerbations on need additional help with certain tasks: 51%(64)
Kuyucu 2011	Uncategorized survey	Expectation of treatment	Cross-sectional survey	No description	(mean (SD) (range)): 64.1 (9.5) (41-92)	Turkey	Secondary and tertiary care centres; primary physician offices	91% male; 9% female	514	Unclear	This national, multi-centered, cross-sectional study was performed in a total of 25 centers including 15 secondary and three tertiary healthcare institutions and seven physician's offices. A total of 514 newly or previously diagnosed COPD patients referring to the related department and meeting the patient inclusion criteria were included regardless of disease severity. Study centers were selected among the healthcare institutions that were treating a high rate of COPD patients in order to obtain a good cross-section of real-life.	Unclear	Astra-Zeneca Turkey	Choice or proportion of choice	Proportion of patients reporting expectation of COPD treatment Greater symptomatic relief: 423 (82.3%) Greater mobility: 360 (70.0%) More rapid symptomatic relief: 314 (61.1%) Improvement in morning activities: 305 (59.3%) To be able to perform daily activities without assistance: 265 (51.6%) Less exacerbations: 244 (47.5%) Less need for reliever therapy: 179 (34.8%) Less hospitalization: 178 (34.6%)
Lynn 2000	Direct choice	Forced choice: treatment	Cohort study	no description	Median (25th, 75th percentile) Died during index hospitalization (n=116) 73 (68, 80) Died after index hospitalization (n=300) 72 (66, 79) Alive at 1 year (n=600) 69 (61, 76)	USA	Hospitalization for exacerbation of COPD at five US teaching hospitals	Died during index hospitalization (n=116) 64/52, 55%/45% Died after index hospitalization (n=300) 150/150, 50%/50% Alive at 1 year (n=600) 309/291, 52%/48%	416 died among 1016 enrolled	Consecutive	The study sample consisted of patients aged 18 years or older enrolled in SUPPORT who had an acute exacerbation of severe COPD and who died within 1 year of study entry and had data collected within the last 6 months of life. SUPPORT included every patient who was hospitalized in one of the five study hospitals with a clinical diagnosis of COPD provided they also met the following criteria	unclear	SUPPORT was made possible by grants from the Robert Wood Johnson Foundation . Dr. Claessens was supported by a Veterans Administration Ambulatory Care Fellowship, White River Junction, Vermont, and a Fellowship in Palliative Medicine, Ottawa, Ontario.	Choice or proportion of choice	preference for Do-Not-Resuscitate (DNR) 29% of patients who were long-term survivors 43% of those who survived to leave the hospital but lived less than a year 42% of those who died during the first hospitalization 41% (31) of for patients 6 to 3 months in hospital before death 51% (50) of for patients 3 to 1 Months in hospital before death 48% (56) of for patients 1 Month to 3 days in hospital before death 51% (37) of for patients 6 to 3 months out of hospital before death 50% (29) of for patients 3 to 1 Months out of hospital before death 69% (22) of for patients 1 Month to 3 days out of hospital before death preference for comfort care 56% of the 1-year survivors 66% of those who died either during the initial hospitalization or within a year 63% (43) of for patients 6 to 3 months in hospital before death 70% (62) of for patients 3 to 1 Months in hospital before death 67% (64) of for patients 1 Month to 3 days in hospital before death 67% (43) of for patients 6 to 3 months out of hospital before death 67% (37) of for patients 3 to 1 Months out of hospital before death 82% (23) of for patients 1 Month to 3 days out of hospital before death
Mahler 2014	Direct choice	Forced choice: treatment	Randomized controlled trial	no description	71.6 (7.4)	UK	unclear	5/15 25%/75%	20	Unclear		unclear	Boehringer Ingelheim, GlaxoSmith Kline, Novartis, and Sunovion	Choice or proportion of choice	Preferences of treatment: Eight patients preferred salmeterol Diskus, seven patients preferred arformoterol solution, and five patients had no preference.

Martínez 2012	Direct choice	Forced choice: treatment	Cross-sectional survey	Narrative explained by interviewer, Booklet/card	Males Mean (SD) at time of survey 73,1 (8,3)	USA	outpatients	273/295	568	Random		7.2%	Unclear	Choice or proportion of choice	Males prefers dry-powdered inhalers: 62.30% Females prefers dry-powdered inhalers: 54.60% Males prefers metered dose inhalers: 57.5 Females prefers metered dose inhalers: 54.20%	
Miravittles 2007	Uncategorized survey	Ideal characteristics of a COPD therapy	Cross-sectional survey	Narrative explained by interviewer, Computer program or Software, Audiobooklet	%Patients age >51= 51%	Germany, France, Italy, Spain and UK and USA	Outpatients	39%/61%	1100	Random		Unclear	Unclear	Choice or proportion of choice	Ideal characteristics of a COPD therapy as listed by survey respondents Quicker symptom relief 55% Longer intervals between flare-ups 40% Fewer side effects 36% Better ability to cope with daily chores again 27% Lower costs of treatment 27% Better doses 23%	
Molimard 2005	Direct choice	Conjoint analysis/Discrete choice analysis	Cross-sectional survey	Computer program or Software, Sawtooth Software's adaptive choice based conjoint analysis and choice-based conjoint analysis product	Mean 60.7	US, UK, Germany, France	Unclear	Unclear	245	Unclear		unclear	Private for profit/ Novartis Pharma	Mean	I am extremely satisfied with my main inhaler: 5.5	
														Choice or proportion of choice	The three main inhaler attributes that the patients considered to be most important were ease of use/convenience, efficacy, and inhaler size which were given primary importance by 66%, 29%, and 27% patients, respectively.	
Moore 2004	Direct choice	Forced choice: inhaler	Cross-sectional survey	questionnaire	Mean: German 58, Dutch 61	German and Dutch	Outpatients	120/136 46.9%/53.1%	256	Unclear		Unclear	Unclear	Choice or proportion of choice	Proportion of patients considering following attributes "very important" Overall ease of using: 86% Being quick to use when you need it: 84% Ease of holding or gripping: 79% Knowing the dose has been taken: 79% Easy to carry it in pocket/handbag: 70% Hygienic to use: 62% Small size: 65% Having a comfortable mouthpiece: 62% Being moisture proof: 64% Having a counter to let you know how many doses are left: 67% Being lightweight: 54% Compact shape: 54% Number of doses in each pack: 41% Having a pleasant taste: 43% Being environmentally friendly: 36% Discreet to use: 27% Having an attached cover: 36% The colour of the device: 6% On the issue of a preloaded device with a month's supply of medication vs one that required single doses to be loaded 74% of German patients and 66% of Dutch patients strongly preferred the preloaded device compared to 5 and 11%, respectively, who strongly preferred single doses. On the issue of devices requiring regular washing and drying compared to maintenance-free devices 87% of German patients and 72% of Dutch patients strongly preferred maintenance-free inhalers compared to 3% and 8%, respectively, who strongly preferred to wash and dry inhalers. Device preference patients clearly considered the Diskus to be significantly better than Handihaler on the three most important attributes for an inhaler device- quick to use, overall ease of use and knowing how many doses are left... Overall, more than twice the number of patients preferred the Diskus (67%) to the Handihaler (33%) which was statistically significant	
Mutterlein 1990	Direct choice	Forced choice: device	Cross-over study	questionnaire	Unclear	Germany	Ambulatory patients	Unclear	60	Unclear		Unclear	Unclear	Choice or proportion of choice	The study showed a highly significant preference on the part of the patients for the new inhalation system. The advantage most emphasized by the patients was the fact that they were able to carry with them their entire daily dose.	
Norris 2005	Direct choice	Forced choice: treatment	Cross-sectional survey	questionnaire	Mean (SD) 67.2 (9.5)	US	outpatient	81/30 73.0%/27.0%	111	Other	Consecutive and mailing to patients/ At the county and university hospitals, a clinician familiar with the patient asked if he or she was willing to talk with study staff. At the VA medical centre and oxygen delivery company a letter was mailed to all patients on oxygen asking them to call a toll-free voice message if they were unwilling to participate; if they did not leave a message declining participation, they received a phone call from the study staff. Overall, out of the 295 eligible patients		76%	Private not for profit and Governmental/ Clinical Research Trainee Award in Critical Care from the CHEST Foundation /K24 Award from the National Heart Lung and Blood Institute (K24 HL68593)	Choice or proportion of choice	Current health (No ventilation): 39.60% Current health (No CPR): 38.40% Permanent coma (No ventilation): 93.60% Permanent coma (No CPR): 91.00% Dementia (No ventilation): 84.50% Dementia (No CPR): 81.70% Dependent for activities of daily living (No ventilation): 83.60% Dependent for activities of daily living (No CPR): 82.10%

											contacted and asked to participate in a 1-h in-person interview, 118 were enrolled for 40% participation. Out of the 118 enrolled patients, 115 completed the interviews and three were unable due to fatigue.				
Ohno 2014	Direct choice	Forced choice: treatment	Trial, non-randomized or non-controlled	Narrative explained by interviewer	75,7±7,0	Japan	outpatients	male/female = 26/2	28	Unclear		29 included/28 completed follow up	Unclear	Choice or proportion of choice	continuation of Ombriz Definitely want to continue: 2 (7.7%) Want to continue: 14 (53.8%) Equivalent: 10 (38.5%)
Ojoo 2002	Direct choice	Forced choice: treatment	Randomized controlled trial	no description	Mean 70.1 in conventional arm and 69.7 in domiciliary arm	UK	inpatient at the beginning, either hospital or at home after	31/29 51.6%/48.4% in total; 15/15 50%/50% in conventional arm and 16/15 53.3%/47.7% in the domiciliary arm	61	Other	Patients with an acute exacerbation of COPD were admitted to the Medical Chest Unit, Castle Hill Hospital and clinical management was instituted according to the British Thoracic Society guideline 5... Recruitment into the study was carried out from Monday to Thursday. Outside these times patients could obtain advice from the Medical Chest Unit through a direct line.	51.2% for response rate. 88.5% (54/61, six patients failed to complete the trial, one patient did not provide preference information)	Governmental and unclear/ Part of the funding of this study was obtained from East Yorkshire Hospitals NHS Trust.	Choice or proportion of choice	treatment preferences Sixteen of the 27 patients (59.3%) in the conventional arm and 26 of the 27 (96.3%) in the domiciliary arm would have preferred domiciliary management. Thirty four carers completed the questionnaires and the respective carer preference figures were 6/14 (42.9%) and 17/20 (85.7%).
Oliver 1997	Direct choice	Ranking: treatment	Cross-over study	Unclear	Unclear	UK	unclear	Unclear	20	Unclear		Unclear	Unclear	Choice or proportion of choice	Accuhaler, autohaler and turbobaler scored highest and diskhaler lowest. Patients ranked the metered dose inhaler and accuhaler highest for ease of use and preference.
Oliszancka-Glinianowicz 2014	Uncategorized survey	Brief Illness Perception Questionnaire	Cross-sectional survey	No description	Mean (SD) 60.0 (13.5)	Poland	general practice	1491/1111 57.3%/42.7%	2602	Consecutive	Polish doctors participating in the study were recruited by medical representatives, and each of them conducted questionnaire interviews with a group of 620 consecutive patients visiting the clinic for asthma or COPD treated with fluticasone propionate and formoterol fumarate using the Fantasma inhaler during two successive visits resulting from the needs of therapy.	Unclear	Unclear	Choice or proportion of choice	impact of COPD on patient's life (adherence patients in the first visit) None at all: 4.5% Slight: 9.0% Moderate: 11.6% Significant: 28.2% Severe: 46.7% impact of COPD on patient's life (adherence patients in the second visit) None at all: 4.4% Slight: 17.6% Moderate: 22.8% Significant: 25.0% Severe: 30.2% impact of COPD on patient's life (non-adherence patients in the first visit) None at all: 0% Slight: 7.2% Moderate: 23.9% Significant : 36.2% Severe : 32.7% impact of COPD on patient's life (non-adherence patients in the second visit) None at all: 0% Slight : 6.5% Moderate : 39.0% Significant : 41.5% Severe : 13.0%
Pallin 2012	Direct choice	Willingness to pay, Forced choice: treatment	Cross-sectional survey	Narrative explained by interviewer	64,4 ±6,7	Ireland	outpatient, or hospitalized on the day of discharge	male 26 (46,4%), female (53,6%)	146 patient approached/ 142 completed survey	Consecutive	Consecutively encountered potential subjects were identified prospectively	97%	Unclear	Choice or proportion of choice	In making a decision to be screened, screening convenience is important Former smoker: 64% Current smoker: 71.4% total: 66.9% In making a decision to be screened, the risk of disease is important Former smoker: 81.4%

										vely in the course of routine clinical care, following prescreening of medical records for inclusion/exclusion criteria				Current smoker: 85.7% total: 83.1% In making a decision to be screened, screening accuracy is important Former smoker: 93% Current smoker: 92.9% total: 93% Willingness to consider screening for lung cancer Former smoker: 94.2% Current smoker: 100% total: 96.5% Willingness to consider paying \$200/200 euro for screening test Former smoker: 74.4% Current smoker: 58.9% total: 68.3% Willingness to accept treatment Former smoker: 94.2% Current smoker: 98.2% total: 95.8%	
Patridge 2011	Uncategorized survey	perception of disease severity	Cross-sectional survey	No description	Mean (SD) 62.4 (8.6)	UK, Germany, France, Italy and Spain	Unclear	406/313 56.5%/43.5%	719	Random	Exact data on response rates following random selection (from among the asthma and COPD patients listed in each country as part of the pre-recruited panel of 1,835,000 individuals) and invitation to participate are unavailable. Approximately 50%	Exact data on response rates following random selection (from among the asthma and COPD patients listed in each country as part of the pre-recruited panel of 1,835,000 individuals) and invitation to participate are unavailable. Approximately 50%	Private not for profit/Chiesi Foundation	Choice or proportion of choice	When offered a choice of 11 diseases, those with COPD ranked COPD as being more serious than epilepsy, asthma, diabetes, hypertension, arthritis, hypercholesterolemia and migraine, with only Parkinson's disease, heart disease and large bowel cancer being regarded as more serious than COPD. agreeing "a lot" or "quite a lot" I notably reduce my physical activity for fear of breathing difficulties: 53.40% I have been forced to plan all of my activities due to COPD: 47% Because of COPD I have difficulty in walking up the stairs or walking: 59.90% I am afraid of COPD worsening as the cold season comes: 54.40% Because of COPD I feel I am a burden on the rest of my family: 22.50% I am always afraid of not having the medicine for COPD with me: 37.10% I am always afraid of the medicine not working when I need it to: 30.20% I feel embarrassed at taking the medicine in front of other people: 18.00% I manage my regular COPD therapy in relation to how I feel: 35% Nothing happens if one day you forget to take regular COPD therapy: 32% Regular therapy does not provide benefits that are easily felt: 25.60% Regular therapy with immediate results gives me reasons for regular taking: 65.80% Regular therapy makes me afraid of possible side effects: 30.60% Medicines to be taken every day can lose their effect the longer you take them: 35.40% Regular therapy gives me the sensation of being more ill: 24.80% (Need: 1 = not at all important; 10 = extremely important) Listening carefully when I talk about my symptoms and problems (Need: 1 = not at all important; 10 = extremely important): 9.30 Understanding clearly what concerns me (Need: 1 = not at all important; 10 = extremely important): 9.20 Explaining well what COPD is and what problems it can cause: 9.20 Emphasising the usefulness of the medicines against COPD, explaining their function: 9.10 Devoting an appropriate amount of time to the visit: 9.10 Explaining clearly how to take the products and use the inhalers: 9.00 Understanding clearly what I am trying to express: 9.00 Explaining clearly which are the possible side effects and risks of the products: 9.00 Asking me a lot of questions on how I feel: 9.00 Giving me advice on how to self-treat episodes of COPD worsening: 8.90 Warning me against the dangers of COPD: 8.80 Not blaming me about the style of life that I lead / that I have led: 8.70 Consulting me with regard to the choice of inhaler: 8.70 Supporting me psychologically and preventing me being gripped by pessimism: 8.70 Giving me suggestions on how to change my life style: 8.50
Persson 2005	Uncategorized survey	Importance of life values	Cohort study	Narrative explained by interviewer	64,7 (min-max - 54-71)	Sweden	hospitalized and outpatients	Male 43 (63%)/ Female 22 (37%)	65	Consecutive	Every 10th patient registered at the Department fulfilling the inclusion criteria was selected	46 (29% drop out rate)	Financially supported by the Medical Faculty, University of Goteborg	Mean (SD)	Importance of life values: Harmony: 88.5 (7.7) Positive relations: 85.3 (9.6) Mobility: 86.4 (10.3) Involvement: 74.8 (15.2) Communication: 93.2 (4.1) Knowledge: 80.3 (17.6) Responsibility: 88.1 (10.0) Comfort: 73.5 (15.5) Religion: 57.7 (27.9) Health: 74.0 (12.4)
Pisa 2013	Direct choice	Conjoint analysis/Discrete choice analysis	Cross-sectional survey	Narrative explained by interviewer	years: 1. 40-50 - 32%; 2. 51-60 - 43%; 3. 61-70 - 25%; Age range - 55,3 years	Germany	Unclear	Male/ female: 63%/37%	300	Unclear	no follow-up	funded by Novartis Pharma GmbH	Choice or proportion of choice	Relative importance of the COPD attributes (%): Total Dyspnea: 36% Performance capability (bodily resilience) due to COPD: 19% Sleep quality due to COPD: 19% Onset of action of the medication: 3% Frequency of administration of the medication: 6% Health state after awakening (day start) due to COPD: 13% Emotional state due to COPD base medication: 4% Stage II Relative importance of the COPD attributes (%): Dyspnea: 36% Performance capability (bodily resilience) due to COPD: 19% Sleep quality due to COPD: 19% Onset of action of the medication: 3% Frequency of administration of the medication: 6% Health state after awakening (day start) due to COPD: 12% Emotional state due to COPD base medication: 5% Stage III Relative importance of the COPD attributes (%): Dyspnea: 36% Performance capability (bodily resilience) due to COPD: 19% Sleep quality due to COPD: 20% Onset of action of the medication: 2% Frequency of administration of the medication: 7% Health state after awakening (day start) due to COPD: 12% Emotional state due to COPD base medication: 3% Effect of attribute levels on health state preference: partworth utilities: Dyspnea 1. Never dyspnea, except on strong exertion: 115.8	

										outreach, magazine, and publication subscriptions)." "					
Siler 2014	Direct choice	Patient's expectation of treatment adherence	Randomized controlled trial	no description	Overall: 61.5 (8.68) Indacaterol /placebo: 62.2 (10.29) Placebo/in dacaterol: 60.8 (6.90)	USA	unclear	Overall: 27/13 68%/32% Indacaterol /placebo: 11/9 55%/45% Placebo/in dacaterol: 16/4 80%/20%	40	Unclear	unclear	Private for profit	Least squares mean (SEM)	Patient's expectation of treatment adherence Indacaterol group: 2.1 (0.21) ; placebo 2.3 (0.21)	
Simon 2013	Uncategorized survey	A 5-point scale, on behaviour and own efforts that the patient is willing to mobilize in order to achieve greater health)	Cross-sectional survey	no description	Age group: number (%) -40 years: 4 (2.7%) 41-60 years: 71 (48.3%) 61- years: 72 (49.0%)	Hungary	six out of the seven pulmonary centers of Hungary	74/73 50.3%/49.7%	147	Other	unclear	Unclear/ The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.	Mean	A 5-point scale, where 5 meant fully agree and 1 meant fully disagree. (forms of behavior, own efforts that the patient is willing to mobilize in order to achieve greater health) Less stressful lifestyle: 3.53 (Male: 3.67, female: 3.38; 41-60 years: 3.44, 61- years: 3.56; condition controlled: 3.13, partly controlled: 3.65, not controlled: 3.42) Gave up smoking: 3.23 (Male: 3.39, female: 2.70; 41-60 years: 2.78, 61- years: 3.71; condition controlled: 2.88, partly controlled: 3.24, not controlled: 3.06) Healthy nutrition: 3.17 (Male: 3.12, female: 3.23; 41-60 years: 3.26, 61- years: 3.12; condition controlled: 2.63, partly controlled: 3.22, not controlled: 3.29) Taking vitamins: 3.1 (Male: 2.73, female: 3.38; 41-60 years: 3.00, 61- years: 3.14; condition controlled: 2.00, partly controlled: 3.26, not controlled: 3.19) Reducing smoking: 3.06 (Male: 3.18, female: 3.29; 41-60 years: 3.50, 61- years: 2.94; condition controlled: 3.14, partly controlled: 3.43, not controlled: 2.93) Controlled body weight: 3.03 (Male: 3.17, female: 3.05; 41-60 years: 3.32, 61- years: 2.95; condition controlled: 3.00, partly controlled: 3.08, not controlled: 3.15) Exercise: 2.88 (Male: 3.05, female: 2.72; 41-60 years: 2.78, 61- years: 3.00; condition controlled: 2.38, partly controlled: 2.97, not controlled: 2.94) No effort: 2.1 (Male: 2.08, female: 2.13; 41-60 years: 2.10, 61- years: 2.05; condition controlled: 2.50, partly controlled: 1.90, not controlled: 2.30)	
Spencer 2013	Uncategorized survey	importance of exercise and support, and the importance of seeing the same person each time	Randomized controlled trial	no description	IG: 65 (8); CG: 66 (8)	Australia	Outpatients	IG: 9/10; CG: 10/7	48	Unclear	75% 36/48	Unclear	Raw score	the importance of exercise (from 0 to 100) 100 in both IG and CG groups	
Stapleton 2005	Direct choice	Forced choice: treatment	Cross-sectional survey	Booklet/card	Median (interquartile range): 67.4 (59.4-74.3)	USA	End of life care/ambulatory pulmonary clinics in three hospitals (university, county, and Veterans Affairs Medical Center) and through an oxygen delivery company	78/23	101	Other	Consecutive and mailing to patients/ At the county and university hospitals, a clinician familiar with the patient asked if he or she was willing to talk with study staff. At the VA medical centre and oxygen delivery company a letter was mailed to all patients on oxygen asking them to call a toll-free voice message if they were unwilling to participate; if they did not leave a message declining participation, they received a phone call from the study staff...Overall, out of the 295 eligible patients contacted and asked to participate in a 1-h in-person interview, 118 were enrolled for 40% participation. Out of the 118 enrolled patients,	34.2% (101/295)	Unclear	Choice or proportion of choice	want mechanical ventilation: 62.20% want CPR: 63.60%

											115 completed the interviews and three were unable due to fatigue.				
Stavem 2002b	Utility, Direct choice	Time trade off, Standard gamble, VAS, 15 D, willingness to pay	Cross-sectional survey	EQ-5D, a script and a payment card with a range of 13 amounts	Mean (SD) 57 (10)	Norway	Outpatients, identified the Central Hospital of Akershus, Norway	34/25 57.6%/42.4%	59	Consecutive		29.8%	Unclear	Median (95% CI, Range) SG 0.95 (0.88-0.97) range: 0.05-1 TTO 0.91 (0.70-0.93) range: 0.05-1 EQ-VAS 0.54 (0.50-0.65) range: 0.05-0.95 15D 0.80 (0.77-0.83) range: 0.54-1	Median (95% CI) NOK 200,000 (95%CI 100,000–300,000), corresponding to US \$24,967 (95%CI 12,048–36,145)
Sutherland 2009	Direct choice	Forced choice: device	Randomized controlled trial	Narrative explained by interviewer	Mean (SD) 62 (10)	USA	outpatients	49/50 50%/50%	99/109	Unclear		73.2% (109 of 149) enrolled; 85.3% (93 of 109) followed	Private for profit/ Dey LP	Choice or proportion of choice	for all participants: 40.3% for IPR-ALB MDI and 50% for FFIS Nebulizer, 9.9% no difference; for severe patients: 28.3% for IPR-ALB MDI and 63.0% for FFIS Nebulizer, 8.7% no difference
Svedsater 2013	Direct choice	Forced choice: inhaler	Cross-sectional survey	Narrative explained by interviewer	Mean: 61	USA	Unclear	Unclear	42	Other	Recruited from other studies	unclear	Private for profit/ GlaxoSmith Kline	Choice or proportion of choice	No (%) of patients expressing preference for the ELLIPTA DPI For patients using DISKUS as comparator device: 18 (86%); For patients using MDI/HFA as comparator device: 17 (85%); For patients using HandiHaler as comparator device: 19 (95%).
Torrance 1999	Utility, Direct choice	HUI, willingness to pay	Randomized controlled trial	HUI	Mean (SE) ciprofloxacin: 54.9 (1.46); Usual care: 55.8 (1.36)	Canada	outpatients	ciprofloxacin: 44/71 38%/62%; Usual care: 53/54 50%/50%	222 in 240	Unclear		Unclear	Private for profit/ Bayer Inc.	Mean (SD) HUI first AECB Ciprofloxacin: 0.72 (0.20), usual care: 0.68 (0.19) At regular visit no.1 Ciprofloxacin: 0.78 (0.21), usual care: 0.77 (0.19) At regular visit no.2 Ciprofloxacin: 0.80 (0.20), usual care: 0.78 (0.18) At regular visit no.3 Ciprofloxacin: 0.82 (0.17), usual care: 0.78 (0.19) At regular visit no.4 Ciprofloxacin: 0.81 (0.19), usual care: 0.78 (0.20)	willingness to pay per patient Ciprofloxacin: CAD \$1235 (1992), usual care: \$868 (1217)
														Median	willingness to pay per patient Ciprofloxacin: CAD \$418, usual care: \$499
Travaline 1995	Direct choice	Forced choice: treatment	Cross-sectional survey	Narrative explained by interviewer	median (range): 67 (43-81)	USA	University Health Center of the University of Maryland Hospital and the Baltimore Veterans Administration Hospital	29/8 78.4%/21.6%	37	Consecutive	Consecutive patients were interviewed after they were seen by their physician	96.25%	Unclear	Choice or proportion of choice	decision to use MV yes 15 (40%); no 8 (22%); unsure: 14 (38%)
Utens 2013	Direct choice	Forced choice: place of treatment	Randomized controlled trial	no description	Mean (SD) usual hospital group 67.8 (11.3); early assisted discharge 68.31 (10.34)	Netherlands	hospitalized patients first and discharge later	usual hospital: 38/31 55.1%/44.9%; early assisted discharge: 48/22 68.6%/31.4%	139	Consecutive	Patients that were considered eligible according to the inclusion and exclusion criteria at admission, and those meeting the criteria of clinical stability on day three of admission, were randomized to usual hospital care or early assisted discharge.	139 of 479 (29.0%)	Governmental/ Netherlands Organization for Health Research and Development (945-50-7730)	Choice or proportion of choice	Preference to be treated at home at T+4 days 25(42%) in the usual hospital treatment group and 56 (86%) in the early assisted group Preference to be treated at home at T+90 days 17 (35%) in the usual hospital treatment group and 33 (59%) in the home treatment group
Utens 2014	Direct choice	Forced choice: place of treatment	Randomized controlled trial	no description	Unclear	Netherlands	hospitalized patients first and discharge later	usual hospital: 38/31 55.1%/44.9%; early assisted discharge: 48/22 68.6%/31.4%	124 (62 caregivers each in either groups)	Consecutive	Patients that were considered eligible according to the inclusion and exclusion criteria at admission, and those meeting the criteria of clinical stability on day three of admission, were randomized to usual hospital care or early assisted discharge.	Unclear	Governmental/ Netherlands Organization for Health Research and Development (945-50-7730)	Choice or proportion of choice	Preference to be treated at home at the end of the 7-day treatment 15 (33.3%) of informal caregivers of patients allocated to usual hospital care and 37 (71.2%) of informal caregivers allocated to hospital-at-home Preference to be treated at home at the end of the follow up 13 (36%) of informal caregivers of patients allocated to usual hospital care and 27 (60%) of informal caregivers allocated to hospital-at-home

van der Palen 2013a	Direct choice, Uncategorized survey	Forced choice: inhaler, willingness to continue inhaler use scale, importance core of inhaler attributes	Randomized controlled trial	No description	Mean (SD) 65.9 (8.6) for the safety population, 65.7 (8.5) for the ITT population	Germany and Netherlands	Unclear	87/42 67.4%/32.6% for the safety population, and 75/30 (71.4%/28.6%) for the ITT population	129	Unclear	response rate unclear, 70.5% 91/105 patients indicating the preference	Private for profit/ Almirall, S.A., Barcelona, Spain, and Forest Laboratories, Inc., New York, USA	Mean (SD)	willingness to continue inhaler use (scale 0 = not willing to 100 = definitely willing) 84.0 (3.2) for Genuair and 62.5 (3.2) for HandiHaler
												Choice or proportion of choice	more patients preferred Genuair than HandiHaler (79.1 vs 20.9%; p < 0.0001) Preference for the attributes Ease of use: 78 (83.9%) for Genuair and 15 (16.1%) for HandiHaler Convenience: 75 (79.8%) for Genuair and 19 (20.2%) for HandiHaler Ease of learning to use: 56 (82.4%) for Genuair and 12 (17.6%) for HandiHaler Ease of holding: 70 (85.4%) for Genuair and 12 (14.6%) for HandiHaler Ease of operating: 71 (84.5%) for Genuair and 13 (15.5%) for HandiHaler Ease of preparation of the dose: 78 (87.6%) for Genuair and 11 (12.4%) for HandiHaler Feedback to indicate correct inhalation: 36 (69.2%) for Genuair and 16 (30.8%) for HandiHaler Dosage (multiple vs single dose): 70 (83.3%) for Genuair and 14 (16.7%) for HandiHaler Ease of use: 48.6% very important, 44.8% important, 4.8% moderately important, 1.9% of little importance Convenience: 47.1% very important, 47.1% important, 5.8% moderately important Ease of learning to use: 41.0% very important, 50.5% important, 6.7% moderately important, 1.0% of little importance, 0.8% unimportant Ease of holding: 46.7% very important, 47.6% important, 2.9% moderately important, 2.9% of little importance Ease of operating: 58.1% very important, 37.1% important, 3.8% moderately important, 1.0% of little importance Ease of preparation of the dose: 48.6% very important, 49.5% important, 1.9% moderately important Feedback to indicate correct inhalation: 48.8% very important, 44.8% important, 5.7% moderately important, 1.0% of little importance Dosage (multiple vs single dose): 42.3% very important, 47.1% important, 9.6% moderately important, 1.0% of little importance	
												Mean	scales (very important, important, moderately important, of little importance, unimportant) Ease of learning to use: 4.3 Dosage (multiple vs single dose): 4.3 Ease of operating: 4.5 Ease of preparation of the dose: 4.5	
van der Palen 2013b	Direct choice, Uncategorized survey	Forced choice: inhaler, willingness to continue inhaler use scale, importance core of inhaler attributes	Randomized controlled trial	Narrative explained by interviewer	Mean (SD) 65.3 (9.8) for overall (both asthma and COPD)	Netherlands	unclear/ Medisch Spectrum Twente Hospital at Enschede, and Gelre Hospital at Zutphen, the Netherlands	52/61 46%/56% for overall study population	113, while 82 for COPD	Unclear	Unclear	Private for profit/ Glaxo Smith Kline, Zeist, the Netherlands	Choice or proportion of choice	COPD inhaler preference 52 (72.2%) for Diskus, 20 (27.8%) for Elpenhaler
												Mean (SD)	willingness to continue inhaler use (scale 0 = not willing to 100 = definitely willing) 78.9 (13) for Diskus, 59.9 (25) for Elpenhaler	
												Mean	Score for the importance of each attribute, independent of inhaler (scale 1-5, lower is better) Ease of handling: 1.52 Dosing: 1.66 Ease of preparation: 1.67 Ease of use: 1.76 Ease of learning: 1.94 Feedback: 1.96 Ease of holding: 2.06	
Wildman 2009	Utility, Direct choice	VAS, forced choice: treatment	Cohort study	EQ-5D	unclear 66.2 (9.9) from patient recruited in CMP	UK	hospitalized patients first and discharge later	316/332 48.8%/51.2% overall (both asthma and COPD)	752 COPD (832 in total)	Consecutive	Clinicians were asked to classify the patient as having either COPD, asthma or a mixture of the two	Governmental/ MRC Health Services Research Fellowship	Mean (SD) Median (IQR)	COPD Intubation not needed 53.9 (19.8) COPD Intubation not needed 50 (40, 66) COPD Intubation not needed 52.3 (32.5) COPD Intubation not needed 62 (36, 74) COPD Intubated 57.2 (18.2) COPD Intubated 55 (45, 70) COPD Intubated 59.6 (26.7) COPD Intubated 69 (52, 78) Not to be intubated (In the "not to be intubated" group there were only two patients with pure asthma, and only one who responded to the 180-day questionnaire, so this group was not subdivided.) 47.6 (18.8) Not to be intubated 50 (30, 63) Not to be intubated 41.6 (31.4) Not to be intubated 52 (19, 64)
													Choice or proportion of choice	Willingness to undergo treatment for the whole population: 96%
Wilson 2005	Direct choice, Uncategorized survey	Forced choice: treatment, importance of mechanical ventilation	Trial, non-randomized or non-controlled	SF-12/SF-36, Decision aid	Mean 68.4, range: 37-68 years Mean (SD) Forego MV (n=23) 71.0 (8.6); uncertain/accept MV (n=10): 62.4 (15.4)	Canada	Outpatients who participated in a pulmonary rehabilitation program	15/8 (65%/35%) for those forego MV, and 3/7 (30%/70%) for those uncertain/accept MV	33	Consecutive	The clinical records of 120 consecutive patients who had participated in a pulmonary rehabilitation program were reviewed to identify potential participants for the study	Governmental/Research Development Fund of The Rehabilitation Centre and by an Ontario Thoracic Society Block Term grant.	Choice or proportion of choice	MV choices after the decision aid After reviewing the decision aid, 31 participants (94%) reported that they had reached a decision about whether they personally would accept or forego MV in the event of a serious exacerbation; only two individuals remained completely uncertain. Of those participants who did arrive at a decision, 23 (74%) indicated that they would forego the MV option in favor of SC without MV.
													Median (IQR)	scales for the specific questions about mechanical ventilation (0=Not at all important;1= a little; 2=quite a bit; 3=very much; 4=extremely important) Easing breathlessness: 2.5 (1.8-3.0) for those forego MV, 3.0 (2.8-4.0) for those uncertain/accept MV Physical discomfort or pain: 3.0 (1.0-4.0) for those forego MV, 2.0 (1.0-3.0) for those uncertain/accept MV Unnatural experience: 2.0 (0.0-3.0) for those forego MV, 1.5 (0.0-2.3) for those uncertain/accept MV MV can prolong life: 1.0 (0.0-2.0) for those forego MV, 3.0 (2.5-4.0) for those uncertain/accept MV MV can prolong death: 3.0 (2.0-3.0) for those forego MV, 3.0 (0.8-3.3) for those uncertain/accept MV Lingering death: 3.0 (2.0-4.0) for those forego MV, 2.5 (0.0-3.0) for those uncertain/accept MV Burden to family: 3.0 (1.0-4.0) for those forego MV, 3.0 (1.0-3.5) for those uncertain/accept MV God's will: 1.0 (0.0-3.0) for those forego MV, 0.0 (0.0-3.0) for those uncertain/accept MV May not get off MV: 3.0 (1.0-4.0) for those forego MV, 2.5 (0.8-4.0) for those uncertain/accept MV SC is less intrusive: 3.0 (0.0-4.0) for those forego MV, 0.0 (0.0-2.0) for those uncertain/accept MV SC is more peaceful: 3.0 (2.0-4.0) for those forego MV, 1.0 (0.0-3.0) for those uncertain/accept MV Without MV, death will come: 2.0 (1.0-3.0) for those forego MV, 1.0 (0.0-3.0) for those uncertain/accept MV SC may not handle symptoms: 0.0 (0.0-2.0) for those forego MV, 2.5 (0.0-3.0) for those uncertain/accept MV MV requires a machine: 3.0 (1.0-4.0) for those forego MV, 1.0 (0.0-2.0) for those uncertain/accept MV
Wilson 2007	Direct choice	Forced choice: device	Randomized controlled trial	no description	unclear (>50 years old)	UK	secondary care	Unclear	30	Unclear	Thirty COPD patients attending secondary care were recruited for the study.	Private for profit/ Glaxo Smith Kline, Zeist, the Netherlands	Ranking	Preference for Accuhaler 2 people ranked it as the first, 13 as the second, 8 as the third, and 7 as the fourth Preference for Aerolizer 5 people ranked it as the first, 7 as the second, 13 as the third, and 5 as the fourth Preference for Handihaler 4 people ranked it as the first, 6 as the second, 6 as the third, and 14 as the fourth Preference for Turbohaler 19 people ranked it as the first, 4 as the second, 2 as the third, and 5 as the fourth

